

The Cass Review

Independent review
of gender identity
services for children
and young people



Independent review of gender identity services for children and young people: Final report

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Foreword from the Chair

“Medicine’s ground state is uncertainty. Wisdom - for both the patients and doctors - is defined by how one copes with it.”

Atul Gawande, Complications (2002)



Dr Hilary Cass

This Review is not about defining what it means to be trans, nor is it about undermining the validity of trans identities, challenging the right of people to express themselves, or rolling back on people’s rights to healthcare. It is about what the healthcare approach should be, and how best to help the growing number of children and young people who are looking for support from the NHS in relation to their gender identity.

The Review has not been conducted in a vacuum. There have been many moving parts and a significant, often challenging public debate. I have been buffeted by different issues along the way but have tried to remain focused on my remit.

One of the great pleasures of the Review has been getting to meet and talk to so many interesting people. I want to thank all those who have generously given their time to share their stories, experiences and perspectives. I have spoken to transgender adults who are leading positive and successful lives, and feeling empowered by having made the decision to transition. I have spoken to people who have detransitioned, some of whom deeply regret their earlier decisions. I have spoken to many parents, with very different perspectives. Some have fought to get their children onto a medical pathway and have spoken about how frustrated they have felt to have to battle to get support. Others have felt a medical pathway

was entirely the wrong decision for their child and have described their dismay about actions taken without their consent and in ignorance of the various other difficulties their child may have been through, such as loss of a parent, traumatic illness, diagnosis of neurodiversity and isolation or bullying in school.

As well as hearing from those with lived experience, I have spoken to a very wide range of clinicians and academics. Clinicians who have spent many years working in gender clinics have drawn very different conclusions from their clinical experience about the best way to support young people with gender-related distress. Some feel strongly that a majority of those presenting to gender services will go on to have a long-term trans identity and should be supported to access a medical pathway at an early stage. Others feel that we are medicalising children and young people whose multiple other difficulties are manifesting through gender confusion and gender-related distress.

One thing unites all these people; they all believe passionately in what they have told me, and those with either parental or clinical responsibility for children and young people are trying their very best to do what they feel is the right thing to support them.

Despite the best intentions of everyone with a stake in this complex issue, the toxicity of the debate is exceptional. I have faced criticism for engaging with groups and individuals who take a social justice approach and advocate for gender affirmation, and have equally been criticised for involving groups and individuals who urge more caution. The knowledge and expertise of experienced clinicians who have reached different conclusions about the best approach to care are sometimes dismissed and invalidated.

There are few other areas of healthcare where professionals are so afraid to openly discuss their views, where people are vilified on social media, and where name-calling echoes the worst bullying behaviour. This must stop.

Polarisation and stifling of debate do nothing to help the young people caught in the middle of a stormy social discourse, and in the long run will also hamper the research that is essential to finding the best way of supporting them to thrive.

This is an area of remarkably weak evidence, and yet results of studies are exaggerated or misrepresented by people on all sides of the debate to support their viewpoint. The reality is that we have no good evidence on the long-term outcomes of interventions to manage gender-related distress.

It often takes many years before strongly positive research findings are incorporated into practice. There are many reasons for this. One is that doctors can be cautious in implementing new findings, particularly when their own clinical experience is telling them the current approach they have used over many years is the right one for their patients. Quite the reverse happened in the field of gender care for children. Based on a single Dutch study, which suggested that puberty blockers may improve psychological wellbeing for a narrowly defined group of children with gender incongruence, the practice spread at pace to other countries. This was closely followed by a greater readiness to start masculinising/feminising hormones in mid-teens, and the extension of this approach to a wider group of adolescents who would not have met the inclusion criteria for the original Dutch study. Some practitioners abandoned normal clinical approaches to holistic assessment, which has meant that this group of young people have been exceptionalised compared to other young people with similarly complex presentations. They deserve very much better.

On a personal note, I would like to talk through this foreword to the children and young people at the heart of this Review. I have decided not to write to you separately because it is important that everyone hears the same message. Some of you have been really clear that you want much better advice on the options available to you and the risks and benefits of different courses of action and will be pleased by what you will read in this report. Others of you have said you just want access to puberty blockers and hormones as quickly as possible, and may be upset that I am not recommending this. I have been very mindful that you may be disappointed by this. However, what I want to be sure about is that you are getting the best combination of treatments, and this means putting in place a research programme to look at all possible options, and to work out which ones give the best results. There are some important reasons for this decision.

Firstly, you must have the same standards of care as everyone else in the NHS, and that means basing treatments on good evidence. I have been disappointed by the lack of evidence on the long-term impact of taking hormones from an early age; research has let us all down, most importantly you. However, we cannot expect you to make life-changing decisions in a vacuum without being able to weigh their risks and benefits now and in the long-term, and we have to build the evidence-base with good studies going forward. That is why I am asking you to join any research

studies that look at the longer-term outcomes of these interventions so you can help all those coming behind you. We have to show that the treatments are safe and produce the positive outcomes you want from them. People in research studies often do better than people who are on regular treatment because they get the chance to try new approaches, as well as getting much closer follow-up and support.

Secondly, medication is binary, but the fastest growing group identifying under the trans umbrella is non-binary, and we know even less about the outcomes for this group. Some of you will also become more fluid in your gender identity as you grow older. We do not know the 'sweet spot' when someone becomes settled in their sense of self, nor which people are most likely to benefit from medical transition. When making life-changing decisions, what is the correct balance between keeping options as flexible and open as possible as you move into adulthood, and responding to how you feel right now?

Finally, I know you need more than medical intervention, but services are really stretched, and you are not getting the wider support you need in managing any mental health problems, arranging fertility preservation, getting help with any challenges relating to neurodiversity, or even getting counselling to work through questions and issues you may have. We need to look at all the elements that are needed in a package of care that will help you thrive and fulfil your broader life goals.

The first step for the NHS is to expand capacity, offer wider interventions, upskill the broader workforce, take an individualised, personal approach to care, and put in place the mechanisms to collect the data needed for quality improvement and research.

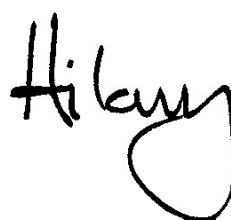
Expanding capacity at all levels of the system will not only allow for more timely care and space to explore, but also free-up the specialist services for those who need them most. I know there are many who have waited too long already and will continue to do so, and that like me, colleagues across the NHS are deeply concerned about this. We can't fix everything overnight, but we must make a start.

I would also like to share some thoughts with all my clinical colleagues. We have to start from the understanding that this group of children and young people are just that; children and young people first and foremost, not individuals solely defined by their gender incongruence or gender-related distress. We have to cut through the noise and polarisation to recognise that they need the same standards of high-quality care to meet their needs as any other child or young person. When you talk to these young people and their parents/carers, they want the same things as everyone else: the chance to be heard, respected and believed; to have their questions answered; and to access help and advice. It is only when they have been on very long waiting lists, and sidelined from usual care in local services, that they are forced to do their own research and may come to a single medical answer to their problems.

As experienced clinicians, you are familiar with dealing with complexity in presentation, but for this group of young people expertise has been concentrated in a small group of people, which has served to gatekeep the knowledge. We have heard many clinical staff question their capacity and capability and this has made them nervous about working within this population. I know you just need the appropriate training, support and most importantly the confidence to do what you have been trained to do and treat this population as you would any other young person in distress.

In conducting this Review I have had to make recommendations based on the currently available information. I am very aware that this is a point in time and as new evidence is gathered different insights might emerge. I have recommended a service model that has inbuilt mechanisms to be able to evolve and adapt with the emerging research overseen by appropriate governance structures both within individual NHS organisations and at a national level.

It is not just children and young people with gender-related distress who are facing emotional and social challenges, but the wider population of adolescents. We can only do our job by being ambitious for all children and young people and prioritising development of services to meet their broader needs.

A handwritten signature in black ink that reads "Hilary". The signature is written in a cursive, flowing style with a large loop at the end of the word.

Dr Hilary Cass, OBE

About this report

The Independent Review of Gender Identity Services for Children and Young People was commissioned by NHS England to make recommendations on the questions relating to the provision of these services as set out in the terms of reference (Appendix 1).

The Review has been forward looking. Its role was to consider how the current clinical approach and service model should be improved. In order to do this, it has been necessary to understand the current landscape and why change is needed, so that any future model addresses existing challenges.

This report is primarily for the commissioners and providers of services for children and young people needing support around their gender. However, because of the wide interest in this topic, effort has been made to make it as accessible as possible, while also representing the data which are sometimes detailed and complex.

The Review is cognisant of the broader cultural and societal debates relating to the rights of transgender people. It is not the role of the Review to take any position on the beliefs that underpin these debates. Rather, this Review is strictly focused on the clinical services provided to children and young people who seek help from the NHS to resolve their gender-related distress.

1. Approach

2. Context

3. Understanding the patient cohort

4. Clinical approach and clinical management

5. Service model

The report has five parts:

Throughout, the Review has focused on hearing a wide range of perspectives to better understand the challenges within the current system and aspirations for how these could be addressed. This report does not contain all that we have heard but summarises consistent themes, using direct quotes to illustrate points made, where appropriate.

The report includes findings from the systematic reviews commissioned from the University of York to inform the work. The full peer reviewed papers are available with open access at <https://adc.bmj.com/pages/gender-identity-service-series>.

The report represents a point in time and draws conclusions and makes recommendations based on the evidence that is currently available.

The Review is independent of the NHS and Government and neither required nor sought approval or sign-off of this report's contents prior to publication.

Language

Labels can be confusing; young people sometimes find them helpful and sometimes find them stigmatising. There is no consensus on the best language to use around this subject. The language surrounding this area has also changed rapidly and young people have developed varied ways of describing their experiences using different terms and constructs that are relevant to them.

The Review tries as far as possible to use language and terms that are respectful and acknowledge diversity, but that also accurately describe the complexity of what we are trying to articulate.

The terms used may not always feel right to some; nevertheless, it is important to emphasise that the language used is not an indication of a position being taken by the Review. A glossary of terms is included. Key definitions are:

Gender incongruence is the term used in the International Classification of Diseases Eleventh Revision (ICD-11) (World Health Organization, 2022) to describe “a marked and persistent incongruence between an individual’s experienced gender and the assigned sex”. It has been moved out of the “Mental and behavioural disorders” chapter and into the “Conditions related to sexual health” chapter so that it is not perceived as a mental health disorder. It does not include references to dysphoria or dysfunction.

Gender dysphoria is the term used in Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision (DSM-5-TR) (American Psychiatric Association, 2022). In the DSM-5-TR definition gender incongruence has to be associated with clinically significant distress or impairment of function. Younger children with gender incongruence may not experience dysphoria, but it commonly arises or increases as they enter puberty.

Gender dysphoria is the more commonly used term in research publications, as well as clinical settings. It is also most likely to be familiar to the lay public since it has been used widely in mainstream and social media. Like depression, it is a label that is used colloquially to describe feelings, as well as being a formal diagnosis.

Within the report, we use the term gender incongruence as defined above, and gender-related distress to describe the feelings that commonly arise or intensify during puberty and lead to a young person seeking help from the NHS.

The term child is used to refer to pre-pubertal children and young people to refer to under 18s who have entered puberty. The report also refers to adolescents when discussing the stages of brain development, and both adolescents and youth where the study being described uses these terms. Young adults refers to those between the ages of 18 and 30.

During the lifetime of the Review, the term trans has moved from being a quite narrow definition to being applied as an umbrella term to a broader spectrum of gender diversity. This report uses 'transgender' to describe binary transgender individuals and 'non-binary' for those who do not have a traditional gender binary of male or female. The term 'gender non-conforming' is used to describe those individuals who do not choose to conform to traditional gender norms and 'gender-questioning' as a broader term that might describe children and young people who are in a process of understanding their gender identity. The term 'trans' is used as the umbrella term.

The terms patient and service user are also used throughout the report. Although these have been used interchangeably, we have used service user when someone has used the service but may no longer be a patient under the service.

This report also includes citations from many other sources. It is important to note that these citations may use language and terminology that the Review would not choose. As a general rule, the report retains the language of the referenced papers. Any adaptation of a citation to provide clarity is represented by square brackets.

The Review was commissioned by and is for the NHS in England, however throughout the report we use the terms NHSE, NHS and UK. This is usually to align with the papers and research being discussed.

Summary and recommendations

1. The aim of this Review is to make recommendations that ensure that children and young people who are questioning their gender identity or experiencing gender dysphoria receive a high standard of care. Care that meets their needs, is safe, holistic and effective. At its heart are vulnerable children and young people and an NHS service unable to cope with the demand.

2. Yet from the start, the Review stepped into an arena where there were strong and widely divergent opinions unsupported by adequate evidence. The surrounding noise and increasingly toxic, ideological and polarised public debate has made the work of the Review significantly harder and does nothing to serve the children and young people who may already be subject to significant minority stress.

3. Within this context the Review set out to understand the reasons for the growth in referrals and the changing epidemiology, and to identify the clinical approach and service model that would best serve this population.

4. There are conflicting views about the clinical approach, with expectation at times being far from usual clinical practice. This has made some clinicians fearful of working with gender-questioning young people, despite their presentation being similar to many children and young people presenting to other NHS services.

5. Although some think the clinical approach should be based on a social justice model, the NHS works in an evidence-based way. Whilst navigating a way through the surrounding 'culture war', the Review has been acutely and increasingly aware of the need for evidence to support its thinking and ultimately the final recommendations made in this report.

6. When the Review started, the evidence base, particularly in relation to the use of puberty blockers and masculinising/feminising hormones, had already been shown to be weak. There was, and remains, a lot of misinformation easily accessible online, with opposing sides of the debate pointing to research to justify a position, regardless of the quality of the studies.

7. To understand the best way to support children and young people, the Review's ambition was therefore not only to understand the existing evidence, but also to improve the evidence base so that young people, their families and carers, and the clinicians working with them have the best information upon which to form their decisions.

8. To scrutinise the existing evidence the Review commissioned a robust and independent evidence review and research programme from the University of York to inform its recommendations and remained cautious in its advice whilst awaiting the findings.

9. The University of York's programme of work has shown that there continues to be a lack of high-quality evidence in this area and disappointingly, as will become clear in this report, attempts to improve the evidence base have been thwarted by a lack of cooperation from the adult gender services.

10. The Review has therefore had to base its recommendations on the currently available evidence, supplemented by its own extensive programme of engagement.

11. Hearing directly from people with lived experience and clinicians has provided valuable insight into the ways in which services are currently delivered and experienced. This has contributed to the Review's understanding of the positive experiences of living as a trans or gender diverse person, as well the uncertainties, complexities and challenges faced by children, young people, their families and carers, and those working in and around services trying to support them.

12. This report is organised into five parts:

- **Part 1** - Approach describes the Review's approach to the work undertaken.
- **Part 2** - Context explores the history of services for children and young people with gender dysphoria, highlighting the changing demographic and the rise in referral rate.
- **Part 3** - Understanding the patient cohort sets out what we have learnt about the characteristics of children and young people who are seeking NHS support for gender incongruence and considers what may be driving the rise in referrals and the change in the case-mix.
- **Part 4** - Clinical approach and clinical management looks at what we need to do to help children and young people to thrive: the purpose, expected benefits and outcomes of clinical interventions in the pathway, including the use of hormones and how to support complex presentations.
- **Part 5** - Service model considers the gender service delivery model, workforce requirements, pathways of care into this specialist service, further development of the evidence base and how to embed continuous clinical improvement and research.

13. At the end of this Review, while there is still uncertainty, the following remains true:

- There are children and young people, families and carers all trying to make sense of their individual situations, often dealing with considerable challenges and upheaval.
- The length of the waiting list to access gender services has significant implications for this population and NHS service delivery.
- Generalisations about children and young people questioning their gender identity or experiencing gender dysphoria are unhelpful. People are individuals.
- Young people's sense of identity is not always fixed and may evolve over time. There should be no hierarchy of gender identity or how this is expressed, be that socially or medically. Nobody should feel the need to invalidate their own experience for fear it reflects badly on other identities and choices.
- Whilst some young people may feel an urgency to transition, young adults looking back at their younger selves would often advise slowing down.
- For some, the best outcome will be transition, whereas others may resolve their distress in other ways. Some may transition and then de/retransition and/or experience regret. The NHS needs to care for all those seeking support.
- The care of this population needs to be holistic and personal. It may comprise a wide range of interventions and services, some of which can be delivered outside NHS specialist services.

- There remains diversity of opinion as to how best to treat these children and young people. The evidence is weak and clinicians have told us they are unable to determine with any certainty which children and young people will go on to have an enduring trans identity.
 - Many primary and secondary care clinicians have concerns about their capacity and competence to work with this population and some are fearful of doing so given the surrounding social debate.
 - Our current understanding of the long-term health impacts of hormone interventions is limited and needs to be better understood.
 - Young people become particularly vulnerable at the point of transfer to adult services.
- 14.** Whatever your views on gender identity, there is no denying there are increasing numbers of children and young people seeking support from the NHS for gender-related distress. They should receive the same quality of care as other children and young people experiencing distress.
- 15.** A compassionate and kind society remembers that there are real children, young people, families, carers and clinicians behind the headlines. The Review believes that each individual child and young person seeking help from the NHS should receive the support they need to thrive.

Key points and recommendations

16. In considering the key questions outlined in the terms of reference, this Report can only set out what is known and unknown and think about how the NHS can respond safely, effectively and compassionately, leaving some issues

for wider societal debate. However, in order to gain as broad an understanding as possible the Review drew on several sources of information (see Figure 1), underpinned by basic scientific and clinical principles.

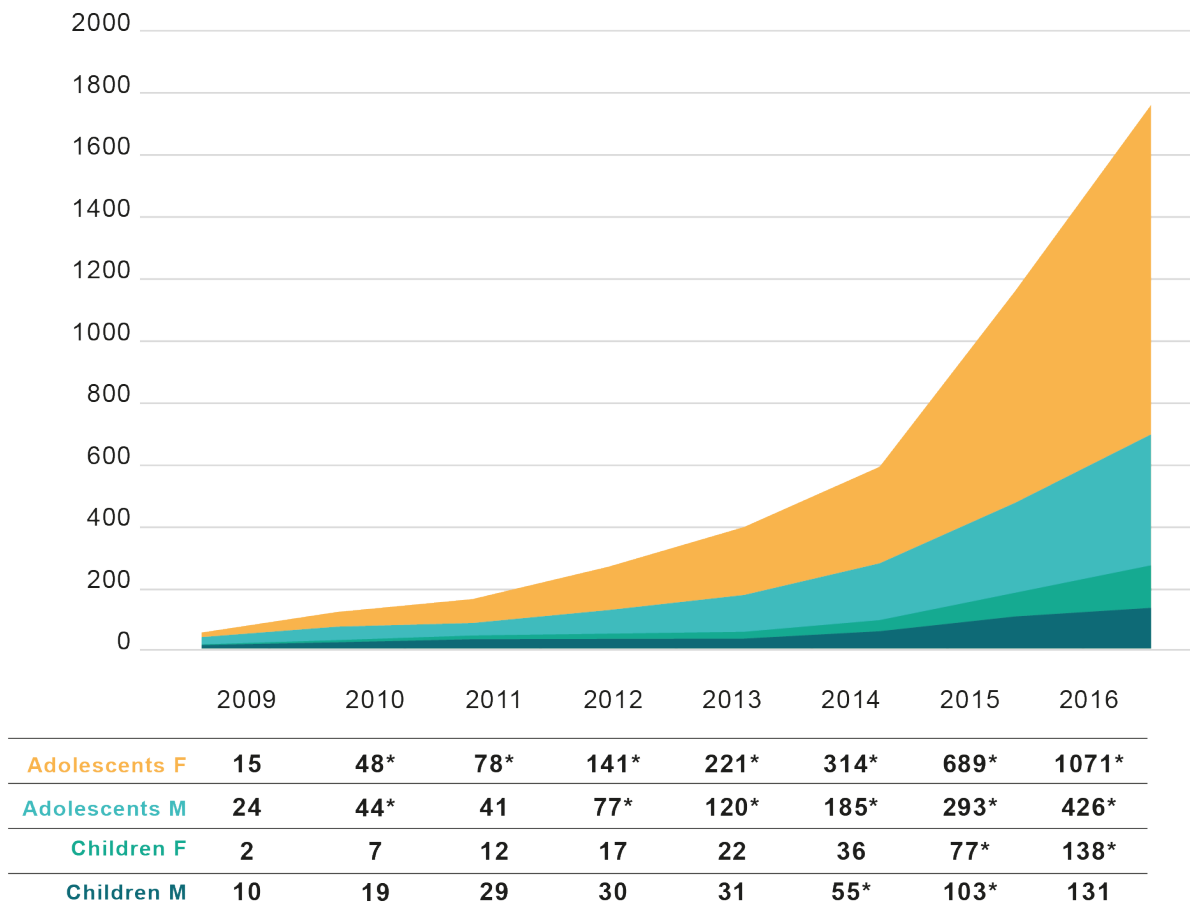
Figure 1: What has informed the Review?



17. The numbers of children and young people presenting to the UK NHS Gender Identity

Service (GIDS) has been increasing year on year since 2009, with an exponential rise in 2014.

Figure 2: Sex ratio in children and adolescents referred to GIDS in the UK (2009-16)



AFAB = Assigned female at birth

AMAB = Assigned male at birth

* Indicates $p < .05$ which shows a significant increase of referrals compared to previous year

Source: Figure adapted from de Graaf, N. M., Giovanardi, G., Zitz, C., & Carmichael, P. (2018). Sex ratio in children and adolescents referred to the Gender Identity Development Service in the UK (2009-2016). *Archives of Sexual Behavior*, 47(5), 1301-1304. <https://doi.org/10.1007/s10508-018-1204-9>, with permission from Springer Nature.

18. Prior to 2009, GIDS did not attract significant attention. At that time, the service saw fewer than 50 children per year, with even fewer receiving medical treatment. However, unprecedented demand and a change in the demographic of young people accessing gender services has generated a series of unresolved issues, a long waiting list and an unsustainable service model, one that was not set up to manage the new population.

19. The Review has focused on future provision and has not scrutinised previous provision, but it is necessary to look back to fully appreciate the context leading to the current circumstances and to learn lessons relating to previous and current clinical management and understand why change is needed.

20. GIDS was established in 1989. At that time, the service saw fewer than 10 children a year, predominantly pre-pubertal birth-registered males, and the main focus was therapeutic, with only a small proportion referred for hormone treatment by around age 16.

21. The approach to treatment changed with the emergence of ‘the Dutch Protocol’ which involved the use of puberty blockers from early puberty. In 2011, the UK trialled the use of puberty blockers in the ‘early intervention study.’

22. Preliminary results from the early intervention study in 2015-2016 did not demonstrate benefit. The results of the study were not formally published until 2020, at which time it showed there was a lack of any positive measurable outcomes. Despite this, from 2014 puberty blockers moved from a research-only protocol to being available in routine clinical practice and were given to a broader group of patients who would not have met the inclusion criteria of the original protocol.

23. The adoption of a treatment with uncertain benefits without further scrutiny is a significant departure from established practice. This, in combination with the long delay in publication of the results of the study, has had significant consequences in terms of patient expectations of intended benefits and demand for treatment.

24. A planned update of the service specification by NHS England in 2019, examined the published evidence on medical interventions in this area and found it to be weak. In the absence of a clear evidence base on how best to support the growing numbers of gender-questioning children and young people seeking help from the NHS this Independent Review was commissioned by NHS England in autumn 2020.

Interim report

25. In 2022, the Review published an interim report, which provided some initial advice. It set out the importance of evidence-based service development and highlighted major gaps and weaknesses in the research base underpinning the clinical management of children and young people with gender incongruence and gender dysphoria, including the appropriate approaches to assessment and treatment. Critically, the interim report highlighted that little is known about the medium- and longer-term outcomes for children and young people receiving NHS support and/or treatment.

26. This lack of evidence placed limitations on the advice that could be given by the Review. An independent research programme was commissioned with the aim of providing the Review with the best available collation of published evidence, as well as qualitative and quantitative research to fill knowledge gaps.

27. The research programme, led by the University of York, comprised appraisal of the published evidence and guidelines, an international survey and quantitative and qualitative research. A Clinical Expert Group (CEG) was established by the Review to help interpret the findings.

28. This final report provides full details of the research approach and methodology used by the research team and a synthesis of the findings alongside interpretation of what they mean for the Review. The peer reviewed systematic reviews have been published alongside this report.

29. In addition to formal research, an extensive programme of engagement has informed the Review. A mixed-methods approach was taken that prioritised input from people with relevant lived experience and organisations working with LGBTQ+ youth or children and young people generally, and clinicians and other professionals with responsibility for providing care and support to children and young people within specialist gender services and beyond.

Understanding the patient cohort

30. The Review explored the reasons for the increase in referrals and why this increase has disproportionately been seen in birth-registered females presenting in adolescence, and the implications of this for the service.

31. This is a different cohort from that looked at by earlier studies. Among referrals there is a greater complexity of presentation with high levels of neurodiversity and/or co-occurring mental health issues and a higher prevalence than in the general population of adverse childhood experiences and looked after children. The increase in referrals and change in case-mix is also being seen internationally.

32. Understanding who is accessing services informs an appropriate clinical approach. Therefore, to gain a complete understanding, the Review examined what is known about the nature and causes of gender incongruence and dysphoria. This goes to the heart of some of the core controversies in this area.

33. A failure to consider or debate the underlying reasons for the change in the patient population has led to people taking different positions about how to respond to the children and young people at the centre of the debate, without reasoned discussion about what has led to their gender experience and distress.

34. There is broad agreement that gender incongruence, like many other human characteristics, arises from a combination of biological, psychological, social and cultural factors.

35. A common explanation put forward is that the increase in presentation is because of greater acceptance. While it certainly seems to be the case that there is much greater acceptance of trans identities, particularly among younger generations, which may account for some of the increase in numbers, the exponential change in referrals over a particularly short five-year timeframe is very much faster than would be expected for normal evolution of acceptance of a minority group. This also does not adequately explain the switch from birth-registered males to birth-registered females, which is unlike trans presentations in any prior historical period.

36. There are different issues involved in considering gender care for children and young people than for adults. Children and young people are on a developmental trajectory that continues to their mid-20s and this needs to be considered when thinking about the determinants of gender incongruence. An understanding of brain development and the usual developmental tasks of adolescence is

essential in understanding how development of gender identity relates to the other aspects of adolescent development.

37. This group of young people should also be considered in the context of a wider group of adolescents with complex presentations seeking help from the NHS. There has been a substantial increase in rates of mental health problems in children and adolescents across the UK over the past decade, with increased anxiety and depression being most evident in teenage girls and a rise in young people presenting with other bodily manifestations of distress; for example, eating disorders, tics and body dysmorphic disorder.

38. Research suggests gender expression is likely determined by a variable mix of factors such as biological predisposition, early childhood experiences, sexuality and expectations of puberty. For some, mental health difficulties are hard to disentangle. The impact of a variety of contemporary societal influences and stressors (including online experience) remains unclear. Peer influence is also very powerful during adolescence as are different generational perspectives.

39. Pragmatically the above explanations for the observed changes in the population are all likely to be true to a greater or lesser extent, but for any individual a different mix of factors will apply.

40. This is a heterogenous group, with broad ranging presentations often including complex needs that extend beyond gender-related distress and this needs to be reflected in the services offered to them by the NHS.

41. Too often this cohort are considered a homogenous group for whom there is a single driving cause and an optimum treatment approach, but this is an over-simplification of the situation. Being gender-questioning or having a trans identity means different things to different

people. Among those being referred to children and young people's gender services, some may benefit from medical intervention and some may not. The clinical approach must reflect this.

42. Working through this multi-layered developmental process takes time, and the role of the clinical team is to help the young person address some of these issues so that they can better understand their gender identity and evaluate the options available to them.

Clinical approach and management

43. Clinicians have a range of viewpoints on the care and treatment of gender-questioning children and young people, with many left confused as to what the best approach might be. There are mixed views on what young people want and need; for example, young people have told us they need space and time to explore, but also that questioning feels intrusive. Some parents feel less questioning is needed, whilst others think the process is not thorough enough.

44. The Review sought to better understand the different clinical approaches and management, including through a standardised procedure for appraising international clinical guidelines (carried out by the research team at the University of York).

45. The findings raise questions about the quality of currently available guidelines. Most guidelines have not followed the international standards for guideline development, and because of this the research team could only recommend two guidelines for practice - the Finnish guideline published in 2020 and the Swedish guideline published in 2022.

46. However, even these guidelines lack clear recommendations regarding certain aspects of practice and would be of benefit if they provided more detailed guidance on how to implement recommendations.

47. The World Professional Association of Transgender Healthcare (WPATH) has been highly influential in directing international practice, although its guidelines were found by the University of York appraisal process to lack developmental rigour.

48. Early versions of two international guidelines - the Endocrine Society 2009 and WPATH 7 - influenced nearly all the other guidelines, except for the recent Nordic guidelines.

49. Given the lack of evidence-based guidelines, it is imperative that staff working within NHS gender services are cognisant of the limitations in relation to the evidence base and fully understand the knowns and the unknowns.

Assessment

50. The interim report advised that a developmentally informed assessment framework is needed to guard against inconsistencies and gaps in the assessment process, with clear responsibility and guidance for the different components of the process at primary, secondary and tertiary level.

51. Despite the agreement within the international guidelines on the need for a multi-disciplinary team, and some commonalities between them in the areas explored during the assessment process, the most striking problem is the lack of any consensus on the purpose of the assessment process.

52. In response to these findings, the Review asked its CEG to develop a consensus on the purpose of and approach to assessment.

53. Cognisant of the inconsistency in the published research and the complexity of presentations, the CEG worked to develop a holistic needs assessment framework. Its purpose is to derive a multi-level formulation leading to an individual care plan that supports the development of the child/young person's broader wellbeing and functioning. This is consistent with approaches for adolescents with other complex multi-faceted presentations.

54. When conducting an assessment, it will be important that clinicians are mindful that presentations, pathways and outcomes for this cohort are very individual, and the focus needs to be on helping each person to find the best pathway for them. Assessments should be respectful of the individual's experience and be developmentally informed.

Recommendation 1:

Given the complexity of this population, these services must operate to the same standards as other services seeing children and young people with complex presentations and/or additional risk factors. There should be a nominated medical practitioner (paediatrician/child psychiatrist) who takes overall clinical responsibility for patient safety within the service.

Recommendation 2:

Clinicians should apply the assessment framework developed by the Review's Clinical Expert Group, to ensure children/young people referred to NHS gender services receive a holistic assessment of their needs to inform an individualised care plan. This should include screening for neurodevelopmental conditions, including autism spectrum disorder, and a mental health assessment. The framework should be kept under review and evolve to reflect emerging evidence.

Diagnosis

55. The Review has heard mixed views about how young people perceive the value of a diagnosis of gender dysphoria. Many young people do not see themselves as having a medical condition and some may feel it undermines their autonomy and right to self-determination. Others see diagnosis as validating, and important when looking to access hormone treatment.

56. Some service users and advocates view an extensive exploration of other conditions and diagnoses as an attempt to find 'any other reason' for the person's distress other than them being trans.

57. There are several reasons why listing all relevant formal diagnoses is important for this group of children and young people:

- To provide the best evidence-based care, it is important that the clinician considers all possible (sometimes multiple) diagnoses that may be hindering the young person's wellbeing and ability to thrive.
- The clinician carries responsibility for the assessment, subsequent treatment recommendations and any harm that might be caused to a patient under their care. They need to define as clearly and reproducibly as they can exactly what condition they are treating to be accountable for their decisions on the options offered to the patient. If they are offering potentially irreversible medical treatments to a patient, it is important to specify whether the patient meets formal diagnostic criteria for gender dysphoria or any other conditions.
- Finally, the Review's commissioned systematic review demonstrated that other diagnoses within the group were not consistently documented, and in order to better understand and support these young people it is essential that all diagnoses are systematically recorded for clinical and research purposes.

58. Although a diagnosis of gender dysphoria has been seen as necessary for initiating medical treatment, it is not reliably predictive of whether that young person will have longstanding gender incongruence in the future, or whether medical intervention will be the best option for them. Understanding how the gender-related distress has evolved in a particular individual, what other factors may be contributing, and the individual's needs and preferences for treatment are equally important.

59. It is also important to ensure that there is a focus on functioning, general well-being and resilience, to ensure the child/young person is able to make considered decisions about their future pathway.

Individualised care plan

60. Historically, the model of care for children and young people presenting with gender incongruence or distress was entirely based on a psychosocial model, with medical interventions being introduced more recently. Most clinical teams would still see psychosocial interventions as the starting point in a care pathway.

61. The controversy surrounding the use of medical treatments has taken focus away from what an individual's care and treatment plan is intended to achieve, both for individual children and young people and for the overall population.

62. The Review has kept at its heart the concern that clinicians are dealing with a group of children and young people who frequently, albeit not always, will be in a state of considerable distress by the time they present to the NHS, and will often have multiple unmet needs.

63. There should be a tiered approach to any intervention package which:

- addresses urgent risk;
- reduces distress and associated mental health issues and psychosocial stressors, so that the young person is able to function and make complex decisions;
- co-develops a plan for addressing the gender issues, which may involve any combination of social, psychological and physical interventions.

64. There should be a distinction for the approach taken to pre- and post-pubertal children when considering the most appropriate

interventions. This is of particular importance in relation to social transition, which may not be thought of as an intervention or treatment because it is something that generally happens at home, online or in school and not within health services.

65. The central aim is to help young people to thrive and achieve their life goals. The immediate goal of the care and treatment plan must be to address distress, if this is part of the child/young person's presentation, and any barriers to participation in everyday life (for example, school community or social activities).

66. For the majority of young people, a medical pathway may not be the best way to achieve this. For those young people for whom a medical pathway is clinically indicated, it is not enough to provide this without also addressing wider mental health and/or psychosocially challenging problems such as family breakdown, barriers to participation in school life or social activities, bullying and minority stress.

Psychological interventions

67. The systematic review of psychosocial interventions found that the low quality of the studies, the poor reporting of the intervention details, and the wide variation in the types of interventions investigated, meant it was not possible to determine how effective different interventions were for children and young people experiencing gender distress.

68. Despite this, we know that many psychological therapies have a good evidence base for the treatment in the general population of conditions that are common in this group, such as depression and anxiety. This is why it is so important to understand the full range of needs and ensure that these young people have access to the same helpful evidence-based interventions as others.

69. In addition to treating co-existing conditions, the focus on the use of puberty blockers for managing gender-related distress has overshadowed the possibility that other evidence-based treatments may be more effective. The intent of psychosocial intervention is not to change the person's perception of who they are, but to work with them to explore their concerns and experiences and help alleviate their distress regardless of whether or not the young person subsequently proceeds on a medical pathway.

70. The role of therapeutic approaches needs to be understood and data and information must be collected on the applicability of approaches for gender-related distress and any co-occurring conditions. This will start to bring understanding the efficacy of treatments in line with those routinely used for other children and young people in distress

Social transition

71. There is no single definition of social transition, but it is broadly understood to refer to social changes to live as a different gender such as altering hair or clothing, name change, and/or use of different pronouns.

Recommendation 3:

Standard evidence based psychological and psychopharmacological treatment approaches should be used to support the management of the associated distress and cooccurring conditions. This should include support for parents/carers and siblings as appropriate.

72. There is a spectrum from young people who make relatively limited gender non-conforming changes in appearance to those who may have fully socially transitioned from an early age and may be living in stealth.

73. One key difference between children and adolescents is that parental attitudes and beliefs will have an impact on whether the child socially transitions. For adolescents, exploration is a normal process, and rigid binary gender stereotypes can be unhelpful.

74. There are different views on the benefits versus the harms of early social transition. Some consider that it may improve mental health for children experiencing gender-related distress, while others consider that it makes it more likely that a child's gender dysphoria, which might have resolved at puberty, has an altered trajectory potentially, culminating in life-long medical intervention.

75. In the UK and internationally, it is now the norm for many children and young people to present to gender clinics having undergone full or partial social transition.

76. The systematic review showed no clear evidence that social transition in childhood has any positive or negative mental health outcomes, and relatively weak evidence for any effect in adolescence. However, those who had socially transitioned at an earlier age and/or prior to being seen in clinic were more likely to proceed to a medical pathway.

77. Although it is not possible to know from these studies whether earlier social transition was causative in this outcome, lessons from studies of children with differences in sexual development (DSD) show that a complex interplay between prenatal androgen levels, external genitalia, sex of rearing and socio-cultural environment all play a part in eventual gender identity.

78. Therefore, sex of rearing seems to have some influence on eventual gender outcome, and it is possible that social transition in childhood may change the trajectory of gender identity development for children with early gender incongruence.

79. The clinician should help families to recognise normal developmental variation in gender role behaviour and expression. Avoiding premature decisions and considering partial rather than full transitioning can be a way of ensuring flexibility and keeping options open until the developmental trajectory becomes clearer.

Recommendation 4:

When families/carers are making decisions about social transition of pre-pubertal children, services should ensure that they can be seen as early as possible by a clinical professional with relevant experience.

Medical pathways

80. The original rationale for use of puberty blockers was that this would buy ‘time to think’ by delaying onset of puberty and also improve the ability to ‘pass’ in later life. Subsequently it was suggested that they may also improve body image and psychological wellbeing.

81. The systematic review undertaken by the University of York found multiple studies demonstrating that puberty blockers exert their intended effect in suppressing puberty, and also that bone density is compromised during puberty suppression.

82. However, no changes in gender dysphoria or body satisfaction were demonstrated. There was insufficient/inconsistent evidence about the effects of puberty suppression on psychological or psychosocial wellbeing, cognitive development, cardio-metabolic risk or fertility.

83. Moreover, given that the vast majority of young people started on puberty blockers proceed from puberty blockers to masculinising/feminising hormones, there is no evidence that puberty blockers buy time to think, and some concern that they may change the trajectory of psychosexual and gender identity development.

84. The Review’s letter to NHS England (July 2023) advised that because puberty blockers only have clearly defined benefits in quite narrow circumstances, and because of the potential risks to neurocognitive development, psychosexual development and longer-term bone health, they should only be offered under a research protocol. This has been taken forward by NHS England and National Institute for Health and Care Research (NIHR).

85. The University of York also carried out a systematic review of outcomes of masculinising/feminising hormones. Overall, the authors concluded that “There is a lack of high-quality research assessing the outcomes of hormone interventions in adolescents with gender dysphoria/incongruence, and few studies that undertake long-term follow-up. No conclusions can be drawn about the effect on gender dysphoria, body satisfaction, psychosocial health, cognitive development, or fertility. Uncertainty remains about the outcomes for height/growth, cardiometabolic and bone health. There is suggestive evidence from mainly pre-post studies that hormone treatment may improve psychological health, although robust research with long-term follow-up is needed”.

86. It has been suggested that hormone treatment reduces the elevated risk of death by suicide in this population, but the evidence found did not support this conclusion.

87. The percentage of people treated with hormones who subsequently detransition remains unknown due to the lack of long-term follow-up studies, although there is suggestion that numbers are increasing.

88. A problem, that has become increasingly apparent as the Review has progressed is that research on psychosocial interventions and longer-term outcomes for those who do not access endocrine pathways is as weak as research on endocrine treatment. This leaves a major gap in our knowledge about how best to support and help the growing population of young people with gender-related distress in the context of complex presentations.

Long-term outcomes

89. One of the major difficulties with planning and evaluating gender identity services for children and young people is the very limited evidence on the longer-term outcomes for people who have accessed GIDS.

90. When clinicians talk to patients about what interventions may be best for them, they usually refer to the longer-term benefits and risks of different options, based on outcome data from other people who have been through a similar care pathway. This information is not currently available for interventions in children and young people with gender incongruence or gender dysphoria, so young people and their families have to make decisions without an adequate picture of the potential impacts and outcomes.

91. A strand of research commissioned by the Review was a quantitative data linkage study. The aim of this study was to fill some of the gaps in follow-up data for the approximately 9,000 young people who have been through GIDS. This would help to develop a stronger evidence base about the types of support and interventions received and longer-term outcomes. This required cooperation of GIDS and the NHS adult gender services.

92. In January 2024, the Review received a letter from NHS England stating that, despite efforts to encourage the participation of the NHS gender clinics, the necessary cooperation had not been forthcoming.

93. This quantitative study represents a unique opportunity to provide further evidence to assist young people, their parents/carers, and the clinicians working with them to make informed decisions about the right pathway for them.

94. Although retrospective research is never as robust as prospective research, it would take a minimum of 10-15 years to extract the necessary follow-up data

95. NHS England has stated a commitment to realising the ambitions of the data linkage study beyond the life of the Review and the Review has detailed the University of York's experience in trying to move the study forward.

Recommendation 5:

NHS England, working with DHSC should direct the gender clinics to participate in the data linkage study within the lifetime of the current statutory instrument. NHS England's Research Oversight Board should take responsibility for interpreting the findings of the research.

Challenges in clinical decision making

96. One of the main areas of contention in the provision of gender services for children and young people is the use of hormone treatments for gender dysphoria. In developing its vision for the new service, the Review has considered the issue of consent, the challenges of which were starkly brought to light by the Bell vs Tavistock case.

97. The Judicial Review's responsibilities could not be extended beyond the issue of capacity and competence to consent. However, consent is more than just capacity and competence. It requires clinicians to ensure that the proposed intervention is clinically indicated as they have a duty to offer appropriate treatment. It also requires the patient to be provided with appropriate and sufficient information about the risks, benefits and expected outcomes of the treatment.

98. Assessing whether a hormone pathway is indicated is challenging. A formal diagnosis of gender dysphoria is frequently cited as a prerequisite for accessing hormone treatment. However, it is not reliably predictive of whether that young person will have longstanding gender incongruence in the future, or whether medical intervention will be the best option for them.

99. In addition, the poor evidence base makes it difficult to provide adequate information on which a young person and their family can make an informed choice.

100. A trusted source of information is needed on all aspects of medical care, but in particular it is important to defuse/manage expectations that have been built up by claims about the efficacy of puberty blockers.

101. Although young people often express a sense of urgency in their wish to access medical treatments, based on personal experience some young adults have suggested that taking time to explore options is preferable. The option to provide masculinising/feminising hormones from the age of 16 is available, but the Review would recommend an extremely cautious clinical approach and a strong clinical rationale for providing hormones before the age of 18. This would keep options open during this important developmental window, allowing time for management of any co-occurring conditions, building of resilience, and fertility preservation, if required.

102. The overarching conclusion from the evidence presented in this Review is that the puberty blocker research protocol, which is already in development, needs to be one part of a much broader research programme that seeks to build the evidence on all potential interventions and determine the most effective way of supporting these children and young people.

Recommendation 6:

The evidence base underpinning medical and non-medical interventions in this clinical area must be improved. Following our earlier recommendation to establish a puberty blocker trial, which has been taken forward by NHS England, we further recommend a full programme of research be established. This should look at the characteristics, interventions and outcomes of every young person presenting to the NHS gender services.

- The puberty blocker trial should be part of a programme of research which also evaluates outcomes of psychosocial interventions and masculinising/feminising hormones.
- Consent should routinely be sought for all children and young people for enrolment in a research study with follow-up into adulthood.

Recommendation 7:

Long-standing gender incongruence should be an essential pre-requisite for medical treatment but is only one aspect of deciding whether a medical pathway is the right option for an individual.

Recommendation 8:

NHS England should review the policy on masculinising/feminising hormones. The option to provide masculinising/feminising hormones from age 16 is available, but the Review would recommend extreme caution. There should be a clear clinical rationale for providing hormones at this stage rather than waiting until an individual reaches 18.

Recommendation 9:

Every case considered for medical treatment should be discussed at a national Multi Disciplinary Team (MDT) hosted by the National Provider Collaborative replacing the Multi Professional Review Group (MPRG).

Recommendation 10:

All children should be offered fertility counselling and preservation prior to going onto a medical pathway.

Service model

103. Since receiving the Review's interim report, NHS England has taken steps to increase capacity, establishing two new services led by specialist children's hospitals. This is the first step in commissioning a network of regional services across the country.

104. The Review had hoped to take learning from these interim services. Instead, it has gained insight from the considerable challenges faced in their establishment within a highly emotive and politicised arena. This, coupled with concerns about the weakness of the evidence base and lack of professional guidance, has impacted on the ability of the new services to recruit the appropriate multi-disciplinary workforce.

105. The Review welcomes the first steps NHS England has taken to establish a regional model of care, but maintains that a distributed model of care is needed to meet current demand and provide a more appropriate holistic, localised and timely approach to caring for children and young people needing support.

106. Services should not be located solely in tertiary centres and a much broader based service model is needed with a flexible workforce working across a regional footprint in partnership with local services. Models of care that deliver a clinical service over multiple sites have a potential to maintain geographical access to services whilst improving quality of care and optimising the use of the workforce.

107. Clinical Network and Multi-Site models provide better continuity of care, closer to home, and the ability for children and young people to move more easily between components of the service at their own pace. They also allow the workforce to be shared across the network without destabilising local services and address some of the recruitment challenges experienced by both GIDS and the new providers.

108. Establishment of a National Provider Collaborative should ensure the regional centres operate to shared standards and operating procedures, developing protocols for assessment and treatment. The Collaborative should have a role in overseeing ethics, training and professional development, data and audit, quality improvement and research requirements, as well as providing a forum for the discussion of complex cases. The aim is that no matter where in the country the child/young person is seen, they will receive the same high standards of evidence-based care.

109. In addition to the single overarching National Provider Network, each Regional Centre should work with local services within their region as a formalised Operational Delivery Network (ODN). These formalised networks and increased number of providers should allow care and risk to be actively managed at different levels according to need, reducing waiting times for specialist care.

110. This model will also support integration between different children's services and facilitate early access to local services along flexible pathways that better respond to individual needs. Overall, this model should improve the experience of care for children and young people questioning their gender identity.

111. The new regional services should establish the National Provider Collaborative without delay and quickly develop their networks, utilising existing local relationships in the first instance to accelerate service provision. This approach would act as a stepping stone to ultimately skilling up all secondary level services to provide assessment and psychological support for these children and young people, with medical intervention remaining at tertiary level.

Recommendation 11:

NHS England and service providers should work to develop the regional multi-site service networks as soon as possible. This could be based on a lead provider model, where NHS England delegates commissioning responsibility to the regional services to subcontract locally to providers in their region.

Recommendation 12:

The National Provider Collaborative should be established without delay.

Workforce

112. The Review recognises that workforce shortfalls are one of the most challenging aspects of delivering this service.

113. Within the existing model of care, the vast majority of gender-questioning children and young people who seek help from the NHS have been referred to a highly specialised workforce working solely in gender care. A smaller number are successfully supported in local Child and Adolescent Mental Health Services (CAMHS) or paediatric services. This approach has had the unintended consequence of deskilling the rest of the workforce and generating unmanageably long waiting lists.

114. Given the increasing numbers of gender diverse and gender-questioning young people, it is important that all clinical staff can support them in a range of settings across the NHS. It is equally important that professionals who are involved in their ongoing care have broad-based skills in adolescent physical and mental health so that young people are treated holistically and not solely on the basis of their gender presentation.

115. In line with international practice, the Regional Centres will need a broad multi-professional workforce. The skills of those working within the service need to reflect the broad and varied needs of this heterogeneous group and the service needs to include the appropriate skill mix to support both individuals for whom medical intervention is clinically indicated and those for whom it is not.

116. This workforce should include psychiatrists, paediatricians, psychologists, psychotherapists, clinical nurse specialists, social workers, specialists in autism and other neurodiverse presentations, speech and language therapists, occupational therapists and, for the subgroup for whom medical treatment may be considered appropriate, endocrinologists and fertility specialists. Social care should also be embedded and there should be expertise in safeguarding and support for looked-after children and children who have experienced trauma.

117. When outlining the future service model, to increase the available workforce without depleting other service areas, the Review has described a flexible, multi-site staff group working under joint contracts that support flexibility.

120. Staff should maintain a broad clinical perspective by working across related non-gender services within the tertiary centre and between tertiary and secondary centres in order to

embed the care of children and young people with gender-related distress within a broader child and adolescent health context. This has the additional benefits of not destabilising existing services, supporting continuity and connection and democratising knowledge.

118. This is a highly challenging, complex and emotive area in which to work. Those working with this group should have professional supervision and support to provide a place for exploration of their own approach and the range of emotions they may feel. There should be formal processes for raising concerns that sit outside immediate supervision. This should also support consistency in approach and improve retention of the workforce.

119. The National Provider Collaborative should also explore running structured forums where all staff, clinical and non-clinical, come together regularly to discuss the emotional and social aspects of working within the service - supporting staff by giving them a safe place to raise issues.

Recommendation 13:

To increase the available workforce and maintain a broader clinical lens, joint contracts should be utilised to support staff to work across the network and across different services.

Recommendation 14:

NHS England, through its Workforce Training and Education function, must ensure requirements for this service area are built into overall workforce planning for adolescent services.

Training and education

120. There is a lack of confidence among the wider workforce to engage with gender-questioning children and adolescents. Many clinicians working with children and young people have transferable skills and expertise, but there is a need for all clinicians across the NHS to receive better training on how to work sensitively and effectively with trans, non-binary and gender-questioning young people.

121. Clinicians working with children and young people and families/carers will need to have the skills to competently engage families/carers from a broad range of backgrounds, and be aware and informed of the range of priorities that young people and their parents/carers can present to services.

122. Young people told the Review that they want clinicians to listen to them, respect how they feel and support them to work through their feelings and options. They expect clinicians to display compassion, understanding and validation, and to treat them as an individual.

123. Training programmes should follow practice in other service areas (for example, safeguarding), where the level of competency and training needs depend on the staff group and clinical area.

124. A consortium of relevant Medical Royal Colleges and professional bodies should develop a shared skills and competency framework relevant to all clinical and social care staff working in this area at different levels within the system. This should include broader skills in adolescent care, as well as the more specific aspects relevant to gender care.

125. Individual professional organisations should determine which of the transferable skills and competencies are already embedded in the training curricula of their specific staff groups and where the gaps are.

126. The consortium should then develop a curriculum to cover topics that are deemed to be missing from existing training programmes and curricula, and necessary for top-up training/ continuing professional development (CPD)/ credentialing for individuals working within this area.

Recommendation 15:

NHS England should commission a lead organisation to establish a consortium of relevant professional bodies to:

- develop a competency framework
- identify gaps in professional training programmes
- develop a suite of training materials to supplement professional competencies, appropriate to their clinical field and level. This should include a module on the holistic assessment framework and approach to formulation and care planning.

Recommendation 16:

The National Provider Collaborative should coordinate development of evidence-based information and resources for young people, parents and carers. Consideration should be given as to whether this should be a centrally hosted NHS online resource.

Service improvement

127. Central to any service improvement is the systematic and consistent collection of data on the outcomes of treatment.

128. Throughout the course of the Review, it has been evident that there has been a failure to reliably collect even the most basic data and information in a consistent and comprehensive manner; data have often not been shared or have been unavailable.

129. It will be critical that the new services form a learning environment. There should be a process of continuous service improvement and clinical reflection, with consideration of how services should evolve as the evidence base grows and care pathways are evaluated.

130. There remains the need for the collection of an agreed core dataset to inform service improvement and research, based on similar approaches already established in other specialties; for example, in paediatric critical care. This will be critical to informing current and future clinical practice and care for this population.

Recommendation 17:

A core national data set should be defined for both specialist and designated local specialist services.

Recommendation 18:

The national infrastructure should be put in place to manage data collection and audit and this should be used to drive continuous quality improvement and research in an active learning environment.

Clinical research capacity

131. The gaps in the evidence base regarding all aspects of gender care for children and young people have been highlighted, from epidemiology through to assessment, diagnosis and intervention.

132. It is troubling that so little is known about this cohort and their outcomes. An ongoing programme of work is required if the new case-mix of children and young people and their needs are to be fully understood, as well as the short- medium- and longer-term impacts of all clinical interventions.

133. Given the uncertainties regarding the long-term outcomes for medical and non-medical interventions, and the broader knowledge gaps in this area, research capacity is needed to:

- provide ongoing appraisal of new research and rapid translation into clinical practice;
- continue to identify areas of practice where further research is needed;
- fast-track the development of an ambitious research portfolio that will inform policy on assessment, support and clinical care of children with gender dysphoria, from presentation through to appropriate social, psychological and medical management.

134. The appropriate research questions and protocols will need to be developed with input from a panel of academics, clinicians, service users and ethicists.

135. To build on the work undertaken by the University of York and maintain an up-to-date understanding of this complex and fast-moving research area, a living systematic review (where the systematic review could be continually updated to reflect new evidence as it becomes available to inform the clinical approach of the new services, ensuring it remains up-to-date and dynamic) should be established.

136. Without an established research strategy and infrastructure, the outstanding questions relating to interventions to support this population will remain unanswered, and the evidence gaps will continue to be filled with opinion and conjecture.

137. Better quality evidence is critical if the NHS is to provide reliable, transparent information and advice to support children, young people, their parents and carers in making potentially life-changing decisions.

Recommendation 19:

NHS England and the National Institute for Health and Care Research (NIHR) should ensure that the academic and administrative infrastructure to support a programme of clinically-based research is embedded into the Regional Centres.

Recommendation 20:

A unified research strategy should be established across the Regional Centres, co-ordinated through the National Provider Collaborative and the Research Oversight Board, so that all data collected are utilised to best effect and for sufficient numbers of individuals to be meaningful.

Recommendation 21:

To ensure that services are operating to the highest standards of evidence the National Institute for Health and Care Research (NIHR) should commission a living systematic review to inform the evolving clinical approach.

Pathways

138. Clear criteria are needed for referral to services along the pathway from primary to tertiary care so that gender-questioning children and young people who seek help from the NHS have equitable access to services.

139. When the Review commenced, access to the specialist GIDS service was unusual in that the service accepted referrals directly from primary care (a GP) and from non-healthcare professionals including teachers and youth workers.

140. NHS England has since consulted on a proposal for all referrals to come via secondary care and the Review supports this approach.

141. This report sets out the different roles and responsibilities within the Review's proposed service delivery model; from primary through to tertiary care and discharge and how the network should ensure that children and young people are appropriately engaged within the health system.

Pathways within the service

142. Discussions with clinicians highlighted the importance of differentiating the subgroups within the referred population who may be at risk and/or need more urgent support, assessment or intervention; there may also be subgroups for whom early advice to parents or school staff may be a more appropriate first step.

143. Children and young people should be able to move flexibly between different elements of the service in a step-up or step-down model, allowing them and their parents/carers to make decisions at their own pace without requiring rereferral into the system.

144. The current evidence base suggests that children who present with gender incongruence at a young age are most likely to desist before puberty, although for a small number the incongruence will persist. Parents and families need support and advice about how best to support their children in a balanced and non-judgemental way. Helping parents and families to ensure that options remain open and flexible for the child, whilst ensuring that the child is able to function well in school and socially is an important aspect of care provision and there should be no lower age limit for accessing such help and support.

Recommendation 22:

Within each regional network, a separate pathway should be established for pre-pubertal children and their families. Providers should ensure that pre-pubertal children and their parents/carers are prioritised for early discussion with a professional with relevant experience.

Transfer to adult gender services

145. Currently, significant numbers of young people are being transferred from GIDS to adult services. Some will have been under the care of GIDS, however another group will still have been waiting for their first GIDS appointment at the time they turned 17, and their wait will now count in their wait for adult services. This is increasing waiting lists for adult services and disadvantaging older adults seeking NHS support.

146. This represents a significant risk of discontinuity in clinical care and loss to follow-up. It also means that data on outcomes, which are essential to improve the knowledge base, are lost.

147. A follow-through service would benefit both this younger population and the adult population. This will have the added benefit in the longer-term of increasing the capacity of adult provision across the country as more gender services are established.

148. This would be consistent with the other service areas supporting young people that are selectively moving to a '0-25 years' service to improve continuity of care.

Recommendation 23:

NHS England should establish follow-through services for 17-25-year-olds at each of the Regional Centres, either by extending the range of the regional children and young people's service or through linked services, to ensure continuity of care and support at a potentially vulnerable stage in their journey. This will also allow clinical, and research follow up data to be collected.

149. The Review requested data on the demographics of referrals into NHS adult gender clinics, which demonstrated that the majority of referrals were birth-registered females under the age of 25.

150. While provision within the adult Gender Dysphoria Clinics (GDCs) is outside the scope of this Review, a number of current and past GDC staff have contacted the Review in confidence with their concerns.

151. The Review will set out the main points of concern to NHS England separately. However, the clinicians highlighted the changing adult demographic and same complexity of presentation as seen in gender services for children and young people.

152. As the services for children and young people develop, a strategic approach will be needed to ensure that adult service provision takes account of different population needs and emerging evidence.

Recommendation 24:

Given that the changing demographic presenting to children and young people's services is reflected in a change of presentations to adult services, NHS England should consider bringing forward any planned update of the adult service specification and review the model of care and operating procedures.

Detransition

153. NHS gender services should support all those presenting with gender incongruence and dysphoria, whether that be to transition, detransition or retransition. Those who detransition should be carefully monitored in a supportive setting, particularly when coming off hormone treatments.

154. The Review has heard that people experiencing regret may be hesitant to engage with the gender services that supported them through their initial transition. Consideration should be given to whether existing service specifications need to be adapted to specifically provide detransition pathways or whether this should be a separately commissioned service. This should be in consultation with people who have been through detransition.

Recommendation 25:

NHS England should ensure there is provision for people considering detransition, recognising that they may not wish to reengage with the services whose care they were previously under.

Private provision

155. The Review has been told that a number of young people have sought private provision whilst on the waiting list for GIDS, and about families trying to balance the risks of obtaining unregulated and potentially dangerous hormone supplies over the internet with the ongoing trauma of prolonged waits for assessment. Feedback from the lived experience focus groups presents this as “a forced choice (because the NHS provision is not accessible

in a timely way) rather than a preference.” The ongoing cost of this treatment and the subsequent monitoring can be prohibitive for some.

156. GPs have expressed concern about being pressurised to prescribe hormones after these have been initiated by private providers and that there is a lack of clarity around their responsibilities in relation to monitoring.

157. The Review understands and shares the concerns about the use of unregulated medications and of providers that are not regulated within the UK. Any clinician who ascertains that a young person is being given drugs from an unregulated source should make the young person and their family aware of the risks of such treatment.

158. In terms of shared care and prescribing responsibility, this should mirror other areas of practice. Specifically, no clinician should prescribe outside their competence, nor should GPs be expected to enter into a shared care arrangement with a private provider, particularly if that private provider is acting outside NHS guidance. Additionally, pharmacists are responsible for ensuring medications prescribed to patients are suitable.

159. However, there should be an arrangement to carry out relevant investigations to ensure a young person is not coming to harm (for example, monitoring bone density).

160. In the case of puberty blockers, NHS England has set out that these will only be available under a research protocol. On entering the trial, the young person will have a number of tests to establish their baseline levels for monitoring purposes (for example, in relation to bone density), as well as other initial assessments. If an individual were to take puberty blockers outside the study, their eligibility may be affected.

Recommendation 26:

The Department of Health and Social Care and NHS England should consider the implications of private healthcare on any future requests to the NHS for treatment, monitoring and/or involvement in research. This needs to be clearly communicated to patients and private providers.

Recommendation 27:

The Department of Health and Social Care should work with the General Pharmaceutical Council to define the dispensing responsibilities of pharmacists of private prescriptions and consider other statutory solutions that would prevent inappropriate overseas prescribing.

Recommendation 28:

The NHS and the Department of Health and Social Care needs to review the process and circumstances of changing NHS numbers and find solutions to address the clinical and research implications.

Implementation

163. The Review recognises that delivery of the aspirations set out in this report will require significant changes. The move to the proposed service model will require a phased approach and it may be several years before the full model is operational across the country. Pragmatic strategic and operational plans are required that set out the steps that will be taken to realise the service transformation.

164. Governance needs to be put in place to oversee implementation of the required changes and provide system-wide leadership. This should be external to NHS England's Specialised Commissioning division and draw clinical leadership from professional bodies. Given the level of external interest in these services progress against the implementation plans should be reported.

165. While the Review has focused on children and young people with gender incongruence and gender-related distress, the NHS needs to be ambitious in its provision for all children and young people seeking NHS support.

NHS number

161. Currently, when a person requests to change their gender on their NHS record, NHS guidance requires that they are issued with a new NHS number. This has implications for safeguarding and clinical management of these children and young people and could affect longer-term health management (for example, the screening they are offered).

162. From a research perspective, the issuing of new NHS numbers makes it more difficult to identify the long-term outcomes for a patient population for whom the evidence base is currently weak.

166. NHS provision for children and young people across the board requires greater service and workforce development and sustained investment. Without this we are letting down future generations. NHS England should use this opportunity to integrate investment and development of gender services with the ambitions set out in the NHS Long Term Plan for broader provision, with consideration given to a complex adolescent pathway.

Recommendation 29:

NHS England should develop an implementation plan with clear milestones towards the future clinical and service model. This should have board level oversight and be developed collaboratively with those responsible for the health of children and young people more generally to support greater integration to meet the wide-ranging needs of complex adolescents.

Recommendation 30:

NHS England should establish robust and comprehensive contract management and audit processes and requirements around the collection of data for the provision of these services. These should be adhered to by the providers responsible for delivering these services for children and young people.

Wider system learning

167. Clinical staff need support and guidance from their professional bodies to apply the evidence-based approaches described in this report. The consortium brought together to develop training resources should also be a vehicle for agreeing professional guidance for their respective clinical groups. This collaborative approach should include processes for listening to the community the service is built for.

Recommendation 31:

Professional bodies must come together to provide leadership and guidance on the clinical management of this population taking account of the findings of this report.

168. Innovation is important if medicine is to move forward, but there must be a proportionate level of monitoring, oversight and regulation that does not stifle progress, but prevents creep of unproven approaches into clinical practice. Innovation must draw from and contribute to the evidence base.

Recommendation 32:

Wider guidance applicable to all NHS services should be developed to support providers and commissioners to ensure that innovation is encouraged but that there is appropriate scrutiny and clinical governance to avoid incremental creep of practice in the absence of evidence.

Approach



1. Methodology

1.1 At the outset, the Review established the core principles that would underpin the approach taken.

- The welfare of the child or young person must remain paramount in all considerations. At the centre of the Review is a group of children and young people who are seeking support, and our responsibility is to devise a model of care that will safeguard their best interests and set each one of them on a pathway that helps them thrive as an individual.
- The Review has to be grounded in a thorough examination of the most robust existing evidence. To support this, we commissioned systematic reviews on a range of issues from epidemiology through to treatment approaches, and international models of current practice.
- The (formal) evidence would only provide part of the picture and we needed to hear from a range of people; crucially the children and young people at the centre of the Review, but also their parents and carers, as well as young adults who have been through gender care in the UK and could give a longer-term perspective.
- We also needed input from a very wide range of professionals from different agencies who have relevant experience and could contribute to our understanding of the population and the evidence.
- Finally, we wanted to ensure that key findings were shared as quickly as possible, through publication of interim findings, blogs, and any communications with NHS England over the course of the Review.

1.2 In considering the questions set out in the terms of reference (Appendix 1), this Review can only set out what is known and unknown and think about how the NHS can best respond safely, effectively and compassionately, leaving some issues for wider societal debate. However, in order to gain as broad an understanding as possible we drew on several sources of information, underpinned by basic scientific and clinical principles.

Understanding evidence

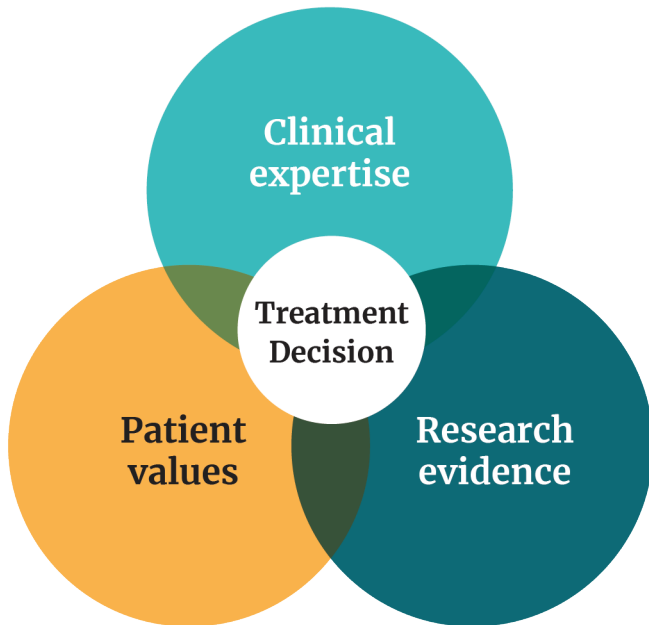
1.3 The Review's interim report in 2022 set out the importance of evidence-based service development and highlighted major gaps and weaknesses in the evidence base underpinning the clinical management of children and young people with gender incongruence and gender dysphoria, including for the appropriate approaches to assessment and treatment. In particular, it became apparent how little was known about the medium- and longer-term outcomes for children and young people receiving NHS support and/or treatment.

1.4 The quality of the evidence base for interventions for gender incongruence and gender dysphoria is a source of debate and contention. This makes it very difficult for young people and their families to know what information to trust and what to expect from the treatments offered.

1.5 A fundamental principle of clinical medicine is that treatments should be offered based on the best available evidence.

1.6 In evidence-based practice, three factors determine treatment decisions; research evidence, clinical expertise and patient values.

Figure 3: Components of evidence-based medicine



1.7 For example, if a doctor diagnoses a patient with depression and recommends a particular antidepressant medication, they should invariably explain that there is strong evidence that the drug is effective; for example, it has an 85% chance of improving the depression.

1.8 The doctor will also point out possible side effects; for example, it has a 5% chance of causing weight gain. If the patient already happens to be very distressed about being overweight, they may not feel that the potential benefits of the drug outweigh the risk that they may gain weight.

1.9 The doctor will then consider other options; for example, there may be a different drug that does not cause weight gain but increases risk of suicide. If the patient has made a recent suicide attempt that would not be an appropriate alternative to offer to this patient.

1.10 Without this evidence for benefits and harms, it is hard for the doctor to advise the patient, and for the patient to decide whether they want to try the proposed treatment.

Explanatory Box 1:

Principles of treatments studies

The following information is intended to provide some accessible explanations of the strengths and limitations of the evidence and treatment studies used to inform the Review's recommendations.

- The development of a new drug or treatment involves a number of steps to ensure that it is safe (there are minimal harms or side effects) and effective (there is a good chance the drug will produce the intended benefit). If another treatment already exists for the condition, an important step is to test whether the new treatment is better, and whether it is cost effective. This is best quantified by undertaking a randomised trial. Sometimes a drug may have severe side effects, but if the condition is life threatening, these side effects may be considered acceptable (for example, some chemotherapies for cancer).
- An important principle in treatment trials is equipoise. This means that the researchers genuinely do not know which treatment is better - the existing treatment or the new treatment. If they have very strong reasons to believe the new treatment is better, or indeed worse, they cannot ethically carry out a trial. Occasionally a trial may be stopped early if it is obvious that the new treatment is causing harm or is strongly beneficial.

Some types of treatment studies

- The 'gold standard' trial is a randomised controlled trial (RCT). In this type of trial there are at least two groups. One is given the new treatment and the other, the control group, is given a standard or alternative treatment, or perhaps no treatment. Patients are randomly allocated to the two groups, and it is important to make sure there are no important differences between the two groups.
- The term blind or blinded is used in RCTs. There are different levels of blinding: firstly, if researchers are doing the assessments, they should not know which group a patient has been allocated to. Secondly, the patient can be blinded so that they do not know if they are on the new treatment or the original treatment, or even on a placebo (dummy pills). Finally, the treating doctor (or team) should ideally be blind to the group allocation, so their treatment of the patients does not differ.
- Participants in a study must be told about blinding processes when they consent to be in the trial. It is not always possible for people to be blind to a treatment; for example, in a trial of acupuncture versus physiotherapy, patients will know which treatment they are receiving. In these situations, people interpreting the results of the study must take into account any possible placebo effect. This is when people believe that the treatment will produce a beneficial outcome and having this belief results in them feeling better.

There are hardly any RCTs in children and young people receiving endocrine treatment for gender incongruence/dysphoria, but the following are the most commonly reported types of studies:

- Two types of studies that are sometimes used to look at the effects of puberty blockers and masculinising/feminising hormones are cohort studies and cross-sectional studies, which are different ways of looking at outcomes in groups who did or did not get a particular intervention. These are all called observational studies whereas RCTs are called experimental studies. This is because in cohort or cross-sectional studies the researcher did not allocate which patients receive an intervention. There may still be a comparison group, but participants will not have been randomly allocated to the two groups.
- The most common study for patients receiving puberty suppression is a pre-post study. This is where study participants are assessed before and after they receive an intervention. Because there is no comparison group of individuals who did not receive the treatment, and because one cannot rule out changes that would have occurred over time without treatment, it is not possible to draw strong conclusions from these studies.

Pitfalls of treatment trials

- A major problem in making sense of trial findings is bias. There are many ways in which results can be biased. For example, if 50% of the sample drops out, this would be referred to as a high attrition rate. It is possible that the people who remained in the study are those who responded well to the treatment, whereas those who dropped out did so because the treatment was not working for them or they had bad side effects. This could result in a positive bias in the study outcomes; in other words showing an effect when there is not one. It could also fail to show the side effects that caused people to drop out.
- Another way of biasing results is if the patients in the treatment and control groups differ in some way; for example, one group has more people who are younger, or sicker. Researchers will assess the groups on several measures and compare them to see if they are similar at the start of the study (baseline assessment). Random allocation of people to the study groups and large numbers of participants help reduce the risk of differences between study groups.
- It is very important to get the inclusion and exclusion criteria of a study right (that is, which patients can and cannot be included). For example, a trial might report that a painkiller is highly effective, but if it turns out that only people with osteoarthritis in the knee were included it would mean that the results cannot be generalised to patients with headache. Although the drug may work very well for headache, it is not possible to be sure about this on the basis of the findings of this particular study.

- In any design where patients are not blinded and know they are getting a particular drug, or where they have chosen a specific treatment rather than being randomised to one, they may show improvement because of a placebo effect (that is, they believe that the treatment will produce a beneficial outcome).
- Sometimes there are confounding factors in a study, such as the patient getting another treatment at the same time as the trial treatment. Though randomisation and blinding minimise the risk of bias and confounding, this is not completely watertight.
- There must also be enough patients in a trial (the term 'sufficiently powered' is often used where there are) to be sure the results reflect the range of possible outcomes and do not give a 'positive' result by chance, a so-called Type 1 (or alpha) error. Study outcome measures are generally reported as the average for a group, but the range is usually also given and can be very wide. For example, if the average outcome for a group is 5 points out of a possible 10, a range of 2-9 would indicate much more varied outcomes across the group than a range of 4-6. Size influences whether the reported outcomes are statistically significant. In very small studies, for example one with only four patients put on a treatment and in which three got better and one got worse, it would not be possible to understand the full range of possible outcomes. Furthermore, the benefits for three individuals could have happened by chance. For a result to be statistically significant, it must be unlikely that the result could have happened by chance. This is why substantial numbers of participants are required and a key requirement of any trial is a pre-recruitment estimate of how many will be needed for the study to produce meaningful results.
- There are many other potential problems, some of which include:
 - unconscious bias in questionnaire design where the questions are written in a way that prompts a more favourable response;
 - using the wrong kind of analysis for the available data;
 - not following up for long enough to see the full benefits or harms of a treatment;
 - seeing an improvement because patients were improving spontaneously over time;
 - publication bias where, for example, only positive results are published.

Building on evidence

Figure 4: What has informed the Review?



1.11 The Review has sought to better understand the existing evidence, as well as fill some of the gaps through qualitative and quantitative research relevant to the Review’s terms of reference (Appendix 1).

1.12 Following a national open procurement process, the University of York was commissioned to deliver an independent research programme. The aim was to provide the Review with the best available collation of published evidence relevant to epidemiology, clinical management, models of care and outcomes, and to understand the experiences and perspectives of service users, their families and clinicians.

1.13 The systematic reviews were commissioned to look at:

- i. How has the population of children presenting with gender dysphoria and/or gender-related distress changed over time?
- ii. What are the appropriate referral, assessment and treatment pathways for children with gender dysphoria and/or gender-related distress?
- iii. What are the short, medium and long-term outcomes for children with gender dysphoria and/or gender-related distress?

1.14 Additionally, an appraisal of an international guidelines and international survey were undertaken to supplement this information, looking at evidence application and clinical practice in other comparable healthcare systems.

1.15 Finally, the qualitative and quantitative studies were designed to try and fill some of the gaps in the existing literature.

1.16 The Review collated the findings from these studies and used them to determine the most appropriate clinical approach and models of care, assessment and treatment. References are made to the studies undertaken by the University of York throughout this Report. For the papers that have informed the University of York’s work, please refer to the source documents (Table 1).

Table 1: Overview of academic research programme commissioned by the Review

RESEARCH TYPE	RESEARCH TITLE	REPORT IN-TEXT CITATION
SYSTEMIC REVIEWS	<u>Characteristics of children and adolescents referred to specialist gender services: a systematic review</u>	Taylor et al: Patient characteristics
	<u>Impact of social transition in relation to gender for children and adolescents: a systematic review</u>	Hall et al: Social transition
	<u>Psychosocial support interventions for children and adolescents experiencing gender dysphoria or incongruence: a systematic review</u>	Heathcote et al: Psychosocial support
	<u>Interventions to suppress puberty in adolescents experiencing gender dysphoria or incongruence: a systematic review</u>	Taylor et al: Puberty suppression
	<u>Masculinising and feminising hormone interventions for adolescents with gender dysphoria or incongruence: a systematic review</u>	Taylor et al: M/F hormones
	<u>Care pathways of children and adolescents referred to specialist gender services: a systematic review</u>	Taylor et al: Care pathways
INTERNATIONAL GUIDELINES	<u>Clinical guidelines for children and adolescents experiencing gender dysphoria or incongruence: a systematic review of guideline quality (part 1)</u>	Taylor et al: Guidelines 1: Appraisal
	<u>Clinical guidelines for children and adolescents experiencing gender dysphoria or incongruence: a systematic review of recommendations (part 2)</u>	Taylor et al: Guidelines 2: Synthesis
INTERNATIONAL SURVEY	<u>Gender services for children and adolescents across the EU-15+ countries: an online survey</u>	Hall et al: Clinic survey
SUMMARY REPORT	<u>The epidemiology, care pathways, outcomes, and experiences of children and adolescents with gender dysphoria/incongruence: a series of linked systematic reviews and an international survey</u>	Systematic review summary (Appendix 2)
QUALITATIVE STUDY	<u>Qualitative Research Summary: Narrative accounts of gender questioning</u>	Qualitative study summary (Appendix 3)
QUANTITATIVE STUDIES	<u>Overview of Study Development: Assessment, Management and Outcomes for Children and Young People Referred to a National Gender Identity Development Service</u>	Data linkage study (Appendix 4)
	<u>Preliminary report: Epidemiology and Outcomes for Children and Young People with Gender Dysphoria: Retrospective Cohort Study Using Electronic Primary Care Records</u>	CPRD study (Appendix 5)

Research governance

1.17 The original research studies were reviewed by the Health Research Authority's (HRA) Research Ethics Committee to ensure the interests, safety, and wellbeing of participants were protected. Where the research was to involve access to pseudonymised patient datasets, approval was also sought from the HRA's Confidentiality Advisory Group. This assessment ensures the research complies with the Data Protection Act 2018.

1.18 The systematic reviews were registered on an international database of prospective research (PROSPERO) to avoid research duplication, promote transparency, and minimise risk of bias.

1.19 The original research studies were reviewed by the Health Research Authority's (HRA) Research Ethics Committee, to ensure the interests, safety, and wellbeing of those affected were being protected. Where the research was going to involve access to pseudonymised patient data sets, approval was also sought from the HRA's Confidentiality Advisory Group. This assessment ensures compliance of the research with the Data Protection Act 2018.

1.20 Final HRA approval ensured overall integrity of the research by bringing together the assessment of governance and legal compliance.

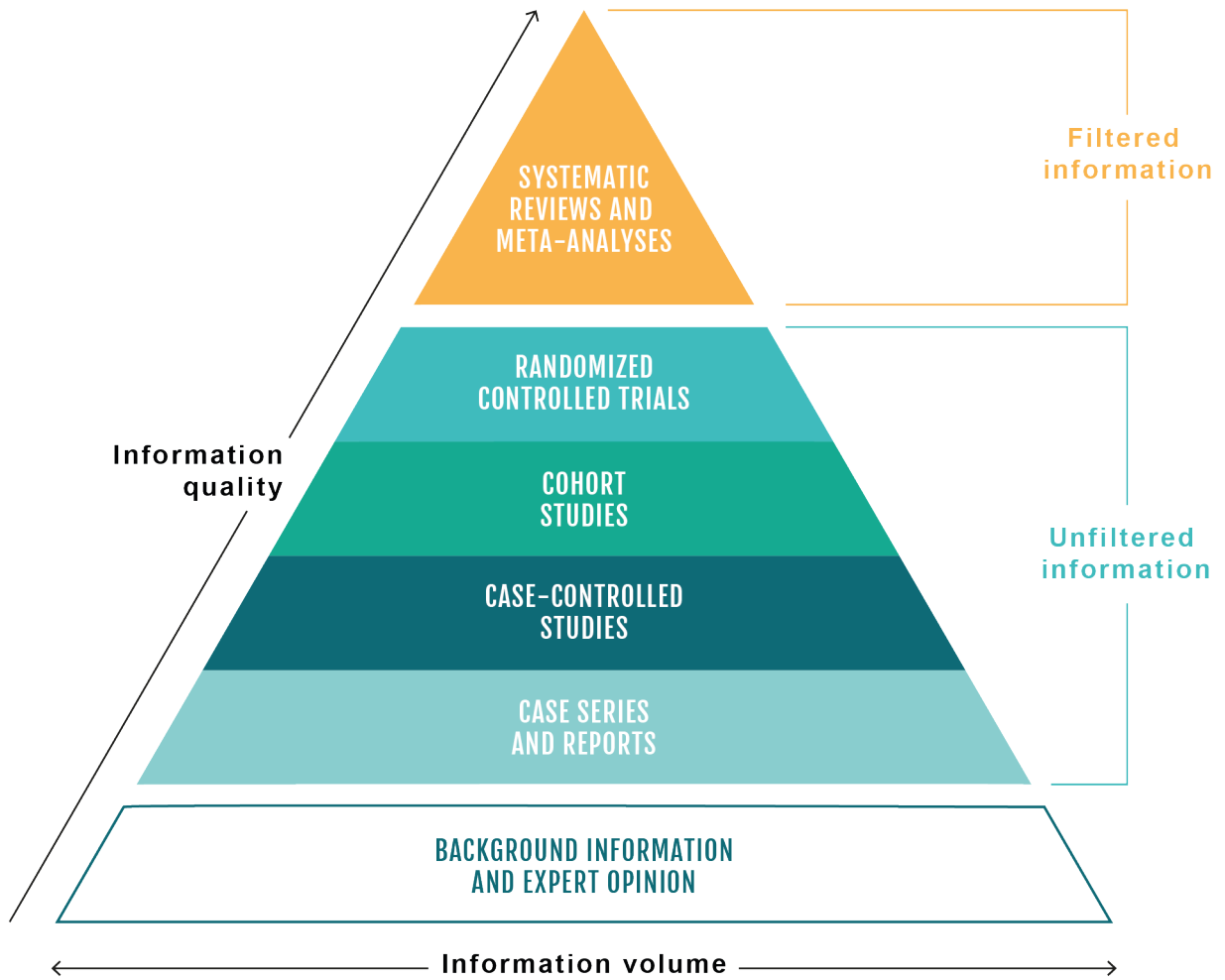
Systemic reviews

Explanatory Box 2:

Systemic reviews

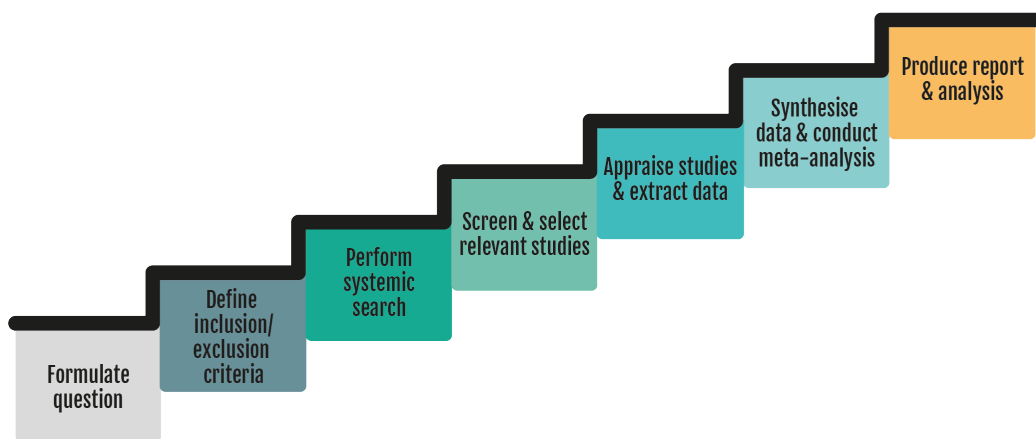
- The highest form of evidence is that generated by a systematic review (Figure 5). A systematic review is different from a general review article. It is a summary of the literature on a particular question that uses explicitly defined and reproducible methods to systematically search, critically appraise, and synthesise primary research information (Cochrane, 2016; NIHRtv, 2010). It is designed to be reproducible, reliable and to eliminate bias.
- Standardised quality assessment tools or questionnaires are available for assessing different types of studies. This ensures that, as far as is possible, different people appraising a paper will come to similar conclusions.

Figure 5: Pyramid of standards of evidence



Source: Reproduced with permission from: OpenMD. (2021, July 17). Levels of evidence. Levels of Evidence in Medical Research. <https://openmd.com/guide/levels-of-evidence>

Figure 6: Steps in a systematic review



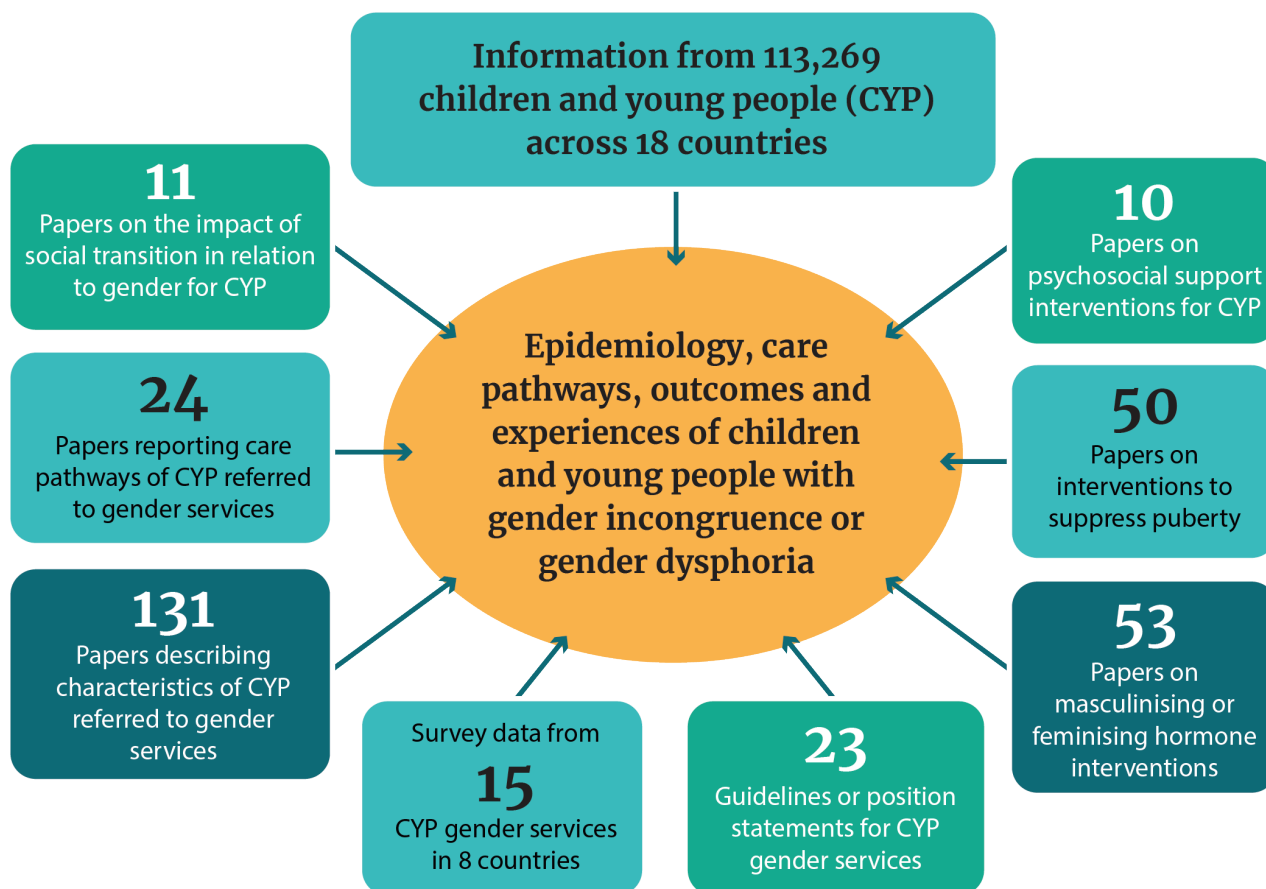
- The purpose of synthesising the data is to combine multiple different studies to get an overall impression of the strength of the evidence; for example, in favour or against a particular intervention. To do this, the reviewers need to assess the quality of the studies in terms of recruitment, bias, design, analysis and all the other factors described above. They will only include studies that meet a quality standard. Provided that those studies have used similar measures and outcomes, their outcomes can be combined (synthesised) across a much larger sample of participants.
- GRADE (Grading of Recommendations, Assessment, Development, and Evaluations) is the system widely used by organisations such as the National Institute for Health and Care Excellence (NICE), Cochrane and the World Health Organization (WHO) to summarise the quality of evidence and make clinical recommendations (GRADE working group, n.d.). There are four levels of certainty about results:
 - **High certainty** - The authors have a lot of confidence that the true effect is similar to the estimated effect.
 - **Moderate certainty** - The authors believe that the true effect is probably close to the estimated effect.
 - **Low certainty** - The true effect might be markedly different from the estimated effect.
 - **Very low certainty** - The true effect is probably markedly different from the estimated effect.
- The certainty is not just based on what kind of trial is used, but also the various pitfalls set out above. So, for example, a RCT will be expected to produce results of high certainty, but if there is high attrition and lots of other sources of bias and confounding, the certainty will drop.
- GRADE is commonly used to describe not single studies, but the overall quality of evidence on a particular question posed in a systematic review.

1.21 The University of York is the home of the Centre for Reviews and Dissemination, one of three bodies funded by the National Institute for Health and Care Research (NIHR) to provide a systematic review service to the NHS.

1.22 The systematic reviews were commissioned because they are considered to provide the most trustworthy summary of what is known (Figure 5).

1.23 A single search strategy was developed for all the systematic reviews to identify studies examining gender dysphoria, gender-related distress or gender incongruence in children/adolescents. The search was conducted between 13 and 23 May 2021 and updated on 27 April 2022. The reference lists of eligible studies and any relevant systematic reviews including clinical guidelines that were identified were also checked.

Figure 7: Overview of studies included in the systematic reviews, international survey and guideline appraisals undertaken by the University of York



Source: The epidemiology, care pathways, outcomes, and experiences of children and adolescents experiencing gender dysphoria/incongruence: a series of linked systematic reviews and an international survey report by University of York (Appendix 2).

1.24 Overall, searches yielded 28,147 records. Figure 7 shows the number of studies that met the criteria for inclusion. In addition, the research team monitored for and appraised relevant references that were published after the primary search.

1.25 Most of the studies in the systematic reviews were cohort, cross-sectional or pre-post design, explanations for which can be found in Explanatory Box 1 and on the NICE website (NICE, 2012).

International guideline reviews and survey of gender clinics

1.26 Achieving consensus on the appropriate approach to care for gender-questioning children and young people is challenging both in the UK and internationally. An essential starting point was to obtain an appraisal and synthesis of international guidelines in order to consider whether practice was transferable to the UK.

1.27 Recognising that not all aspects of service delivery were documented in local guidelines and that some countries had changed their approach since their guidelines were written, a survey of gender clinics for children and adolescents across the UK and EU-15+ countries was carried out. This aimed to identify: the range of services provided across a group of countries with similar health services; and consistency/divergence in practice.

1.28 The results of the review of guidelines and international survey are detailed throughout this report.

Quantitative research

1.29 The Clinical Practice Research Datalink (CPRD) collects anonymised patient data from a network of GP practices across the UK to support clinical studies. For more than 30 years, research using CPRD data and services has informed clinical guidance and best practice.

1.30 Epidemiology and outcomes for children and young people with gender dysphoria: Retrospective cohort study (Appendix 5), commissioned by the Review, utilised linked primary and secondary data from the CPRD.

1.31 The overall aim was to use electronic primary care records to describe the epidemiology of gender dysphoria in people aged 18 and under in England from 2009 to 2021.

Explanatory Box 3:

Qualitative versus quantitative studies

- Quantitative research generates numerical or measurable data, whereas qualitative research generates information about subjective experiences, feelings and thoughts. Both types of research make a unique contribution to considerations about service provision, treatment options and patient-centred care.
- The methods for conducting qualitative research are as robust as the methods for quantitative research, and also involve identifying a question, and then collecting, analysing, and interpreting data, although the data will be interview-based rather than numerical.

Data linkage study

1.32 Little is known about the support and interventions received by the children and young people who accessed the Gender Identity Development Service (GIDS) and their outcomes.

1.33 The data linkage study, using data held by the NHS, was commissioned to improve the level and quality of evidence for their treatment and care by using existing data held by the NHS. Data from GIDS, hospital wards, outpatient clinics, emergency departments and adult gender dysphoria clinics (GDCs) would be used to track the journeys of all children and young people (approximately 9,000) referred to GIDS through the system and provide a population-level evidence base of the different pathways people take and the outcomes.

1.34 The objectives stated in the study protocol were:

- i. To describe the clinical and demographic characteristics of this population of children and their clinical management in the GIDS service.
- ii. To assess the intermediate outcomes of this population of children utilising national healthcare data.

1.35 There have been challenges in progressing this study and the findings are not available to inform this report. Further details are contained in Chapter 15 and Appendix 4.

Qualitative research

1.36 The Review commissioned a participative, qualitative research project with the aim of understanding the full range of experiences and outcomes for young people with gender dysphoria. This research used robust internationally endorsed methods appropriate for qualitative research.

1.37 It sought to capture children's, young people's and young adults' experiences of gender-related dysphoria/distress, their perspectives on their journeys, and their views on how services could and should be delivered in the future, exploring barriers or facilitators to providing this care.

1.38 The study also gathered the perspectives of parents/carers and professionals delivering services on the referral, assessment and treatment pathways currently open to them.

1.39 The objectives of the study were:

- i. To explore how children, young people and young adults understand, respond and negotiate gender-related dysphoria/distress and discomfort within the context of their social networks.
- ii. To examine the perspectives, understandings and responses of parents (or carers), including how they support their child.
- iii. To investigate how children, young people, young adults and their families experience and negotiate current referral, assessment and possible treatment and intervention options within the national specialist service referral, assessment and (possible) treatment.
- iv. To understand the role and experiences of care professionals who offer support, including identifying shared and potentially divergent views of what constitutes optimal care.

Stakeholder engagement

1.40 In addition to the formal qualitative research, the Review has been underpinned by an extensive programme of proactive engagement.

1.41 Support and advocacy groups advised that to hear from the young people at the heart of the Review, opportunities needed to be created where they felt safe, could be supported before, during and after their contribution, and would be engaged around topics on which they have a genuine ability to inform and influence decisions.

1.42 The sensitivity of the subject matter, coupled with the fierce public debate, meant that some of the usual methods one might employ when conducting a review of this kind were not appropriate. Indeed, one of the major challenges for the Review has been the difficulty in having open, honest debate as people with differing views can find it uncomfortable to sit together in the same room or on the same stage.

It was abundantly clear that opportunities for people to contribute would need to be carefully navigated and well planned.

1.43 A mixed-methods approach was taken that prioritised two categories of stakeholders:

- People with relevant lived experience (direct or as a parent/carer) and organisations working with LGBTQ+ children and young people generally.
- Clinicians and other relevant professionals with responsibility for providing care and support to children and young people within specialist gender services and beyond.

1.44 Overall, the Review has met with over 1,000 individuals, some in one-to-one meetings and some in bespoke meetings on a particular topic or others focused on building awareness and improving understanding of the issues among interested parties and organisations. Below is an outline of the structured processes employed.

Figure 8: Proactive engagement methods



Lived experience engagement

Personal narratives

1.45 In the early stages of the work the team met with individuals who had conducted comparable reviews and inquiries to learn what they had done to ensure that the views of people affected were captured. Consideration was given to the merits of making an open call for evidence but, unlike for formal public inquiries, there would be no legal status for the information being provided. It was conceded that with no formal process or capacity to analyse the submissions and validate their authenticity, the Review ran the risk of raising expectations and collecting a large volume of potentially sensitive information that it would not be able to effectively process.

1.46 However, the Review did receive a number of written submissions describing individuals' personal experiences of gender services or gender identity exploration. While there was no formal process for analysing these submissions, all were read by the Review to see if the issues they raised were consistent with what had been heard from other sources or were new and relevant. If the latter, the individual was invited to attend a listening session.

Listening sessions (lived experience and professional)

1.47 The Review Chair held weekly listening sessions to hear directly from people with primary lived experience (individuals who identify as transgender, non-binary, gender fluid and/or who have been through a period of gender-questioning) or secondary lived experience relevant to the Review (a parent/carer of a gender-questioning child or young person or a clinician or other professional with direct and relevant experience working with these children and young people). These confidential sessions have provided the Review

with invaluable insight into how services are currently experienced. They have contributed to the Review's understanding of the positive experiences of living as a trans or gender diverse person as well as uncertainties, complexities and challenges faced by children, young people and their families/carers.

Focus groups - (lived experience)

1.48 In autumn 2022, the Review team hosted a series of focus groups specifically to discuss the proposed data linkage study. Due to the ages of those whose data would be accessed for the research, and concern that the sessions could attract interest from those outside the scope of the study, it was deemed inappropriate to issue an open invitation to the sessions. Instead, the focus groups were promoted via the GIDS stakeholder group, related NHS-funded services, and support and advocacy groups. While this did restrict the team's ability to recruit participants, it ensured that the sessions were conducted in a safe and protected environment.

1.49 Reflecting on and responding to the previous recruitment difficulties, in spring 2023 the Review commissioned (through an Expression of Interest process) six support and advocacy organisations to facilitate 18 focus groups to better understand the thoughts and ideas of young people and adults (aged 14-30) with lived experience. This approach was taken as the commissioned organisations had access to the target audience and were able to provide a supportive environment in which participants felt comfortable and confident to speak freely.

1.50 The Review developed three sets of questions to be used in the groups. These explored:

- Past and current experiences of services including assessment, diagnosis and expectations of clinicians.
- Thoughts and ideas about future services including location, environment and support and the interventions they would want access to.
- Information needs and wider support.

[View summary report.](#)

Regular meetings with support and advocacy organisations

1.51 The Review met regularly with support and advocacy organisations for which support of gender-questioning young people is their primary function or a significant element of their work. Separate meetings were held with each organisation to encourage open and frank conversations. This two-way communication has provided the Review with a better understanding of how service users are experiencing services and policy changes, and given these organisations a greater level of understanding in the work of the Review.

Clinical and professional engagement

1.52 The Review received a high level of clinical input in a variety of forms including listening sessions, group events and workshops (for example, to test thinking on the proposed future service model). Presentations and discussion with different professional groups at conferences or training sessions helped raise awareness of the Review and the dilemmas around clinical care.

Importantly, this created opportunities for a much wider group of clinicians to pose questions, share experiences and contribute to thinking. There have also been regular meetings with the heads of relevant Royal Colleges and professional bodies.

Clinical Expert Group

1.53 A Clinical Expert Group was established to consider the strength of the evidence and findings from the Review's research programme, and assist the Review in achieving clinical consensus where evidence is not available or limited. Membership included clinical experts on children and adolescents in relation to gender, development, physical and mental health, safeguarding and endocrinology.

Thematic roundtables

1.54 Roundtable discussions were facilitated with experts in a range of associated topics to explore specific questions in greater depth. Roundtable discussions were held on:

- intersection of mental health, psychosexual development and gender-related distress
- safeguarding
- workforce
- learning from lived experience.

1.55 These discussions are reflected throughout this report.

Professional panel and gender specialists survey

1.56 In autumn 2021, in order to understand the challenges and establish a picture of competency, capacity and confidence among the workforce outside the specialist gender development service, an online professional panel was established to explore issues around

gender identity services for children and young people. The panel engaged in weekly individual or group activities over a six-week period.

[View summary report.](#)

1.57 Following the conclusion of the professional panel the Review undertook an online survey of gender specialists - clinicians and associated professionals who predominantly or exclusively work with children and young people who need support around their gender identity. The survey contained some service specific questions, but also reflected and sought to test some of what the Review had heard from specialists through our listening sessions and from primary and secondary care professionals engaged in the professional panel activities.

[View summary report.](#)

1.58 The outputs from these activities were reported in the interim report (4.29-4.39) and have continued to inform our work.

Engagement with gender specialists

1.59 Much of the clinical experience of working with these children and young people resides among staff with experience of working in GIDS.

1.60 Since the early stages of the Review, the team established fortnightly meetings with clinical and managerial leads from GIDS, providing space to hold open conversations and discuss challenges and ideas.

1.61 The Review has drawn on GIDS' insight, knowledge and experience in several ways. Senior clinical staff have participated in workshops hosted by the Review and two senior clinicians from GIDS sat on the Review's Clinical Expert Group.

1.62 In addition to the gender specialists survey, many of the GIDS clinicians (both current and former) have shared their experience and thoughts in one-to-one listening sessions and their insights have been valuable in building understanding of the challenges of and opportunities for developing a new approach.

1.63 In the latter stages, the Review hosted focus groups with GIDS staff to test and develop emerging thinking on a number of key areas:

- i. workforce and training
- ii. packages of care
- iii. pathways and wider system working

1.64 The Review has also engaged with clinicians working in gender services in other countries.

Summary

1.65 The strengths and weaknesses of the evidence base on the care of children and young people are often misrepresented and overstated, both in scientific publications and social debate. Systematically reviewing and evaluating the evidence has been fundamental to the Review's approach.

1.66 Hearing directly from the children and young people at the heart of this Review, their parents/carers and the clinicians working in and around services trying to support them, has provided valuable insight into the ways in which services are currently delivered and experienced. This has contributed immeasurably to the Review's understanding of the positive experiences of living as a transgender or gender diverse person, as well the uncertainties, complexities and difficulties faced.

1.67 Pulling insights together from these different activities has not been easy. There are areas where there is no clear consensus and finding a middle ground is not possible where perspectives are so polarised.

1.68 Sometimes, there is a mismatch in expectations between service users, their families and advocates and what it is possible for the NHS to provide. In those instances, the Review has needed to think about what would be normal practice in the NHS and then to consider whether there is any reasonable and rational reason for services for this cohort to respond or operate differently.

1.69 This report describes what has been learnt in the course of the Review and provides advice on how the services need to operate in future. A summary of the evidence base underpinning each area of consideration is provided and links to corresponding papers are provided where available.



Context



2. History of gender services for children and young people

2.1 This Review is about services for children and young people who experience gender incongruence/dysphoria or gender-related distress. However, the evolution of care for this group, and some of the dilemmas that have emerged, need to be understood in the broader context of the struggle that transgender people have faced - and still continue to face - in accessing care, support and understanding of their clinical needs.

2.2 There are polarised debates about a range of societal issues involving transgender people in the UK, ranging from use of single-sex spaces to participation in sports. Although these issues are outside the scope of this Review, they have an impact on gender-questioning young people because of the inflexibility of the factional opinion and resulting toxicity of the debates. Services for children and young people have evolved within the context of this broader picture and every person involved in this work has been and continues to be affected by the dialogue.

Early gender services for children and young people

2.3 Services for children and young people with gender incongruence started in the mid-1970s in Canada, and in 1987 in the Netherlands. It is important to understand the early populations accessing these services to make sense of how they have changed in more recent years.

2.4 The Gender Identity Development Service (GIDS) was established in 1989 by Domenico Di Ceglie at St George's Hospital, London later moving to The Tavistock and Portman NHS Foundation Trust. Initially, the numbers seen were small (fewer than 10 per annum in the first few years), with pre-pubertal birth-registered males being the largest group.

2.5 The main focus of the early services was on therapeutic work with children and families, with only a small proportion with persisting gender incongruence being referred for hormone treatment from around age 16.

2.6 Several studies from that period (Green et al., 1987; Zucker, 1985) suggested that in a minority (approximately 15%) of pre-pubertal children presenting with gender incongruence, this persisted into adulthood. The majority of these children became same-sex attracted, cisgender adults. These early studies were criticised on the basis that not all the children had a formal diagnosis of gender incongruence or gender dysphoria, but a review of the literature (Ristori & Steensma, 2016) noted that later studies (Drummond et al., 2008; Steensma & Cohen-Kettenis, 2015; Wallien et al., 2008) also found persistence rates of 10-33% in cohorts who had met formal diagnostic criteria at initial assessment, and had longer follow-up periods. It was thought at that time that if gender dysphoria continued or intensified after puberty, it was likely that the young person would go on to have a transgender identity into adulthood (Steensma et al., 2011).

Emergence of the Dutch protocol

2.7 The approach to treatment changed with the emergence of ‘the Dutch protocol’, which was developed by Dr Peggy Cohen-Kettenis founder of the Utrecht clinic. One of the drivers for developing gender care services for children was the recognition of poor mental health outcomes for the adult transgender population, much of which was attributed to minority stress and difficulty “passing” in their expressed gender (Cohen-Kettenis & Van Goozen, 1998).

2.8 In 1998, a single case study (Cohen-Kettenis & Van Goozen, 1998) described a female to male transition where puberty blockers were started at age 13. The rationale for the approach was two-fold; to support the diagnostic procedure by buying time to think and to improve the longer-term ability to pass in the preferred gender.

2.9 The Dutch protocol was further elaborated in an article in 2006 (Delemarre-van de Waal & Cohen-Kettenis, 2006) by which time 54 patients were being treated, and in 2011 the Dutch team published a prospective study (de Vries et al., 2011b) of 70 patients who had received early treatment with puberty blockers between 2000 and 2008. Inclusion criteria were that the patients had to be minimum age 12, have suffered from life-long gender dysphoria that had increased around puberty, be psychologically stable without serious comorbid psychiatric disorders that might interfere with the diagnostic process, and have family support. The authors discussed the challenge in adolescents with an autistic spectrum disorder (ASD) of disentangling “whether gender dysphoria evolves from a general feeling of being just “different” or whether a true “core” cross-gender identity exists”.

2.10 The 70 patients in the study (de Vries et al., 2011b) were a subset of a larger group of 111 cases consecutively referred for puberty blockers; the 70 were selected because they were the first ones ready to start the next stage of treatment - masculinising or feminising hormones. Of the 70 patients, 89% were same-sex attracted to their birth-registered sex, with most of the rest being bisexual. Only one patient was exclusively heterosexual. The outcomes for the remaining 41 cases were not reported.

2.11 During puberty suppression, there was no change in body dysphoria, but behavioural and emotional problems decreased, and general functioning improved. However, not all participants (59-73% on the various measures) completed questionnaires after treatment, a potential source of bias, making it difficult to draw conclusions from the results.

2.12 A confounding factor was that all patients in the Dutch service were seen regularly by their psychiatrist or psychologist whilst on puberty blockers, so it is difficult to separate the therapeutic effects of these sessions from the role of puberty blockers alone.

Explanatory Box 4:

Dutch protocol:

Minimum age 12, life-long gender dysphoria increased around puberty, psychologically stable without serious comorbid psychiatric disorders that might interfere with the diagnostic process and family support.



Move to an affirmative model

2.13 In 2007 Norman Spack established a clinic in Boston, USA modelled on the Dutch protocol and began prescribing puberty blockers from early puberty (Tanner stage 2).

2.14 Practice in the USA began to diverge from the models of care in Canada and the Netherlands, following instead a gender affirmative model advocated by Diane Ehrensaft (Ehrensaft, 2017).

She described the three approaches as follows (Ehrensaft, 2017):

“The first model, represented in the work of Drs Susan Bradley and Ken Zucker [Canada], assumes that young children have malleable gender brains, so to speak, and that treatment goals can include helping a young child accept the gender that matches the sex assigned to them at birth.

The second model, represented in the work of practitioners in the Netherlands, allows that a child may have knowledge of their gender identity at a young age, but should wait until the advent of adolescence before engaging in any full transition from one gender to another.

The third model, represented in the work of an international consortium of gender affirmative theoreticians and practitioners, allows that a child of any age may be cognizant of their authentic identity and will benefit from a social transition at any stage of development.”

2.15 The third model - the ‘affirmative model’ - has subsequently become dominant in many countries. As a result, some gender services have moved away from a more exploratory approach, and this is seen by some advocacy and support groups as a move to ‘gatekeeping’ model.

2.16 It is important to note that staff at GIDS have told us that in their practice an affirmative

model can encompass respecting the young person’s experience and sense of self whilst still exploring the meaning of that experience in a non-directive therapeutic relationship.

Use of puberty blockers in the UK

2.17 The ‘watchful waiting’ approach continued in the UK until 2011, when puberty blockers were trialled under a research protocol; the ‘early intervention study’. This was an uncontrolled study with inclusion criteria in line with the original Dutch protocol, and similar outcome measures. It is unfortunate that a controlled study was not conducted by the UK team, given that this was the only formal attempt to replicate the Dutch approach using directly comparable outcome measures. Using the same methods as the Dutch observational study meant that the same limitations apply; that is, confounding of endocrine and psychological interventions and significant attrition at follow-up.

Early intervention study

2.18 Between 2011 to 2014, 44 patients aged 12-15 were recruited to the ‘early intervention study’ and preliminary results were reported to The Tavistock and Portman NHS Foundation Trust Board in 2015 (Tavistock and Portman NHS Foundation Trust Board papers, 2015), at which point patients had received at least one year of treatment, and at the 2016 World Professional Association for Transgender Health (WPATH) conference when all patients had been followed up for at least two years (<https://www.youtube.com/watch?v=8HQBfuV3V98>).

2.19 In contrast to the Dutch group, the UK’s preliminary findings did not demonstrate improvement in psychological wellbeing, and in fact some birth-registered females had a worsening of ‘internalising’ problems (depression, anxiety) based on parental report. In response to the Youth Self Report Scale, there was a significant increase after one

year on treatment in adolescents scoring the statement “I deliberately try to hurt or kill myself” as ‘sometimes true’, especially among birth-registered females (The Tavistock and Portman NHS Foundation Trust Board Papers, 2015).

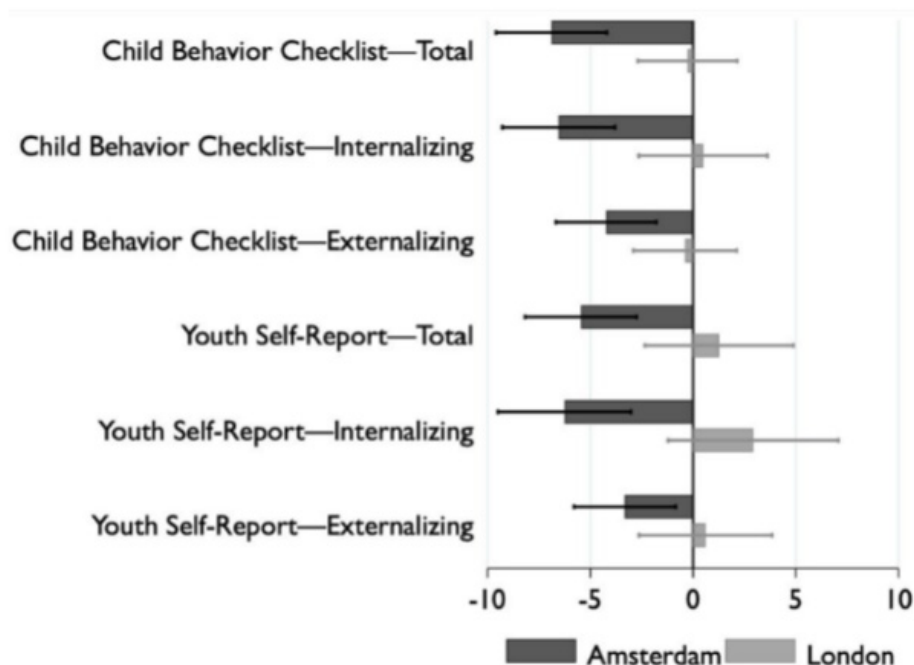
2.20 The early intervention study results were not published in preprint until December 2020 (Carmichael et al., 2021). There were no statistically significant changes reported in gender dysphoria or mental health outcome measures whilst on puberty blockers, and 98% proceeded to masculinising or feminising hormones.

2.21 A secondary analysis of the data from the Dutch and UK studies demonstrated that the two groups were the same at baseline on the key mental health outcome measures that were used to assess changes (Biggs, 2022).

Figure 9 shows the level of improvement in the Dutch cohort and the lack of improvement in the UK cohort after puberty suppression. The reasons for this are not clear but may be due to other baseline differences in the two samples, or differences in the quality of care offered by the two clinics.

2.22 A subsequent re-analysis of the early intervention study (McPherson & Freedman, 2023), using original anonymised data from the study, took account of the direction of change in mental health outcomes for individual young people rather than just reporting group means. This secondary analysis found that 37-70% experience no reliable change in distress across time points, 15-34% deteriorate and 9-29% reliably improve.

Figure 9: Change in psychological functioning after puberty suppression with GnRH [puberty blocker]



Source: Biggs, M. (2022). *The Dutch protocol for juvenile transsexuals: Origins and evidence*. *Journal of Sex & Marital Therapy*, 49(4), 348-368. <https://doi.org/10.1080/0092623x.2022.2121238>. Published with license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>) by Taylor & Francis Group, LLC.

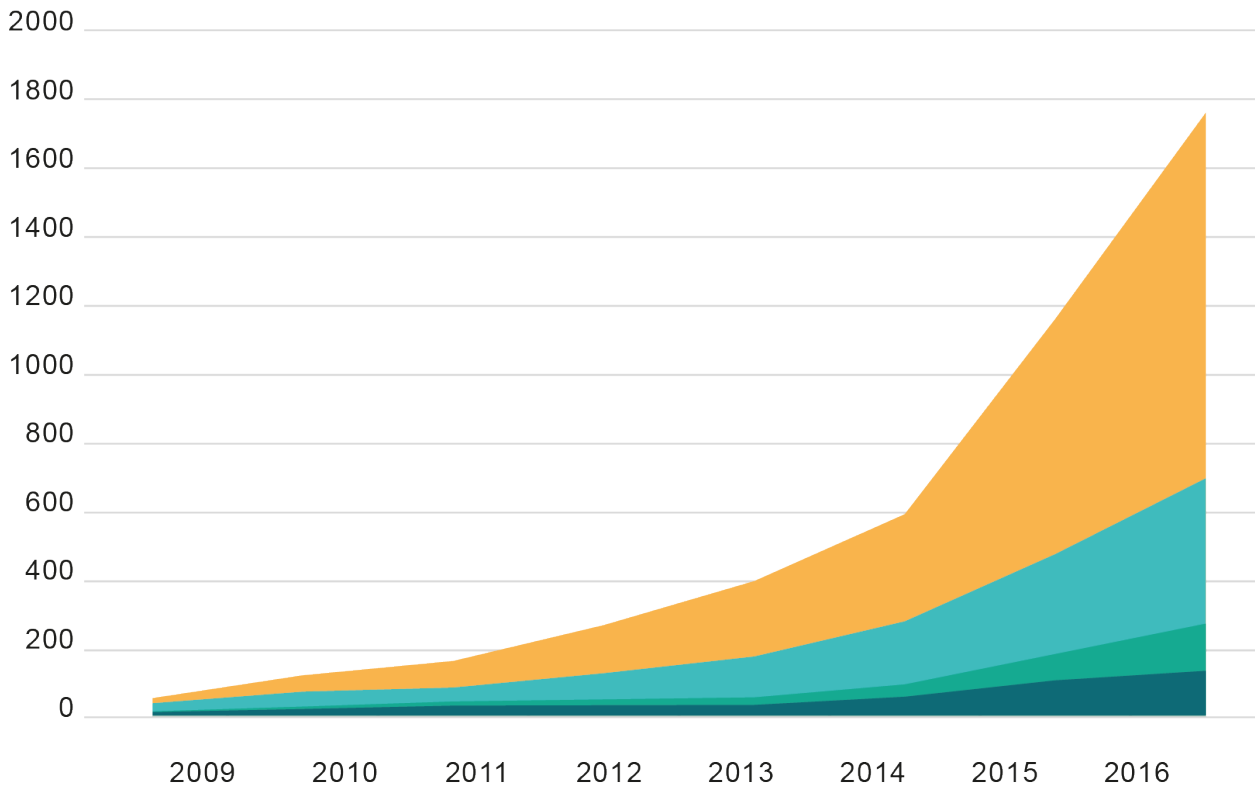
NB: The bar shows the change in T-score from baseline; negative values indicate reduced problems. The line traces the 95% confidence interval. N=54 at Amsterdam, N=41 at London. Data reported from de Vries et al. (2011, Table 2) and Carmichael et al. (2021).

Research into routine practice

2.23 As highlighted in the interim report, in 2014 the number of referrals started to grow exponentially in the UK with a higher number of birth-registered females presenting in early teenage years (Figure 10).

2.24 From 2014, puberty blockers moved from a research-only protocol to being available through routine clinical practice. In light of the above findings, the rationale for this is unclear.

Figure 10: Sex ratio in children and adolescents referred to GIDS in the UK (2009-16)



AFAB = Assigned female at birth

AMAB = Assigned male at birth

* Indicates $p < .05$ which shows a significant increase of referrals compared to previous year

Source: Figure adapted from de Graaf, N. M., Giovanardi, G., Zitz, C., & Carmichael, P. (2018). Sex ratio in children and adolescents referred to the Gender Identity Development Service in the UK (2009-2016). *Archives of Sexual Behavior*, 47(5), 1301-1304. <https://doi.org/10.1007/s10508-018-1204-9>, with permission from Springer Nature.

2.25 In addition, the strict inclusion criteria of the Dutch protocol were no longer followed, and puberty blockers were given to a wider range of adolescents than would have met the inclusion criteria in either the Dutch or UK studies.

These included patients with no history of gender incongruence prior to puberty, as well as those with neurodiversity and complex mental health presentations.

2.26 On its establishment, NHS England took on responsibility for commissioning services for children and young people experiencing gender dysphoria. Gender services for children and young people is considered a highly specialised service; these services for very rare and/or complex conditions are usually provided to no more than 500 patients a year. Because of the small number of patients, the services are provided in a limited number of hospitals which enables the clinicians to maintain their expertise.

2.27 In 2016, NHS England refreshed the GIDS service specification, which sets out what a healthcare provider needs to deliver (NHS England, 2019). The Tavistock and Portman NHS Foundation Trust was recontracted to deliver the service.

2.28 The service specification described a therapeutic service providing “psychological/ psychosocial support aimed at increasing the wellbeing and resilience of the client” and “therapeutic exploration of gender identity development and gender expression, including in relation to the client’s familial, social and cultural situation” (NHS England, 2019).

2.29 The specification recognised that “the research evidence around the long-term impacts of some treatments is limited and still developing and that by no means all clients with [gender dysphoria] choose to have physical interventions”. Recognising the uncertainty, it set out that “hormone blockers will be considered as an appropriate treatment alongside psychological intervention” (NHS England, 2019).

2.30 The specification allowed for referral of “carefully selected clients who are at least in Tanner Stage 2 of puberty and are up to the age of 15” to the Paediatric Endocrine Liaison Team’s Early Intervention’ Clinic. The specification stated that “The Early Intervention Clinic will continue to follow the Service’s 2011 research protocol, which following evaluation, has now become established practice, with the exception that hormone blockers will now be considered for any children under the age of 12 if they are in established puberty.” (NHS England, 2019).

2.31 Clinical practice subsequently appears to have deviated from the parameters set out in the service specification which required that the narrow criteria of the 2011 research protocol be followed when considering medical intervention. The adoption of a medical treatment with uncertain risks, based on an unpublished trial that did not demonstrate clear benefit, is a departure from normal clinical practice.

2.32 This, in combination with the long delay in publication of the results of the early intervention study, is likely to have had an impact on patient expectations of the benefits of the intervention and subsequent demand for treatment.

2.33 The Review has been focused on future service provision and did not have a remit to explore in detail the factors contributing to the situation that necessitated an independent review.

2.34 However, there are clearly lessons to be learned by everyone in relation to how and why the care of these children and young people came to deviate from usual NHS practice, how clinical practice became disconnected from the clinical evidence base, and why warning signs that the service delivery model was struggling to meet demand were not acted on sooner.

2.35 One of the problems that has been exposed is the governance of innovative clinical practice. Whilst care cannot improve without innovation, good clinical governance should require collection of data and evidence with appropriate scrutiny to prevent the incremental creep of new practices without adequate oversight.

3. Why this Review?

3.1 In January 2020, a Policy Working Group (PWG) was established by NHS England to undertake a review of the published evidence on the use of puberty blockers and masculinising/feminising hormones in children and young people with gender dysphoria to inform a policy position on their future use.

3.2 Given the increasingly evident polarisation among clinical professionals, Dr Cass was asked to chair the group as a senior clinician with no prior involvement or fixed views in this area.

NHS England Policy Working Group (PWG)

3.3 The PWG comprised:

- 2 senior members of the GIDS team
- 3 endocrinologists working in the linked gender services
- 3 representatives with lived experience
- representatives from the Royal College of Paediatrics and Child Health and the Royal College of Psychiatrists
- an academic child psychiatrist
- a primary care academic
- an academic ethicist

NHS England staff:

- a public health consultant
- the national head of safeguarding
- the senior pharmacy lead
- relevant members of the specialised commissioning team

3.4 NHS England uses a standardised protocol for developing clinical policies (NHS England, 2020). The first step of this involves defining the PICO (the Population being treated, the Intervention, a Comparator treatment, and the intended Outcomes). This of itself was challenging, with a particular difficulty being definition of the intended outcomes of puberty blockers, and identification of suitable comparators for both hormone interventions. However, agreement was reached on what should be included in the PICO and subsequently the National Institute for Health and Care Excellence (NICE) was commissioned to review the published evidence, again following a standardised protocol that has strict criteria about the quality of studies that can be included (NICE, 2020a; NICE, 2020b).

NICE evidence reviews

Puberty blockers (GnRH analogues)

3.5 The key questions for this evidence review were (NICE, 2020a):

- For children and adolescents with gender dysphoria, what is the clinical effectiveness of treatment with GnRH analogues compared with one or a combination of psychological support, social transitioning to the desired gender or no intervention?
- For children and adolescents with gender dysphoria, what is the short-term and long-term safety of GnRH analogues compared with one or a combination of psychological support, social transitioning to the desired gender or no intervention?

3.6 The review of the evidence looked at nine studies that met the inclusion criteria. A key limitation of all the studies examined was the lack of reliable comparative studies, as well as of clear expected outcomes. All the studies were small uncontrolled observational studies, and all the results were of low certainty. Many did not report statistical significance.

3.7 The studies that reported impact on gender dysphoria, mental health, body image and psychosocial impact were of very low certainty and suggested little change from baseline to follow-up. The studies that reported bone density outcomes were similarly unreliable so no safety outcomes could be confirmed.

Masculinising/feminising hormones

3.8 The key questions for this evidence review were (NICE, 2020b):

- In children and adolescents with gender dysphoria, what is the clinical effectiveness of treatment with gender-affirming hormones compared with one or a combination of psychological support, social transitioning to the desired gender or no intervention?
- In children and adolescents with gender dysphoria, what is the short-term and long-term safety of gender-affirming hormones compared with one or a combination of psychological support, social transitioning to the desired gender or no intervention?

3.9 Ten uncontrolled observational studies met the inclusion criteria. Again, the key limitation to identifying the effectiveness and safety of gender-affirming hormones for children and adolescents with gender dysphoria was the lack of reliable comparative studies.

3.10 The included studies had relatively short follow-up, with an average duration of treatment with gender-affirming hormones between around 1 year and 5.8 years.

3.11 Results from five uncontrolled, observational studies suggested that, in children and adolescents with gender dysphoria, gender-affirming hormones are likely to improve symptoms of gender dysphoria, and may also improve depression, anxiety, quality of life, suicidality and psychosocial functioning. The impact of treatment on body image was unclear.

3.12 Most studies included in this review did not report comorbidities and no study reported concurrent treatments in detail. Because of this it is not clear whether any of the changes seen were due to gender-affirming hormones or other treatments the participants may have received.

Outcome of PWG and NICE evidence reviews

3.13 The evidence produced by the NICE reviews was inconclusive to the extent that NHS England could not form a policy position on the use of these medications.

3.14 It was clear that although the PWG and NICE evidence reviews were an important step, they did not give NHS England all the answers needed.

3.15 At the same time, concerns about the increasing numbers of gender-questioning children and young people presenting to the NHS were growing. There had also been questions raised about the capacity of GIDS to manage the caseload, as well as the clinical practice.

Commissioning of the Independent Review

3.16 The need for an independent review was clear and driven by the changing situation over the last 10-15 years:

- The exponential increase in the numbers of children and young people presenting to the NHS for help, outstripping the capacity of services to support them. This had led to a waiting list for specialist services in excess of 2 years.
- The marked change in the case-mix, from predominantly pre-pubertal birth-registered males to predominantly peri or post-pubertal birth-registered females, with no clear explanation for this changed demographic.

- The introduction of earlier medical intervention and the weakness of the evidence underpinning the use of puberty blockers (the ‘Dutch approach’) prior to masculinising or feminising hormones at age 16.
- The lack of long-term follow-up, and a weak evidence base to support decision making and development of a policy position on appropriate care.

3.17 This independent Review was commissioned to make recommendations on models of care, appropriate treatment approaches, audit, long-term follow-up and research, as well as workforce requirements. It was also asked to explore the reasons for the increase in referrals and the change in the demographics of the referred population.



4. Wider context

4.1 Since the Review was commissioned, there have been a number of public policy initiatives that, while outside the scope of the Review, have nudged up against its work and may have an effect on the support offered to young people in the future.

4.2 These have led to increased public attention on these issues, creating increasingly hostile and polarised debate. Within this, the Review and the children and young people at its heart have at times been weaponised or misrepresented to justify different positions.

4.3 On occasion the Review has been asked to speak to teams developing these policy areas. In such instances, the Review has provided evidence-based information but has tried not to step beyond the clinical focus of its remit.

Bell v Tavistock

4.4 In October 2019, a legal complaint was lodged against GIDS. It raised concerns about the adequacy of the consent procedures for hormone treatment and described hormone therapy as “experimental” (*Bell v Tavistock*) ([2020] EWHC 3274 (Admin)).

4.5 The case was based on whether the processes whereby the complainant was assessed and referred for hormone treatment were adequate and lawful. The case was heard as a Judicial Review, which focuses on the lawfulness of a particular practice. The High Court found that the processes were lawful.

4.6 The High Court considered that the information that the child would need to understand to have the requisite competence in relation to puberty blockers, would be as follows ([2020] EWHC 3274 (Admin)):

- the immediate consequences of the treatment in physical and psychological terms;
- the fact that the vast majority of patients taking puberty blockers go on to cross-sex hormones and therefore that s/he is on a pathway to much greater medical interventions;
- the relationship between taking cross-sex hormones and subsequent surgery, with the implications of such surgery;
- the fact that cross-sex hormones may well lead to a loss of fertility;
- the impact of cross-sex hormones on sexual function;
- the impact that taking this step on this treatment pathway may have on future and life-long relationships;
- the unknown physical consequences of taking puberty blockers; and
- the fact that the evidence base for this treatment is as yet highly uncertain.

4.7 Controversially they went on to conclude that it would be “doubtful” that 14/15-year-olds have such competence, and “highly unlikely” that children aged 13 or under have competence.

4.8 This High Court decision was overruled on appeal ([2021] EWCA 1363 (Civ)). The Court of Appeal was critical of the High Court’s reliance on contested evidence and of the age-based guidelines for competence, given that the very basis of *Gillick* is that the stage at which a child can demonstrate competence in relation to a decision about a particular medical intervention is individual.

4.9 The *Bell v Tavistock* case points to the contested nature of the evidence around the factors listed above and the understanding needed in order for a child or young person to be able to consent to enter onto a hormone pathway.

4.10 The ability of the child or young person to lawfully consent to this proposed treatment is only one issue. There are two other issues to be addressed; the judgement that the clinician makes as to whether a treatment is indicated for a patient, and the information they provide to them about the potential benefits, risks and alternatives.

Care Quality Commission (CQC) report

4.11 In October and November 2020, the Care Quality Commission (CQC) inspectors carried out an announced, focused inspection of GIDS due to concerns reported to them by healthcare professionals and the Children’s Commissioner for England. Concerns related to clinical practice, safeguarding procedures, and assessments of patients’ ability to consent to treatment.

4.12 The CQC report, published in January 2021 (CQC, 2021), gave the service an overall rating of inadequate. The report noted the high level of commitment and caring approach of the staff but identified a series of issues that needed improvement. In addition to the growing waiting list pressures, the CQC identified problems in several other areas including: the assessment and management of risk; the variations in clinical approach; the lack of clarity and consistency of care plans; the lack of any clear written rationale for decision making in individual cases; and shortfalls in the multidisciplinary mix required for some patient groups. Recording of capacity, competency and consent had improved since new procedures were put in place in January 2020; however, there remained a culture in which staff reported feeling unable to raise concerns.

4.13 The CQC reported that when it inspected GIDS, there did not appear to be a formalised assessment process, or standard questions to explore at each session, and it was not possible to tell from the notes why an individual child might have been referred to endocrinology whilst another had not. Current GIDS data demonstrate that a majority of children and young people seen by the service do not get referred for endocrine treatment, but there is no clear information about what other diagnoses they receive, and what help or support they might need.

4.14 In response to both the original *Bell v Tavistock* judgment and the CQC findings, NHS England established a Multi-Professional Review Group (MPRG). Its remit is to review cases referred to the endocrinology clinic for puberty blockers to determine whether the agreed processes for assessment and informed consent have been properly followed.

The outcome of the Bell Court of Appeal decision did not change this requirement, given the concerns raised by CQC regarding consent, documentation and clarity about decision making within the service.

Interim report and subsequent developments

4.15 The Review has taken an iterative approach and has provided advice at various stages where there was sufficient clarity and clinical agreement about the way forward. In March 2022, the Review published an Interim Report and has subsequently written to NHS England in July 2022 (Appendix 6) and January 2023 (Appendix 7) setting out initial findings and early advice.



4.16 In response, NHS England has begun to implement changes to the clinical service offer in parallel to the Review conducting its business. This includes its decision to decommission GIDS as part of a managed transition of the service, initially to two new nationally networked services (Phase 1 providers) based in specialist children's hospitals.

4.17 While it is positive that improvements have already been made, it has added a layer of complexity to the work of the Review as the clinical landscape has shifted. This will be described in more detail in Part 5 of this report.

4.18 This has inevitably meant that, alongside establishing the longer-term vision for NHS gender identity services for children and young people, some of the Review's focus was redirected to ensure that the development of these interim services focused on the comprehensive, patient and family centred service the Review has outlined.

4.19 It is against this ever-moving, often turbulent backdrop and significant public, political and media attention, that the Review has been conducting its own programmes of work.



Understanding the patient cohort



This part of the report sets out what is currently understood about the characteristics of children and young people who are seeking NHS support for gender incongruence and/or dysphoria and considers what may be driving the rise in prevalence and the change in the case-mix.

Within its terms of reference (Appendix 1), the Review was asked to explore “the reasons for the increase in referrals and why the increase has disproportionately been [birth-registered] females, and the implications of these matters”.

This goes to the heart of some of the core controversies in this area, specifically the nature and causes of gender incongruence and dysphoria, which then has bearing on the appropriate clinical response.

A failure to consider the cause, potential influences and contributory factors can lead to people taking polarised positions. Nuanced discussion is needed about how best to understand and respond to the children and young people at the centre of the debate.

Explanatory Box 5:

Gender incongruence

A marked and persistent incongruence between an individual’s experienced gender and the assigned sex (ICD-11).

Gender dysphoria

Clinically significant distress or impairment of function (DSM-5).

5. Changes in the patient profile

5.1 Throughout the lifetime of the Review, the long waiting lists to access clinical services have been a significant concern for the NHS, and all those supporting this group of children and young people. Child and Adolescent Mental Health Services (CAMHS) and paediatric services are stretched across the UK, but as highlighted in the Review's interim report, gender-questioning children and young people appear to be disproportionately disadvantaged because they are frequently bypassed by local services once on a waiting list for gender services.

5.2 Understanding the numbers being referred is not enough of a basis for the NHS to plan gender services for children and young people. Underlying the numbers is a group of young people who often have a range of needs and/or associated conditions. Any service design has to take account of their holistic needs, not just their gender identity.

Sources of information

5.3 Several sources of information were used to understand the patient profile. These included:

- a systematic review (Taylor et al: Patient characteristics)
- data from the Clinical Practice Research Datalink (CPRD), a database of anonymised patient data from general practices across the UK
- an audit of referral data to the Gender Identity Development Service (GIDS), carried out by NHS Arden & GEM Commissioning Support Unit

- information from international colleagues
- discussions with a range of clinical staff through roundtable events and one-to-one meetings. The points represented are those where there was consistency in clinical perspective.

5.4 The systematic review (Taylor et al: Patient characteristics) examined the numbers of children and adolescents up to the age of 18 referred to specialist NHS gender or endocrinology services. It aimed to determine whether the change in characteristics of the population reported by various national clinics was reflected in published evidence, and how the population had changed over time.

5.5 In total, 131 papers met the inclusion criteria for the systematic review. These covered a wide international base but were primarily from North America, Europe and Australia.

5.6 Information on demographics, gender-related data, mental health, neuro-developmental conditions and adverse childhood experiences were collated from the study papers.

5.7 Where comparable numeric data were available between studies, these data were combined to improve understanding. Where numeric data were not available, the authors described the findings of the research studies in a narrative form.

5.8 At the time of writing, the CPRD study has reported preliminary findings on prevalence of gender dysphoria, co-occurrence of autism spectrum disorder (ASD), anxiety and

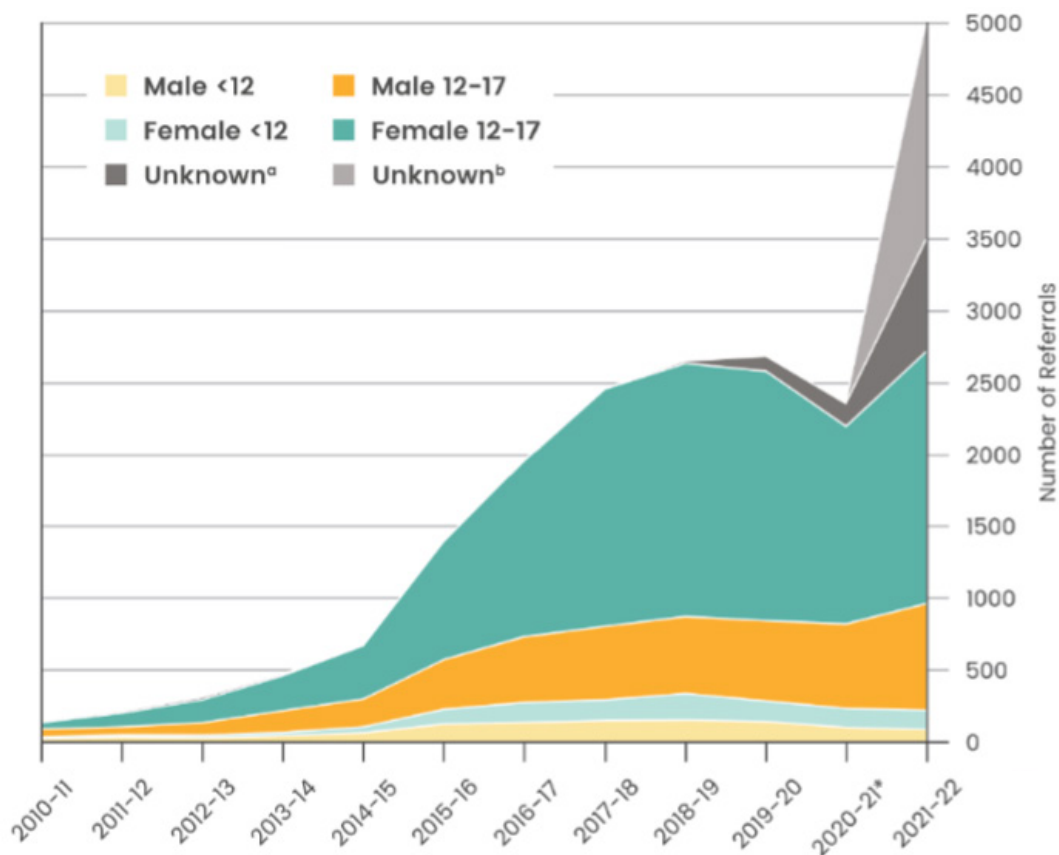
depression. Data for 3,782 people with gender dysphoria under the age of 18 were identified by primary care and hospital care codes for the study period 2009 to 2021. The full methodology for the CPRD study can be found in Appendix 5, as well as the strengths and limitations of the data. Only the incidence and prevalence data are included in this report, pending release of the fuller findings by the University of York on completion of the study.

Demographics

UK data

5.9 From 2014 referral rates to GIDS began to increase at an exponential rate, with the majority of referrals being birth-registered females presenting in early teenage years (Figure 11).

Figure 11: Child and Adolescent Referrals for Gender Dysphoria (UK, GIDS), 2010/11 to 2021/22



*Referral activity to GIDS/Tavistock was sharply limited in 2020-2021 due to COVID-19.

^a Beginning in 2018-19, increasing numbers of referrals are not reported by birth registered sex.

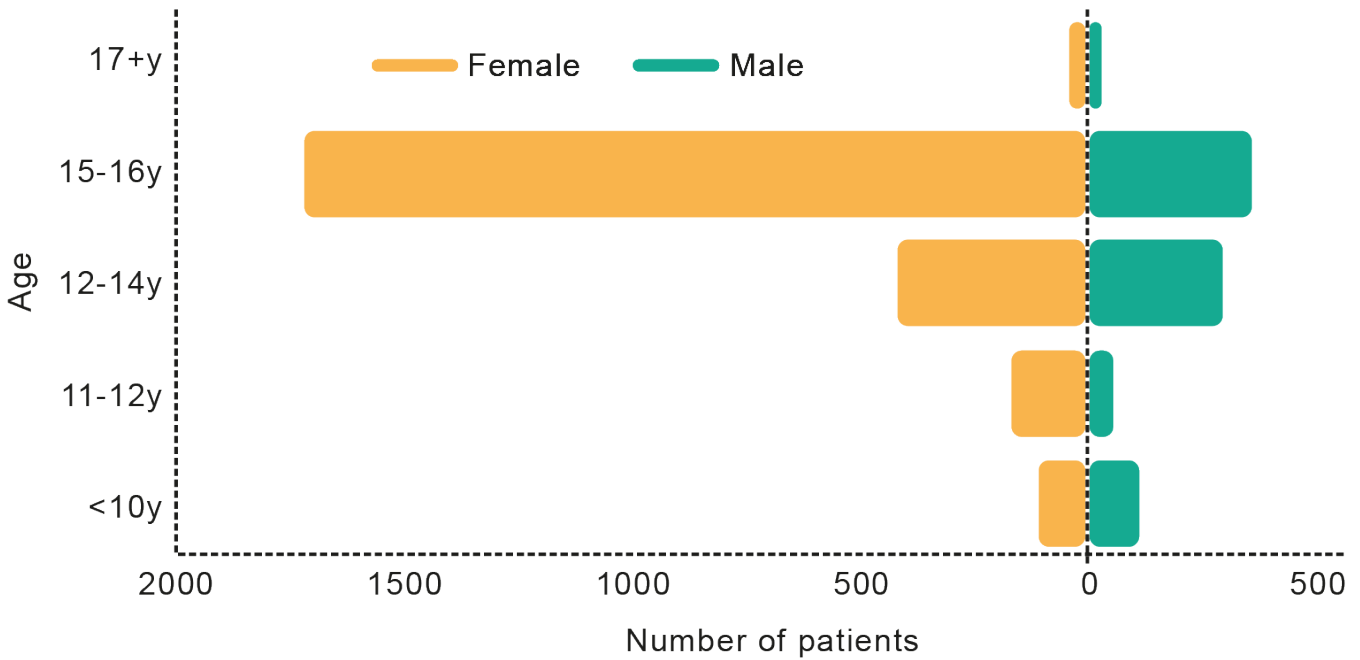
^b Limitations of the data: From the end of July 2021, AGEM CSU received referrals for GIDS from non-NHS sources (GP, schools, local authority, voluntary sector). All NHS referrals into GIDS went directly to the Tavistock and Portman GIDS. Data from the Tavistock and Portman GIDS website indicated that during 2021/22 they received in excess of 3000 referrals and further referrals received by AGEM CSU (approximately 1500 referrals) were not counted. Combined this indicated that the GIDS received a total of approximately 5000 referrals in 2021/22 alone. When reviewing the data that the GIDS provided against the number of referrals transferred into AGEM CSU as part of the waiting list transfer, the CSU only received 3115 referrals that were "new". This is significantly less than the number expected considering that they reported that in 2021/22 there were over 5000 referrals received. It is difficult to know if the quoted, over 5000 referrals in 2021/22, is correct. There is a strong possibility that there was double counting during 2021/22 as the referral numbers received by AGEM CSU were being reported to the GIDS who were then also sharing this information with the Care Quality Commission.

AGEM CSU: Arden & GEM Commissioning Support Unit.

5.10 Figure 12 below shows referral data from an audit of discharge notes of GIDS patients discharged from the service between 1 April 2018 and 31 December 2022 (Appendix 8). The youngest age of patients referred to GIDS was

3 years, the oldest age was 18 years and the mean and median 14 years. Of these referrals, 73% were birth-registered females and 27% birth-registered males.

Figure 12: Distribution of patient's age on referral and birth-registered gender on referral to GIDS, 1 April 2018 to 31 December 2022

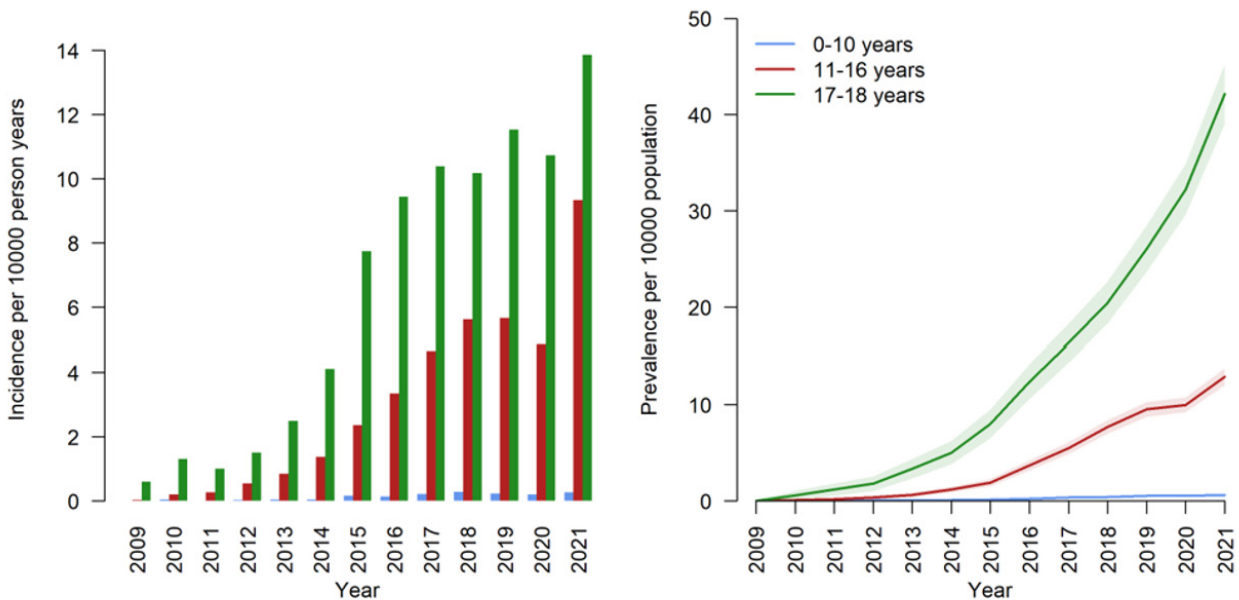


Source: *The Gender Identity Development Service Audit Report, Arden & GEM.*

5.11 In the sample drawn from CPRD data (Figures 13 & 14) (Appendix 5), recorded prevalence of gender dysphoria in people aged 18 and under increased over 100-fold between 2009 and 2021. This increase occurred in two phases; a gradual increase between 2009

and 2014, followed by an acceleration from 2015 onwards. Increases in this second phase were more rapid for people registered as female, although clinical records do not indicate whether their recorded gender had been changed.

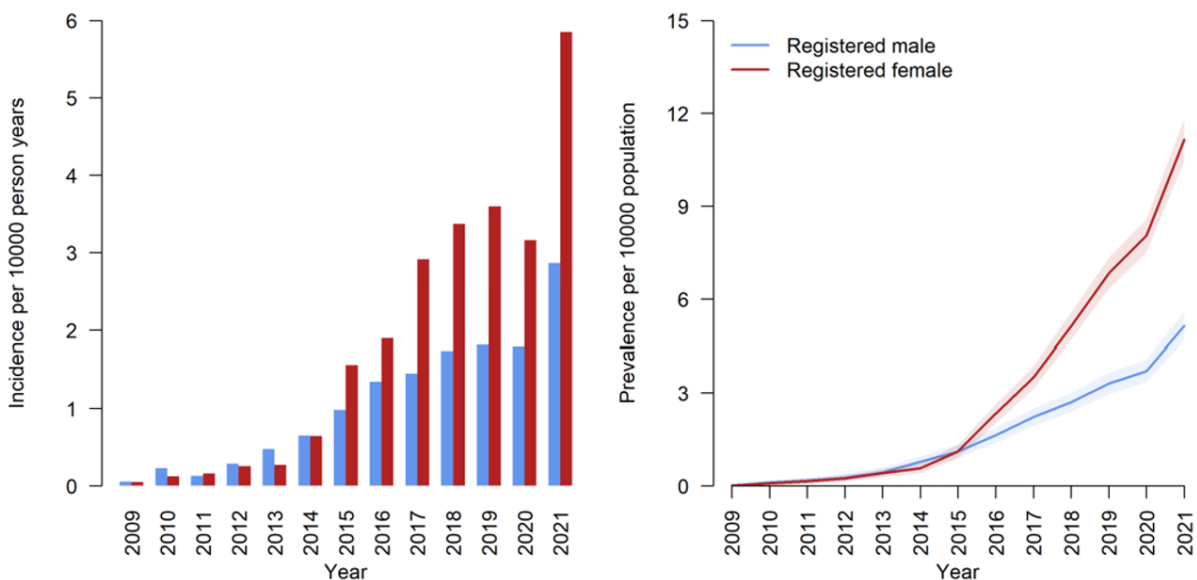
Figure 13: Incidence and recorded prevalence of gender dysphoria by age group



Source: *Epidemiology and Outcomes for Children and Young People with Gender Dysphoria: Retrospective Cohort Study Using Electronic Primary Care Records*. (Appendix 5).

NB: Shaded areas on prevalence graph denote 95% confidence intervals.

Figure 14: Incidence and recorded prevalence of gender dysphoria by registered gender



Source: *Epidemiology and Outcomes for Children and Young People with Gender Dysphoria: Retrospective Cohort Study Using Electronic Primary Care Records* (Appendix 5).

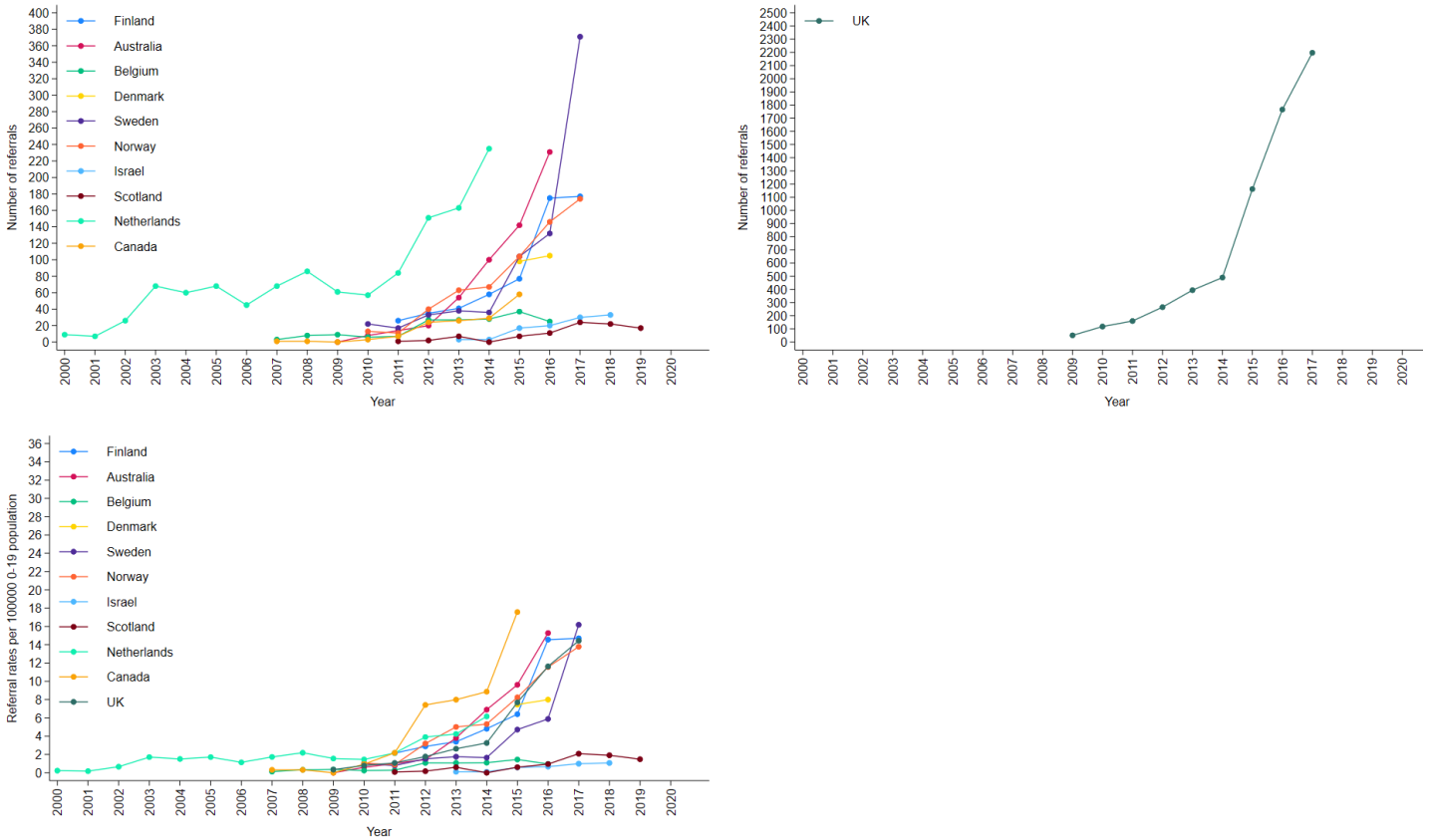
NB: Shaded areas on prevalence graph denote 95% confidence intervals. Patients can request to have their recorded gender changed on their clinical records without undergoing gender reassignment treatment, and CPRD reports the latest recorded gender only.

Comparison of UK and international data

5.12 The systematic review (Taylor et al: Patient characteristics) documented the increase in referrals across 11 countries. Around 5-6 years

into each graph there is a sharp increase in referrals. The inflection point for the increase in referrals in the UK was in 2014, with similar timing in several other countries. In the Netherlands, the increase started from 2001, with an inflection point in 2011.

Figure 15: Number of referrals over time by country



Source: Taylor et al: patient characteristics

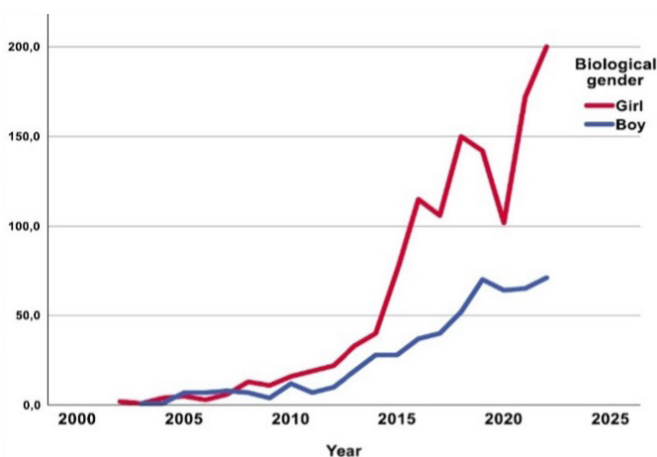
5.13 The first two graphs (Figure 15) show absolute numbers of referrals, and the UK appears to be an outlier with much larger numbers of referrals. However, the third graph is adjusted for the size of the 0-19 year old population in each country (that is, numbers per 100,000) and this brings the UK in line with other countries.

5.14 Whereas in the early days of providing gender services for children and young people, the majority of referrals were pre-pubertal children, between 2006 and 2013 both the Canadian and Dutch gender clinics reported that adolescent referrals had overtaken child referrals (Aitken et al., 2015).

5.15 Multiple countries reported a gradual switch in sex ratio towards a birth-registered female prevalence. Further data from Canada and the Netherlands showed that child referrals of birth-registered males still outnumbered those of birth-registered females, with the ratio switching in adolescence.

5.16 Figure 16 from the Norwegian national gender clinic demonstrates the divergence of the birth-registered male/female curves, and a transient fall off during the Covid-19 pandemic (Anne Wæhre, personal communication, 2023).

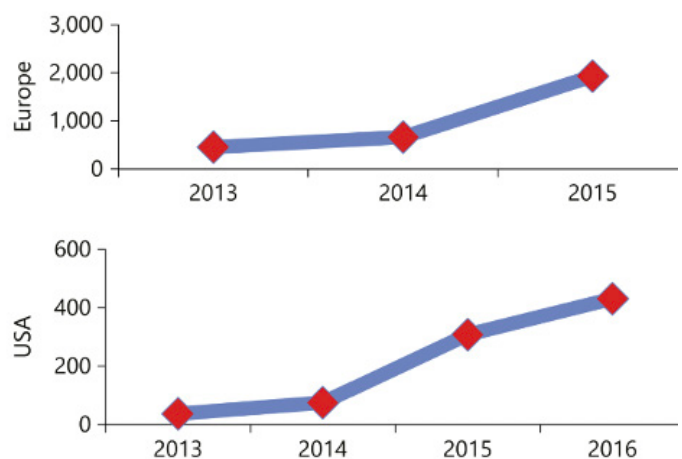
Figure 16: Referrals to the National Gender Clinic for children and young people in Norway



Source: Anne Wæhre, personal communication, 2023

5.17 The number of children and young people referred to endocrine clinics has increased in parallel to the numbers referred to gender clinics (Figure 17). An international survey conducted by the European Society of Paediatric Endocrinology and Paediatric Endocrinology Society in 2017 collated data over the preceding three years from 25 centres across Europe, the USA and South America (Skordis et al., 2019). This represents the largest single international pooled sample of referrals. Again, this shows an increase in referrals beginning in 2014. Of this group, 63% were transitioning from female to male.

Figure 17: Numbers of referrals to participating endocrine European and U.S. centres, 2013-2016



Source: Skordis, N., Butler, G., de Vries, M. C., Main, K., & Hannema, S. E. (2019). ESPE and PES International Survey of Centers and Clinicians Delivering Specialist Care for Children and Adolescents with Gender Dysphoria. *Hormone Research in Paediatrics*, 90(5), 326-331. <https://doi.org/10.1159/000496115>
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Gender characteristics

5.18 The systematic review (Taylor et al: Patient characteristics) looked at four key features of gender presentation: gender identity; formal diagnosis; age at onset; and social transition. Reporting of these characteristics was inconsistently documented and highly variable. Data on the percentage of children and young people who had socially transitioned prior to referral is discussed in Part 4.

5.19 Formal diagnosis of gender dysphoria was reported in 65 studies, with proportions ranging from 29% to 100%. The variable rates may be because of the different criteria for referral to the specialist gender clinics.

5.20 In most studies gender identity was not specifically reported. Where it was, estimates of non-binary identity ranged from 0-19%. The UK census, capturing data on the UK population over the age of 16, first enquired about gender identity in 2021 (Office for National Statistics, 2023a). Methodological issues regarding terminology have raised concerns about the validity of some of the data (Office for National Statistics, 2023c). However, the data is of interest in relation to young people and adults identifying as non-binary. The 16-to-24-year age-group had the highest proportions of people who identified as a transgender woman (0.15% or 9,000), as a transgender man (0.22% or 14,000), and as non-binary (0.26% or 17,000). The proportions who identified with these categories then decreased in each increasing age group.

5.21 The higher number of people who identified as non-binary compared to those who identified as a transgender woman or transgender man is important in raising awareness of the need to recognise and deliver

appropriate support for this group when they present to the NHS. The census data are also consistent with clinicians reporting seeing an increasing number of non-binary young people.

Co-occurring conditions

5.22 In addition to the change in referral numbers, sex ratio and gender identities, clinical staff working in GIDS and other gender services internationally have reported a change in the case-mix. Adolescents in particular seem to have more complex presentations, with greater mental health and psychosocial needs, as well as additional diagnoses of ASD and/or attention deficit hyperactivity disorder (ADHD).

5.23 The Review has spoken to clinicians working in child and adolescent mental health and in paediatric services. They report seeing an increase in children and young people presenting with issues around gender identity alongside mental health difficulties, suggesting young people are seeking and accessing care across a broader range of NHS services.

5.24 An important aim of this Review is to find ways to ensure that these children and young people are able to get their needs met as efficiently as possible, regardless of their point of first contact so that they are not having to navigate and negotiate multiple referrals.

5.25 A serious shortcoming of the literature was that it was challenging to track changes over time due to overlapping datasets, and a lack of consistency in the reporting of key characteristics of the population. This is a major problem in trying to understand how the pattern of co-occurring conditions has evolved, which is key to understanding what approaches have been put in place to help young people address them and whether these delivered benefit to the young person.

Mental health needs

General mental health problems

5.26 Of the studies identified in the systematic review (Taylor et al: Patient characteristics) almost 50% reported data on depression and/or anxiety, and close to 20% reported other mental health issues. In short, rates of depression, anxiety and eating disorders were higher in the gender clinic referred population than in the general population.

5.27 Table 2 gives synthesised summary data on mental health where these are available.

5.28 A study comparing Dutch and Canadian gender clinic populations (de Vries et al., 2015) found that mental health problems were more common among them than in the general population, but levels were similar to those children and young people referred to mental health services for other non gender-related problems.

5.29 The Dutch clinic cohort, where a puberty blocker protocol was first introduced (the Dutch protocol), was found to have a lower incidence of associated problems compared to the Canadian clinic cohort. Other studies

also demonstrated lower rates of mental health problems in the population referred in the Netherlands (de Vries, et al., 2011a) (only approximately 33%) compared to the Finland and the UK gender clinics.

5.30 In Finland (Kaltiala-Heino et al., 2015; Karvonen et al., 2023) more than three-quarters of the referred adolescent population needed specialist child and adolescent psychiatric support due to problems other than gender dysphoria, many of which were severe, predated and were not considered to be secondary to the gender dysphoria.

5.31 A more recent paper from Finland (Kaltiala et al., 2023) looked at whether the mental health needs of children and young people referred to gender services had changed in combination with the increase referral rate. This found that the gender dysphoria group had much greater mental health needs than age matched peers, and that those presenting more recently (2016-2019) had greater needs than those presenting in earlier cohorts (1996-2000). This appears to be the only paper which has systematically reported on changes over time in mental health needs.

Table 2: Synthesised data on mental health diagnoses in the gender clinic referred population

DIAGNOSIS	COUNTRIES INCLUDED	DATE RANGE	% REFERRED CYP	95% CI	RANGE (%)
Eating disorders	8	1998-2019	5	2-8	0-23
Depression	13	1980-2021	38	31-45	3-78
Anxiety	13	1980-2021	38	31-46	8-100

Source: Taylor et al: Patient characteristics.

NB: A patient population (country) may have had multiple study reports over time. In which case, data, from the study over the longest time period or that was most representative of the population was selected.

CYP: Children and young people; CI: confidence interval.

Specialist mental health conditions

5.32 The Review held a series of discussions with clinicians seeing children and young people with conditions usually referred to specialist services, for example, clinicians working in: specialist clinics for children with body dysmorphic disorder; specialist eating disorder services; and services for children with tics. A common factor with many of these specialist conditions is that they can occur when a person's mental stress or distress shows itself through physical symptoms, such as pain, tics, neurological symptoms or other problems which affect their ability to function.

5.33 The consultants and psychologists working in these services described young people presenting with these conditions in combination with gender-questioning or gender-related distress.

5.34 One example is functional movement disorders, particularly functional tic-like behaviours (FTLB). Classic neurodevelopmental tics usually start in childhood and if they last longer than a year a child could be diagnosed with Tourette's syndrome; of those diagnosed, around 70-80% are boys. In contrast, "FTLB are typically found to occur in young females, with complex, disabling and tic-lookalike patterns, usually triggered by exposure to videos portraying tic-like behaviours on social media". FTLB are associated with high levels of depression and anxiety (Nilles et al., 2022).

5.35 The association between FTLB and gender diversity described by clinical staff is reported in the literature, with one study (Martino et al., 2023) reporting that 41% of patients with functional tics had a gender minority identity, and the gender minority group also had significantly higher rates of anxiety, depression, social phobia and social interaction anxiety.

5.36 Body dysmorphic disorder (BDD) is another condition for which there has been an increase in presentations of young people. It is one of the obsessive-compulsive disorders (OCD), where there is a preoccupation with body image and with compulsive revisiting or avoidance of thoughts to manage distress. A recent study using population data (Krebs et al., 2024) found that BDD is more common in females than males (prevalence of 1.8% versus 0.3%), and that adolescent girls are at highest risk with an estimated prevalence of 3.4%. The condition is relatively rare before puberty. Many patients were found to be on the autistic spectrum and 80% of patients with BDD included in the study had suicidal ideation.

5.37 BDD is often underdiagnosed or misdiagnosed - young people do not access mental health services because they feel that their concerns about their appearance may be dismissed. However, there are improved treatment outcomes for young people who have profound distress from BDD, with exposure-based cognitive behavioural therapy (CBT), sometimes combined with medication (Rautio et al., 2022).

5.38 Clinicians have described to the Review how in patients with BDD, the intense focus on appearance is most commonly on facial features, but that some experience distress about genitalia or breasts. In this situation it can be difficult to determine whether the distress is due to BDD or gender dysphoria. However, at the end of a treatment package for BDD some young people say they no longer feel ill at ease with their birth-registered gender, while some may have less distress about their genitalia or breasts but still have marked gender incongruence and proceed to a social or medical gender transition.

5.39 The distressing symptoms that occur in these ‘body and mind’ conditions are real, and like pain or discomfort that arises from other causes can be addressed and helped with psychological interventions. It is very important that gender-questioning young people are able to access these evidence-based treatments alongside any other clinically appropriate interventions to support their gender care.

Neurodiversity

5.40 Table 3 shows synthesised summary data on prevalence of ASD and ADHD where this was available in the papers included in the systematic review.

5.41 Some research studies have suggested that transgender and gender diverse individuals are three to six times more likely to be autistic than cisgender individuals, after controlling for age and educational attainment (Warrier et al., 2020).

5.42 These findings are echoed by clinicians who report seeing teenage girls who have good cognitive ability and are articulate, but are struggling with gender identity, suicidal ideation and self-harm. In some of these young people the common denominator is undiagnosed autism, which is often missed in adolescent girls. Others may go on to receive a diagnosis of emotionally unstable personality disorder (EUPD) when they enter adult services.

5.43 Despite often being highly articulate, intelligent and skilled in many areas, autistic young people have difficulties with social communication and peer relationships, which may make it difficult for them to feel accepted and ‘fit in’.

5.44 Difficulties with interoception (making sense of what is going on in their bodies) and alexithymia (recognising and expressing their emotions) can sometimes make it hard for these young people to express how they are feeling about their internal sensations, their gender identity and their sexual identity.

Table 3: Synthesised data on neurodiversity in the gender clinic referred population

DIAGNOSIS	COUNTRIES INCLUDED	DATE RANGE	% REFERRED CYP	95% CI	RANGE (%)
ASD	9	1998-2019	9	6-11	0-26
ADHD	9	1998-2021	10	7-13	2.5-27

Source: Taylor et al: Patient characteristics

NB: A patient population (country) may have had multiple study reports over time. In which case, data, from the study over the longest time period or that was most representative of the population was selected.

CYP: Children and young people; CI: confidence interval; ASD: Autistic Spectrum Disorder; ADHD: Attention Deficit Hyperactivity Disorder

5.45 In addition, mental health disorders including anxiety, depression, eating disorders, functional neurological disorder, OCD and BDD are more common in autistic children and young people (González-Herrero et al., 2022; Lai et al., 2019).

5.46 Mind and body understanding and integration are dependent on an individual child/young person's chronological age, developmental level and the presence or absence of neurodevelopmental differences. These factors may mean that these individuals identify and communicate experiences of stress/distress differently from other neurotypical individuals.

5.47 Working this out may take longer than it does for neurotypical individuals, making neurodiverse young people potentially vulnerable into their early 20s or longer because of their tendency to want black and white answers, and their difficulty in tolerating uncertainty.

Adverse childhood experiences

5.48 The systematic review (Taylor et al: Patient characteristics) highlighted the fact that relatively few studies reported on adverse childhood experiences (ACEs), but those that did demonstrated high rates amongst children and young people referred to gender services (ranges given below):

- combined neglect or abuse (11-67%)
- physical abuse (15-20%)
- sexual abuse (5-19%)
- emotional abuse (14%)
- maternal mental illness or substance abuse (53% and 49%)
- paternal mental illness or substance abuse (38%)

- exposure to domestic violence (23-25%)
- death or permanent hospitalisation of parent (8-19%)
- loss of parent through abandonment resulting in adoption (1-8%), foster care (1-12%) or children's home placement (0.5 - 5%).

5.49 While the high numbers of ACEs reported in the systematic review are notable, as relatively few studies have documented ACEs, it is not possible to determine how the number has varied over time.

5.50 However, a review of the first 124 cases seen by GIDS (Di Ceglie et al., 2002) found that just over a quarter of all referrals had spent some time in care and nearly half of all referrals had experienced living with only one parent. It showed that 42% of the children covered by the audit experienced the loss of one or both parents, mainly through separation; 38% had family physical health problems; and 38% had family mental health problems. Physical abuse was documented in 15% of cases.

5.51 This suggests that regardless of the change in demographics, ACEs and broader adversity within the family unit are important issues to be aware of when assessing young people's needs and planning a support package for them.

Suicidality and death by suicide

5.52 There is considerable concern about the risk of death by suicide among gender diverse youth and debate about whether gender-affirming treatments reduce this risk. This section discusses what is known about suicidality and the risk of suicide in this population and Chapter 15 discusses what is known about whether gender-affirming treatments reduce that risk.

5.53 Suicide is the act of taking one's own life voluntarily and intentionally, whilst suicidality encompasses suicidal thoughts (sometimes called suicidal ideation), suicide plans and suicide attempts.

5.54 Understanding the factors that can put young gender-questioning people at risk is of crucial importance to the young people themselves, their families and the clinical staff looking after them. Balanced information, which is realistic and practical, and does not over-exaggerate or underestimate the risks, is essential to support everyone involved and identify young people in most urgent need of help.

5.55 Table 4 gives synthesised summary data on suicide attempts, self-harm and suicidal ideation where this was available. The majority of studies that separated self-harm or suicidality by birth-registered sex found higher rates in birth-registered females versus males.

5.56 A large study (de Graaf et al., 2020) examined rates of suicidality across Canadian, UK and Dutch gender clinic cohorts, generating 2,771 youth in the sample. Suicidality was assessed using two questions from standardised scales. Carers and young people were asked to rate 'now or within past 6 months' in response to: carers - "Deliberately harms self or attempts suicide", "Talks about killing self"; and young people - "I deliberately try to hurt or kill myself", "I think about killing myself". The

study compared rates of suicidality in the gender clinic referred population with standardised data from the general adolescent population and non-trans identified youth referred to child and adolescent mental health services.

5.57 There was variation between clinics, but across the three clinics, rates of suicidality ranged from 27% to 55%. These rates of suicidality were significantly higher than for the general adolescent population, but similar to non-trans identified youth referred to child and adolescent mental health services. Higher rates of suicidality were observed in birth-registered females, as is the case in the general adolescent population.

5.58 The same paper (de Graaf et al., 2020) reviewed 17 previous studies that had reported rates of suicidal ideation ranging from 17% to 87%, and of suicide attempts ranging from 12% to 54%. The wide range reflects different methodologies and gender clinic populations.

Deaths by suicide

5.59 Deaths by suicide in children and young people are relatively rare events, compared to adult suicide. However, each one is a tragic event. In the UK, the death of every child and young person under 18 is reviewed and information about causation is collected by the National Child Mortality Database (NCMD).

Table 4: Synthesised data on suicide attempts, self-harm and suicidal ideation in the gender clinic referred population

DIAGNOSIS	COUNTRIES INCLUDED	DATE RANGE	% REFERRED CYP	95% CI	RANGE (%)
Suicide attempts	11	1976-2021	14	11-17	9-30
Self-harm	11	1976-2021	29	23-25	8-56
Suicidal ideation	10	2002-2021	39	30-48	10-87

Source: Taylor et al: Patient characteristics

NB. A patient population (country) may have had multiple study reports over time. In which case, data, from the study over the longest time period or that was most representative of the population was selected.

CYP: Children and young people CI: Confidence interval.

5.60 The latest NCMD report on suicide in children and young people (NCMD, 2021) looked at deaths between 1 April 2019 and 31 March 2020. There were 108 deaths that were assessed as highly or moderately likely to be due to suicide (about 2 deaths per week of under 17-year olds). The overall suicide rate in England was 1.8 per 100,000 9-17-year olds.

5.61 The Child Death Overview Panel reviewed 91 of the cases (NCMD, 2021). They examined a range of background factors which included household functioning (for example, family members with a medical or mental health problem, domestic abuse, divorce or parental separation), mental health needs, neurodevelopmental conditions, sexual orientation, sexual identity and gender identity, abuse and neglect, bullying, problems in school, social media use, and drug or alcohol use.

5.62 Household functioning was found to be the most common factor - 63 (69%) of deaths, with mental health needs in 50 (55%), bullying in 21 (23%), neurodevelopmental conditions in 15 (16%) and sexual orientation, sexual identity and gender identity in 8 (9%).

5.63 Of the children or young people, 81 (89%) had more than one recorded factor and 51 (56%) had factors in five or more categories. Over one-third (33, 36%) had never been in contact with mental health services.

5.64 Another source of data in the UK is the National Confidential Inquiry into Suicide and Safety in Mental Health (2023). This looked at all-age suicide in people already under the care of mental health services. Between 2016-2020, there were 223 deaths by suicide of patients who identified as lesbian, gay or bisexual and 37 patients that the report described as “within a trans group” in the UK. They qualified this by explaining that “we are using “trans” as an umbrella term to include transgender,

transsexual, or non-binary but we acknowledge that the terms people use to describe their own identity can be dynamic and we will be monitoring this in future reports”. The report stated that 13 of the 37 were under 25. A high proportion of these individuals had experienced childhood abuse. Self-harm and personality disorder diagnosis were common in this group.

5.65 The Review met with The Tavistock and Portman NHS Foundation Trust to discuss deaths of patients (where known) who had been referred to or were currently or previously under the care of GIDS. The patients who died by suicide between 2018 and 2023 were described as presenting with multiple comorbidities and/or complex backgrounds. In addition, the trust observed that risk of suicidality was heightened at transition points in patient care; for example, between child and adult services. The young people were more likely to be registered female at birth, identifying as male in adolescence.

5.66 Looking to international data, a recent study in Finland (Ruuska et al., 2024) reviewed all gender clinic referred adolescents between 1996 and 2019 (2,083) and compared them to age-matched controls (16,643). There were 55 deaths in the study population, of which 20 were deaths by suicide. Although the suicide rate in the gender-referred youth was higher than in the general population, this difference levelled out when specialist-level mental health treatment was taken into account. Overall, it is difficult to draw firm conclusions because the absolute risk of suicide in the population of gender dysphoric youth and in the control population was very low, so numbers were thankfully small.

5.67 Although the data suggest that the numbers of deaths by suicide in this group of young people is very low, every death of a children or young people is a tragedy and a devastating loss. In each case, there is a strong need to understand what happened and why, so that anything that can be done to prevent future deaths is identified and acted upon.

Changes in the patient profile

5.68 The systematic review (Taylor et al: Patient characteristics) documented the rapid increase in referrals across many countries and concluded “These children show higher than expected levels of ASD, ADHD, anxiety, depression, eating disorders, suicidality, self-harm, and ACEs. Agreement on the core characteristics data to be collected at referral/assessment would help to ensure studies measure key outcomes and enable services to develop to meet the needs of these children. Services need to assess and respond to any co-occurring needs and complexities”.

5.69 Today’s population is different from that for which clinical practice was developed with a higher proportion of birth-registered females presenting in adolescence. They are a heterogenous group with wide-ranging co-occurring conditions, often including complex needs. This needs to be reflected in the services offered by the NHS.

6. Developmental considerations for children and adolescents

6.1 Two particularly critical periods of development are early childhood and adolescence. It is very important to understand several aspects of typical development - from what happens before birth through early childhood to adolescence, as well as the range of normal variations.

6.2 This has bearing on what might happen when clinical interventions are used and on the different issues involved in considering gender care for children and young people compared to that for older adults.

6.3 The issues covered in this section have relevance for:

- understanding what is known about the biology of gender incongruence.
- understanding about mental health vulnerability.
- considerations for social transition (see Chapter 12).
- potential impacts of puberty blockers (see Chapter 14).
- potential impacts of masculinising/feminising hormones (see Chapter 15).
- obtaining consent (See Chapter 16).

Gender development through childhood and adolescence

6.4 Biological sex is determined by sex chromosomes. Males have an X and Y chromosome (XY) and females have two X chromosomes (XX). In early pregnancy, all

foetuses have the potential to become male or female. A gene on the Y chromosome drives production of testosterone, which is necessary to produce internal and external male genitalia. In the absence of testosterone, the foetus will develop female anatomy.

6.5 There are many biological differences between males and females; for example, height, muscular strength, life expectancy, as well as susceptibility to certain illnesses such as lung cancer or heart disease. There are also very large overlaps between characteristics.

6.6 Academics have identified three important ways in which sex differences are expressed (Babu & Shah, 2021):

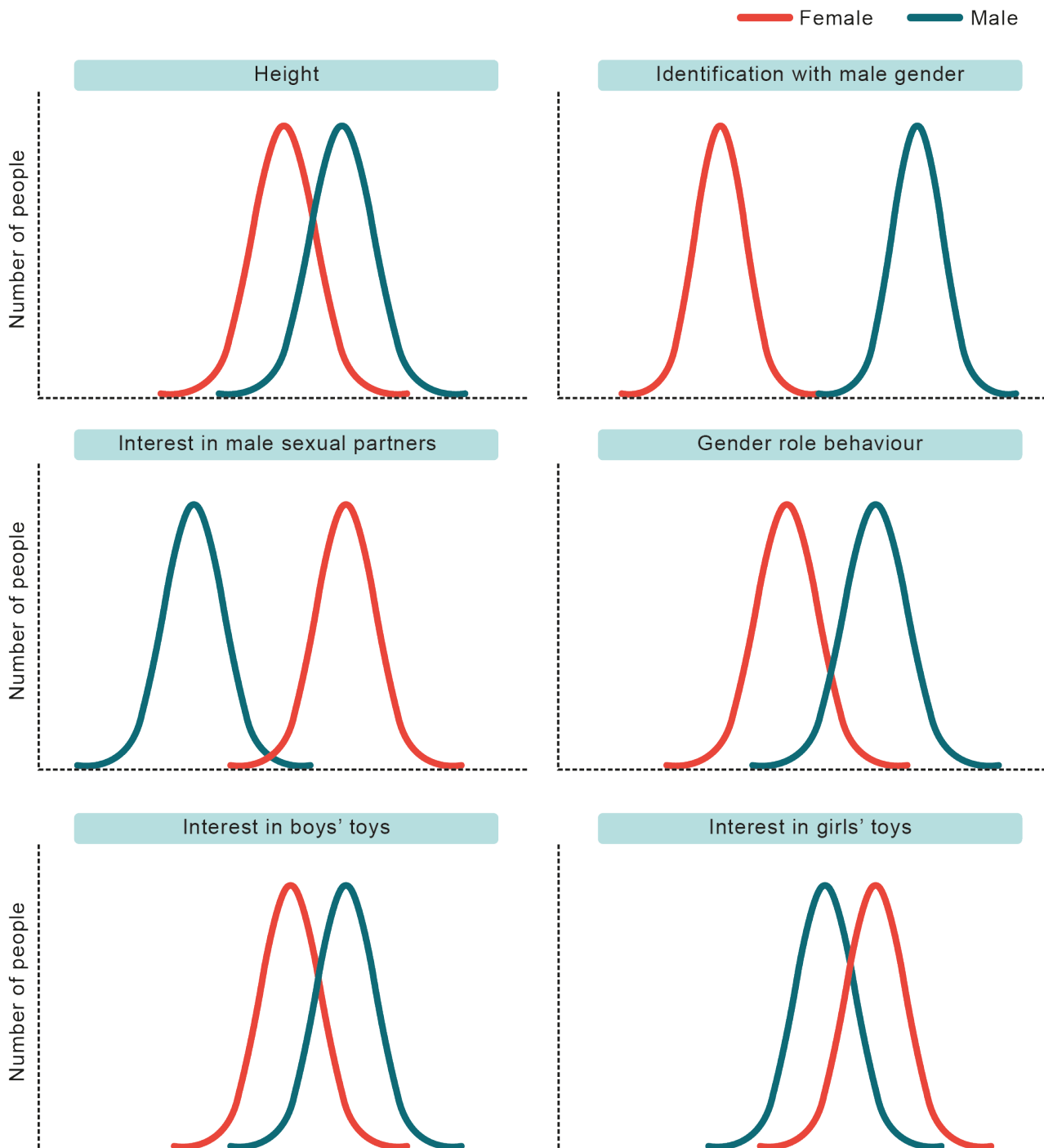
- gender role behaviours (these are behaviours such as toy preferences, play, physicality)
- gender identity (an innate sense of belonging and self-identification of one's gender as male, female or an alternative gender)
- and later, sexual orientation (the sex of the individuals to whom one is sexually attracted).

6.7 It is thought that all three of these can be influenced by biological and social factors, and this is an evolving area of research.

6.8 Figure 18 summarises these characteristic sex differences in humans. The use of the terms ‘boys’ toys’ and ‘girls’ toys’ by the author may feel uncomfortable but it is a classification that is used in academic study. The figure also

illustrates the size of the sex difference in adult human height. Height is included to provide a familiar comparator for contextualising the sizes of the behavioural/psychological sex differences (Hines, 2020a).

Figure 18: Illustration of the overlap in distributions of scores for males and females for psychological/behavioural characteristics that show large and reliable sex differences



Source: Adapted from Hines, M. (2020). Human gender development. *Neuroscience & Biobehavioral Reviews*, 118, 89-96. <https://doi.org/10.1016/j.neubiorev.2020.07.018>, with permission from Elsevier.

NB: Higher scores for gender role behaviour represent more male-typical behaviour. The overlap for height is included as a familiar comparison.

6.9 In the UK, the average male is 5'9" tall and the average female 5'4". Some females are taller than some males, and this is part of normal variation. It would be very difficult to guess whether a 5'7" person was male or female from their height alone, because this falls right in the middle of the overlap.

6.10 Societal expectations and stereotypes have driven the idea that gender role behaviours, gender identity and sexuality should all align with birth-registered sex. This is not always the case. Gender role behaviours, gender identity and sexuality can vary independently of each other.

6.11 Females are most commonly attracted to male partners, and vice versa, but there is an overlap between males and females, with some individuals being same-sex attracted, attracted to both sexes, neither sex, or more fluid in their sexual preferences.

6.12 Children's sense of gender identity most commonly aligns with their birth-registered sex, but there is considerable variability in the rate at which they develop gender constancy, and the expression of their gender identity.

6.13 Some children will have gender role behaviours that do not align strongly with their birth-registered sex, but a gender identity that does align. They may grow up to be heterosexual or same-sex attracted.

Development of gender role behaviours

6.14 Like other areas of development, gender identity and gender role behaviours have typical milestones (de Vries et al., 2013; deMayo et al., 2022).

6.15 Differences in gender role behaviours are apparent in pre-school, when children start to show gender stereotyped behaviour in their play. Around this time, they seek to play with same-sex peers.

6.16 Toy choice has been extensively studied. Researchers classify toys into those that are typically preferred by boys (for example, cars and trucks) and those that are typically preferred by girls (for example, dolls). A systematic review (Davis & Hines, 2020) demonstrated that these differences in toy choice are very large.

6.17 Like biological characteristics such as height, there is a large overlap in gender role behaviours. This variability in gender role expression exists from an early age (some girls exhibit behaviours that are traditionally perceived as more masculine, and some boys exhibit behaviours that are perceived as more feminine).

6.18 A common assumption is that toy choice and other gender role behaviours are solely a result of social influences; for example, that boys will only be given trucks and girls will only be given dolls to play with. Although this is partially true, there is evidence for prenatal and postnatal hormonal influence on these behaviours, which will be discussed later.

Development of gender identity

6.19 In 1966, Kohlberg set out a theory of gender identity development (Kohlberg, 1966). Kohlberg's theory describes the typical progression of children acquiring gender identity (realising they are boys or girls) at 2-3 years old, acquiring gender stability (realising that gender does not change) at 3-4 years, and acquiring gender constancy (realising that superficial indicators such as clothes do not change gender) at 5-6 years.

6.20 Modern childhood experiences are different from when Kohlberg was writing, and contemporary research is needed to better understand and examine these fundamental principles, as well as the influence of early childhood experiences on gender identity development.

Interaction of nature and nurture

6.21 Sex differences in the brain emerge in the second half of pregnancy. There is strong evidence from animal studies that these changes are driven by the presence or absence of testosterone and have a long-term effect on sex-typed development (Bakker, 2014).

6.22 All three of the human characteristics that show particularly large sex differences (childhood sex-typed play, sexual orientation and gender identity) have been found to relate to early testosterone exposure.

6.23 Sex-typed play has been studied more extensively than any other human behaviour in this context, and at least 10 independent research groups have reported a link to prenatal testosterone exposure (Hines, 2015).

6.24 Much of this work is based on children who are born with atypical sex hormone levels. These conditions are called differences in sex development (DSD), previously termed intersex.

6.25 The most commonly studied DSD is congenital adrenal hyperplasia (CAH). In this condition, genetic females (XX) usually have high levels of testosterone caused by changes in their genes. These high testosterone levels start antenatally, and result in partially masculinised genitalia (Babu & Shah, 2021).

6.26 Genetic females (XX) with CAH are usually reared as females as they have female internal organs with reproductive capacity, yet they are more likely than other females to have male role behaviours (for example, male-type play and toy choice), and reduced female-typical play. In adulthood, 50-75% will be exclusively heterosexual, whilst the remainder will be bisexual or same-sex attracted. Only 2-5% will have gender dysphoria that leads to gender reassignment; however, some will have a weaker female identity (Berenbaum & Beltz, 2011). Therefore, it appears that in CAH, while prenatal testosterone exposure has a strong impact on gender role behaviour, gender identity predominantly aligns with sex of rearing.

6.27 Similarly, genetic males (XY) with complete androgen insensitivity syndrome (CAIS) have functioning testes but their cells are unable to respond to testosterone, and they show female-typical play patterns (Hines, 2020a).

6.28 A more unpredictable situation is when genetic males (XY) are born with a range of conditions where they have normal testosterone levels but have a very deformed or absent penis. If these children are raised as girls, the majority will continue to identify as female, despite their normal male hormone levels (Meyer-Bahlburg, 2005).

6.29 There are numerous other forms of DSD. Practice has changed from the earlier era management approach of early surgical modification to match an individual's assigned sex. Now the emphasis is on assessing the

infant's biology and using that to predict the most likely developmental outcomes with which to guide sex of rearing. This approach makes it less likely that irreversible surgery or medical intervention will be given before the individual is able to understand their body (and its capabilities), and their psychosexual development is advanced.

6.30 An important finding is that some DSD conditions have more predictable gender identity outcomes. In other DSD conditions, long-term predictions are less reliable, and in those cases sex of rearing seems to be a stronger predictor of gender identity in childhood and beyond.

6.31 In summary, studies of children with DSD suggest that a complex interplay between testosterone levels, external genitalia, sex of rearing and socio-cultural environment all play a part in eventual gender identity. This is important to consider when trying to understand the range of pathways that might lead to gender incongruence.

Changes from adolescence into adulthood

6.32 There are two important periods of brain development - the first up to age three, and the second from adolescence into adulthood.

6.33 Adolescence is a period of rapid social, emotional, physical and cognitive development that can be difficult for some young people to navigate. Pubertal changes in hormones result in changes to the physical body and the brain, alongside major changes in social expectations and demands.

6.34 An understanding of brain development and the stages of adolescence is essential in understanding how gender identity relates to the other aspects of adolescence. It is also important to consider in relation to the management of gender incongruence and gender-related distress during this period.

Changes in the brain during adolescence

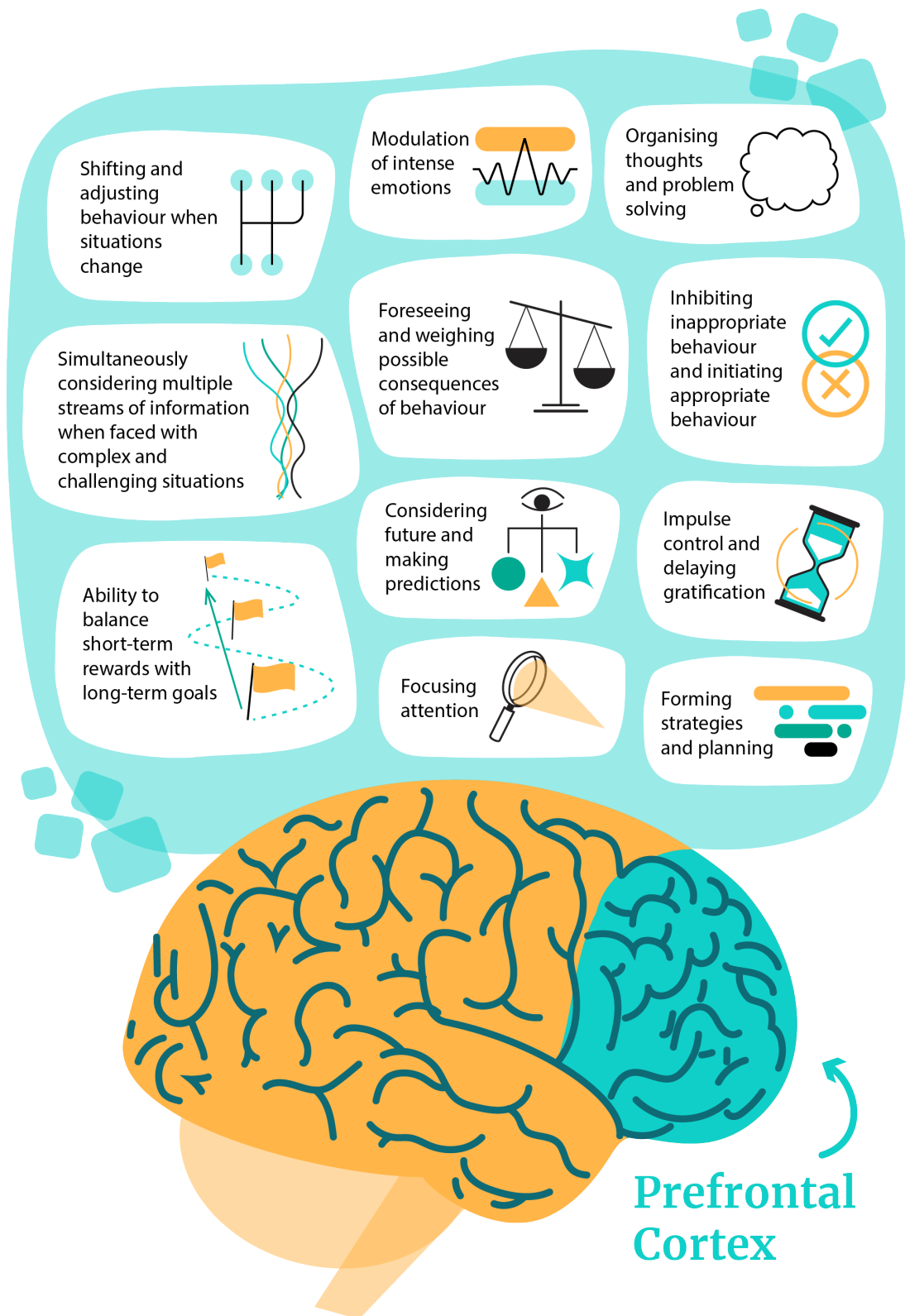
6.35 Starting in early puberty unused neural connections are pruned, and other important connections are made stronger and faster.

6.36 It used to be thought that brain maturation finished in adolescence, but it is now understood that this remodelling continues into the mid-20s as different parts become more interconnected and specialised (Giedd, 2016).

6.37 This brain remodelling does not proceed evenly. Changes in the limbic area, which is 'present-orientated' and concerned with risk taking and sensation seeking, begin with puberty; this part of the brain becomes super sensitised, drives emotional volatility, pleasure and novelty seeking, and also makes adolescents more sensitive to social rejection, as well as vulnerable to addiction and a range of mental health problems.

6.38 The 'future orientated' prefrontal cortex matures later, with development continuing into an individual's 20s, and as illustrated in Figure 19, is concerned with executive functions such as complex decision making, rational judgement, inhibition of impulsivity, planning and prioritisation.

Figure 19: Maturation of the adolescent brain



Neuropsychiatric Disease & Treatment 2013;9 449-461 - Originally published by, adapted and used with permission from Dove Medical Press Ltd.

6.39 By the age of 15 an adolescent will make similar decisions in relation to hypothetical situations as an adult. However, although adolescents can balance the possible harm or benefit of different courses of action in theory, in the real world they may still engage in dangerous behaviours, despite understanding the risks involved. Hence, both the role of emotions and the connection between feeling and thinking are relevant to how adolescents make decisions (Arain et al., 2013).

The ‘social brain’

6.40 The ‘social brain’ is the network of brain regions that are involved in understanding other people’s intentions, desires and beliefs. The slowly maturing prefrontal cortex is a key part of this network, so there are considerable changes in these abilities through teens to adulthood.

6.41 Through adolescence, peers have an increasing influence and parents a lessening influence. Adolescents’ evaluation of their social and personal worth is strongly influenced by what their peers think about them. Studies have shown adolescents to be hypersensitive to social isolation, so much so that going along with peers in order to avoid social risk, even if it means taking health and legal risks, might be seen as the rational choice because it reduces the possibility of social exclusion (Blakemore, 2018).

Role of sex hormones in brain maturation

6.42 There is increasing evidence that the changes in brain maturation described above are driven by a combination of chronological age and sex hormones released through puberty (Goddings et al., 2019; Ravindranath et al., 2022; Sisk & Zehr, 2005). Sex hormones are also responsible for increasing divergence in the structure of the male and female brain (Beck et al., 2003).

6.43 Some researchers have suggested there may be a ‘critical period’ in adolescence for the development of more complex thinking and analytical processes (Baxendale, 2024; Larsen & Luna, 2018), and more work is needed to clarify this.

6.44 In summary, childhood, adolescence and young adulthood are dynamic developmental periods for gender expression, cognitive development and overall brain maturation, and at the same time, young people are having to navigate an increasingly complex world. This important developmental backdrop needs to be taken into account when thinking about how gender incongruence may develop in any one individual and how best to address it.



7. Growing up in the 2000s

7.1 A generation is a group of people who share similar birth years, life experiences and cultural influences. Every generation encounters new experiences, advances, technologies, challenges and stressors that have a profound effect on their behaviours, attitudes and beliefs.

7.2 It may appear somewhat simplistic to divide people by birth year, but this is a helpful way of understanding how perspectives, as well as health and illness, can be shaped by major world events (most recently the Covid-19 pandemic), as well as social and economic conditions.

7.3 Generation Z is the generation in which the numbers seeking support from the NHS around their gender identity have increased, so it is important to have some understanding of their experiences and influences.

7.4 They are defined as those who were born between 1995 and 2009 and are characterised by their digital nativism (proficiency in using technology and social media) and unique characteristics such as being entrepreneurial, socially conscious, pragmatic and diverse (Jayatissa, 2023).

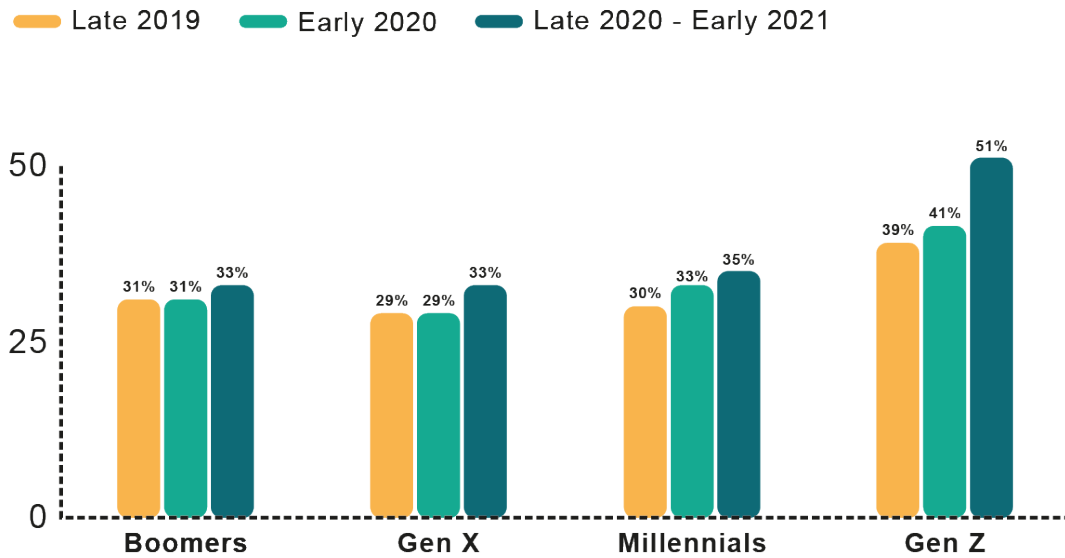
7.5 In terms of broader context, Generation Z and Generation Alpha (those born since 2010) have grown up through a global recession, concerns about climate change, and most recently the Covid-19 pandemic. Global connectivity has meant that as well the advantages of international peer networks, they are much more exposed to worries about global threats.

Generational beliefs and gender identity

7.6 Generation Z and some younger Millennials (Generation Y) generally have different beliefs about the fluidity and mutability of gender than older generations. Attitudes have changed at speed, such that within a 6-month period between early 2020 and late 2020/early 2021 Generation Z adults surveyed in the USA became the first generation in which the majority responded negatively to the statement “there are only two genders, male and female” (Twenge, 2023).

7.7 There are also generational differences in the numbers of young adults reporting that their experienced gender does not align with their birth-registered sex. Based on US Census data, in 2021-2022, 5.6% of Generation Z adults identified as transgender or non-binary, compared to 2.4% of Millennials and 1.5% of Generation X.

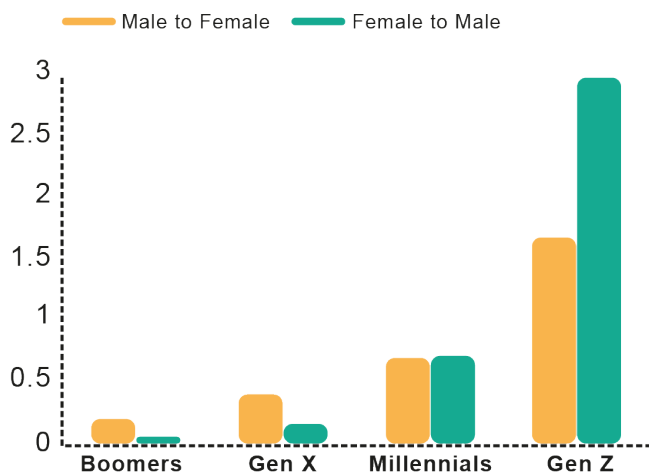
Figure 20: Percentage of U.S. adults who believe there are more than two genders, by generation 2019-2021



Source: Adapted from Twenge, J. M. (2023). *Generations: The real differences between gen Z, millennials, gen X, boomers, and silents - and what they mean for America's future*. Atria Books.

NB: Shows percent who disagree with the statement "There are only two genders, male and female." Late 2019 data were collected July 18 to December 26; early 2020 data were collected January 2 to June 25; late 2020-early 2021 data were collected July 2, 2020 to January 12, 2021.

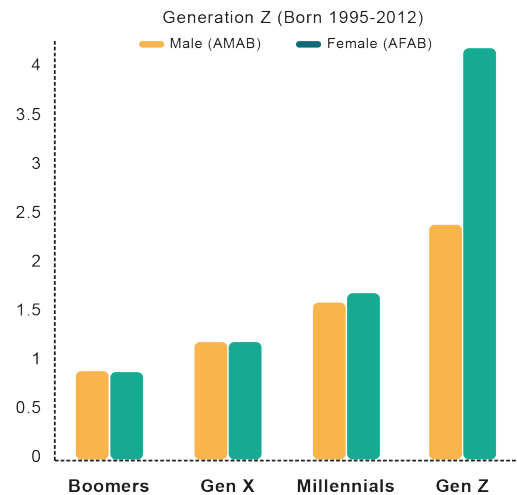
Figure 21: Percent of U.S. adults identifying as transgender, by sex assigned at birth and generation, 2021-2022



Source: Adapted from Twenge, J. M. (2023). *Generations: The real differences between gen Z, millennials, gen X, boomers, and silents - and what they mean for America's future*. Atria Books.

NB: Data collected between July 21, 2021, and October 17, 2022. Terms are from the BRFSS survey, although they are increasingly considered outdated and are replaced with transgender women and transgender men, respectively.

Figure 22: Percent of U.S. adults identifying as nonbinary, by sex assigned at birth and generation, 2021-2022



Source: Adapted from Twenge, J. M. (2023). *Generations: The real differences between gen Z, millennials, gen X, boomers, and silents - and what they mean for America's future*. Atria Books.

NB: Data collected between July 21, 2021 and October 17, 2022. AMAB = assigned male at birth; AFAB = assigned female at birth.

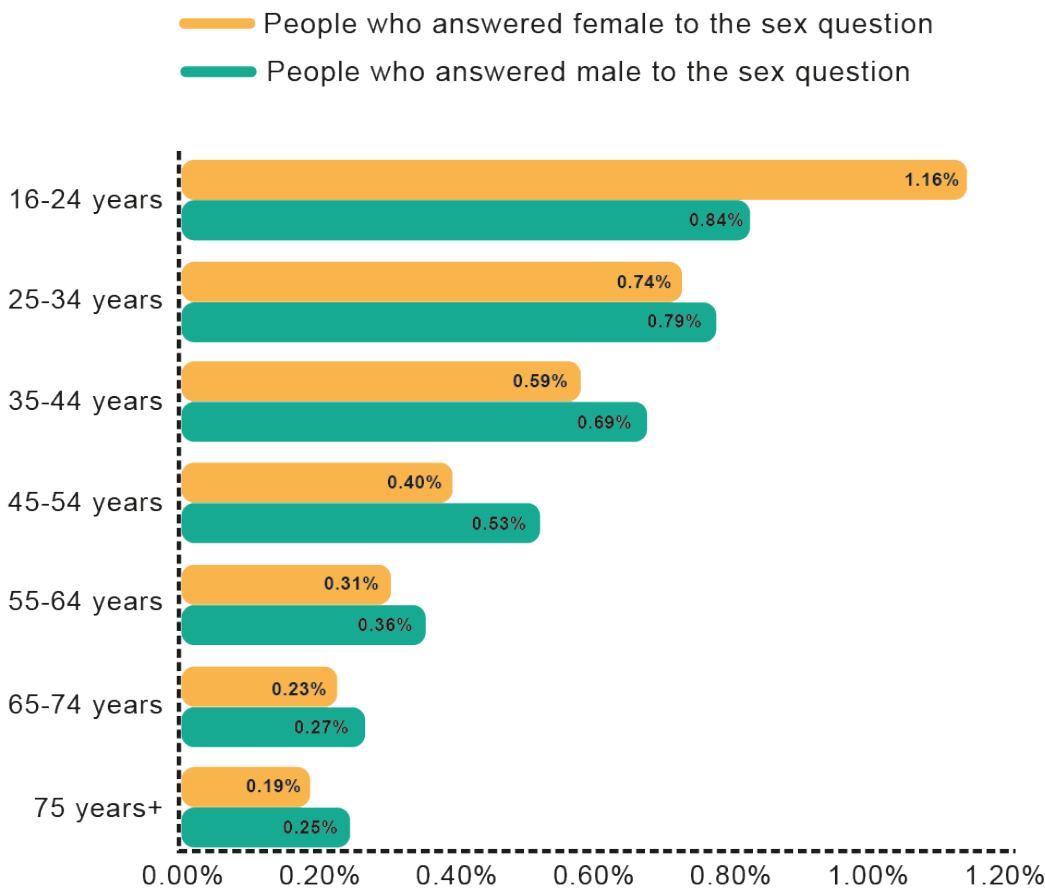
7.8 In common with other trends documented internationally, the 2022 UK census (Office for National Statistics, 2023a) reported that the group with the highest percentage (1.16%) identifying as transgender (defined as gender different from that registered at birth) was birth-registered females aged 16-24. This was the only age group in which the number of birth-registered females identifying as trans exceeded the number of birth-registered males identifying as trans.

7.9 Changes in beliefs about gender identity in Generation Z have led to much more flexible thinking about how gender is expressed, and

a move away from gender stereotypes. Young people within Generation Z, as well as younger Millennials, are much more open to experiment with gender expression than previous generations.

7.10 Many of these young people will not require any input from the NHS. They may see themselves as being anywhere on a spectrum from gender non-conforming through to binary trans. Many will remain fluid in their gender identity for an extended period. Some will partially or fully socially transition, but not seek medical intervention.

Figure 23: Percentage of usual residents aged 16 years and over who identified as trans by sex and age, England and Wales, 2021



Source: Office for National Statistics. (2023b, January 25). *Gender identity: age and sex, England and Wales: Census 2021*. Contains public sector information licensed under the [Open Government Licence v3.0](#).

Online stressors and harm

7.11 Generation Z and Generation Alpha (the generation born since 2010) have grown up with unprecedented online access. This has huge advantages, but also brings new risks and challenges. Access to the online world has given children and young people learning resources, global information and methods of communication unavailable to previous generations, but it has also made them vulnerable to new dangers.

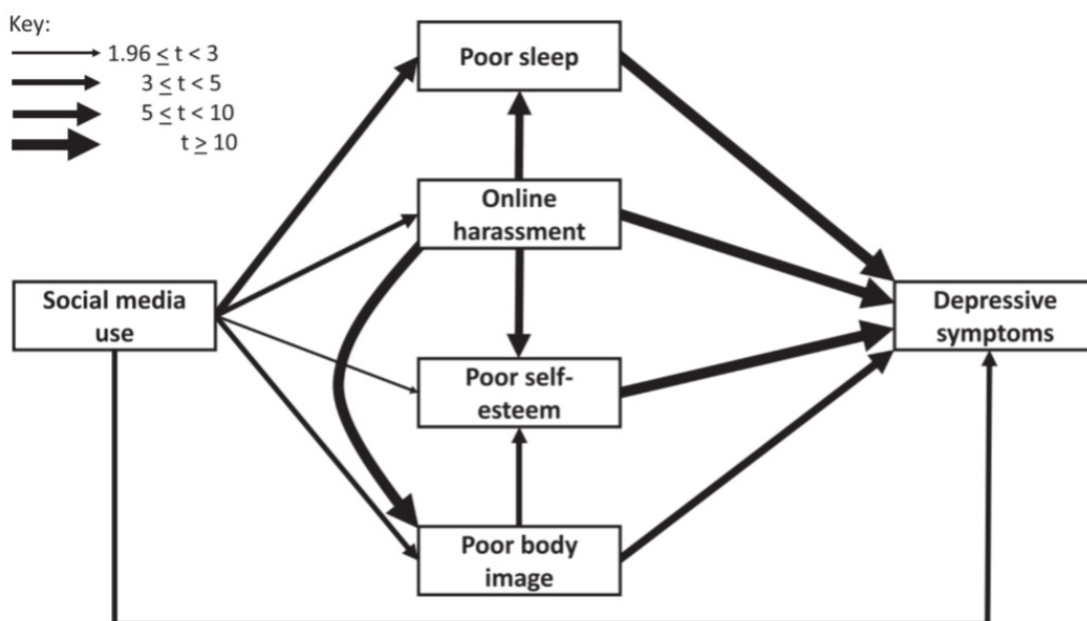
7.12 The Millennium Cohort Study (MCS) is a UK nationally representative prospective cohort study of children born into 19,244 families between September 2000 and January 2002. A study (Kelly et al., 2018) used this data to examine the relationship between social media use and mental health for 14-year-olds within the cohort (10,904 individuals):

- girls reported more hours of social media use than boys; 43% of girls used social media for three or more hours per day compared with 22% of boys.

- girls were more likely to be involved in online harassment as a victim or perpetrator (38.7% versus 25.1% respectively).
- girls were more likely to have low self-esteem (12.8% versus 8.9% of boys), to have body weight dissatisfaction (78.2% versus 68.3% of boys) and to be unhappy with their appearance (15.4% versus 11.8% of boys).
- girls were more likely to report fewer hours of sleep than boys and to report experiencing disrupted sleep often (27.6% versus 20.2%) or most of the time.

7.13 On average, girls had higher depressive symptom scores compared with boys. Online harassment, poor sleep quality and quantity, poor self-esteem and body image were all strongly associated with depressive symptom scores. Figure 24 illustrates the relationship between these different factors. The thickness of the arrows shows the strength of the relationships.

Figure 24: Social media use and depressive symptoms - summary of path analysis



Source: Kelly, Y., Zilanawala, A., Booker, C., & Sacker, A. (2018). Social Media Use and Adolescent Mental Health: Findings from the UK millennium cohort study. *EClinicalMedicine*, 6, 59-68. <https://doi.org/10.1016/j.eclinm.2018.12.005>
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NB: The thickness of the arrow shows the strength of the relationships.

7.14 As social media use increased from 0 to 5 or more hours a day, there was a stepwise increase in depressive symptom scores and the proportion of young people with clinically relevant symptoms (Kelly et al., 2018).

7.15 A systematic review of 20 studies found that use of social media was associated with body image concerns and disordered eating (Holland & Tiggermann, 2016). Numerous other studies implicate smartphone and social media use in mental distress and suicidality among young people, particularly girls, with a clear dose-response relationship (Abi-Jaoude et al., 2020); that is, the more hours spent online the greater the effect. The mediating effects of social media on poor sleep, poor body image and cyberbullying are common themes across much of the literature.

Access to sexually explicit content

7.16 The Children's Commissioner's report in 2023 (Children's Commissioner, 2023) found that pornography is so widespread and normalised that children cannot 'opt out'. The average age when children first see pornography is 13, but 10% have seen it by age 9, and 27% by 11. The pornography that they are exposed to is frequently violent, depicting coercive, degrading or pain-inducing acts. Younger exposure had a negative impact on self-esteem.

7.17 Young people may passively stumble on pornography online, receive explicit images from people they know and, by the age of 16-21, 58% of boys and 42% of girls were actively seeking out pornographic material.

7.18 Young people aged 16-21 were more likely than not to assume that girls expect or enjoy sex involving physical aggression. Among all respondents, 47% stated that girls 'expect' sex to involve physical aggression such as airway restriction or slapping, a further 42% stated that most girls 'enjoy' acts of sexual aggression. A greater proportion of young people stated that girls 'expect' or 'enjoy' aggressive sex than boys do.

7.19 Several longitudinal studies have found that adolescent pornography consumption is associated with subsequent increased sexual, relational and body dissatisfaction (Hanson, 2020).

7.20 Research commentators recommend more investigation into consumption of online pornography and gender dysphoria is needed. Some researchers (Nadrowski, 2023) suggest that exploration with gender-questioning youth should include consideration of their engagement with pornographic content.

Mental health in children and adolescents

7.21 The striking increase in young people presenting with gender incongruence/dysphoria needs to be considered within the context of poor mental health and emotional distress amongst the broader adolescent population, particularly given their high rates of co-existing mental health problems and neurodiversity.

7.22 Internationally, there have been increasing concerns about the mental health of Generation Z. The reasons for this are highly speculative, although there is ongoing debate about the contribution of excessive smartphone use and social media as discussed above.

7.23 The Review spoke to a wide range of mental health professionals about their observations of rising mental health presentations across the child and adolescent population, and reviewed some of the available UK data.

7.24 UK national surveys between 1999 and 2017 show that there has been a substantial increase in rates of mental health problems in child and adolescent populations, with increased anxiety and depression being most evident in teenage girls. In 2014, there was a marked increase in young women aged 16-24 presenting with anxiety, depression and self-harm (NHS Digital, 2018).

7.25 The prevalence of ‘probable mental health disorder’ in children aged 8-16 years rose from 12.5% in 2017 to 20.3% in 2023. In young people aged 17-19 years, rates increased from 10.1% in 2017 to 23.3% in 2023 (NHS Digital, 2023).

7.26 Some conditions (for example, eating disorders) have increased more than others, particularly in girls and young women (Table 5).

7.27 Studies of rates of self-harm have shown similar increases. For example, between 2011 and 2014 there was an almost 70% increase in young girls between 13 and 16 years old presenting with self-harm, which was not paralleled in boys or in other age groups. Rates of self-harm in 13 and 19 year old girls were elevated throughout compared to boys (Morgan et al., 2017).

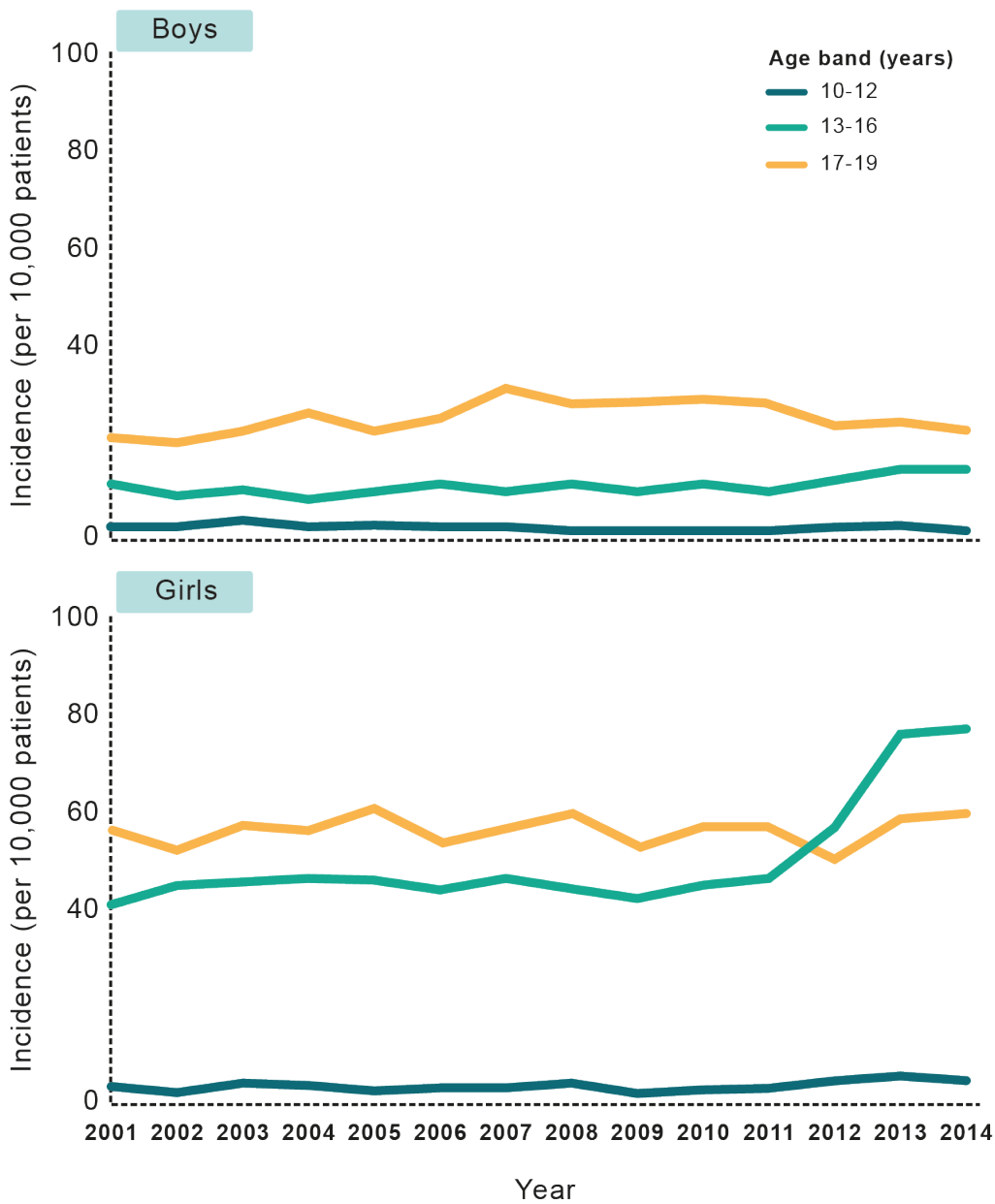
7.28 The increase in presentations to gender clinics has to some degree paralleled this deterioration in child and adolescent mental health. Mental health problems have risen in both boys and girls, but have been most striking in girls and young women. In addition to increasing prevalence of depression and anxiety, presentations of eating disorders and self-harm have increased since the Covid-19 pandemic (Trafford et al., 2023).

Table 5: Percentage of children and young people with an eating disorder, by age and sex, 2017 and 2023

	11 - 16-YEAR OLDS			17 - 19-YEAR OLDS		
	BOYS %	GIRLS %	ALL %	YOUNG MEN %	YOUNG WOMEN %	ALL %
2017	0.2	0.9	0.5	0	1.6	0.8
2023	1.0	4.3	2.6	5.1	20.8	12.5

Source: NHS Digital (2023, November 21). *Mental Health of Children and Young People in England, 2023 - wave 4 follow up to the 2017 survey*.

Figure 25: Temporal trends in annual age specific self-harm incidence stratified by sex, 2001-2014



Source: Reproduced from Morgan, C., Webb, R. T., Carr, M. J., Kontopantelis, E., Green, J., Chew-Graham, C. A., Kapur, N., & Ashcroft, D. M. (2017). Incidence, clinical management, and mortality risk following self harm among children and adolescents: Cohort study in primary care. *BMJ*. <https://doi.org/10.1136/bmj.j4351> with permission from BMJ Publishing Group Ltd.

NB: Standardised by index of multiple deprivation fifth and region of residence.

7.29 As well as the issues highlighted above, clinicians working in the NHS have seen increased rates of some more specialist mental health conditions such as functional tic-like behaviours, BDD and functional neurological conditions. These changes have been observed internationally, and preceded Covid-19, although some got worse during the pandemic.

7.30 Many young people with gender dysphoria are presenting with combinations of the above conditions. Sometimes the associated conditions pre-date the gender dysphoria and sometimes they follow it. The complex interplay between these issues is not well understood.



8. Possible factors influencing the change in patient profile

8.1 More than two decades ago, Cohen-Kettenis and Gooren (1999) wrote: “Adult gender identity and gender role behaviour develop gradually over a long period of time and are influenced by multiple, interacting factors, active at different developmental periods... our understanding of this process has increased considerably, but a large part of it still remains enigmatic”. This quote still resonates in 2024.

8.2 This report has described the very altered profile of the children and young people who are now being seen in NHS gender services. To inform how to best care for them, it is essential to understand more about the factors that are influencing the change in patient profile.

8.3 The change in the profile (with the majority now being adolescent, birth-registered females) needs to be considered in the context of changes in the wider population discussed in Chapter 7.

8.4 This chapter explores the evidence for biological factors in the development of a transgender identity and discusses the more dynamic contemporary psychosocial factors.

Biological factors

8.5 For many centuries transgender people have been predominantly trans females, commonly presenting in adulthood. Some transgender adults describe being aware of their gender incongruence and/or being gender dysphoric from childhood.

8.6 The search for a biological cause for gender incongruence is important to some transgender people and for some clinicians it is seen to strengthen the justification that medical treatment is warranted.

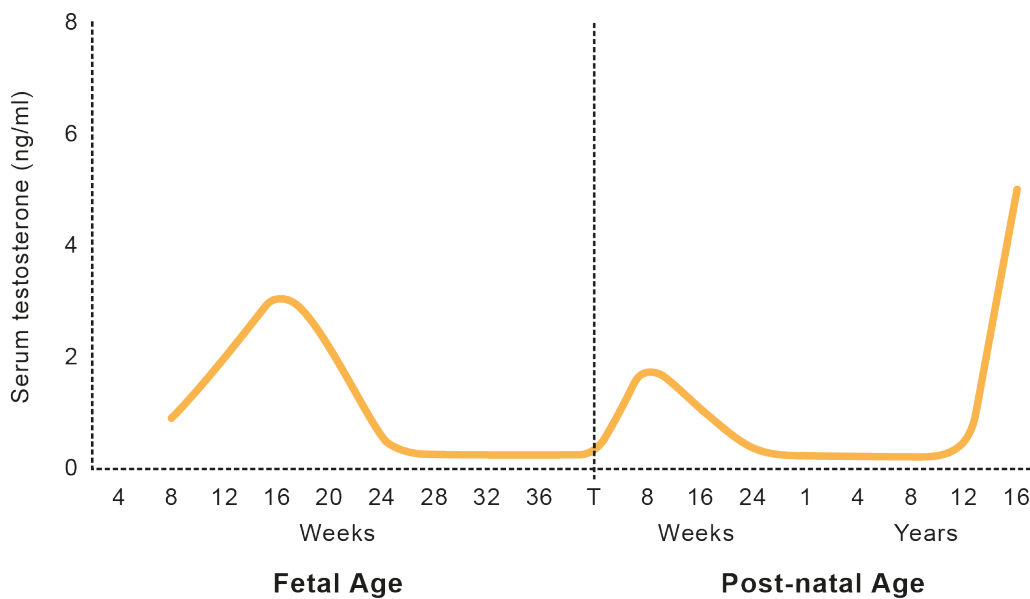
8.7 There are three main areas of research relating to biological factors: prenatal and/or pubertal hormone exposure; genetics (twin studies); and brain structure (imaging studies).

Prenatal and/or pubertal hormone exposure

8.8 Some authors have hypothesised that because sexual differentiation of the genitals takes place in the first two months of pregnancy but sexual differentiation of the brain only starts in the second half of pregnancy, these two processes can be influenced independently, which may result in gender incongruence (Swaab & Garcia-Falgueras, 2009).

8.9 As discussed previously, most of the evidence about the influence of prenatal hormones comes from the study of people with DSD. That evidence suggests that prenatal hormones have a large effect on gender role behaviours, a moderate effect on sexual orientation and a small effect on gender identity.

8.10 The second potential period when hormones may influence gender expression is puberty. There is evidence that masculinising/feminising hormone treatments alter brain structure (Ristori et al., 2020). The neuropsychological impact of arresting pubertal development with puberty blockers remains poorly understood (Baxendale, 2024).

Figure 26: Concentrations of serum testosterone in males from conception to puberty.

Source: Adapted from Hines, M. (2020b). *Neuroscience and sex/gender: Looking back and forward. The Journal of Neuroscience*, 40(1), 37-43. <https://doi.org/10.1523/jneurosci.0750-19.2019> under: <https://creativecommons.org/licenses/by/4.0/>

8.11 However, there is still no clear evidence that altered hormonal levels prenatally or during puberty are responsible for the development of gender incongruence, apart from in those with DSD, and this is a difficult area in which to test hypotheses.

Genetics (twin studies)

8.12 As identical twins have identical genes, when a single gene is responsible for a characteristic (for example, blood group), the twins will always have the same outcome (they will both have the same blood group). Non-identical twins are like any other siblings; they only share approximately 50% of their genes, so they may have different blood groups. Twin studies compare how often identical twins are concordant for a condition (that is, both have the same condition), compared to non-identical twins. If a condition is strongly genetically determined, identical twins will have a high level of concordance compared to non-identical twins.

8.13 Twin studies in gender identity are complicated; until recently, most of the large studies just looked at masculinity or femininity and did not include diagnosis of gender incongruence or dysphoria. The few studies that have included diagnosis primarily relied on parental report, did not follow through into adulthood and/or had small sample size. The older studies suggested that identical twins were more likely to manifest the same gender identity than non-identical twins, suggesting some genetic influence (Klink & Den Heijer, 2014).

8.14 In contrast, a more recent paper (Karamanis et al., 2022) looked at a large register-based population in Sweden over the period 2001 to 2016 and found no evidence for genetic influence in individuals who had been formally diagnosed with gender dysphoria and/or had gender-affirming treatment. The most important finding was that non-identical twins of different sex were much more likely than ordinary siblings to be concordant for gender

dysphoria (37% compared to 0.16%). One explanation is that environmental influences during pregnancy are a more likely explanation for the development of gender dysphoria than genetics. This finding therefore gives more credence to the theories about sex hormone exposure in the womb mentioned above, than to genetic factors.

Brain structure

8.15 Researchers have also investigated whether there are differences in brain structure in people with gender incongruence. Studies that look at brain structure, either from post-mortem evidence or neuroimaging, are complex. To date, some evidence has suggested that the brains of transgender females have some commonalities with the brains of birth-registered females in terms of the size of certain structures. However, as there are large overlaps in the characteristics of male and female brains it is not possible to tell if a brain is male or a female (Steensma et al., 2013a).

8.16 Notwithstanding the problems in determining how 'male' or 'female' a brain is outside of extremely large group averages, some studies do suggest that the brains of male-attracted transgender females have changes in a female direction, whilst those who are female-attracted do not. So, if there are differences, they may be related to sexuality rather than gender identity (Steensma et al, 2013a).

8.17 A further issue is that brains are not static. They change and adapt over time in response to various activities like learning a new skill, meditation, exercise or stress. This is known as brain plasticity. Thus, even if it were possible to reliably observe any differences in the brain, these could be a result of rather than a cause of a transgender identity.

8.18 Interpretation of studies on the brain are also problematic for a number of other reasons. For example, most studies:

- have examined brains of transgender females and not of transgender males
- are based on small numbers and have not been reliably replicated
- have examined brain structures after treatment with feminising hormones (rather than before and after treatment), so changes could be caused by treatment rather than any inherent differences.

8.19 More recently there has been a shift from studies that examine whether brains of transgender individuals are more 'male' or 'female' to trying to determine whether there is a unique 'transgender brain' (Mueller, 2021). To examine this, researchers combined the results of previous imaging studies in one 'mega' analysis. The researchers reported that "rather than being merely shifted towards either end of the male-female spectrum, transgender persons seem to present with their own unique brain phenotype". However, this type of analysis commonly generates false-positive findings. Given that this is such a heterogeneous population, this would be equivalent to suggesting that all neurodiverse people had the same unique brain, which does not seem to be a plausible hypothesis.

8.20 As imaging technology continues to advance, brain studies will remain a rich source of further information. However, to date, research in this area has not reliably identified brain changes directly linked to gender incongruence. Even if they could, this might not provide information on causality.

Summary of biological evidence

8.21 While there is no clear evidence for a straightforward biological cause for gender incongruence, it is possible that some individuals have a biological predisposition, which may make them more likely to develop gender incongruence.

8.22 Expressions of being human vary greatly in how much biological versus psychological versus social (environment) causes contribute. As an unrelated but illustrative example to help explain this, people who carry the BRCA gene have a high genetic risk of breast cancer, whereas for those without the BRCA gene and with no family history, factors like smoking, obesity and lack of exercise play a much greater part. In other words, the end result is the same, but the causes are different.

8.23 For children and young people with gender incongruence, 'innate' or biological factors may play a part in some individuals, in ways that are not yet understood, and in others psychosocial factors, including life experiences, societal and cultural influences, may be more important. Since biological factors have not changed in the last 10 years it is necessary to look at other possible reasons for the increase in referrals and the disproportionate representation of birth-registered females.

Psychosocial factors

8.24 Various explanations have been advanced for the increase in predominantly birth-registered females presenting to gender services in early adolescence often with complex presentations, and/or additional mental health problems and/or neurodiversity:

- **Societal acceptance:** The proposition is that greater acceptance of transgender identities has allowed young people to come out more easily and the increased numbers now reflects the true prevalence of gender incongruence within society.
- **Changes in concepts of gender and sexuality:** These might include a change in expressions of sexuality versus gender and a wider spectrum of expression (for example, non-binary and other gender identities that are more common presentations in birth-registered females).
- **Manifestation of broader mental health challenges:** For example, in the same way that distress can manifest through eating disorders or depression, it could also show itself through gender-related distress.
- **Peer and socio-cultural influence:** For example, the influence of media and changing generational perceptions. This is potentially the most contested explanation, with the term 'social contagion' causing particular distress to some in the trans community.
- **Availability of puberty blockers:** The change in the trajectory of the referral curve across many countries coincided with the implementation of the Dutch approach, starting first in the Netherlands and then similarly adopted in other countries.

8.25 Simplistic explanations of either kind (“all trans people are born that way” or “it’s all social contagion”) do not consider the wide range of factors that can lead young people to present with gender-related distress and undervalues their experiences.

Societal acceptance

8.26 Although it is certainly the case that there is much greater acceptance of trans identities, particularly amongst Generation Z, and this may account for some of the increase in numbers, this is not an adequate explanation for the overall phenomenon. Arguments that counter this explanation include:

- the exponential increase in numbers within a 5-year timeframe is very much faster than would be expected for the normal evolution of acceptance of a minority group;
- the rapid increase in numbers presenting to gender services across Western populations;
- the change in prevalence from birth-registered males to birth-registered females. The current profile of transgender presentations is unlike that in any prior historical period;
- the sharp differences in the numbers identifying as transgender and non-binary and presenting to gender services in Generation Z and younger Millennials compared to those over the age of 25-30. It would be expected that older adults would also show some signal of distress regarding their gender, even if they felt unable to ‘come out’;
- the failure to explain the increase in complex presentations.

Changes in concepts of gender and sexuality

8.27 The relationship between sexuality and gender identity is complex and contested. A transgender identity does not determine an individual’s sexuality. However, in the context of the Review, it is important to consider the relationship between sexual identity and gender identity given that sexuality contributes to a person’s sense of identity, and both may be fluid during adolescence.

8.28 In the original Dutch study (de Vries et al., 2011b), 89% of the 70 patients were same-sex attracted to their birth-registered sex, with most of the others being bisexual. Only one patient was heterosexual.

8.29 In contrast, in a detailed study of young people with ASD and gender dysphoria (de Vries et al., 2010), it was noted that “while almost all adolescents with GID [gender identity dysphoria] are sexually attracted to individuals of their birth sex, the majority of the gender dysphoric adolescents with ASD were sexually attracted to partners of the other sex”.

8.30 A paper from the GIDS service in 2016 (Holt et al., 2016) reported sexual orientation in 57% (97) of a clinic sample of patients over 12 years of age for whom this information was available. Of the birth-registered females, 68% were attracted to females, 21% were bisexual, 9% were attracted to males and 2% were asexual. Of the birth-registered males, 42% were attracted to males, 39% were bisexual and 19% were attracted to females.

8.31 The Review has not been able to obtain recent data relating to the sexual orientation of the GIDS patient cohort. When asked, mixed responses were given by GIDS clinicians about the extent to which they explore sexuality with patients seen in the service, and this may reflect differences in practice.

8.32 In terms of narratives and case histories, the Review received several reports from parents of birth-registered females that their child had been through a period of trans identification before recognising that they were cisgender same-sex attracted. Similar narratives were heard from cisgender adults (some same sex-attracted and some heterosexual) regarding early experiences of gender-questioning.

8.33 Clinicians and parents reported that gay students are still being stigmatised and bullied in school and there is sometimes a perception that there is less validation for them than for trans pupils. However, the Review also heard multiple testimonies attesting that having a diverse gender identity is a difficult path with young people subjected to bullying and abuse.

8.34 It is widely accepted that exposure to sexuality is happening at a younger age. The impact of this on young people's understanding of their sexuality and/or gender identity is unclear.

8.35 In some strictly religious cultures, being transgender is seen as preferable to being same-sex attracted as it is then perceived as a physical rather than a psychological issue.

8.36 It is common in adolescence to experience same-sex attraction and not to conform to gender stereotypes. In making sense of these feelings young people are now having to navigate an increasingly complex interplay between sex and gender.

8.37 In reality, for any individual young person, there will be different socio-cultural influences that impact on their understanding of both their gender and sexual identity, and this is an area that warrants better exploration and understanding.

Manifestation of broader mental health challenges

8.38 As described previously, rates of mental ill health in the general population of children and young people, particularly in girls and young women, have increased over the past decade. This parallels the increase in numbers of children and young people seeking support from NHS gender clinics.

8.39 The gender clinic referred population has high rates of mental health diagnoses, neurodiversity and adverse childhood experiences (ACEs). At the same time, young people now seem more likely to mention gender identity when they attend mental health services.

8.40 Early audits and research suggest that ACEs are a predisposing factor. This was demonstrated from the earliest audit of the GIDS service (Di Ceglie et al., 2002) and in the systematic review (Taylor et al: Patient characteristics)

8.41 Some people rebut the notion that trans identity may be secondary to mental health problems, and instead suggest that the mental health problems that are observed are a response to minority stress.

8.42 The association is likely to be complex and bidirectional - that is, in some individuals, preceding mental ill health (such as anxiety, depression, OCD, eating disorders), may result in uncertainty around gender identity and therefore contribute to a presentation of gender-related distress. In such circumstances, treating the mental health disorder and strengthening an individual's sense of self may help to address some issues relating to gender identity. For other individuals, gender-related distress may

be the primary concern and living with this distress may be the cause of subsequent mental ill health. Alternatively, both sets of conditions may be associated with and influenced by other factors, including experiences of neurodiversity and trauma.

8.43 There are well established effective treatments for many common mental health disorders. Individuals presenting with gender dysphoria should be able to access these if required, including those with neurodevelopmental differences who are frequently disadvantaged in being able to access mental health services.

8.44 Diagnosis and treatment of mental ill health in a young person with gender incongruence/dysphoria should not be a barrier to their gender issues being considered and evaluated in parallel.

Peer and socio-cultural influences

8.45 Sources of information for young people are predominantly online and peer-to-peer, and this applies to multiple aspects of their lives.

8.46 The generational changes in understanding and beliefs about the mutability of gender form the basis for many young people's understanding of their own experiences and the experiences of those around them.

8.47 It is the norm that all experiences of health and illness are understood through the norms and beliefs of an individual's trusted social group. Thus, it is more likely that bodily discomfort, mental distress or perceived differences from peers may be interpreted through this cultural lens.

8.48 More specifically, gender-questioning young people and their parents have spoken to the Review about online information that describes normal adolescent discomfort as a possible sign

of being trans and that particular influencers have had a substantial impact on their child's beliefs and understanding of their gender.

8.49 The Review's focus groups with gender diverse young people found that "Young people struggle to find trusted sources of information, favouring lived experience social media accounts over mainstream news outlets".

"I've always found that talking to people who have life experience is the best, either on like forums or like places like Reddit or on social media and other places"

"A lot of trans people make YouTube videos which I think is a [major] informational source for a lot of people, and that's mainly where I get my information from, not so much professional services."

"I have to spend time picking apart information and assessing it. I feel like I always have to be sceptical of the information I read, and really think about why they are writing it."

**Young people
Lived experience focus groups**

Availability of puberty blockers

8.50 The dramatic increase in presentations to NHS gender clinics from 2014, as well as in several other countries, coincided with puberty blockers being made available off protocol and to a wider group of young people. The only country with an earlier acceleration in referrals is the Netherlands, where the Dutch protocol was developed.

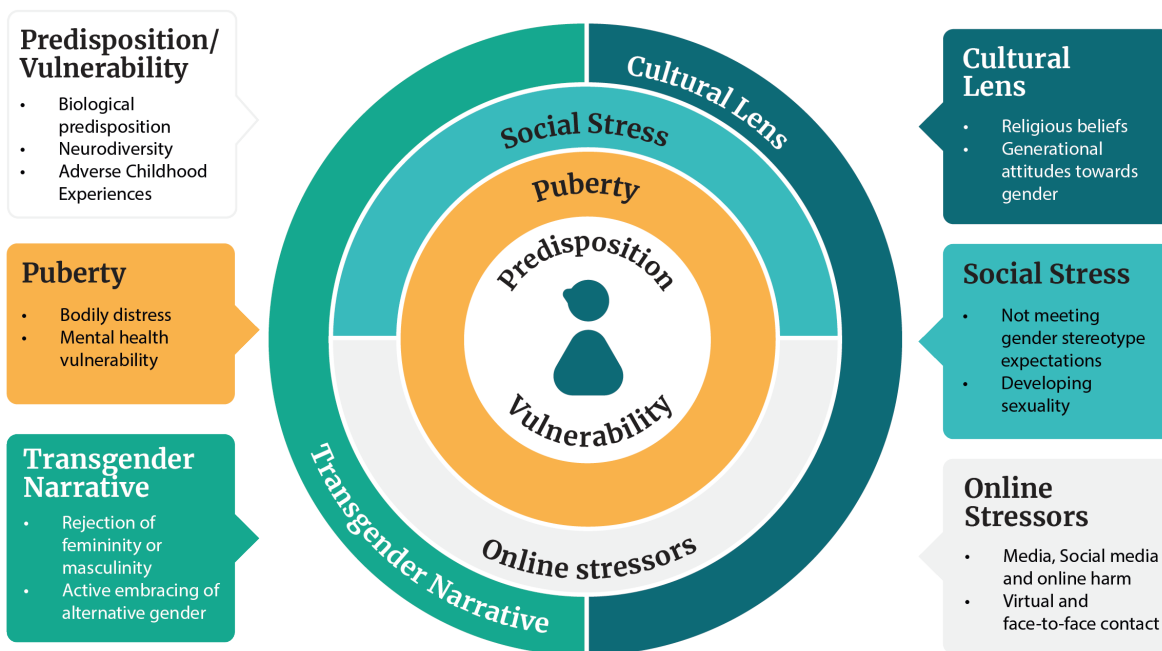
8.51 It is not possible to attribute causality in either direction to this association, but it remains a possibility that a lower threshold for medicalisation has had an influence on the number of young people seeking this intervention.

Conclusion

8.52 There is broad agreement that gender incongruence is a result of a complex interplay between biological, psychological and social factors. This ‘biopsychosocial’ model for causation is thought to account for many aspects of human expression and experience including intelligence, athletic ability, life expectancy, depression and heart disease.

8.53 Figure 27 demonstrates how in any one individual, gender incongruence and/or dysphoria may be a result of one or two factors, or it may result from a series of factors that underpin a young person’s experience and sense of self.

Figure 27: Complex interplay between biological, psychological and social factors



Presentation will vary with each individual



Illustrative examples

8.54 Although we do not have definitive evidence about biological causes of gender incongruence it may be that some people have a biological predisposition. However, other psychological, personal and social factors will have a bearing on how gender identity evolves and is expressed.

8.55 In later childhood and into early puberty, online experience may have an effect on sense of self and expectations of puberty and of gender. As discussed in relation to adolescent development, this is a time where the drive to fit in with peers is particularly strong. Young people who are already feeling 'different' may have that sense exacerbated if they do not fit in with the demonstrations of masculinity and femininity they are exposed to socially and/or online.

8.56 Peer influence during this stage of life is very powerful. As well as the influence of social media, the Review has heard accounts of female students forming intense friendships with other gender-questioning or transgender students at school, and then identifying as trans themselves.

8.57 It is the norm for people to view their experiences of life events, health and illness through their own cultural lens and personal beliefs. Cultural norms in younger people might impact how they interpret their personal, sexual and gender identity.

8.58 Puberty is an intense period of rapid change and can be a difficult process, where young people are vulnerable to mental health problems, particularly girls. Unwelcome bodily changes and experiences can be uncomfortable for all young people, but this can be particularly distressing for young neurodiverse people who may struggle with the sensory changes.

8.59 The data on young people's mental health, social media use and increased risks associated with online harm give an appreciation and understanding that going through the teenage years is increasingly difficult, with stressors that previous generations did not face. This can be a time when mental distress can present through physical manifestations such as eating disorders or body dysmorphic disorders. It is likely that for some young people this presents as gender-related distress.

8.60 A study followed 2,772 adolescents from age 11 to 26. Gender non-contentedness (as defined by the question "I wish to be of the opposite sex") was high in early adolescence, reduced into early 20s, and was associated with a poorer self-concept and mental health throughout development. It was also more often associated with same-sex attraction when compared to those who did not have gender non-contentedness (Rawee et al., 2024).

8.61 There is no single explanation for the increase in prevalence of gender incongruence or the change in case-mix of those being referred to gender services. Pragmatically all the above explanations for the observed changes in this heterogeneous population are likely to be true to a greater or lesser extent, but for any individual a different mix of factors will apply.

8.62 Working through this complex multi-layered personal development with the young person is likely to take some time, and the role of the clinical team is to help them address some of these complex issues so that they can better understand their gender identity and evaluate the options available to them.



Clinical approach & clinical management



This section looks at clinical approaches and clinical management. It seeks to address the following areas on which the Review has been asked to provide recommendations:

- clinical management approaches at each point of the specialised pathway of care from assessment to discharge, including a description of objectives, expected benefits and expected outcomes for each clinical intervention in the pathway;
- best clinical approach for individuals with other complex presentations;
- the use of gonadotropin-releasing hormone analogues and gender affirming drugs.

Any treatment recommendations will include a description of treatment objectives, expected benefits and expected outcomes, and potential risks, harms and effects to the individual.

Where relevant, each chapter summarises the Review's commissioned research, other published work and insights from engagement with service users, parents/carers, clinicians and others.

9. International practice and guidelines

9.1 There is understandable public focus on young people who access medical interventions. However, from the outset, the Review has tried to understand what happens for all gender-questioning children and young people seeking NHS support, including those who do not go on to a medical pathway.

9.2 The question is: what is the best way to address, support and manage the whole population of children and young people presenting to services with gender incongruence and/or dysphoria?

9.3 When considering the best clinical approach, the Review first wanted to understand how care is arranged and delivered in other health systems. If good guidance and practice already exists internationally it was important to learn from this and adopt it where appropriate.

9.4 The Review commissioned the University of York to undertake:

- an appraisal and synthesis of available international guidelines (Taylor et al: Guidelines 1: Appraisal; Taylor et al: Guidelines 2: Synthesis)
- an international survey of gender services (Hall et al: Clinic survey)
- a review of published papers on other service models.

9.5 During the lifetime of the Review, it has become apparent that practice is changing

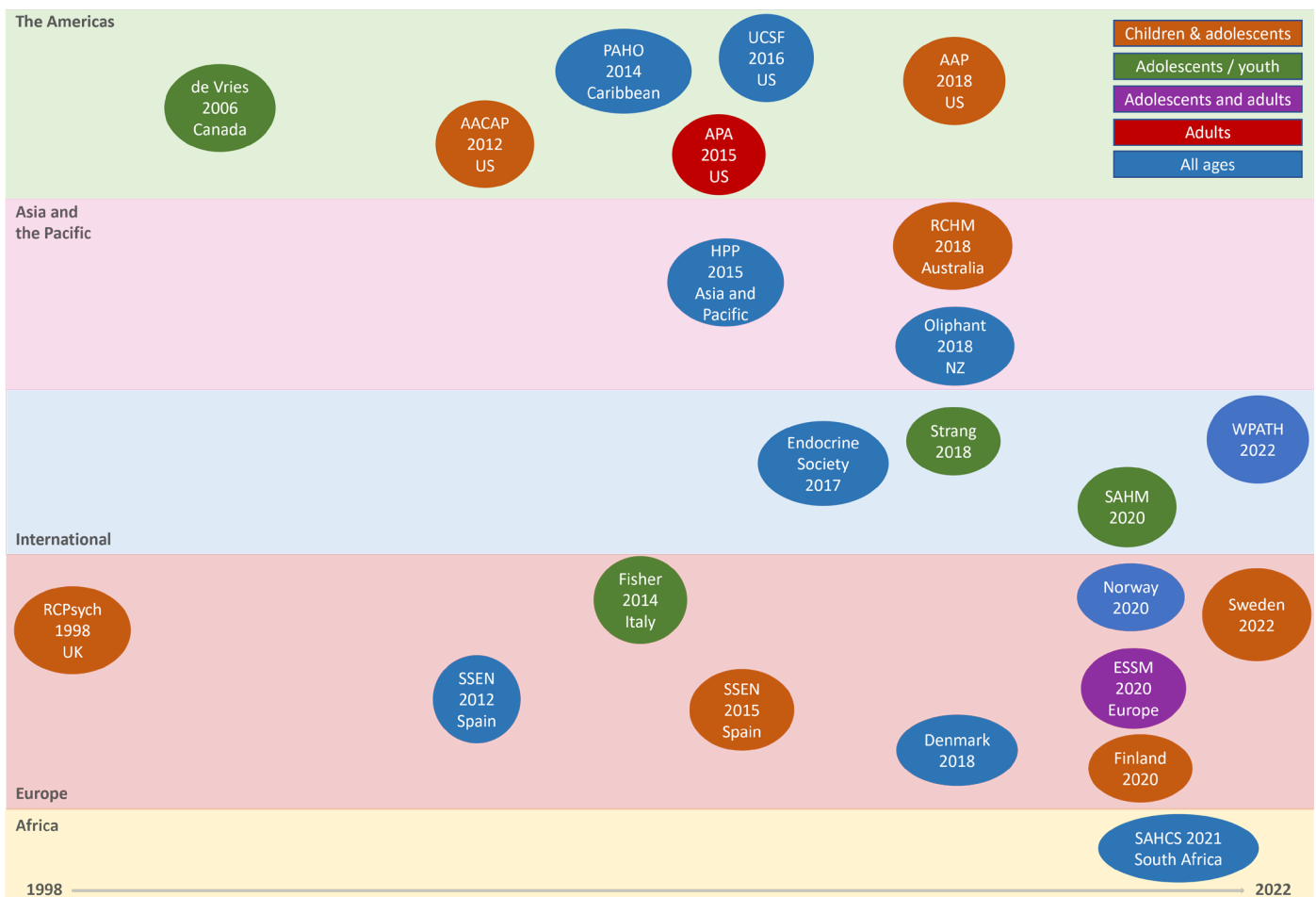
rapidly on the international stage with Nordic countries, and France, as well as some clinics in Australia, taking a more cautious approach to gender-related care for children and young people. The Review's interim report (2022) also advised a more cautious approach for the NHS in England, pending the more comprehensive findings presented in this final report.

Guideline appraisal

9.6 Clinical guidelines are recommendations on how healthcare and other professionals should care for people with specific conditions; for example NICE guidelines in England and SIGN guidelines in Scotland. Recommendations are based on the best available evidence and expert consensus. There are standard methods for analysing the research evidence, with systematic reviews being the highest level of analysis and most trusted way to determine what the available research tells us (see Figure 28).

9.7 A number of guidelines on the care of children and young people with gender incongruence and/or gender dysphoria have been published, some specific to individual countries and some intended for international audiences.

Figure 28: A timeline for the included guidelines by geographical region, country and target population.



Source: Taylor et al: Guidelines 1: Appraisal

NB: AACAP, American Academy of Child and Adolescent Psychiatry; AAP, American Academy of Pediatrics; APA, American Psychological Association; ESSM, European Society for Sexual Medicine; HPP, Health Policy Project; PAHO, Pan American Health Organisation; RCHM, Royal Children’s Hospital Melbourne; RCPsych, UK Royal College of Psychiatrists; SAHCS, South African HIV Clinicians Society; SAHM, Society for Adolescent Health and Medicine; SSEN, Spanish Society of Endocrinology and Nutrition; UCSF, University California, San Francisco; WPATH, World Professional Association for Transgender Health.

9.8 The starting point for the Review was to seek an appraisal of these guidelines and determine if some components might be directly transferable to the NHS in England.

9.9 The University of York identified 23 guidelines published between 1998 and 2022 that contained recommendations about children and young people with gender dysphoria (four international, three regional and 16 national).

9.10 The guidelines covered the following key areas of practice:

- care models, principles and practices
- multi-disciplinary team (MDT) composition, roles, competencies, and training
- assessment
- psychosocial care (child and family)
- information, education and advocacy
- social transition
- puberty suppressant hormones
- cross-sex hormones
- surgical interventions
- fertility care
- other interventions (for example, voice therapy, hair removal)
- sexual health and functioning
- physical health and lifestyle.

9.11 The quality of clinical guidelines was assessed using AGREE II (AGREE Next Steps Consortium, 2017), which is the most commonly applied and comprehensively validated appraisal tool. The AGREE II approach considers six domains:

- scope and purpose
- stakeholder involvement

- rigour of development
- clarity of presentation
- applicability
- editorial independence.

9.12 This was followed by an overall assessment of quality and whether a guideline should be recommended for use in practice.

9.13 Rigour of development is an important bedrock of guideline development. It includes systematically searching the evidence, being clear about the link between recommendations and supporting evidence, and ensuring that health benefits, side effects and risks have been considered in formulating the recommendations.

9.14 A 2018 study (Hoffmann-Eßer et al., 2018) looked at which of the AGREE II domains were most influential in the overall assessment scores. The authors found that experienced reviewers were most strongly influenced by rigour of development and editorial independence. This is not a surprising finding. A guideline may be clear in scope, purpose and presentation, and have good stakeholder engagement, but would be hard to recommend for use in practice if there were weaknesses in the development process.

9.15 Of the 23 guidelines identified, four did not provide any information about the development process, so could not be appraised. The remaining guidelines were appraised independently by three reviewers.

Table 6: Critical appraisal domain scores

Guideline ID	Scope and Purpose	Stakeholder involvement	Rigour of development	Clarity of presentation	Applicability	Editorial Independence
AACAP 2012	65	39	44	63	7	31
American Academy of Paediatrics 2018	70	26	12	30	6	69
American Psychological Association 2015	74	74	24	50	18	14
Council for Choices in Healthcare Finland 2020	91	69	51	72	56	0
de Vries 2006	63	31	10	74	17	6
Endocrine Society 2009	65	33	44	70	22	31
Endocrine Society 2017	63	33	42	72	21	92
European Society for Sexual Medicine 2020	63	52	39	70	7	58
Fisher 2014	65	20	12	35	17	44
Health Policy Project 2015	63	63	16	24	33	6
Norwegian Directorate of Health 2020	76	81	30	57	47	17
Oliphant 2018	44	39	12	33	21	0
Pan American Health Organisation 2014	52	44	13	31	21	0
Royal Children's Hospital Melbourne 2018	81	59	19	41	19	14
Society for Adolescent Health and Medicine 2020	41	24	17	41	7	0
South African HIV Clinicians Society 2021	59	59	21	43	24	69
Strang 2018	87	31	18	37	15	19
Swedish National Board of Health & Welfare 2022	91	87	71	83	25	36
UCSF 2016	70	41	23	37	26	0
WPATH 2012	85	61	26	56	17	17
WPATH 2022	83	63	35	56	24	39

≥70%,
31%-69%,
≤30%.
AACAP, American Academy of Child & Adolescent Psychiatry; UCSF, University of California, San Francisco; WPATH, World Professional Association for Transgender Health

Source: Taylor et al: Guidelines 1: Appraisal

9.16 Most guidelines scored well on the scope and purpose domain, but poorly on the rigour of development, applicability and editorial independence domains. Only the Finnish guideline (Council for Choices in Healthcare in Finland, 2020) and Swedish guideline (Swedish National Board of Health and Welfare, 2022) scored above 50% for rigour of development.

9.17 Most of the guidelines were developed by a core group of experts in broader consultation with other professional stakeholders, although there was lack of clarity about how this input was incorporated. Just over half engaged with service users, and again it was unclear how this influenced recommendations.

9.18 Only five guidelines described using a systematic approach to searching for and/or selecting evidence (AACAP 2012, Endocrine Society 2017, Finland 2020, Sweden 2022 and WPATH 2022).

9.19 For many of the guidelines it was difficult to detect what evidence had been reviewed and how this informed development of the recommendations. For example, most of the guidelines described insufficient evidence about the risks and benefits of medical treatment in adolescents, particularly in relation to long-term outcomes. Despite this, many then went on to cite this same evidence to recommend medical treatments.

9.20 Alternatively, they referred to other guidelines that recommend medical treatments as their basis for making the same recommendations. Early versions of two international guidelines, the Endocrine Society 2009 and World Professional Association for Transgender Healthcare (WPATH) 7 guidelines influenced nearly all the other guidelines.

9.21 These two guidelines are also closely interlinked, with WPATH adopting Endocrine Society recommendations, and acting as a co-sponsor and providing input to drafts of the

Endocrine Society guideline. WPATH 8 cited many of the other national and regional guidelines to support some of its recommendations, despite these guidelines having been considerably influenced by WPATH 7. The links between the various guidelines are demonstrated in the graphics in the guideline appraisal paper (Taylor et al: Guidelines 1: Appraisal).

9.22 The circularity of this approach may explain why there has been an apparent consensus on key areas of practice despite the evidence being poor.

9.23 Only the Swedish and Finnish guidelines differed by linking the lack of robust evidence about medical treatments to a recommendation that treatments should be provided under a research framework or within a research clinic. They are also the only guidelines that have been informed by an ethical review conducted as part of the guideline development. However, these guidelines like others lack clear recommendations regarding certain aspects of practice and would benefit from more detailed guidance regarding implementation of recommendations.

9.24 The guideline appraisal raises serious questions about the reliability of current guidelines. Most guidelines have not followed the international standards for guideline development (AGREE Next Steps Consortium, 2017). Therefore, only the Finnish (2020) and the Swedish (2022) guidelines could be recommended for use in practice.

9.25 Because of the very widespread influence and adoption of the WPATH guidance and the very different approach in the Swedish and Finnish guidelines, some further detail on the link between evidence and recommendations in these guidelines is discussed below.

World Professional Association for Transgender Healthcare (WPATH) 8 guideline (2022)

9.26 The WPATH 8 commentary on adolescence gives a clear account of how dynamic this period of life is in terms of cognitive, emotional, gender and personal development, and how individualised that can be. The guideline also sets out some of the knowns and unknowns about the possible biological contributions to gender incongruence, as well as recent changes in how gender diverse young people present to healthcare services, and the uncertainty regarding how stable or fluid their gender identity may be.

9.27 WPATH commissioned a systematic review to underpin version 8, an approach it had not undertaken for WPATH 7. This systematic review (Baker et al., 2021) found that “hormone therapy was associated with increased quality of life, decreased depression, and decreased anxiety”. However, “certainty in this conclusion is limited by high risk of bias in study designs, small sample sizes, and confounding with other interventions”. The recommendation was that “future studies should investigate the psychological benefits of hormone therapy among larger and more diverse groups of transgender people using study designs that more effectively isolate the effects of hormone treatment”.

9.28 The WPATH 8 narrative on gender-affirming medical treatment for adolescents does not reference its own systematic review, but instead states: “Despite the slowly growing body of evidence supporting the effectiveness of early medical intervention, the number of studies is still low, and there are few outcome studies that follow youth into adulthood. Therefore, a systematic review regarding outcomes of treatment in adolescents is not possible. A short narrative review is provided instead”.

9.29 Within the narrative account the guideline authors cite some of the studies that were already deemed as low quality, with short follow-up periods and variable outcomes, as well as a selected account of detransition rates.

9.30 WPATH 8 concludes in its statement on the use of gender-affirming medical treatment that: “The evolving evidence has shown a clinical benefit for transgender youth who receive their gender-affirming treatments in multidisciplinary gender clinics (de Vries et al., 2014; Kuper et al., 2020; Tollit et al., 2019)”.

- De Vries et al. (2014) is the original study of the Dutch protocol sample, which has marked differences to the population being treated currently, and as discussed had much stricter criteria for treatment.
- Kuper et al. (2020) is a study with a one year follow-up that showed very modest change. It fell into the group rated by the University of York research team as too low quality to be included in their synthesis of evidence on masculinising/feminising hormones (Taylor et al: M/F hormones).
- Tollit et al. (2019) is a study protocol and does not include any results.

9.31 The systematic review commissioned by WPATH is referenced in the chapter on WPATH 8 standards as one of several references in support of the statements that “There is strong evidence demonstrating the benefits in quality of life and well-being of gender-affirming treatments, including endocrine and surgical procedures, properly indicated and performed as outlined by the Standards of Care (Version 8), in transgender people in need of these treatments” and “Gender-affirming interventions are based on decades of clinical experience and research; therefore, they are not considered experimental, cosmetic, or for the mere convenience of a patient. They are safe and effective at reducing gender incongruence and gender dysphoria”.

9.32 Clinical consensus is a valid approach to guideline recommendations where the research evidence is inadequate. However, instead of stating that some of its recommendations are based on clinical consensus, WPATH 8 overstates the strength of the evidence in making these recommendations.

Swedish (2022) and Finnish (2020) guidelines

9.33 The Swedish guideline took a different stance to WPATH 8 based on three considerations:

- The change in epidemiology and lack of understanding of the cause of the more recent presentations to gender services.
- The lack of clear data on how frequently detransition or regret occurs in young adults.
- A re-evaluation of the evidence base through its own systematic review, which demonstrated uncertainty about the strength of evidence in favour of gender-affirming care. It was also noted that previous guidelines relied much more heavily on expert opinion rather than on systematic reviews of the evidence.

9.34 Based on the above considerations, the Swedish guideline recommended that medical treatment should follow the original Dutch criteria and should only be given under a research protocol, or in exceptional circumstances.

9.35 The Finnish guideline had reached similar conclusions on the uncertainty of the evidence and proposed extreme caution in relation to the use of puberty blockers in young people under the age of 18, also reverting largely to

the original Dutch entry criteria. The guideline recommended that puberty blockers should be administered under the supervision of the national specialist clinic.

Key points of learning for the NHS

9.36 The University of York has produced a narrative synthesis of the guidelines (Taylor et al: Guidelines 2: Synthesis). Relevant information from this synthesis can be found in later chapters in this report.

9.37 It was clear from the guideline quality appraisal process that no single guideline could be applied in its entirety to the NHS in England, although some had useful and transferrable recommendations that have been incorporated where consistent with the rest of the Review's findings.

9.38 The Review has based its recommendation on its commissioned systematic reviews, advice from clinical experts across a range of relevant areas in the care of children and young people with gender dysphoria and in other relevant and important areas of child and adolescent health, as well as on the mixed methods approach to stakeholder engagement described earlier.

9.39 When the new clinical services are well-established and there is further available evidence, it may be possible to employ more formal guideline development approaches to those aspects of gender-related care that still remain contested.



10. Assessment and diagnosis

10.1 As set out in Part 3 of this report, the individual presentations of many of the children and young people seeking support are diverse and complex.

10.2 The heterogeneity of the patient cohort makes assessment and diagnosis challenging, and many clinicians, both nationally and internationally, have told us that there is no reliable way to accurately predict which young people might benefit from a medical transition and which might benefit from alternative pathway(s) or intervention(s).

International practice

10.3 The York synthesis of international guidelines (Taylor et al: Guidelines 2: Synthesis) found that all guidelines recommend multi-disciplinary assessment of the child/young person, usually over multiple sessions.

10.4 There is limited clarity about the purpose of assessment. Some guidelines were focused on diagnosis, some on diagnosis and eligibility for hormones, some on psychosocial assessment, and some on readiness for medical interventions.

10.5 Only the Swedish and WPATH 8 guidelines contain detail on the assessment process. Both recommend that the duration, structure and content of the assessment be varied according to age, complexity and gender development.

10.6 Within the international guidelines there is also marked variability in whether both children and adolescents should be assessed and if so, how these assessments might differ.

10.7 All guidelines recommend that discussion of gender development and identity forms part of assessment, but few provide detail. Several recommend assessing duration, severity and persistence of gender dysphoria, and exploring different aspects including incongruence, distress, identity, expression, plans and future desires.

10.8 Very few guidelines recommend formal measures/clinical tools to assess gender dysphoria, and a separate analysis demonstrated that the formal measures that exist are poorly validated.

10.9 Five guidelines recommend assessing for neurodevelopmental conditions.

10.10 The range of recommendations in the guidelines regarding domains that should be assessed are shown in Table 7.

Table 7: Recommended assessment domains

Guideline ID	Gender	Body image	Mental health difficulties	Neuro-diversity or ASC	Sexuality or sexual orientation	Sexual functioning or health	Psychosocial functioning	Cognitive functioning / intelligence	Family functioning or support	Physical health or conditions
American Academy of Child & Adolescent Psychiatry	Yes	No	Yes	No	Yes	Yes	Yes	No	Yes	No
American Psychological Association	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
Danish Health Authority	Yes	No	Yes	No	Yes	No	Yes	No	Yes	Yes
de Vries <i>et al</i>	Yes	Yes	Yes	No	Yes*	Yes*	Yes	No	Yes	No
Endocrine Society	Yes	No	Yes	No	Yes†	No	Yes	No	Yes	No
European Society for Sexual Medicine	Yes	No	Yes	No	No	No	Yes	No	Yes	No
Health Policy Project	Yes	No	Yes	No	Yes*	Yes*	Yes	No	Yes	Yes
Norwegian Directorate of Health	Yes	No	Yes	No	Yes	No	Yes	No	Yes	Yes
Oliphant <i>et al</i>	Yes	No	Yes	Yes	No	Yes	Yes	No	Yes	No
Pan American Health Organisation	Yes	No	Yes	No	No	No	No	No	No	Yes
Royal Children's Hospital Melbourne	Yes	No	Yes	No	No	No	Yes	Yes	Yes	No
Royal College of Psychiatrists	Yes	No	Yes	No	No	No	Yes	No	Yes	No
SIAMS-SIE-SIEDP-ONIG	Yes	No	Yes	No	Yes	No	Yes	Yes	Yes	No
South African HIV Clinicians Society	Yes	No	Yes	Yes	No	No	Yes	No	Yes	No
Swedish National Board of Health and Welfare	Yes	No‡	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
World Professional Association for Transgender Health	Yes	No	Yes	Yes	No	No	Yes	Yes	Yes	Yes

*HEEADSSS suggested as tool which includes sexuality. †Assessment of psychosexual development. ‡Body image scale identified as useful tool.

ASC, autism spectrum condition; HEEADSSS, psychosocial assessment tool covering Home & Environment, Education & Education, Eating & Exercise, Activities, Drugs/Substances, Sexuality, Suicide/depression, Safety .

Source: Taylor *et al*: Guidelines 2: Synthesis

10.11 The University of York's international survey (Hall *et al*: Clinic survey) provides insight into how clinical practice compares to guideline recommendations and found marked variability:

- Duration and number of assessment appointments that a young person would receive varied within and between clinics and were often said to be tailored to individual need. Only Spain had a single assessment appointment with psychology involvement optional.
- Most clinics assess mental health and gender development, and usually psychosocial functioning.

Only five clinics reported routine discussion of fertility preferences, and only two discussed sexuality. Finland was the only country to report routinely assessing for history of trauma.

- Fourteen tools were used across 10 clinics to measure gender incongruence. Only five were used in more than one clinic. There were 36 measures used to assess co-occurring conditions, with only 10 used by more than one clinic.

NHS practice

10.12 In a survey of the Gender Identity Development Service (GIDS) clinicians conducted by the Review in its early stages, the range of opinion on the purpose of assessment was apparent. The survey found that “There is not a clear view amongst the specialists who responded to the survey as to the purpose of the assessment. Some respondents felt that assessment should be focused on whether medical interventions are an appropriate course of action for the individual. Other respondents believe that assessment should seek to make a differential diagnosis, ruling out other potential causes of the child or young person’s distress.”

(PowerPoint Presentation: cass.independent-review.uk)

10.13 The majority (79%) of respondents to the gender specialists survey agreed or strongly agreed that psychological formulation can be helpful in assessing children and young people needing support around their gender identity. Those respondents who agreed reasoned that it can provide a structured process for understanding the child/young person’s distress and provide a more holistic picture of them which can be helpful in developing an appropriate care plan.

10.14 The University of York also invited GIDS to participate in the international survey (Hall et al: Clinic Survey) to record practice in England, but GIDS did not respond.

10.15 In the absence of a formal clinical audit from GIDS or a response to the international survey, the Multi-Professional Review Group’s (MPRG’s) updated report (Appendix 9) represents the most comprehensive review of clinical notes and approach available, albeit only for those children and young people referred for puberty blockers.

10.16 The MPRG’s reflections should be considered with General Medical Council guidance in mind: “Medical notes should provide an accurate record of the exchange of information leading to a decision in order to inform [the patient’s] future care and to help explain and justify the clinician’s decisions and actions” (General Medical Council, 2020).

In summary, the MPRG's findings are as follows:

- The structure of the assessment process was rarely provided.
- It was not clearly evidenced how thoroughly 'gender identity and consideration of different options for gender expression' and 'different treatment options/choices' [as per the Standard Operating Procedure] were explored.
- There was inconsistent evidence as to whether the individual impact of social transition had been explored.
- The clinical notes rarely provided a structured history or physical assessment even though the children and young people presenting had a wide range of familial and congenital conditions.
- Sexuality was not consistently discussed.
- The history of the child/young person's gender journey was rarely examined closely for signs of difficulty, regret or wishes to alter any aspect of their gender trajectory.
- Autism spectrum disorder (ASD) or attention deficit hyperactivity disorder (ADHD) traits or diagnoses were mentioned in the majority of cases, but it is not clear how fully or appropriately these had been explored.
- No family trees were made available, making it difficult to understand family structure and relationships.
- There was a lack of evidence of professional curiosity as to how the child/young person's specific social circumstances may impact on their gender dysphoria journey and decisions.
- Although external reports (for example, from the child/young person's school) were useful, they were frequently not up-to-date.

Perspectives from service users and families

10.17 There was also a general lack of understanding among service users participating in the lived experience focus groups about what the assessment was for and confusion about what was assessment and what was diagnosis. Thoughts on the purpose of assessment included:

- To support young people to explore their options and access the care that's right for them.
- To get validation of their trans identity and access to the medication pathway.
- To make the person comfortable and focus on what they're looking for from the service.
- To ensure patients have an understanding of the healthcare options available.

"What is needed is a space whereby people's understandings of themselves are valued, whilst also providing an open space for exploration of what this means to the individual, and what support they need in order to live a happy and fulfilled life."

**GIDS clinician
Specialist questionnaire**

10.18 Young people describe a mismatch between what they want and expect from the process and their experience or perception of what actually happens. While the public narrative has often asserted that decisions about interventions were taken with insufficient exploration, the experiences or perceptions of some of the young people who were seen by GIDS, and some of their parents was that the process of assessment was too onerous and invasive.

10.19 Qualitative research, undertaken by the University of York (Appendix 3), found that service user experiences and perceptions of the assessment process vary. "Some young people looked forward to talking with someone who understood them. Some, however, felt uncomfortable and initially found it difficult to talk about how they felt. Others expressed frustration, disappointment and at times, anger. They believed talking slowed down or prevented access to medical pathways."

"Everyone's needs are different and I think having an open space where it's patient focused and patient-led is essential."

**Young person
Focus group**

10.20 There was consensus among service users, parents/carers and clinicians around the need for a holistic approach to care, where children and young people and their families feel listened to and able to explore what they may need to feel happy, confident and able to thrive.

Holistic assessment framework

10.21 Based on the uncertainties, differing recommendations and lack of clear detail found in international guidelines and practice, the Review's Clinical Expert Group (CEG) concluded that there was no approach to assessment that could be directly adopted for use in the NHS.

Development process

10.22 It was agreed that the CEG should work with the Review to develop a consistent, reproducible, developmentally informed, holistic assessment framework to:

- support identification of individual needs
- allow outcomes to be measured more consistently and
- ensure children and young people have a similar experience of the service.

10.23 Clinical experts in a range of related areas of child and adolescent development, health, and wellbeing contributed to the development of the framework and the views of stakeholders have been considered and incorporated where appropriate.

10.24 The CEG agreed the following statement of the key aims and principles for assessment:

“The purpose of assessment is to derive a multi-level formulation for a child or young person who presents to the NHS seeking help around their gender or experience of gender-related distress.

Assessment should seek to understand the holistic needs of the child or young person and their family. This process should determine whether there are any cooccurring and/or contributory elements of the individual's presentation that are affecting their psychosocial wellbeing or functioning and require support as the basis of an individual care plan.

Presentations, pathways and outcomes for this cohort are very individual, and there needs to be a focus on helping each person to find the best pathway for them. Assessments should be respectful of their experience and be developmentally informed.

Not all children and young people will need an in-depth assessment and will get what they need from other forms of local support, informed by consultation and advice from specialist practitioners.

Clinicians along the pathway should remain open and explore the patient's experience and the range of support and treatment options that may best address their identified needs. Taking a collaborative needs-based approach supports the development of the child or young person's broader wellbeing and functioning with the aim of reducing distress, improving their psychological functioning, sense of wellbeing and quality of life.”

The framework provides a starting point for services to assess immediate risk and determine the complex care needs of the children and young people referred to the service.

Structure and content

10.25 The holistic assessment framework has been split into eight non-sequential domains centred around the individual child/young person and their parents/carers. Weight given to each component is dependent on individual needs. These domains are consistent with assessment models used in the care of children, young people and families in other child, adolescent clinical care, and consider the individual as a whole.

10.26 Domains that connect more specifically to understanding gender development, gender

incongruence and gender-related distress and dysphoria have also been incorporated drawing upon relevant literature.

10.27 When undertaking an assessment, clinicians should remain open-minded, have no preconceived outcome and should have an appreciation that the child/young person's priorities may change over time. They should also be aware of parent/carer expectations and the impact these may have on the young person's priorities, or alternatively the potential for significant disagreement/fragmentation within families about the nature of the child/young person's distress.

Figure 29: Holistic needs assessment - essential components



Family context

10.28 Understanding children in the context of their families and home environments, including family makeup, key relationships, strengths, resources and social circumstances, as well as parental/carer health and well-being, is a core principle of good practice across health and social care settings.

10.29 It is particularly important in this group of young people given that there is evidence of an increased frequency of family parental physical and/or mental ill health and other family stressors in this group (Di Ceglie et al., 2002; Taylor et al: Patient characteristics).

Development

10.30 A detailed developmental history seeks to gather information from parents/carers about the young person's development, including physical, language, cognitive and social development.

10.31 Environmental, social and psychological factors unique to every child and family can affect development. During the transition from childhood to adolescence young people can experience substantial social, emotional and physical changes. This domain requires additional areas of focus where a neurodevelopmental condition is either confirmed or suspected.

10.32 Given the high prevalence of neurodiversity identified within this population, all those attending children and young people's NHS gender services should receive screening for neurodevelopmental conditions (Strang et al., 2018). Where appropriate, consideration should be given to cognitive and language assessments.

Physical health needs

10.33 An understanding of the child or young person's physical health history and the impact of any health issues on development and wellbeing is important.

10.34 Long-term health conditions can influence various aspects of children's development and may include elevated anxiety around health and wellbeing for both children and their parents.

10.35 The child/young person may have needed to make complex adjustments both socially and emotionally. They could also have experienced trauma in relation to medical experiences or hospitalisations.

Mental health

10.36 Children and young people referred to specialist gender services have higher rates of mental health difficulties than the general population. Because gender incongruence is not considered to be a mental health condition clinicians are often reluctant to explore or address co-occurring mental health issues in children and young people presenting with gender distress. Regardless of any other causes for mental health conditions, living with gender issues and the process of transitioning (if this is felt to be the appropriate path for an individual) comes with challenges.

10.37 The mental health assessment within a gender clinic should follow the structure of a standard evidence-based core CAMHS assessment. There are many published examples of suggested structures for this assessment, which may involve the use of validated questionnaires for children and young people and their carers to inform further assessment.

10.38 In a standard mental health assessment, all of the other seven domains described as part of this holistic assessment framework are usually considered in depth in relation to mental health. Systematic questioning should include enquiry about mood, anxiety, emotional regulation, beliefs around weight, potential somatic symptoms, concentration, sleep and appetite, self-harm, and suicidal thoughts and behaviours. A mental state examination should be included as appropriate.

10.39 A mental health diagnostic formulation incorporates diagnosis, level of impairment, risk assessment, and consideration of predisposing, precipitating and perpetuating/maintaining factors and how they impact on current functioning.

10.40 Identifying and treating mental health difficulties should be an integrated part of the care for children and young people presenting with gender dysphoria. Evidence-based treatments to support mental health and resilience, should be available to children and young people presenting with gender issues as they would be to any other young people presenting to NHS services.

Education, peer relationships and social context

10.41 Consideration of the child/young person's functioning in relation to education, their broader well-being and the nature of their peer relationships is important in assessing their overall functioning and supports a holistic understanding of their strengths and vulnerabilities.

10.42 It is important to obtain information about school attendance and any difficulties in educational achievement, as well as a recent Education, Health and Care plan for any young person with special educational needs.

Safeguarding

10.43 As with all health care provision, when working with children and young people safeguarding must be a consideration. There are complex ways in which safeguarding issues may be present. Clinicians working with children and young people experiencing gender dysphoria have highlighted that safeguarding issues can be overshadowed or confused when there is focus on gender or in situations where there are high levels of gender-related distress.

10.44 Sources of risk in this group include:

- transphobic bullying in school and in other settings
- breakdown in relationships with families
- online grooming or harm
- cultural or religious pressure.

10.45 The Review has heard about a small number of cases where the child's gender identity was consciously or unconsciously influenced by the parent. It is very important that the child/young person's voice is heard and that perceptions of gender identity represent the child/young person's sense of self.

10.46 The Review has also heard a series of accounts of children and young people at safeguarding risk being lost to follow-up and/or of young people presenting to the emergency department with a safeguarding history that staff were unaware of because of changes of name and NHS number.

10.47 Staff should remain alert to these complexities and know when to act, raising them during supervision and with the wider Multi-Disciplinary Team (MDT), and adhering to recognised principles of safeguarding and risk management as applied to children/young people and their parents/carers.

10.48 Clinicians should assess and consider safeguarding across each domain of the assessment framework, documenting issues fully within this dedicated domain.

Gender development and experiences

10.49 Clinicians should undertake an in-depth assessment of the child/young person's gender development over time, how this manifested and how it has been managed within the family.

10.50 Clinicians should seek to understand whether any steps have been taken towards social transition and any impacts on well-being, or whether the child/young person wants to make changes.

10.51 An assessment of the presence and impact of any distress should be undertaken, including the impact and experience of puberty and pubertal changes. The clinician should examine the impact of any distress on, for example, daily functioning, social or relationship issues, any sensory issues that may be contributing to the distress and steps that may have been taken to manage this.

10.52 The child/young person's expectations and hopes about support pathways, their understanding of the range of pathways and outcomes, and the pros and cons of interventions at different points in time should also be considered, including potential fertility and broader health impacts.

10.53 Depending on the age and stage of development of each individual child/young person, this may need to be discussed with the child/young person and parent/carer, both together and apart to generate a thorough record of what has been observed, by whom and when, to gain a sense of their individual gender feelings and history. It is also important to understand whether there are any differences in perception between the child/young person and their parents/carers and whether this has been the cause of conflict or family breakdown.

Sexual development, knowledge and sexual orientation

10.54 Clinicians should seek to understand the child/young person's emerging sexuality and sexual orientation, consistent with assessments in other adolescent settings, where deemed appropriate to age and context.

10.55 If this has been an area of concern for younger children, the clinician could capture this elsewhere, for example when looking at safeguarding, developmental history and exposure to adversity and trauma.

Formulation, diagnosis and care plan

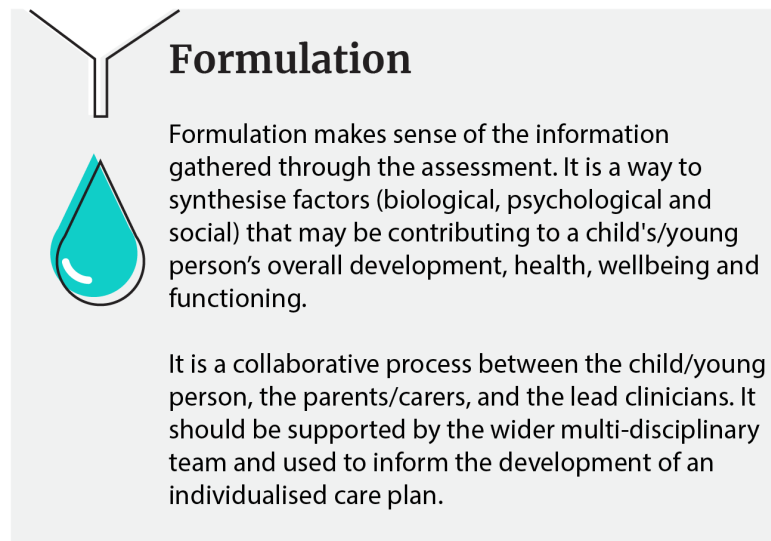
10.56 The assessment is a first step in forming a relationship with a child/young person and their family/carers and developing an understanding of the child/young person as an individual in the context of their aspirations and needs. The assessment should lead to three further steps:

- A formulation of all the factors that are important to the child/young person's presentation
- A list of any relevant diagnoses
- An individualised care plan.

Formulation

10.57 The clinician working with the child/young person should use the information gathered to develop an evidenced formulation. This should be created and agreed with the child/young person and their parents/carers.

Figure 30: Formulation



10.58 Formulation is used to make sense of and pull together information gathered through an assessment to create a shared understanding of the child/young person's strengths and assets, as well as difficulties and needs, to inform the development of an individualised holistic care plan. It is a widely practised approach by a range of professionals and across health services and is endorsed by professional and other organisations (Havighurst & Downey, 2009; Skills for Health, 2016).

10.59 The formulation approach offers a structure for synthesising the information gathered during the assessment and for negotiating differences of opinion. It can be carried out at various levels of detail and complexity and can be helpful in identifying other factors that may be influencing gender-related distress and where there is agreement about areas to work on, even if differences of opinion remain. Importantly, it allows all parties to hold an open and mutually respectful position about a child/young person's gender identity whilst defining a personalised intervention package.

Diagnosis and differential diagnosis

10.60 The clinician's role in a consultation is to integrate information from a patient's history, assessment and any investigations or tests, in order to determine the most likely cause of their symptoms, and how best to address them.

10.61 In addition to the process of formulation described above, this often involves arriving at a formal diagnosis. The diagnostic process is a complex, collaborative activity that involves clinical reasoning and information gathering to understand the patient's problem (Balogh et al., 2015).

10.62 Differential diagnosis is the process of ruling out other possible diagnoses that present in a similar way.

10.63 Differential diagnosis is seen by some as an attempt to find 'any other reason' for the person's distress rather than them being transgender and they feel strongly that clinicians should not be actively looking for reasons to "excuse away" how the young person feels.

10.64 There are several reasons why listing all relevant formal diagnoses is important for this group of children and young people:

- In order to provide the best evidence-based care, it is important that the clinician considers all possible diagnoses which may be hindering the young person's wellbeing and ability to function and thrive.
- The clinician carries responsibility for the assessment, subsequent treatment recommendations, and for any harm that might be caused to a patient under their care. They need to define, as clearly and reproducibly as they possibly can, exactly what condition they are treating, in order to be accountable for their decisions on the options offered to the patient. In the case of offering potentially irreversible medical treatments to patients, it is important to specify whether they meet formal diagnostic criteria for gender dysphoria or any other conditions.
- The University of York's systematic review (Taylor et al: Patient characteristics) demonstrated that other diagnoses were not consistently documented, and in order to better understand and support these children and young people it is essential that all diagnoses are systematically recorded for clinical and research purposes.

10.65 There are two widely used frameworks which provide diagnostic criteria. The International Classification of Diseases (ICD), which is the World Health Organization (WHO) mandated health data standard, and the Diagnostic and Statistical Manual of Mental Disorders (DSM), which is the classification system for mental health disorders produced by the American Psychiatric Association. The current versions - ICD-11 and DSM-5-TR - came into effect in January 2022 and March 2022 respectively.

10.66 ICD-11 (WHO, 2022) has attempted to de-pathologise gender diversity, removing the term 'gender identity disorders' from its mental health section and creating a new section for gender incongruence and transgender identities in a chapter on sexual health. ICD-11 defines gender incongruence as being "characterised by a marked incongruence between an individual's experienced/expressed gender and the assigned sex." It refers to a mismatch between birth registered and experienced gender but does not include dysphoria (distress) as part of its diagnostic requirements. Gender variant behaviour and preferences alone are not a basis for assigning the diagnosis. The full criteria for gender incongruence of childhood and gender incongruence of adolescence or adulthood are listed in Appendix 10.

10.67 DSM-5 (American Psychiatric Association, 2013), revised in 2022 (DSM-5-TR) (American Psychiatric Association, 2022) is the most widely used framework for diagnosing gender dysphoria (Appendix 10). In addition to describing the incongruence between experienced/expressed gender and assigned gender, DSM-5-TR specifies that "In order to meet criteria for the diagnosis, the condition must also be associated with clinically significant distress or impairment in social, occupational, or other important areas of functioning."

10.68 The University of York (Taylor: Guidelines 2: Synthesis) found no clear consensus across international guidelines reviewed as to whether DSM-5 diagnosis of gender dysphoria or ICD 11 diagnosis of gender incongruence is preferred. However, the international survey (Hall et al: Clinic Survey) demonstrated that in clinical practice the DSM-5 diagnosis of gender dysphoria is more widely used, this also applies to research publications.

10.69 The Review has heard mixed views about how young people perceive the value of a diagnosis of gender dysphoria. Many young people do not see themselves as having a medical condition and some may feel it undermines their autonomy and right to self-determination. Others see diagnosis as validating, and important when looking to access hormone treatment.

"It is a good thing because then solutions can be made. However, the way that it is diagnosed is important so that dysphoria is not increased. It is important to be able to make sure people are safe and mentally well."

"I don't care personally, but it is important to me that medical professionals understand that I require gender-related medical care, and that diagnosis can function for that. I would prefer that diagnosis is not a prerequisite for care."

"Having a diagnosis doesn't make you "any more trans" than someone who doesn't."

Young people
Lived experience focus groups

10.70 The qualitative research conducted by the University of York (Appendix 3) found that:

"For many young people - and young adults - dysphoria is a useful medical label, helping to legitimise and explain experience. It also helped justify asking for support [...] Overtime, however, some expressed ambivalence. They continued to understand the value of dysphoria, but thought it could also represent an unhelpful diagnosis, in which their social experience could only be regarded as legitimate if a medical label were attached."

10.71 The qualitative study goes on to say "Clinicians understand the importance of diagnosis, particularly when justifying decision making, but remained sensitive to over-medicalisation, especially when a person's dysphoria was socially located."

10.72 Previously, a diagnosis of gender dysphoria has been the basis for initiating medical treatment, however, this is not predictive that the individual will go on to have longstanding trans identity.

10.73 Understanding how the gender-related distress has evolved in that particular individual, what other factors may be contributing, and the individual's needs and preferences for treatment are equally important. It is also important to ensure that there is a focus on functioning, general well-being and resilience, to ensure the child/young person is able to make considered decisions about their future pathway.

Individualised care plan

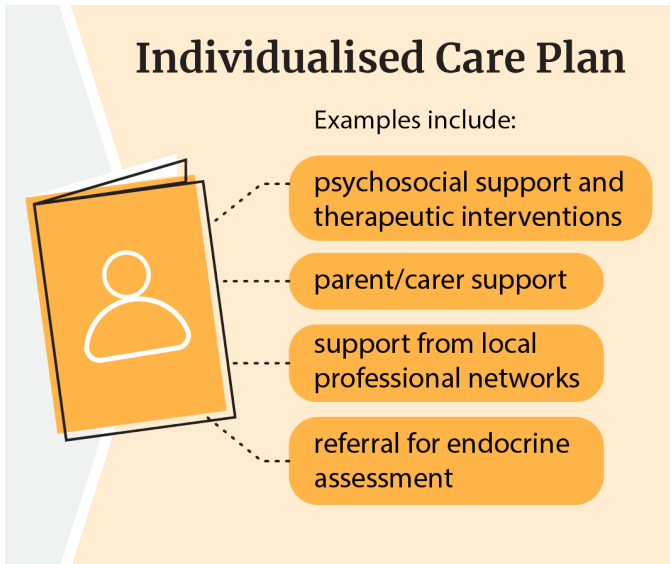
10.74 The holistic needs assessment and subsequent formulation should lead to the development of an individualised care plan with input from the multidisciplinary team.

10.75 This should be a collaborative process that involves a young person and their healthcare professional working together to reach a joint decision about care. Shared decision making involves choosing treatments based both on evidence, and on the person's individual preferences, beliefs and values (NICE, 2021).

10.76 An individualised care plan should include potential pathways of psychosocial support, recommendations on therapeutic interventions, referral for endocrine assessment where clinically indicated, parent/carer and

sibling support options as well as wider recommendations for further support that might be accessed from local professional networks.

Figure 31: Individualised Care Plan



10.77 The Review has kept at its heart the concern that the NHS is dealing with a group of young people who frequently, albeit not always, will be in a state of considerable distress by the time they reach the NHS, and will often have multiple unmet needs.

10.78 There should be a tiered approach to any intervention package outlined in an individualised care plan which:

- addresses urgent risk
- reduces distress and any associated mental health issues and psychosocial stressors, so the child/young person is able to function and make complex decisions
- co-develops a plan for addressing the gender dysphoria, which may involve a combination of psychological and physical treatment options.

10.79 The controversy surrounding the use of medical treatments has taken focus away from what the individualised care and treatment plan is intended to achieve, both for the individual seeking support from NHS gender services and for the overall population.

10.80 Young adults, interviewed for the University of York’s qualitative research study, “expressed an incredibly diverse range of experiences and pathways. Many benefitted from access to medical pathways, which they said, enabled them to lead the lives they wanted. Others explored equally empowering options, such as social transitioning and more fluid and non-binary expressions of gender.” (Appendix 3).

10.81 Several young people and young adults participating in the lived experience focus groups similarly reflected that it is important to inform people that medical transition is not the only option and that choosing not to go down that route does not invalidate their identity.

“I think it’s helpful for people to know that there’s not only one route or one set way to transition or be trans. They might want just hormones, or just surgery, people are different with different experiences, presentations and bodies. It’s fine for that to be the case, it’s okay to have different plans for your medical transition.”

Young person
Lived experience focus group

10.82 The qualitative study found that “For some, initial gender questioning created a sense of urgency, much of which focused on accessing medical pathways. These young adults acknowledged that their original response was to “fix” the problem. This became less important to them as they grew older. Some explained that discovering different ways to express gender identity was one of the most important things they had learned. They wished this had been explained to them when younger but remain uncertain about the extent they would have listened to such advice.” (Appendix 3).

10.83 The central aim of the assessment process and individualised care plan is to help young people to thrive and achieve their life goals. For the majority of young people, a medical pathway may not be the best way to achieve this. For those young people for whom a medical pathway is clinically indicated, it is not enough to provide this in the absence of addressing any wider mental health and/or psychosocially challenging problems such as family breakdown, barriers to participation in school life or social activities, bullying and minority stress.

Recommendation 1:

Given the complexity of this population, these services must operate to the same standards as other services seeing children and young people with complex presentations and/or additional risk factors. There should be a nominated medical practitioner (paediatrician/child psychiatrist) who takes overall clinical responsibility for patient safety within the service.

Recommendation 2:

Clinicians should apply the assessment framework developed by the Review’s Clinical Expert Group, to ensure children/young people referred to NHS gender services receive a holistic assessment of their needs to inform an individualised care plan. This should include screening for neurodevelopmental conditions, including autism spectrum disorder, and a mental health assessment. The framework should be kept under review and evolve to reflect emerging evidence.



11. Psychological and psychosocial interventions

11.1 There are many different ways of helping gender-questioning young people improve their health and wellbeing, regardless of their longer-term decisions about medical or social transition.

11.2 Part 3 described the wide range of associated conditions that may be part of a picture of gender related distress. A holistic package of care to address these issues may involve a broad range of options such as:

- supporting a young person to get back into school
- diagnosing autism or ADHD
- supportive group sessions
- psychological interventions to help anxiety, depression or trauma
- building resilience
- working with the whole family to address breakdowns in relationships
- providing more information about gender expressions and the range of possible interventions.

11.3 The terms psychological therapies, psychotherapy, psychosocial interventions and talking therapies are often used interchangeably in everyday settings. Strictly speaking, psychological interventions refer to treatments based on a theory of psychological functioning, while the term psychosocial interventions is less specific and is used to describe a wide range of supportive approaches to improving mental health, wellbeing and functioning.

11.4 The role of psychological therapies in supporting children and young people with gender incongruence or distress has been overshadowed by an unhelpfully polarised debate around conversion practices. Terms such as ‘affirmative’ and ‘exploratory’ approaches have been weaponised to the extent that it is difficult to find any neutral terminology. This has given the impression that a young person can have either therapeutic interventions or a medical pathway.

11.5 Whilst the Review’s terms of reference do not include consideration of the proposed legislation to ban conversion practices, it believes that no LGBTQ+ group should be subjected to conversion practice. It also maintains the position that children and young people with gender dysphoria may have a range of complex psychosocial challenges and/or mental health problems impacting on their gender-related distress. Exploration of these issues is essential to provide diagnosis, clinical support and appropriate intervention.

11.6 The intent of psychological intervention is not to change the person’s perception of who they are but to work with them to explore their concerns and experiences and help alleviate their distress, regardless of whether they pursue a medical pathway or not. It is harmful to equate this approach to conversion therapy as it may prevent young people from getting the emotional support they deserve.

11.7 No formal science-based training in psychotherapy, psychology or psychiatry teaches or advocates conversion therapy. If an individual were to carry out such practices they would be acting outside of professional guidance, and this would be a matter for the relevant regulator.

Perspectives from service users and families

11.8 The Review's work with service users, parents/carers and clinicians revealed a perceived gap in provision for those who are exploring/questioning their gender identity but are unsure of what it means for them. The length of the wait before being seen means many young people are forced to undertake this exploration on their own.

"Good mental health services would have really been a big benefit for me as I was exploring my identity, dealing with things like dysphoria...."

Young person
Lived experience focus group

"I would hope that going forwards, there would be more treatment options available for young people experiencing gender-based distress as well as physical interventions, such as third wave CBT, family therapy or psychotherapy at GIDS"

GIDS clinician
Specialist questionnaire

"My GP was fine with gender stuff but he was only willing to give me one diagnosis in my life... I can have more than one thing 'wrong' with me, many people do, there's also a link between ADHD, Autism and Gender stuff – but it all feels ignored, like they just see my diagnosis for dysphoria and they refuse to see the rest. It doesn't feel like my other experiences are valid."

Young person
Lived experience focus group

11.9 Young people want a non-judgemental space to talk about how they are feeling and options for care. They also want help to reduce the dysphoria (distress) that they are feeling.

11.10 Parental and personal narratives described children and young people having more than one issue presenting, but services (e.g. GIDS, CAMHS, GP), dealing with each issue in isolation, without considering the impact of issues on each other. This may include neurodivergence or significant mental health issues, including past history of eating disorders, experiences of loss and/or trauma and bullying.

"I knew walking in that I wasn't going to get any help from them, I just had to tell them what they wanted to hear. I knew that they were the doorway to getting me what I wanted. I wouldn't speak openly about any concerns I had because I knew that could prevent me from accessing the care I needed."

Young person
Lived experience focus group

11.11 Some young people have spoken about the perception that disclosing neurodiversity, mental health issues or trauma would be used to discredit their sense of identity. It is concerning that young people may not feel they can be honest with their health professionals. They describe the sense that they need to play a role and manage services to get what they need. This has led to some people actively not seeking help with their mental health or hiding mental health issues.

International guidelines and practice

11.12 Historically the model of care for children and young people presenting with gender incongruence or distress was entirely based on a psychosocial model, with early medical intervention with puberty blockers being introduced more recently. Most clinical teams would still see this as the starting point in a care pathway.

11.13 This is in part reflected in the University of York's synthesis of international guidelines (Taylor et al: Guidelines 2: Synthesis) which found that all but two guidelines describe psychosocial support as a key component of care.

11.14 Earlier guidelines described psychosocial care as the mainstay of treatment, and the recent Finnish and Swedish guidelines describe it as the first line treatment. However, there is now an emerging international divergence, with five guidelines saying that not all children or adolescents will need psychosocial care, and all but one of these five promoting a gender-affirmative approach to care.

11.15 Another problem across the international guidelines is the lack of detail on the aims, approach or end point of psychological/ psychosocial interventions. There is variability, and a lack of definition and consensus about gender exploration, in particular about whether it should form part of the assessment, and whether it is important for children and adolescents or just children.

11.16 These discrepancies in approach echo the tensions that have entered the debate in the UK about affirmative or exploratory approaches.

11.17 Most guidelines discuss psychosocial support for parents and highlight the importance of parental care and support for children and young people in their gender care. Most also suggest providing education about gender development and identity to young people and their families.

11.18 The additional challenges in supporting looked after children are flagged in six guidelines.

11.19 Despite recommendations regarding the need for psychosocial interventions, the international survey (Hall et al: Clinic Survey) reported that in practice psychosocial interventions were quite limited across the responding gender services. Five clinics had no in-house provision, and others offered a small range of options and/or psychoeducation. This highlights a gap between aspiration and delivery.

Understanding the evidence

11.20 The University of York conducted a systematic review to identify and summarise evidence on the outcomes of psychosocial interventions for children and adolescents experiencing gender incongruence (Heathcote et al: Psychosocial support).

11.21 Only ten studies met the inclusion criteria. Study quality was assessed as low in nine of the studies and moderate in one study. Selection criteria for participants were not clearly defined, and the studies lacked appropriate comparators.

11.22 The studies used various interventions:

- Some using standardised approaches such as cognitive behaviour therapy, mindfulness and self-compassion, or attachment-based family therapy,
- Some using more focused approaches developed or adapted specifically for gender or sexual minority youth.

11.23 All studies included in the final analysis used validated instruments to assess outcomes, but there was little congruence between studies on the measures used.

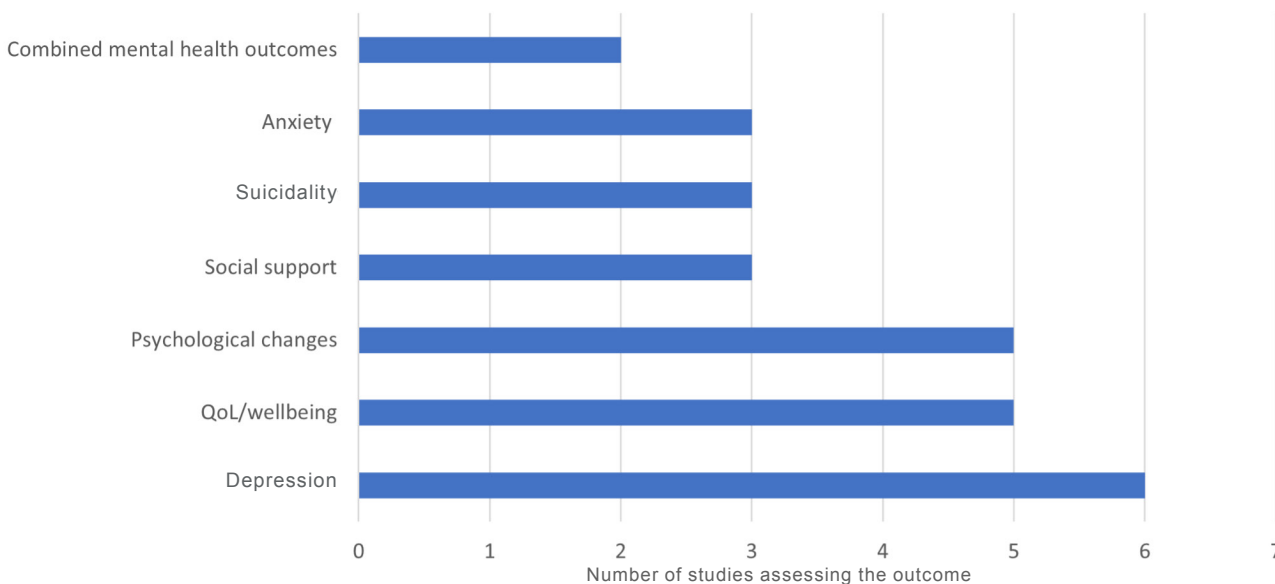
11.24 The most commonly reported outcomes related to mental health (depression, anxiety and suicidality).

- Four out of eight studies which reported on depression (either alone or within a combined mental health outcome) reported significant improvements.
- Three out of five studies which reported on anxiety (either alone or within a combined mental health outcome) also reported significant improvement.
- Three out of four studies that looked at suicidality found significant improvements in suicidality scores, and one found no change.

11.25 The studies focusing on psychological changes and/or psychosocial changes found improvements in a range of aspects such as resilience, self-compassion and self-acceptance, as well as quality of life, global functioning, participation and well-being.

11.26 Where there was adequate follow-up, studies found that many of these outcomes fell off over time. There was no indication across the studies of adverse or negative effects.

Figure 32: Psychosocial support interventions: outcomes measured



Source: Data from Heathcote et al: Psychosocial support

QoL: Quality of Life

11.27 Because of the low quality, poor reporting of the intervention details and heterogeneity of the interventions and their aims and outcome measures, it was not possible to directly compare the different types of interventions. It was also not possible to determine which specific approach might work best for whom.

11.28 The University of York concluded that there is limited research evaluating outcomes of psychosocial interventions for children and adolescents experiencing gender incongruence, and low quality and inadequate reporting of the studies identified. Therefore, firm conclusions about their effects cannot be made. Identification of the core approach and outcomes for these interventions would ensure they are addressing key clinical goals, attending to the needs of children and families as well as supporting future aggregation of evidence.

Current NHS practice

11.29 GIDS reports that only a minority of children and young people go on to an endocrine pathway, so the Review was keen to hear about what support and treatment packages were offered to those who did not go on to a medical pathway. However, despite a number of discussions and a focus group with GIDS staff on this topic, it has not been possible to obtain any clear information about the range of options offered.

11.30 Within the GIDS service, patients may have had anything from a one or two appointments to in excess of 100. This indicates that some practitioners must have been providing therapeutic input to patients, despite the fact that there was not a formal structured programme in place.

11.31 Because the assessment process at GIDS appears to have been organic, without a clear end point, it seems that an assessment has formed the starting point for a therapeutic relationship which could continue over many sessions.

11.32 It appears that, for those young people for whom an endocrine option was not the best option, staff at GIDS were doing their best to provide ongoing support, perhaps because local services were not able to offer this. In addition, staff were clearly in a difficult position balancing the needs of ongoing patients with the pressure of the waiting list.

“It's bit controversial and I don't wanna upset or anger anyone, but like buffer periods and I know it is just like a touchy subject but I personally when I was 14, like found [social media influencer] YouTube and was like, oh my gosh, I'm a trans man. This is me, like I need to go on testosterone, I need to get top surgery, I need to like do all these things. And I was so sure I wanted to testosterone for like 2, 3 years.

I am really glad that I didn't go on testosterone, because I realized during like my 17 sessions at GIDS that that wasn't for me. And it was really through those sessions and also a lot of self-exploration, and I was so, so, sure that I wanted it.

So I think, buffer periods of like 7 years - no, that's not the vibe, but having spaces where you can have proper informed consent. Like is really important and exploring all of your options and being aware of all of the consequences. Consequences is a very negative, heavy loaded term, but like, yeah, consequences because, sometimes people do things and it's not right for them at the time, or maybe it is right for them at the time, but isn't later on. So yeah. Sorry, if that offends anyone.”

Young person
Lived experience focus group

“If someone is like dead set on wanting something be that like hormone treatment or surgery. Making sure those referrals happen and they don't have to wait years on years just to get on the list. I think that's quite important. You know, if someone is well informed they know exactly what they want, I don't see why there should be any, like obviously giving informed consent, but I don't see why there should be like a buffer period if someone's very much like, no I know what I want.”

Young person
Lived experience focus group

11.33 Clinicians have also reported that the length of the waiting list can be a barrier to having exploratory discussions with children and young people that could provide them with a broader range of options for addressing their distress. This is because by the time young people are seen they have often made their minds up that an endocrine pathway is their chosen option and do not want to consider other approaches.

11.34 The Review also heard that some staff had looked at how standard evidence-based treatments (in this case third-wave CBT) could be used to help young people to manage their gender-related distress, stressing that this can be achieved without pathologising or changing a young person's gender identity (Canvin 2022). However, this was not developed into a full research study.

Summary – psychological and psychosocial interventions

11.35 Psychological and psychosocial interventions serve multiple different purposes for this group of children and young people, dependent on any underlying mental health problems and the particular features of their gender presentation. However, there has been a failure to systematically consider how psychosocial interventions should be used and to research their efficacy.

11.36 Some therapies, which are well proven for associated mental health problems, already have a strong evidence base. Where it is clear that children/young people have such problems, they should receive the appropriate therapies in the same way as any other young person seeking support from the NHS. Outcome measures should include evaluating the impact on the associated medical health condition, and any additional impact on the gender-related concerns and distress.

11.37 Beyond this first line approach, it is important to understand how specific therapeutic modalities may help the core gender dysphoria and bodily distress.

11.38 One of the given rationales for puberty blockers is that they may improve gender dysphoria or overall mental health. The evidence to date does not provide strong support for this (see Chapter 14). Furthermore, even after masculinising/feminising hormones, dysphoria may still persist. Therefore, it is important to explore other approaches for addressing the gender-related distress, which in itself is debilitating. These may be of value regardless of whether or not an endocrine pathway is chosen.

11.39 Navigating life as a transgender person can be challenging. Individuals may encounter hostility for being who they are and are likely to suffer from minority stress. If the ultimate goal of any intervention is to help the child or young person to function and thrive, they need to be provided with tools and strategies to give them the best opportunity to do so.

“I also feel there should be support with mental health. Whether it be towards gender identity or towards the stress. And having a way to cope with the stress that comes with going through the process and that comes with being trans in general.”

Young person
Lived experience focus group

“I know lots of trans kids who are really struggling with their mental health, not because of their gender not because they struggle with where they fit in but because of how society and institutions treat them.”

Parent
Listening session

11.40 Children and young people thrive best when in a supportive family environment and facilitating the health and well-being of all family members will be important in achieving this end. Some participants in the Review’s lived experience focus groups highlighted the positive role of families, carers and others in supporting them to navigate transition and related care.

11.41 Other participants spoke of the personal damage that a lack of parental support had had on their adult relationships with their family. They suggested that in-person and online support groups for parents and carers to meet other parents and carers and professionals who can answer their questions and provide mental health support/counselling if needed was incredibly important.

“I think that access to informational texts are really important. I did a lot of my research on the internet and got told so much false information because there were so many sources, so some trustworthy informational sources about being transgender, social and medical transitions, etc, would have benefited me a lot.”

Young person
Lived experience focus group

“I feel like there is a lack of support for parents who are uneducated and want to learn how they can support their child, and also for ones who have to essentially go through a loss in their life. It may be hard for them to come to terms with the fact that they've lost something and gained another, so a service that could provide support and guidance for parents would be extremely useful.”

Parent
Listening session

11.42 The role of family therapists in addressing some of the above problems and challenges should also be considered.

11.43 In summary, there is a lack of evidence about alternative approaches for managing gender-related distress, and it is difficult to obtain information about routine clinical practice or pathways of care for children and young people who do not receive medical interventions. An explicit clinical pathway must be developed for non-medical interventions, as well as a research strategy for evaluating their effectiveness.

Recommendation 3:

Standard evidence based psychological and psychopharmacological treatment approaches should be used to support the management of the associated distress and cooccurring conditions. This should include support for parents/carers and siblings as appropriate.

12. Social transition

12.1 Through discussions with stakeholders, it is clear that social transition is a cause of concern for many people, and our remarks about social transition were some of the most quoted parts of the Review's interim report.

12.2 The approach taken to social transition is very individual but it is broadly understood to refer to social changes to live as a different gender such as altering hair or clothing, name change and/or use of different pronouns. There is a spectrum from relatively limited gender non-conforming changes in appearance in adolescence to young people who may have fully socially transitioned from an early age and be 'living in stealth' (that is, school friends/staff may be unaware of their birth-registered sex).

12.3 There are different views on the benefits versus the harms of early social transition. Some consider that it may improve mental health and social and educational participation for children experiencing gender-related distress. Others consider that a child who might have desisted at puberty is more likely to have an altered trajectory, culminating in medical intervention which will have life-long implications.

12.4 One key difference between children and adolescents is that parental/carer attitude and beliefs will have an impact on a child's ability to socially transition, whereas adolescents have more personal agency.

12.5 Social transition may not be thought of as an intervention or treatment, because it is not something that happens in a healthcare setting and it is within the agency of an adolescent to do for themselves. However, in an NHS setting it is important to view it as an active intervention because it may have significant

effects on the child or young person in terms of their psychological functioning and longer-term outcomes.

12.6 Although the focus of the Review is on support from point of entry to the NHS, no individual journey begins at the front door of the NHS, rather in the child's home, family and school environment. The importance of what happens in school cannot be under-estimated; this applies to all aspects of children's health and wellbeing. Schools have been grappling with how they should respond when a pupil says that they want to socially transition in the school setting. For this reason, it is important that school guidance is able to utilise some of the principles and evidence from the Review.

International practice

12.7 The University of York's review of international guidelines (Taylor et al: Guidelines 2: Synthesis) found that most guidelines recommend providing information about the benefits and risks of social transition but vary in whether the recommendations apply to both children and adolescents or just to children.

12.8 WPATH 8 guidance has moved from a 'watchful waiting' approach for children to a position of advocating for social transition as a way to improve children's mental health.

12.9 Several guidelines recommend that social transition should be framed in a way that ensures children can reconsider or reconceptualise their gender feelings as they grow older.

12.10 Several guidelines discuss education about the risks and benefits of binders and packers, and safe use as appropriate.

Reflections from the Multi-Professional Review Group

12.11 The Multi Professional Review Group (MPRG) report (Appendix 9) notes that many children and young people attending GIDS have changed their names by deed-poll, attend school in their chosen gender and some have changed NHS numbers by the time they are seen. Based on the MPRG review of the notes, this history/journey was rarely examined closely by GIDS for signs of difficulty, regret or wishes to alter any aspect of the child/young person's gender journey trajectory.

12.12 The MPRG is concerned that some children living in stealth have a common, genuine fear of "being found out", suffering rejection either due to not having taken friends into their confidence (withholding personal information regarding biological sex or specific sex-based experiences), or due to trans-prejudice or transphobia. They observed that this fear of "being found out" is driving a sense of urgency to access puberty blockers, which may not allow consideration of other pros and cons of the treatment.

12.13 The MPRG also observed that living in stealth appears to increase a child's level of stress and anxiety with resultant behaviour and mental health problems. These included social withdrawal, with children becoming increasingly isolated, including resorting to home-schooling or tutoring and even rarely leaving their house.

Perspectives from service users and families

12.14 Young people and young adults have spoken positively about how social transition helped to reduce their gender dysphoria and feel more comfortable in themselves. However, it is the reaction of those around them that can make it difficult. Young people identified that space to talk about socially transitioning and how to handle conversations with parents would be helpful. They feel that parents and carers need more information about social transition and the best way to support their child through that process.

"It would be helpful to show that there is no judgement in experimenting with their appearance such as clothing and makeup. Also to be shown how they don't need to have a specific label to use and should try to feel as comfortable as they can."

**Young person
Lived experience focus group**

"To me social transition is an act undertaken by the child, so I wouldn't call it an active intervention. [The] question is whether to support it or not and to factor in if the child is considering it or has already announced it. [The] act by community is supporting or not supporting."

**Young trans adult
Listening session**

12.15 The qualitative research conducted by the University of York (Appendix 3) found that, while waiting for clinical input many young people “took steps to help manage how they felt and most socially transitioned while waiting. The process, although dynamic and flexible, was positively regarded by young people. Many parents, although initially hesitant, come to understand the value of social transitioning. A few, however, remained anxious about its impact. Families would have welcomed advice on how to negotiate social transitioning but many experienced difficulties in accessing support”.

12.16 However, the Review heard concerns from many parents about their child being socially transitioned and affirmed in their expressed gender without parental involvement. This was predominantly where an adolescent had “come out” at school but expressed concern about how their parents might react. This set up an adversarial position between parent and child where some parents felt “forced” to affirm their child’s assumed identity or risk being painted as transphobic and/or unsupportive.

12.17 Some parents who spoke to the Review felt that social transition was of more benefit to their child in terms of its social impact than it helping to manage their gender incongruence. They describe how their children were previously isolated and bullied but their status amongst peers had improved as a result of “coming out”.

“Pre-social transition, [child] had social difficulties due to ASD and was bullied. After social transition [child] was given enormous kudos at school. They were geeky and awkward, but became a celebrity.”

Parent
Listening session

“Her whole friends group has some sort of trans or nonbinary identity. Older friends don’t seem to be in that camp – they are open and supportive but not identifying. It seems to have been socially beneficial to her to present as trans – as a high functioning autistic person – it has helped her with her social life. Her friends seem to be celebrating in trans identities.”

Parent
Listening session

12.18 Clinicians have said that most children have already socially transitioned before reaching the specialist gender service. Some clinicians have suggested that support to think through social transition could happen within local services and does not need to sit within NHS specialist services.

“Ideally local services should be available to young people where they can discuss and explore their gender, be supported to try out social transition etc. If this was the case a specialist service would only be needed if they wanted assessment for physical interventions or there were multiple factors at play that local services felt unable to support with.”

Clinician
Specialist survey

Understanding the evidence

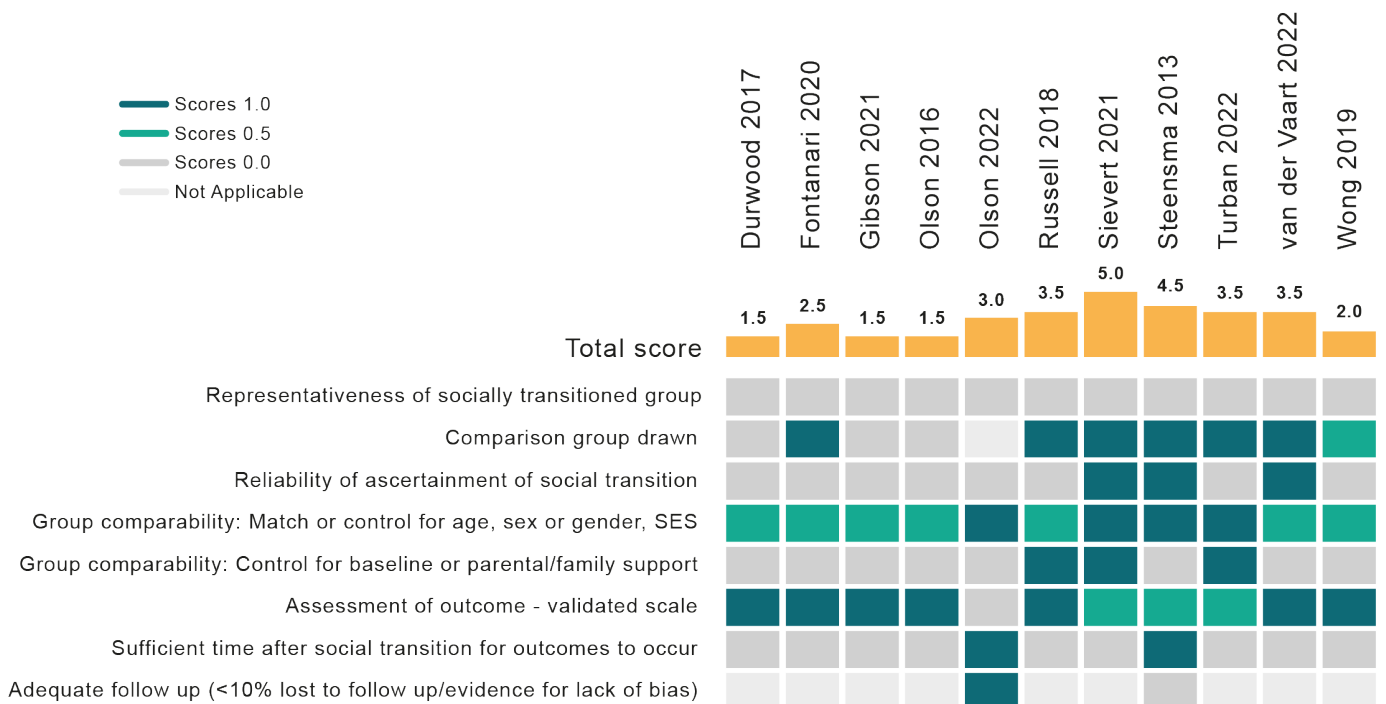
12.19 The University of York’s systematic review on social transition aimed to identify and summarise evidence on the outcomes of social transition for children and adolescents with gender dysphoria. (Hall et al: Social transition).

12.20 This systematic review is a useful example demonstrating how systematic reviewers rate the quality of studies. The scale (called a modified version of the Newcastle-Ottawa Scale) was used to assess the items shown in Figure 33 and then give a summary score for each of the studies. The maximum score is 8, a score of 0-3.5 is low quality, 4-5.5 moderate quality and 6-8 high quality.

12.21 Of the 11 studies that met the search criteria, nine were low quality (scoring between 1.5 and 3.5) and two were moderate quality (scoring between 4.5 and 5.0). The most problematic aspects were sample selection, and samples were not reliably representative of the broader population. Most studies were US based.

12.22 The quality of the studies was not good enough to draw any firm conclusions, so all results should be interpreted with caution.

Figure 33: Quality scores for included studies assessed using a modified Newcastle-Ottawa Scale



Source: Hall et al: Social transition

NB: The grid indicates individual scores for each study on each of the criteria. Bars at the top (and numbers at top of bars) indicate overall score. SES: socioeconomic status.

Mental health outcomes

12.23 Different studies looked at different outcomes of social transition. The only consistent benefit from social transition was for use of chosen name in adolescence:

- one study found this was associated with some improvements in mental health and reduced suicidality for 15-21 year-olds
- another study found that parental use of chosen name and being able to express one's gender was associated with some improvements in mental health/distress for 16-24 year-olds.

12.24 One study looking at transgender adults found that lifetime suicide attempts and suicidal ideation in the 'past year' was higher among those who had socially transitioned as adolescents compared to those who had socially transitioned in adulthood.

Gender identity outcomes

12.25 One study (Olson et al, 2022) used a self-selected community sample of children (the Trans Youth Project). Children had to be between three and 12 years of age at enrolment and had to have made a "complete" binary social transition, including changing their pronouns to the binary gender pronouns that were not those used at their births. The

study found that 93% of those who socially transitioned between three and 12 years old continued to identify as transgender at the end of the study (about 5.4 years later). Of the remainder, 2.5% were living as cisgender, 3.5% as non-binary and 1.3% had retransitioned twice. This study also demonstrated that the majority of children who had socially transitioned went on to progress to medical interventions.

12.26 Another study (Steensma et al., 2013b) found that childhood social transition was a predictor of persistence of gender dysphoria for those birth-registered male, but not those birth-registered female. In this study 96% of those birth-registered male and 54% of those birth-registered female who later desisted had not socially transitioned at point of referral and none had fully socially transitioned (see Table 8). The study noted that the possible impact of the social transition on cognitive representation of gender identity (that is, how the child came to see themselves) or on persistence had not been studied.

12.27 However, there was also an association between childhood social transition and more intense gender dysphoria, so it may be that the intensity of the dysphoria was the factor that led to persistence and the more pressing drive for the children to socially transition.

Table 8: Childhood social transition and likelihood of persistence

	PERSISTERS % (n=47)		DESISTERS % (n=80)	
	BR-M (n=23)	BR-F (n=24)	BR-M (n=56)	BR-F (n=24)
No social transition	57	42	96	54
Partial social transition	30	54	4	45
Full social transition	13	4	0	0
Total	100	100	100	100

Source: Data from Steensma et al., 2013b.

BR-M: birth-registered male | BR-F: birth-registered female

Relevance to existing guidelines

12.28 There has been a shift in recommendations between WPATH 7 (2012), which was more cautious about social transition, and WPATH 8 (2022) which argues in favour of social transition in childhood.

12.29 WPATH 8 justifies this change in stance on the basis that there is more evidence on improved mental health outcomes with social transition, that fluidity of identity is an insufficient justification not to socially transition, and that not allowing a child to socially transition may be harmful.

12.30 However, none of the WPATH 8 statements in favour of social transition in childhood are supported by the findings of the University of York's systematic review (Hall et al: Social Transition).

Summary – social transition

12.31 Given the weakness of the research in this area there remain many unknowns about the impact of social transition. In particular, it is unclear whether it alters the trajectory of gender development, and what short- and longer-term impact this may have on mental health.

12.32 Early research cited in Chapter 2 found low rates of persistence of childhood gender incongruence into adulthood, around 15% (for example, Zucker, 1985). Papers from this period were criticised because the children were not formally diagnosed using ICD or DSM. At that time, it was rare for children to have socially transitioned before being seen in clinic.

12.33 Later studies, which showed higher rates of persistence at 37% (for example Steensma et al., 2013b) did use formal diagnostic criteria, but by that time a greater proportion of the referrals had socially transitioned prior to being seen.

12.34 It is not possible to attribute causality in either direction from the findings in these studies. This means it is not known whether the children who persisted were those with the most intense incongruence and hence more likely to socially transition, or whether social transition solidified the gender incongruence.

12.35 Earlier in this report it was explained that much has been learnt about the role of sex of rearing on the development of gender identity from follow-up studies of individuals with health conditions known as differences of sex development (DSD). It is helpful to recap on some of this learning when considering the role of social transition. In summary:

- Individuals who are genetically female (XX) but have high androgen levels (i.e. those with Congenital Adrenal Hyperplasia) are usually reared as females; they tend to have some male role behaviours but are most commonly heterosexual and usually have a female gender identity.
- In those with DSD in whom gender identity outcome is less well established, the sex of rearing is a better predictor of gender identity outcome than prenatal androgen exposure.
- The conclusion is that a complex interplay between prenatal androgen levels, external genitalia, sex of rearing and socio-cultural environment all play a part in eventual gender identity, and we have yet to understand the relative influence of these various elements.

12.36 The information above demonstrates that there is no clear evidence that social transition in childhood has positive or negative mental health outcomes. There is relatively weak evidence for any effect in adolescence. However, sex of rearing seems to have some influence on eventual gender outcome, and it is possible that social transition in childhood may change the trajectory of gender identity development for children with early gender incongruence. For this reason, a more cautious approach needs to be taken for children than for adolescents:

Children:

- Parents should be encouraged to seek clinical help and advice in deciding how to support a child with gender incongruence and should be prioritised on the waiting list for early consultation on this issue.
- Clinical involvement in the decision-making process should include advising on the risks and benefits of social transition as a planned intervention, referencing best available evidence. This is not a role that can be taken by staff without appropriate clinical training.
- It is important to ensure that the voice of the child is heard in any decision making and that parents are not unconsciously influencing the child's gender expression.
- For those going down a social transition pathway, maintaining flexibility and keeping options open by helping the child to understand their body as well as their feelings is likely to be advantageous. Partial rather than full transition may be a way of ensuring flexibility, particularly given the MPRG report which highlighted that being in stealth from early childhood may add to the stress of impending puberty and the sense of urgency to enter a medical

Adolescents:

- For adolescents, exploration is a normal process, and rigid binary gender stereotypes can be unhelpful. Many adolescents will go through a period of gender non-conformity in terms of hairstyle, make-up, clothing and behaviours. They also have greater agency in how they present themselves and their decision-making.
- For those considering full social transition, the current long waiting lists make it unlikely that a formal clinical assessment will be available in a timely manner. However, it is important to try and ensure that those already actively involved in their welfare (parents/carers, any involved clinical staff such as their GP, school staff or counsellors) provide support in decision making and plans to ensure that the young person is protected from bullying and has a trusted source of support.

For both children and adolescents:

- Outcomes for children and adolescents are best if they are in a supportive relationship with their family. For this reason parents should be actively involved in decision making unless there are strong grounds to believe that this may put the child or young person at risk.
- Help may be needed if a child/young person wishes to reverse their decision on transitioning, which can be a difficult step to take.

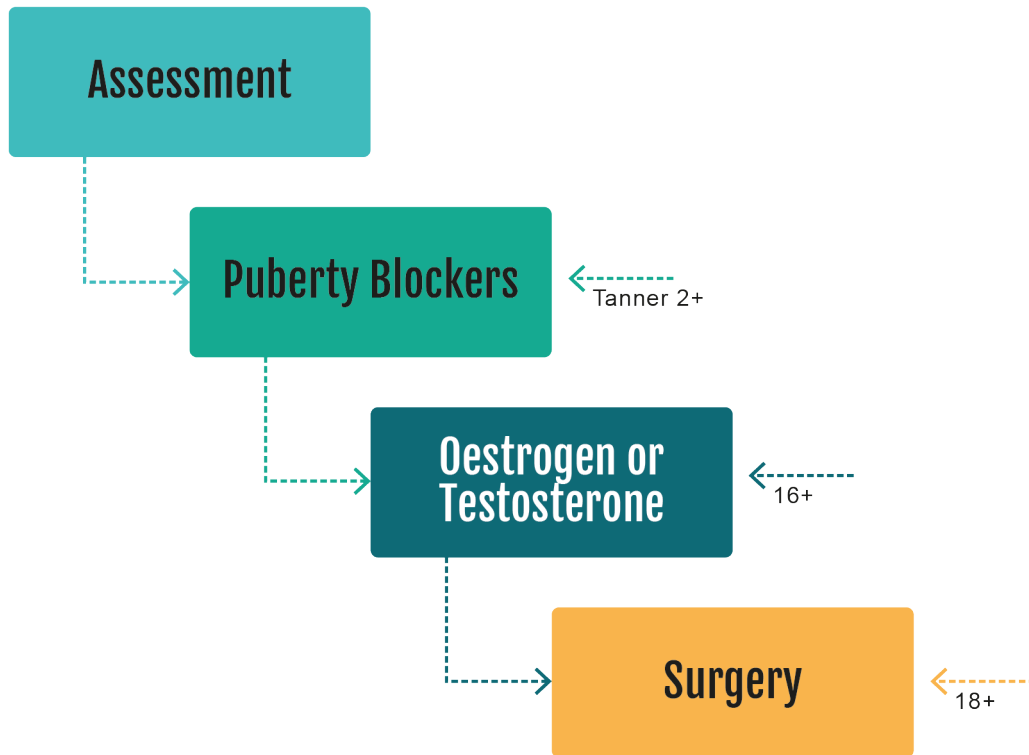
- **12.37** The clinician should help families to recognise normal developmental variation in gender role behaviour and expression. Avoiding premature decisions and considering partial rather than full transitioning can be a way of ensuring flexibility and keeping options open until the developmental trajectory becomes clearer.

Recommendation 4:

When families/carers are making decisions about social transition of pre-pubertal children, services should ensure that they can be seen as early as possible by a clinical professional with relevant experience.

13. Medical pathways

Figure 34: Outline of medical pathway at start of Review



13.1 When the Review began, the medical interventions for gender incongruence/dysphoria available on the NHS were puberty blockers followed by masculinising or feminising hormones. The history of their use was outlined in Part 2.

Perspectives from service users and families

13.2 Young people participating in the lived experience focus groups explained that while they do want access to counselling and spaces to openly explore their gender, this should be alongside not instead of the option to medically transition. They also felt there needed to be

recognition that mental health may still be a concern after starting on a medical pathway, while waiting for changes to take effect.

“I just wanted to get my bloody hormones, that was what I was there for, that’s what I wanted, that would’ve been my therapy, all my distress was related to needing to get on hormones and I was expressing this, I had a trans history, I was clearly aware of what I wanted and what care was on offer.”

Young person
Lived experience focus group

13.3 For those who are considering a medical transition, there is a strong sense among service users that this should be facilitated by the NHS, but a recognition that there is a need for better information on which to base decisions/consent.

13.4 Young people and young adults participating in the Review's focus groups highlighted a lack of reliable and accurate information about medical transition. In particular, the need to be informed of any known and unknown risks and potential side effects of hormone interventions when making informed decisions about care and treatment. Some participants felt there needed to be more information for people wanting to come off the medical pathway.

“What are the benefits, what have people who've gone through each process thought about it, what are the side-effects, what are the possible drawbacks, what is the time-scale, how reversible is it, what the process actually involves (e.g. not being able to do stuff for several months after certain surgeries), what medical professionals think about it, what everyday people who've done it think about it, what are the things nobody tells you (e.g. post-surgery dysphoria), what is the satisfaction rate (preferably with some stories of people who've done it and loved it, and some who've done it and didn't love it as much).”

**Young person
Lived experience focus group**

Existing endocrine practice in the UK

13.5 One of the most problematic data gaps for the Review has been trying to obtain robust data on the numbers of young people who go on to a hormone pathway at GIDS, and what care pathways or interventions are available for those who do not. This seems unacceptable in the digital age.

13.6 Our working assumption, based on original data provided to the Review, was that approximately 20% of those referred to GIDS go on to a medical pathway.

13.7 Performance data received by NHS England and shared with the Review indicated that this was probably an accurate proportion of all cases seen by the service. However, the data suggested that around 50% of these patients received only one appointment before being discharged from GIDS, usually because they had 'aged out' of the service before the assessment could be completed.

13.8 If those patients are discounted, it appeared that a significantly higher percentage of active cases (those undergoing full assessment) were being referred to endocrinology. In order to get a clear picture, the Review wrote to NHS England requesting that an audit of discharge records be undertaken.

13.9 NHS England approached NHS Arden and Greater East Midlands Commissioning Support Unit to undertake this audit on behalf of the Review and NHS England. The audit (Appendix 8) looked at discharge records of patients who had been discharged from GIDS between 1 April 2018 and 31 December 2022. This covered the period pre and post the *Bell v Tavistock* judgments.

13.10 The following patients were included in the data collection:

- patients who have attended at least two appointments at GIDS
- patients who have been discharged from GIDS between 01 April 2018 and 31 Dec 2022.

13.11 Of the 3,499 patients audited, 3,306 were included within the analysis. 73% were birth-registered female and 27% birth-registered male. The audit did not include patients who had received fewer than two appointments at GIDS or those who lived outside England and Wales. Headline findings from the audit were:

- Overall, 27% of patients were referred to endocrinology (34.6% of [birth-registered] males compared to 24.2% of [birth-registered] females). This equates to 584 birth-registered females and 308 birth-registered males.
- Patients received an average of 6.7 appointments prior to referral to endocrinology.
- 81.5% of patients referred into endocrinology received puberty blockers, of whom 52.5% were between 15-16 years old.

At the point of discharge from GIDS:

- 54.8% of all patients referred to endocrinology were on both puberty blockers and masculinising/feminising hormones (57.9% of [birth-registered] females compared to 47.7% of [birth-registered] males).
- For patients who initially received puberty blockers upon referral to endocrinology, 64% had gone on to receive both puberty blockers and masculinising/feminising hormones at point of discharge from GIDS.
- < 10 patients detransitioned back to their [birth-registered] gender, all of whom were female, and all but one were confirmed as having received puberty blockers as their first intervention. These patients had received an average of 6.5 appointments prior to referral to endocrinology (range 3-10 appointments).
- 89% of patients who were referred to endocrinology were discharged to an adult Gender Dysphoria Clinic (GDC).

13.12 Table 9 on the next page shows the end point intervention recorded on patients' discharge summaries: 54.8% ended up on both puberty blockers and masculinising/feminising hormones.

Table 9: Final intervention received by GIDS patients referred to endocrinology

FIRST INTERVENTION TYPE	% OF PATIENTS
Puberty blockers AND cross-sex hormones	54.8
Puberty blockers ONLY	19.9
Patient declined treatment	11.4
Accessed treatment outside of the NHS	3.9
Did not access physical treatment	3.3
Puberty assessment ONLY	2.0
Treatment withdrawn	1.5
Detransitioned/detransitioning	X
Unknown/unclear	X
Puberty blocker not started due to JR	X
Treatment recommended but supply issues (GP prescribing or pharmacy)	X
Treatment withdrawn - professional advice/side effects	X
Cross-sex hormones ONLY	X
Puberty blockers AND cross-sex hormones (privately)	X

Source: *The Gender Identity Development Service Audit Report, Arden & GEM*

NB: X indicates <10 patients

13.13 The GIDS audit report (Appendix 8) also sets out that 73% (2,415) of the audited patients were not referred to endocrinology by GIDS. Of these:

- 93.0% did not access any physical treatment whilst under GIDS
- 5.0% accessed treatment outside NHS protocols
- 1.5% declined treatment
- 0.5% of patients detransitioned or were detransitioning back to their [birth-registered] gender.
- 69% were discharged to an adult GDC (possibly due to ageing out of the GIDS service). It is not known how many of these went on to hormone treatment through the adult services.

13.14 The Review received reports from support and advocacy groups that some young adults who had been discharged from GIDS remained on puberty blockers into their early to mid 20s, but did not progress to masculinising/feminising hormones. A review of the audit data suggested 177 patients were discharged whilst still on puberty blockers only (that is, not with masculinising/feminising hormones), but it is not possible to tell from this data how many subsequently came off puberty blockers and/or progressed to masculinising/feminising hormones through adult or private services.

13.15 Puberty blockers are intended to be a short-term intervention and the impact of use over an extended period of time is unknown, although the detrimental impact to bone density alone makes this concerning. The Review raised this with NHS England and GIDS.

International practice

13.16 The University of York carried out a systematic review and narrative synthesis of the international care pathways of children and young people referred to specialist gender or endocrinology clinics (Taylor et al: Care pathways). This places GIDS data in a wider context.

13.17 The systematic review aimed to synthesise information on numbers referred, assessed, diagnosed and considered eligible for medical intervention, numbers who later desist or detransition, reasons for leaving the service/pathway and provision of psychological care.

13.18 The systematic review included 23 studies across nine countries; 14 specialist gender and nine endocrinology services. A major problem in interpreting these results is that models of care differ and there is a lack of clarity in the source papers as to how individual clinics function. Some endocrinology services may receive patients who have already been assessed by a gender service, as is the case in the UK, whilst in other countries, referrals may go directly to endocrinologists. This will affect the percentage diagnosed with gender dysphoria and/or offered endocrine treatments.

Patients accessing medical pathways

13.19 The numbers of young people receiving puberty blockers was reported in 21 of the papers, with the pooled estimates from across these services being 36% of those referred (95% confidence interval 23-51%). The ages at which they received puberty suppression ranged from 9 to 18, with an average age of 15.

13.20 Across all clinics, 68% received either puberty blockers and/or masculinising/feminising hormones, although there was very wide variability between clinics.

There was neither any information about what happened to the approximately one-third of patients who did not access an endocrine pathway, nor any information about psychological care for those under the care of the specialist gender service.

13.21 Four studies published since the systematic review search are of interest, two from the Netherlands (van der Loos et al., 2023; van der Loos et al., 2022) and two from the UK (Butler et al., 2022; Masic et al., 2022).

13.22 In the UK clinic, more birth-registered female (65%) than birth-registered male (35%) adolescents were referred to endocrinology (Masic et al., 2022). Of those adolescents referred to the endocrinology clinic, 100% consented to a medical pathway, 98% of whom were on a puberty blocker pathway and 2% directly on masculinising/feminising hormones. The mean age of consenting to puberty blockers was 15.8. Not all of those who consented went on to access endocrine treatment.

The second UK paper (Butler et al., 2022) reported on discharge outcomes; 91.7% of those discharged continued to identify as transgender or gender variant, and 86.8% were discharged to adult GDCs.

13.23 In one Dutch study (van der Loos et al., 2023), 882 adolescents received puberty blockers, again with higher rates in birth-registered females than males (73% compared to 47%). Of 707 adolescents who received puberty blockers and were eligible for masculinising/feminising hormones during follow up 93% progressed to treatment. The other Dutch study (van der Loos et al., 2022) reported a 98% progression from puberty blockers to hormones.

Patients discontinuing medical pathways

13.24 The care pathways systematic review (Taylor et al: Care pathways) reported that 0-8% of patients discontinued puberty suppression (discussed in Chapter 14) and 0-2 patients discontinued masculinising/feminising hormones.

13.25 In the two UK studies published since the University of York's systematic review search, there were no discontinuations of masculinising/feminising hormones in the first UK study (Masic et al., 2022), but in the second UK study (Butler et al., 2022) 90 (8.3% of those referred for medical treatment) stopped identifying as gender incongruent, and 58 (5.3%) stopped treatment with either puberty blockers or masculinising/feminising hormones. However, the lack of information about length of time to discharge makes interpretation difficult.

Summary – medical pathways

13.26 A common theme in examining both the GIDS and international data is how difficult it is to understand the different pathways that young people follow, what alternative options are available for those who do not follow a medical pathway, and the reasons for treatment decisions at all stages along the pathway.

13.27 The GIDS audit found that 27% of patients were referred to endocrinology, and that 89% of patients referred to endocrinology were discharged to an adult GDC.

13.28 Of the 73% of patients not referred to endocrinology, 69% of these were referred to an adult GDC.

13.29 Since it is common for people attending an adult GDC to receive masculinising/feminising hormones, it is all the more critical to get follow-up data to better understand the outcomes for those who are referred to adult GDCs and those who are not.

14. Puberty blockers

14.1 When the Review began, the medical interventions for gender incongruence/dysphoria available on the NHS were puberty blockers, followed by masculinising/feminising hormones. The history of their use was outlined in Part 2.

Normal pubertal development

14.2. Puberty begins between 8 and 13 in girls (average age 11) and between 9 and 14 in boys

(average age 12). The process starts in an area of the brain called the hypothalamus.

14.3. Puberty is triggered when the hypothalamus starts a hormone cascade which results in the ovaries and testes producing oestrogen and testosterone respectively. Both males and females proceed through the 5 stages of puberty known as Tanner stages.

Table 10: Tanner stages

TANNER	MALES	FEMALES
Stage 1	<ul style="list-style-type: none"> No major physical changes yet Brain is starting to signal the body to start making changes 	
Stage 2	<ul style="list-style-type: none"> Testes begin to grow Public hair around base of penis 	<ul style="list-style-type: none"> Breast buds, darker nipple Small amount of pubic hair
Stage 3	<ul style="list-style-type: none"> Penis gets longer Thicker pubic hair Wet dreams Voice starts to change Muscles get larger Start of growth in height 	<ul style="list-style-type: none"> Breast buds increase in size More pubic hair Hair under armpits Acne Most rapid growth in height Start to increase fat on hips and thighs
Stage 4	<ul style="list-style-type: none"> Testes, penis and scrotum continue to grow, scrotum gets darker Hair in armpits Deeper voice Acne Most rapid growth in height 	<ul style="list-style-type: none"> Further breast growth First period Growth in height slows Pubic hair gets thicker
Stage 5	<ul style="list-style-type: none"> Testicles, penis, scrotum adult size Pubic hair spread to inner thighs Facial hair Growth in height slows down 	<ul style="list-style-type: none"> Adult breast size Periods more regular Adult height Hips, thighs, buttocks fill out

Rationale for the use of puberty blockers for gender dysphoria

14.4 As set out in Chapter 2, the practice of pausing puberty at Tanner Stage 2 was initiated in the Netherlands, and subsequently adopted in the UK and internationally. The idea was based on a theory from Dr Peggy Cohen-Kettenis whose initial clinical experience was in adult care. Her rationale was that pausing puberty early would help young people to 'pass' better in adulthood and 'extend the diagnostic period' by buying time to think. The use of puberty blockers for this purpose was initially reported in a single case study (Cohen-Kettenis & van Goozen, 1998) and then in the original Dutch cohort (de Vries et al., 2011b).

14.5 It may appear surprising that the novel use of a drug for this purpose did not require a more rigorous drug trial. This is because of the way drugs are licensed and can be used off-label (see Explanatory Box 5).

14.6 GnRH hormones (referred to as puberty blockers in the treatment of young people) are licensed for patients with precocious puberty (that is, young children who enter puberty too early), as well as for the treatment of some cancers in adults and some gynaecological issues in adults. They have undergone extensive testing for use in precocious puberty (a very different indication from use in gender dysphoria) and have met strict safety requirements to be approved for this condition.

Explanatory Box 5:

Licensing, indications and contraindications

Licences are granted for a drug if strict safety and quality standards are met for its use. In the UK, licences are granted by the Medicines and Healthcare products Regulation Agency (MHRA).

An indication for a drug is a medical condition that the drug can be used to treat. Drugs are licensed for specific indications or purposes; for example, semaglutide was originally licensed for the treatment of diabetes. Recently some brands of semaglutide (Wegovy) have received additional licensing for weight loss.

If a drug is used for a purpose for which it is not licensed, this means it is being used off-label. This may be because it is considered to be effective for this indication, but the manufacturer has not gone through the processes to apply for a licence for that particular condition. For example, tetracycline, a kind of antibiotic, is licensed for a range of conditions including acne and rosacea. It is also used to treat *Helicobacter pylori*, a bacteria that infects the stomach lining and can cause stomach ulcers, but it is not licensed for that purpose.

Many drugs are not licensed for use in children, but can still be given to them safely. This is because the trials to test safety were only done in adults, so the licence specifies adult use only. In these circumstances the drug is usually given to children for exactly the same reason as for adults (for example, treatment of a severe infection).

14.7 The situation for the use of puberty blockers in gender dysphoria is different. Although some endocrinologists have suggested that it is possible to extrapolate or generalise safety information from the use of puberty blockers in young children with precocious puberty to use in gender dysphoria, there are problems in this argument. In the former case, puberty blockers are blocking hormones that are abnormally high for, say, a 7-year-old, whereas in the latter they are blocking the normal rise in hormones that should be occurring into teenage years, and which is essential for psychosexual and other developmental processes.

14.8 This approach to the use of puberty blockers in gender dysphoria has been an ongoing source of controversy both nationally and internationally.

14.9 The lack of consensus across the clinical community was highlighted by a 2015 study (Vrouenraets et al., 2015), which approached 17 multi-professional treatment teams worldwide to determine their views on use of puberty blockers. They identified seven themes on which there were widely disparate views:

- the (non-) availability of an explanatory model for gender dysphoria
- the nature of gender dysphoria (normal variation, social construct or [mental] illness)
- the role of physiological puberty in developing gender identity
- the role of comorbidity
- possible physical or psychological effects of refraining from) early medical interventions
- child competence and decision-making authority
- the role of social context in how gender dysphoria is perceived.

14.10 The professionals who participated in the study were often conflicted because they recognised the distress of young people and felt the urge to treat them, but at the same time, most had doubts because of the lack of information on long-term physical and psychological outcomes. For several participants, a reason to use puberty suppression was the fear of increased suicidality in untreated adolescents with gender dysphoria.

14.11 The authors of the study concluded that as long as debate remains on these seven themes and only limited long-term data are available, there will be no consensus on treatment. Eight years later, the position is unchanged and many of the same considerations apply to the use of masculinising/feminising hormones in young people.

International practice

14.12 The synthesis of international guidelines by the University of York (Taylor et al: Guidelines 2: Synthesis) found that there is no clarity about the treatment aims of puberty suppression, with options including reducing gender dysphoria, improving quality of life, allowing time to make decisions, supporting gender exploration, extending the diagnostic phase and 'passing' better in adult life.

14.13 Most guidelines emphasise full reversibility as a justification for their use, whilst highlighting potential adverse effects on bone health and uncertainty regarding cognitive development.

14.14 Where eligibility is discussed, the earlier requirement to wait for the patient to reach age 12 before they can access puberty blockers has been removed from some guidelines (for example, WPATH 8). The majority of guidelines recommend waiting until a child has reached Tanner Stage 2 of puberty. The Swedish guideline recommends Tanner Stage 3.

14.15 There is also considerable variation about the criteria for starting puberty blockers, with the commonest being the presence of gender dysphoria that has emerged or worsened at puberty. Only two guidelines specified the need for gender incongruence rather than dysphoria. Several specified that mental health difficulties should be managed and/or were unlikely to impact treatment. Another specification in several guidelines was that the young person has decision-making capacity, parental consent is obtained and/or that there is family social support.

14.16 The Swedish and Finnish guidelines differ from others in recommending that puberty suppression should be provided under a research protocol or the supervision of a research clinic.

14.17 The international survey (Hall et al: Clinic survey) looked at what is happening in practice. All clinics offered puberty blockers and masculinising/feminising hormones apart from one regional service. Menstrual suppression with progestogens (the contraceptive pill) was routine in four clinics.

14.18 Most clinics required a diagnosis of gender dysphoria or incongruence, reaching Tanner stage 2 and stable mental health for

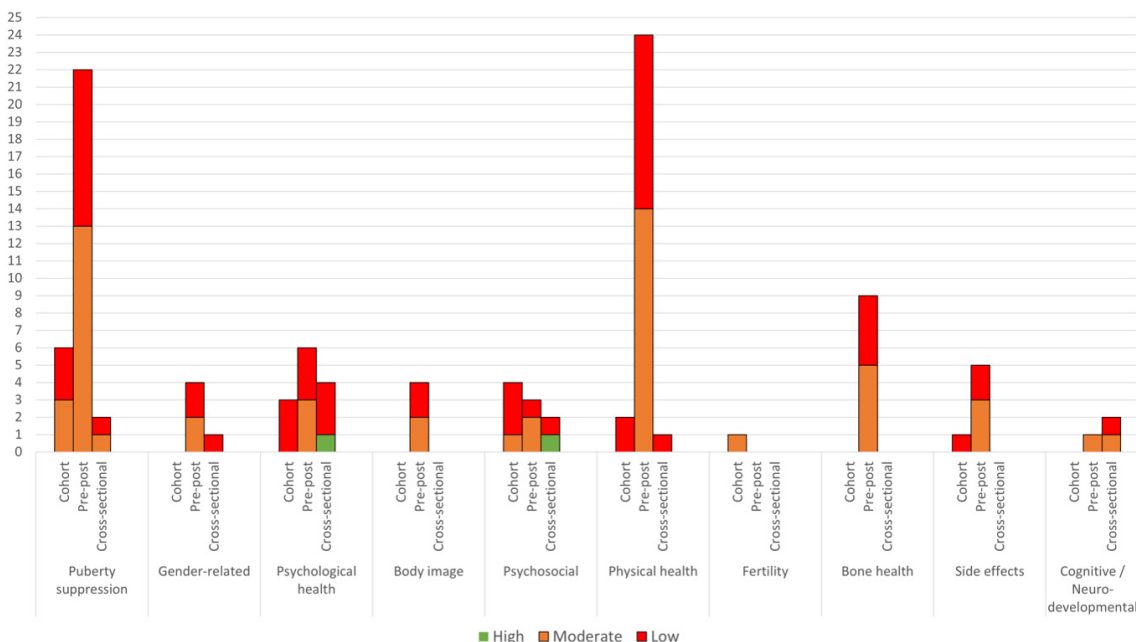
puberty blockers. Belgium, Finland, Denmark and Norway required gender dysphoria/ incongruence to have been long-lasting/since childhood and Finland specified that distress had to intensify in puberty. Five clinics excluded those in late puberty from having blockers.

Understanding intended benefits and risks of puberty blockers

14.19 The systematic review on interventions to suppress puberty (Taylor et al: Puberty suppression) provides an update to the NICE review (2020a). It identified 50 studies looking at different aspects of gender-related, psychosocial, physiological and cognitive outcomes of puberty suppression. Quality was assessed on a standardised scale. There was one high quality study, 25 moderate quality studies and 24 low quality studies. The low quality studies were excluded from the synthesis of results.

14.20 A large proportion of the studies only looked at how well puberty was suppressed (expected effects) and at side effects, with fewer looking at the other intended outcomes. There was evidence from multiple studies that puberty suppression exerts its expected physiological effect, and this has never been at issue.

Figure 35: Outcome categories by study quality and design (puberty blockers)



Source: Taylor et al: Puberty Suppression

Intended benefits

14.21 As set out in Explanatory Box 5, an indication for a drug is the purpose for which it is prescribed. As the Review has progressed it has become more difficult to be clear about the indications for puberty blockers in this population of young people.

14.22 As explained above, when the Dutch gender clinic first started using puberty blockers to pause development in the early stages of puberty, it was hoped that this would lead to a better cosmetic outcome for those who went on to medical transition and would also aid diagnosis by buying more time for exploration. Since then, other proposed benefits have been suggested, including improving dysphoria and body image, and improving broader aspects of mental health and wellbeing.

Buying time to think/explore

14.23 The University of York's systematic review of care pathways (Taylor et al: Care pathways) reported that 0-8% of young people discontinued puberty suppression. Compared to those who continued with treatment, young people who discontinued had initiated treatment at an older age and included a higher proportion of those with mental health and autism spectrum conditions. In the gender clinic with a discontinuation rate of 8% (6 of 73), median age at start of treatment was 15.2 years (range 15.0-15.6 years) and all were post-pubertal at presentation.

14.24 In the UK early intervention study (Carmichael et al., 2021), 98% (43 of 44) of those who started on puberty suppression progressed to masculinising/feminising hormones. A more recent discharge study (Butler et al., 2022) looked at 1,089 patients referred from GIDS to the paediatric endocrine clinic. It showed that 7.4% (16 of 217) of those under 16 at referral discontinued puberty blockers.

14.25 These data suggest that puberty blockers are not buying time to think, given that the vast majority of those who start puberty suppression continue to masculinising/feminising hormones, particularly if they start earlier in puberty. It was on the basis of this finding that the High Court in *Bell v Tavistock* suggested that children/young people would need to understand the consequences of a full transition pathway in order to consent to treatment with puberty blockers ([2020] EWHC 3274 (Admin)).

Reducing gender dysphoria/improving body satisfaction

14.26 Only two moderate quality studies looked at gender dysphoria and body satisfaction; the original Dutch protocol (de Vries et al., 2011b) and the UK early intervention study (Carmichael et al., 2021). Neither reported any change before or after receiving puberty suppression.

Psychological and mental health improvements

14.27 As outlined in Chapter 2, the original Dutch protocol (de Vries et al., 2011b) found improvements in mental health in a pre-post study without a comparison group, but the GIDS early intervention study (Carmichael et al., 2021) did not replicate this finding. The systematic review on interventions to suppress puberty (Taylor et al: Puberty suppression) identified one other good quality study (van der Miesen et al., 2020), which produced an intermediate result with improvements in some mental health measures but not others.

14.28 The University of York concluded that there is insufficient and/or inconsistent evidence about the effects of puberty suppression on psychological or psychosocial health. This is in line with the finding of the NICE review (2020) and other systematic reviews, apart from the systematic review commissioned by WPATH (Baker et al., 2021), which reported some benefit. However, in the latter systematic review,

eight of the 12 studies reporting psychological outcomes were rated as low quality, which may explain the difference.

14.29 It is often the case that when an intervention is given outside a randomised control trial (RCT), a large treatment effect is seen, which sometimes disappears when an RCT is conducted. This is especially the case when there is a strong belief that the treatment is effective. The fact that only very modest and inconsistent results were seen in relation to improvements in mental health, even in the studies that reported some psychological benefits of treatment with puberty blockers, makes it all the more important to assess whether other treatments may have a greater effect on the distress that young people with gender dysphoria are suffering during puberty.

Cosmetic outcomes/‘passing’ in adult life

14.30 The Multi-Professional Review Group (MPRG) request a letter from young people being put forward for puberty blockers so they can ensure that they hear the young person’s voice and understand their aspirations. The MPRG have now reviewed approximately 200 such letters. As explained in Chapter 12, many young people are living ‘in stealth’ and consequently often in a state of considerable anxiety about developing pubertal changes that may ‘out’ them to their friends. However, since most young people are not starting puberty blockers until the age of 15 and above, it is unclear how helpful they might be in maintaining stealth, particularly for birth-registered girls who will often be in the later stages of puberty by that time.

14.31 In the longer-term, being able to ‘pass’ is of great importance to some transgender adults, and not to others. Although there is a lack of long-term outcome data for children and young

people in adult life, the Review team has been able to talk to both young people and older adults about their experience of early access to puberty blockers. This has been particularly important for the transgender women, who were able to access puberty blockers before developing facial hair and dropping their voice.

14.32 In terms of helping young people to ‘pass’ in adult life, an important question is what impact puberty blockers might have on adult height for those who subsequently go on to masculinising/feminising hormones. Evidence to date suggests that puberty blockers neither lead to substantially reduced adult height in transgender females (Boogers et al., 2022), nor increased eventual height in transgender males (Loi-Koe et al., 2018). This is an important issue for further research.

Risks

14.33 When the use of puberty blockers was introduced by the Dutch clinic, the target population was patients who had been gender incongruent since childhood. Prior to the introduction of puberty blockers, the clinical experience of that group suggested that although in the vast majority the gender incongruence resolved by puberty, for those for whom persisted into puberty, a long-term transgender identity was more likely.

14.34 For the more recently presenting population of predominantly birth-registered females who develop gender dysphoria in early to mid-puberty, there is even less understanding of what in medical terms is called the ‘natural history’ of their gender dysphoria (that is, what would happen without medical intervention). Because an intervention intended for one group of young people (predominantly pre-pubertal birth-registered males) has been given to

a different group, it is hard to know what percentage of these young people might have resolved their gender-related distress in a variety of other ways.

14.35 Earlier, this Report set out the very complex events that take place in the adolescent brain during puberty. Neuroscientists believe that these changes are driven by a combination of chronological age and sex hormones. Blocking the release of these sex hormones could have a range of unintended and as yet unidentified consequences.

Altering the trajectory of development of sexuality and gender identity

14.36 Adolescence is a time of overall identity development, sexual development, sexual fluidity and experimentation.

14.37 Blocking this experience means that young people have to understand their identity and sexuality based only on their discomfort about puberty and a sense of their gender identity developed at an early stage of the pubertal process. Therefore, there is no way of knowing whether the normal trajectory of the sexual and gender identity may be permanently altered.

Impact on neurocognitive development

14.38 A further concern, already shared with NHS England (July 2022) (Appendix 6), is that adolescent sex hormone surges may trigger the opening of a critical period for experience-dependent rewiring of neural circuits underlying executive function (i.e. maturation of the part of the brain concerned with planning, decision making and judgement). If this is the case, brain maturation may be temporarily or permanently disrupted by the use of puberty blockers, which could have a significant impact on the young person's ability to make complex risk-laden decisions, as well as having possible longer-term neuropsychological consequences.

14.39 The University of York's systematic review identified one cross-sectional study that measured executive functioning. This found no difference between adolescents who were treated with puberty blockers for less than one year compared to those not treated, but found worse executive functioning in those treated for more than one year compared to those not treated (Taylor et al: Puberty suppression).

14.40 A recent review of the literature on this topic found very limited research on the short-, medium- or longer-term impact of puberty blockers on neurocognitive development (Baxendale, 2024).

Impact on subsequent genital surgery

14.41 If puberty suppression is started too early in birth-registered males it can make subsequent vaginoplasty (creation of a vagina and vulva) more difficult due to inadequate penile growth. In some transgender females this has necessitated the use of gut in place of penile tissue, which has a higher risk of surgical complications.

14.42 A recent paper suggests that for transgender females it is recommended to wait until Tanner Stage 4 to allow adequate penile growth for vaginoplasty (Lee et al., 2023).

Other physical health impacts

14.43 Multiple studies included in the systematic review of puberty suppression (Taylor et al: Puberty suppression) found that bone density is compromised during puberty suppression, and height gain may lag behind that seen in other adolescents. However, much longer-term follow-up is needed to determine whether there is full bone health recovery in adulthood, both in those who go on to masculinising/feminising hormones and those who do not.

14.44 The same is true of other short-term physical effects of puberty suppression, with little knowledge about whether it leads to any long-term effects, such as on metabolic health and weight.

Prolonged exposure to puberty suppression

14.45 Puberty suppression was never intended to continue for extended periods, so the complex circumstances in which young people may remain on puberty blockers into adulthood is of concern. In some instances, it appears that young adults are reluctant to stop taking puberty blockers, either because they wish to continue as non-binary, or because of ongoing indecision about proceeding to masculinising or feminising hormones. For others, there may have been a delay in adult services taking over their care.

Summary – puberty blockers

14.46 There are many reports that puberty blockers are beneficial in reducing mental distress and improving the wellbeing of children and young people with gender dysphoria, but as demonstrated by the systematic review the quality of these studies is poor.

14.47 The Review has heard that the widespread claims that puberty blockers reduce the risk of death by suicide in this population may place pressure on families to obtain private treatment.

14.48 The Review has also heard from GPs who have been put under pressure to continue prescribing such treatments on the basis that failing to do so will put young people at risk of suicide.

14.49 The University of York systematic review found no evidence that puberty blockers improve body image or dysphoria, and very limited evidence for positive mental health outcomes, which without a control group could be due to placebo effect or concomitant psychological support.

14.50 It is important not to lose sight of the fact that hormonal surges are a normal part of puberty and are known to lead to mood fluctuations and depression, the latter particularly in girls.

14.51 It is not unexpected that blocking these surges may dampen distress and improve psychological functioning in the short-term in some young people, but this may not be an appropriate response to pubertal discomfort.

14.52 Conversely, a known side effect of puberty blockers on mood is that it may reduce psychological functioning. This variability in individual response to predicted physiological effects is reflected in the secondary analysis of the GIDS early intervention study (McPherson & Freedman, 2023).

14.53 The very strongly held beliefs amongst some young people and parents/carers that puberty blockers are highly efficacious may be attributed to a number of factors:

- the support for this position in published papers and from some clinicians working in the field
- signposted information and advice provided to children, young people and their families on the perceived benefits, including on social media
- the fact that puberty blockers have come to be seen as the entry point into and start of a transgender treatment pathway
- a lack of information about the limitations of the evidence base
- the lack of other options offered to address symptoms of distress and bodily discomfort.

14.54 The focus on puberty blockers and beliefs about their efficacy has arguably meant that other treatments (and medications) have not been studied/developed to support this group, doing the children and young people a further disservice.

14.55 Studies should evaluate whether simple measures such as stopping periods with the contraceptive pill have the potential to manage immediate distress, as well as other more conventional evidence-based techniques for managing depression, anxiety and dysphoria. None of these alternative approaches preclude continuing on a transition pathway, but they may be more effective measures for short-term management of distress.

14.56 Transgender males masculinise well on testosterone, so there is no obvious benefit of puberty blockers in helping them to ‘pass’ in later life, particularly if the use of puberty blockers does not lead to an increase in adult height.

14.57 For transgender females, there is benefit in stopping irreversible changes such as lower voice and facial hair. This has to be balanced against adequacy of penile growth for vaginoplasty, leaving a small window of time to achieve both these aims.

14.58 In summary, there seems to be a very narrow indication for the use of puberty blockers in birth-registered males as the start of a medical transition pathway in order to stop irreversible pubertal changes. Other indications remain unproven at this time.



15. Masculinising/feminising hormones

15.1 The use of masculinising/feminising hormones in transgender adults was pioneered by Magnus Hirshfield in the first half of the 20th century. It is a well-established practice that has transformed the lives of many transgender people.

15.2 Treatment with masculinising/feminising hormones is not without long-term problems and side effects, but for those who have undergone a successful transition, the physical costs are dramatically outweighed by the long-term benefits.

15.3 The use of masculinising/feminising hormone in those under age 18 is a more recent development that started in the late twentieth century (Carswell et al., 2022), so is less well understood. As set out in Part 3, it is not the practice of masculinising/feminising hormones that has changed more recently, but the heterogeneous population of people seeking this treatment.

15.4 Studies looking at outcomes of those taking masculinising/feminising hormones are not straightforward. As is the case with puberty blockers, the desired effects - in this case masculinisation/feminisation - are predictable and well understood. Understanding side effects and longer-term complications are important for the health of the transgender community, but in terms of patient choice are unlikely to have a major impact on treatment decisions.

15.5 The key questions are therefore, what are the short- and long-term outcomes in terms of mental health, psychosocial functioning, quality

of life and satisfaction with gender transition including sexual functioning?

International practice

15.6 The University of York's synthesis of commissioned guidelines (Taylor et al: Guidelines 2: Synthesis) found that almost all international guidelines discuss the use of masculinising/feminising hormones.

15.7 Most require that gender dysphoria or incongruence has persisted over time and that an individual has the capacity to consent to taking these hormones as part of their treatment. Most also reference age 16 as a typical starting point, but a smaller number specify this as a minimum age.

15.8 In some guidelines, other requirements are that mental health difficulties are managed/ unlikely to impact treatment. Some guidelines require parental consent and/or family/social support.

15.9 Only the Swedish and Finnish guidelines recommend that hormone treatment is given under a research framework or in exceptional circumstances.

15.10 The majority of guidelines recommend providing information on the impact of hormones and surgery on fertility, and fertility preservation measures.

15.11 The Swedish and WPATH guidelines mention the need to support those who discontinue treatment or detransition, but no detail is provided on how this should be managed.

15.12 Most guidelines recommend that gender is viewed as a spectrum, but only three discuss treatment for those who identify as non-binary. The Swedish and Norwegian guidelines do not recommend hormone treatments in this group due to lack of evidence, whilst WPATH recommends providing tailored hormones treatments in a separate chapter on non-binary people, rather than in the adolescent chapter, so it is unclear if this applies to adults only or includes adolescents.

15.13 The international survey (Hall et al: Clinic survey) found that in practice most gender clinics require stable mental health in those prescribed masculinising/feminising hormones. Some clinics have no minimum ages, and the range for those that do is 14-16. There is also variation in the required duration of gender dysphoria, ranging from since childhood to

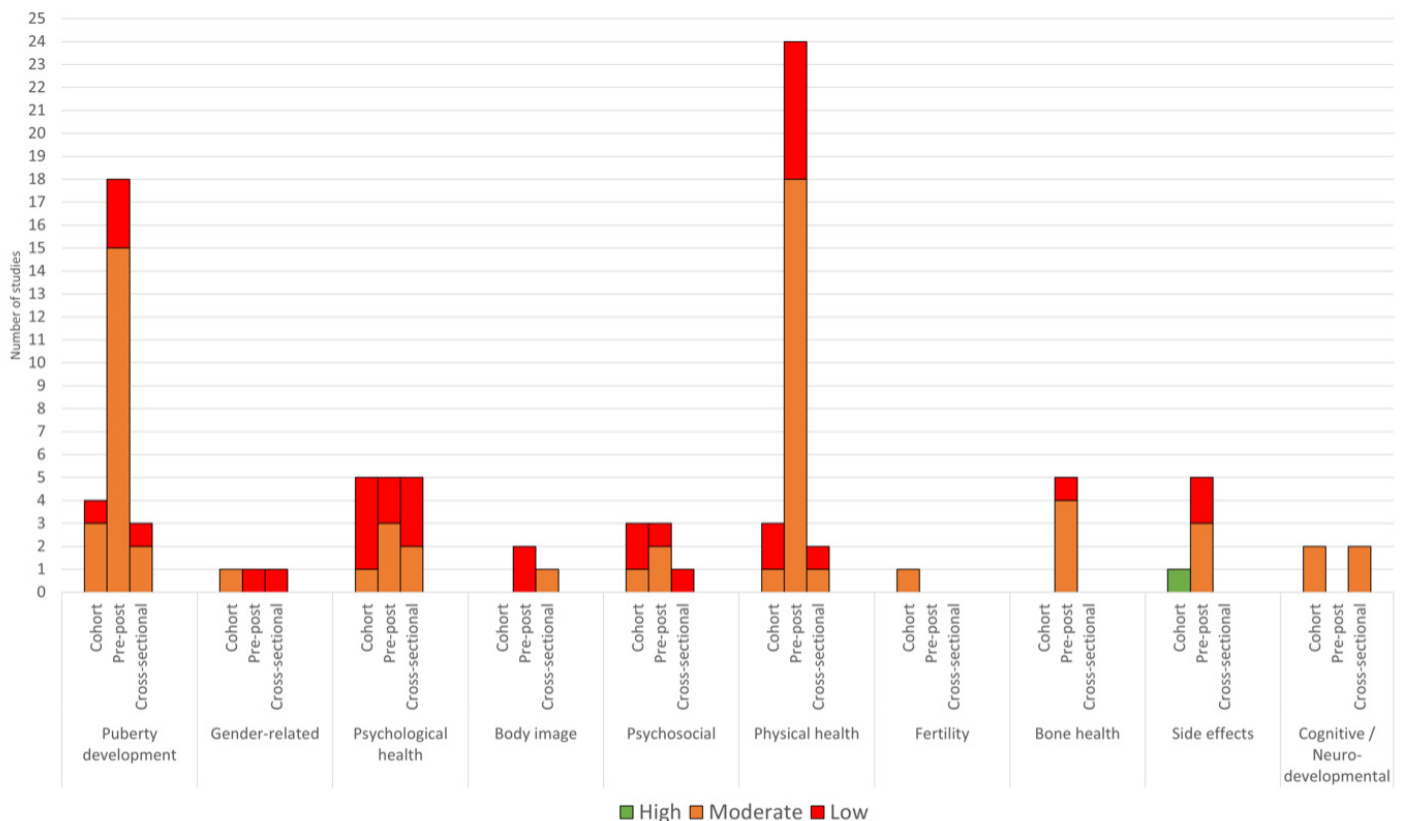
long-lasting/permanent and stable, or stable over two years.

15.14 Most gender clinics provide access to fertility preservation services.

Understanding the evidence

15.15 In addition to the systematic review on care pathways (Taylor et al: Care pathways) discussed in Chapter 13, the University of York conducted a systematic review of the use of masculinising/feminising hormones in adolescents with gender dysphoria (Taylor et al: M/F hormones). This systematic review aimed to synthesise the evidence for gender-related, psychosocial, physiological or cognitive outcomes for the use of masculinising/feminising hormones in adolescents with gender dysphoria/incongruence.

Figure 36: Outcome categories by study quality and design (masculinising/feminising hormones)



Source: Taylor et al: M/F hormones

15.16 A total of 53 studies met the inclusion criteria. The most frequently reported outcomes were adverse physical health outcomes and the intended development of puberty in the identified gender. A smaller number of studies looked at side effects in relation to bone health and fertility.

15.17 Psychological/mental health was measured in 15 studies, psychosocial in seven, and cognitive outcomes in four. Gender dysphoria and body satisfaction were each measured in three studies.

15.18 The only high-quality study identified by the systematic review was one that looked at side effects. All the rest were moderate or low quality.

15.19 The studies had many methodological problems including the selective inclusion of patients, lack of representativeness of the population, and in many of the studies there were no comparison groups. Where there was a comparison group, most studies did not control for key differences between groups.

15.20 As expected, hormone treatment induced puberty in the desired gender. Inconsistent results were found for height/growth, bone health and cardiometabolic health. Evidence relating to gender dysphoria, body satisfaction, psychosocial and cognitive outcomes was insufficient to draw clear conclusions. No study assessed fertility in birth-registered females.

15.21 There was moderate quality evidence from mainly pre-post studies that hormone treatment may improve psychological health in the short-term.

15.22 There were inconsistencies regarding suicidality and/or self-harm, with three of four studies reporting an improvement and one no change.

15.23 A significant weakness of the studies evaluating psychological or psychosocial function was the short follow-up interval, with many following-up for less than 1 year, and a smaller number for up to 3 years.

15.24 The University of York also looked at studies published since the original search for the systematic review. Two further studies were reported, which added to the moderate quality evidence that hormones may improve psychological health.

15.25 Overall, the systematic review authors concluded that: “There is a lack of high-quality research assessing the outcomes of hormone interventions in adolescents with gender dysphoria/incongruence, and few studies that undertake long-term follow up. No conclusions can be drawn about the effect on gender dysphoria, body satisfaction, psychosocial health, cognitive development, or fertility. Uncertainty remains about the outcomes for height/growth, cardiometabolic and bone health. There is suggestive evidence from mainly pre-post studies that hormone treatment may improve psychological health although robust research with long-term follow-up is needed”. This is in line with other systematic reviews published previously (Ludvigsson et al., 2023).

Key considerations

Mental health and psychosocial outcomes

15.26 It is not just the methodological issues highlighted that make it hard to draw firm conclusions about the role of masculinising/feminising hormones in mental health and psychosocial outcomes. There are important clinical considerations that complicate the picture.

15.27 When a young person has been on puberty blockers, a short-term boost in mental wellbeing is to be expected when sex hormones are introduced. Testosterone is faster to produce physical changes than oestrogen, and birth-registered girls can expect to start seeing body changes in line with their identified gender within a few months. The start of long anticipated physical changes would be expected to improve mood, at least in the short term, and it is perhaps surprising that there is not a greater effect size. However, much longer-term follow-up is needed to understand the full psychological impact of medical transition.

15.28 Discussions in Chapter 11 touched on whether mental health problems may be caused by gender dysphoria and minority stress or whether in some instances a range of adverse childhood experiences and stressors could lead to gender-related distress. Regardless of causality, the focus should be on treating all the young person's needs, rather than expecting that hormone treatment alone will address longstanding mental ill health.

15.29 This point is illustrated in a recent Australian paper (Elkadi et al., 2023), which reviewed outcomes of a clinic cohort of young people 4-9 years post presentation. At initial assessment 70 of 79 (88.6%) received comorbid mental health diagnoses or displayed other indicators of psychological distress. A diagnosis of gender dysphoria was received by 68 young people who were deemed eligible for a gender-affirming pathway. Of these, six stopped medical treatment, three while on puberty blockers alone and three after starting on masculinising/feminising hormones. Where follow-up data were available, ongoing mental health concerns were reported by 44 of 50 participants (88.0%), and educational/occupational outcomes varied widely.

15.30 Recent national register-based studies from Finland and Denmark have been published that examine mental health needs of people presenting to specialist gender services before and after treatment. Using data from a national health register is a much more robust way of capturing total population data. Both studies compared those presenting to the gender services with age-matched controls.

15.31 The Danish national register-based study of 3,812 transgender people examined a range of outcomes in routine health records compared to age-matched controls (Glintborg et al., 2023). This was a mixed group of adults and children/young people. Follow-up was a maximum of 10 years after diagnosis.

15.32 At baseline, transgender persons were five times more likely than controls to have mental health disorders. The proportion of transgender persons with a prescription for psychopharmacological agents (medications to treat mental health) increased from less than 20% at baseline to more than 30% during follow-up. After the first year of treatment, there was a decreasing trend for the risk of mental and behavioural disorders in transgender persons, but they still remained at higher risk than controls throughout follow-up, especially transgender persons registered male at birth.

15.33 This demonstrates how difficult it is to separate out and understand the impact of the various elements of care; for example, the extent to which psychopharmacological treatments improve mental health, and how much of the improvements is a result of gender-affirming treatment.

15.34 The Finnish paper (Russka et al., 2024) identified 3,665 individuals between 1996 and 2019. Again, this was a mixed group of children, young people and adults. The gender dysphoria group had received many times more specialist-level psychiatric treatments, both before and after contacting gender services, than their matched controls. There was also a marked increase over time in psychiatric needs in 2016-2019 compared to 1996-2000. The need for psychiatric support persisted, regardless of gender-affirming treatment.

15.35 In summary, both young people and adults presenting with gender dysphoria often have complex additional mental health needs. It is hard to know the extent to which hormone treatment mitigates these issues, and the role played by treatment and support in the additional ongoing mental health issues.

Suicidality

15.36 As discussed in Part 3, it is well established that children and young people with gender dysphoria are at increased risk of suicide, but suicide risk appears to be comparable to other young people with a similar range of mental health and psychosocial challenges. Some clinicians feel under pressure to support a medical pathway based on widespread reporting that gender-affirming treatment reduces suicide risk. This conclusion was not supported by the University of York's systematic review (Taylor et al: M/F hormones).

15.37 Commonly suggested reasons for the suicidality in the gender diverse population are:

- the inherent distress from the gender dysphoria
- minority stress due to discrimination and bullying
- distress caused by delayed access to medical treatment

- underlying co-occurring mental health problems that are common in the population.

15.38 A systematic review of suicide-related outcomes following gender-affirming treatment (Jackson, 2023) reported that in a majority of studies there was a reduction in suicidality following gender-affirming treatment. However, there were major methodological problems in most of the studies, with the biggest problem being a failure to adequately control for the presence of psychiatric comorbidity and treatment, such that no firm conclusions could be drawn.

15.39 A UK paper (Lavender et al., 2023) reporting a retrospective analysis of 38 children who had received puberty blockers followed by masculinising/feminising hormones noted that suicidality and self-harm showed a general decrease. However, there had been 109 eligible participants, and of the 38 included in the study only 11 had completed the suicidality/self-harm questions, rendering this observation flawed.

15.40 The authors of a paper reporting on psychosocial outcomes of 315 young people treated with masculinising/feminising hormones (Chen et al., 2023) stated that the most common adverse event was suicidal ideation (11 participants [3.5%]) and two participants [0.6%] died by suicide. Suicidality at baseline was one of the exclusion criteria for this study.

15.41 A paper from the Belgium gender clinic reported five deaths by suicide among 177 adolescents clients aged 12-18 years who were seen between 2007 and 2016 (Van Cauwenberg et al., 2021) All five had commenced on masculinising/feminising hormones.

15.42 Another recent paper (Ruuska, 2024), compared deaths by suicide in young people who had been seen in the Finnish national gender service with age-matched controls. The study also did not find a statistically

significant link between hormone treatment and reduced risk of suicide. However, there was a statistically significant relationship between a high rate of co-occurring mental health difficulties and increased suicide. Because suicides were fortunately very rare events, regardless of transition status, it is hard to draw firm conclusions from this study.

15.43 In summary, the evidence does not adequately support the claim that gender-affirming treatment reduces suicide risk. However, the distress is real for these children and young people, some of whom hold strong beliefs about the efficacy of both puberty blockers and masculinising/feminising hormones. This will be exacerbated by long waits to be seen in specialist gender services with only internet and peer group sources of support and information, and without access to clinical advice on the range of available options to manage their distress. Thus, fear that delayed access to medical treatment may lead to suicidal thoughts and behaviours remains high in parents and clinicians, and this is regardless of how effective the treatments may be once accessed.

Detransition

15.44 The term detransition is generally used to describe people who have previously medically/surgically transitioned and then reverted to their birth-registered gender. It is not necessarily applied to those who have a period of trans identification, potentially with a social transition, and later revert to live as their birth-registered gender. This tends to be referred to as 'desistance'.

15.45 During the lifetime of the Review, the term trans has moved from being a quite narrow definition to being applied as an umbrella term to a broader spectrum of gender diversity. This clearly has implications for conceptualisations of detransition.

15.46 Narratives around detransition and regret have become increasingly fraught and weaponised in the time since the Review started. Initially, the Review heard from those who strongly support gender-affirming care and contested that cases are vanishingly rare and are mostly a response to lack of acceptance and minority stress.

15.47 Over time there has been an increasing acceptance that people choose to detransition for many reasons. The term has been rebadged by some as 'retransition'. Some young adults who have detransitioned have told the Review that they would not want their experience to be used to invalidate that of other people.

"I felt like it wasn't, you know, acceptable to go back. It wasn't a thing to go back, you know. It wasn't something that was talked about. It didn't feel like an option that they wanted to discuss or even mention [...] I want detransition to be something that can be openly talked about, and regret to be openly talked about."

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15.48 Young people may also choose to stop hormone treatment but carry on identifying as transgender or non-binary.

15.49 A retrospective case note review from an NHS adult GDC (Hall et al., 2021) reported on the outcomes of 175 consecutively discharged service users; 12 cases (6.9%) met the criteria for detransitioning, and a further six had some ongoing uncertainties about their gender identities or treatment goals.

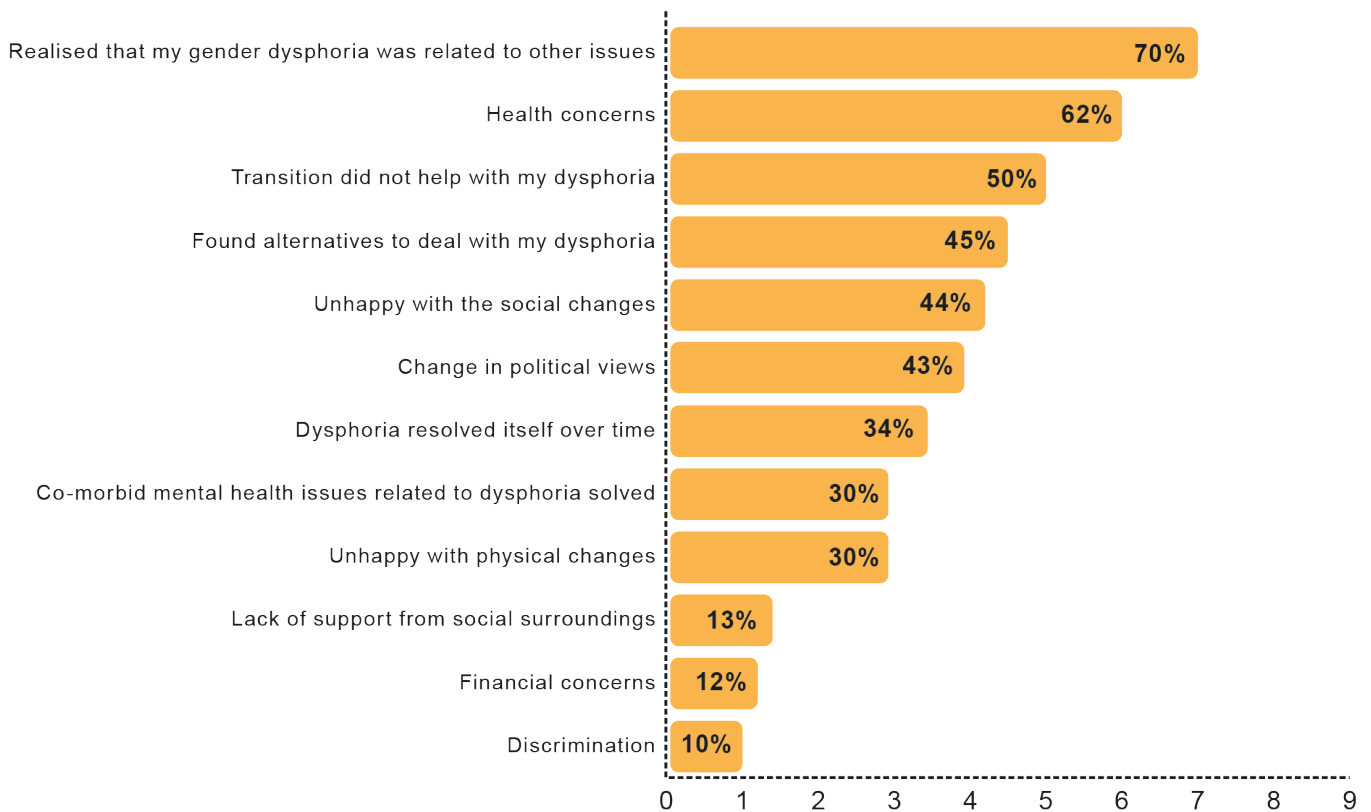
15.50 Estimates of the percentage of individuals who embark on a medical pathway and subsequently have regrets or detransition are hard to determine from GDC clinic data alone. There are several reasons for this:

- those who do detransition may not choose to return to the gender clinic and are hence lost to follow-up
- the Review has heard from a number of clinicians working in adult gender services that the time to detransition ranges from 5-10 years, so follow-up intervals on studies on medical treatment are too short to capture this
- the inflection point for the increase in presentations to gender services for children and young people was 2014, so even studies with longer follow-up intervals will not capture the outcomes of this more recent cohort.

15.51 One primary care audit from a multi-site general practice sited near a university (Boyd et al., 2022) reported on a cohort of 68 patients at various stages along the gender pathway with a mean age 27.8 years. Of 41 patients who were started on hormones, eight (20%) chose to stop after a mean period of 5 years (range 17 months to 10 years). These comprised six trans men and two trans women.

15.52 Regardless of the numbers who detransition, reasons for detransition are complex, and there is a lack of adequate service provision for this group of individuals who have a range of physical and psychological needs.

15.53 A self-identified sample of 100 detransitioners (Littman, 2021) completed an anonymous online questionnaire. Of these, 69% were birth-registered females and 31% were birth-registered males. A range of issues were reported prior to onset of gender dysphoria, including diagnosis of mental illness, neurodiversity, a history of trauma or self-injury. Reasons for detransition were diverse and included individuals becoming more comfortable in their natal sex, being concerned about medical complications of transitioning, that mental health did not improve during transitioning, being dissatisfied with physical results, and discovering gender dysphoria was caused by something specific such as trauma or abuse. Homophobia or difficulty accepting themselves as lesbian, gay or bisexual was expressed by 23.0% as a reason for transition and subsequent detransition.

Figure 37: Self-reported reasons for detransitioning

Source: Vandebussche, E. (2021). *Detransition-related needs and support: A cross-sectional online survey*. *Journal of Homosexuality*, 69(9), 1602-1620. <https://doi.org/10.1080/00918369.2021.1919479>. Published with <http://creativecommons.org/licenses/by-nc/4.0/> license by Taylor & Francis Group, LLC.

15.54 Figure 37 shows some of the reasons given for detransitioning in response to a cross-sectional online survey of 237 self-identified participants (Vandebussche, 2022).

15.55 An audit was undertaken at The Tavistock and Portman GDC on the characteristics of individuals who had detransitioned. Most papers on detransition are based on community samples, and questionnaire reports, but this was a case series of 40 patients who had all been examined by a psychiatrist.

15.56 Findings from the audit were discussed with the Review. The time for people to choose to detransition was 5-10 years (average 7 years). Common presenting features and risk factors such as high levels of adverse childhood

experiences, alexithymia (inability to recognise and express their emotions) and problems with interoception (making sense of what is going on in their bodies) were identified in the audit, and this audit would be informative for clinicians assessing young people with a view to starting masculinising/feminising hormones. The Review asked to have access to this audit in order to understand some of the qualitative findings, but the trust did not agree to this.

Long-term outcomes

15.57 One of the major difficulties with planning interventions for children and young people is the very limited evidence on the longer-term outcomes for people who have accessed GIDS.

15.58 When clinicians talk to patients about which interventions may be best for them, they usually talk about the longer-term benefits and risks of different options, based on outcome data from other people who have been through a similar care pathway. This information is not currently available for interventions in children and young people with gender incongruence or gender dysphoria, so young people and their families have to make decisions without an adequate picture of the potential impacts and outcomes.

15.59 A strand of the research the Review commissioned from the University of York was a data linkage study. The study aimed to use existing data held by the NHS, including data from GIDS, hospital wards, outpatient clinics, emergency departments and NHS adult GDCs, to track the journeys of all young people (approximately 9,000) referred to the GIDS service through the system to provide a population-level evidence base of the different pathways people take and the outcomes.

15.60 This type of research is usual practice in the NHS when looking to improve health services and care received. However, this has not been the case for gender-questioning children and young people and the hope was that this data linkage would go some way to redress this imbalance.

15.61 The study received ethics approval from the Health Research Authority (HRA), a process that took over a year. While the methodology proposed for the research is not particularly unusual, the robust scrutiny and consideration its Research Ethics Committee (REC) and Confidentiality Advisory Committee (CAG) applied to the study was entirely appropriate given the sensitivity of the subject matter.

15.62 The University of York undertook stakeholder engagement and developed the patient notifications and communications resources to explain the research and provide information about how to opt-out of the study should an individual choose to do so. It was at the point of trying to launch the 3-month opt-out period that the NHS gender clinics indicated their unwillingness to participate.

15.63 In January 2024, the Review received a letter (Appendix 11) from NHS England stating that, despite efforts to encourage the participation of the NHS gender clinics, the necessary co-operation had not been forthcoming.

15.64 This research represents a unique opportunity to provide further evidence to assist young people, their parents/carers and the clinicians working with them to make informed decisions about the right pathway for them.

15.65 Although retrospective research is never as robust as prospective research, a prospective study would take a minimum of 10-15 years to extract the necessary follow-up data.

15.66 NHS England in its letter has committed to realising the ambitions of this study beyond the life of the Review. As a single integrated health service, which for the period in question had one provider of specialist gender care for children and young people, the NHS offers a world leading opportunity to look at outcomes for around 9,000 patients and add to the evidence base.

15.67 NHS England will take over responsibility for this work and the NHS National Research Oversight Board for Children and Young People's Gender Services will support the task.

15.68 NHS England asked the Review for details on the circumstances that led the University of York to reach the conclusion that it was not yet possible to move ahead with the next stages of the data linkage study and specific recommendations for moving forward. The Review wrote to NHS England in March 2024 (Appendix 12).

Recommendation 5:

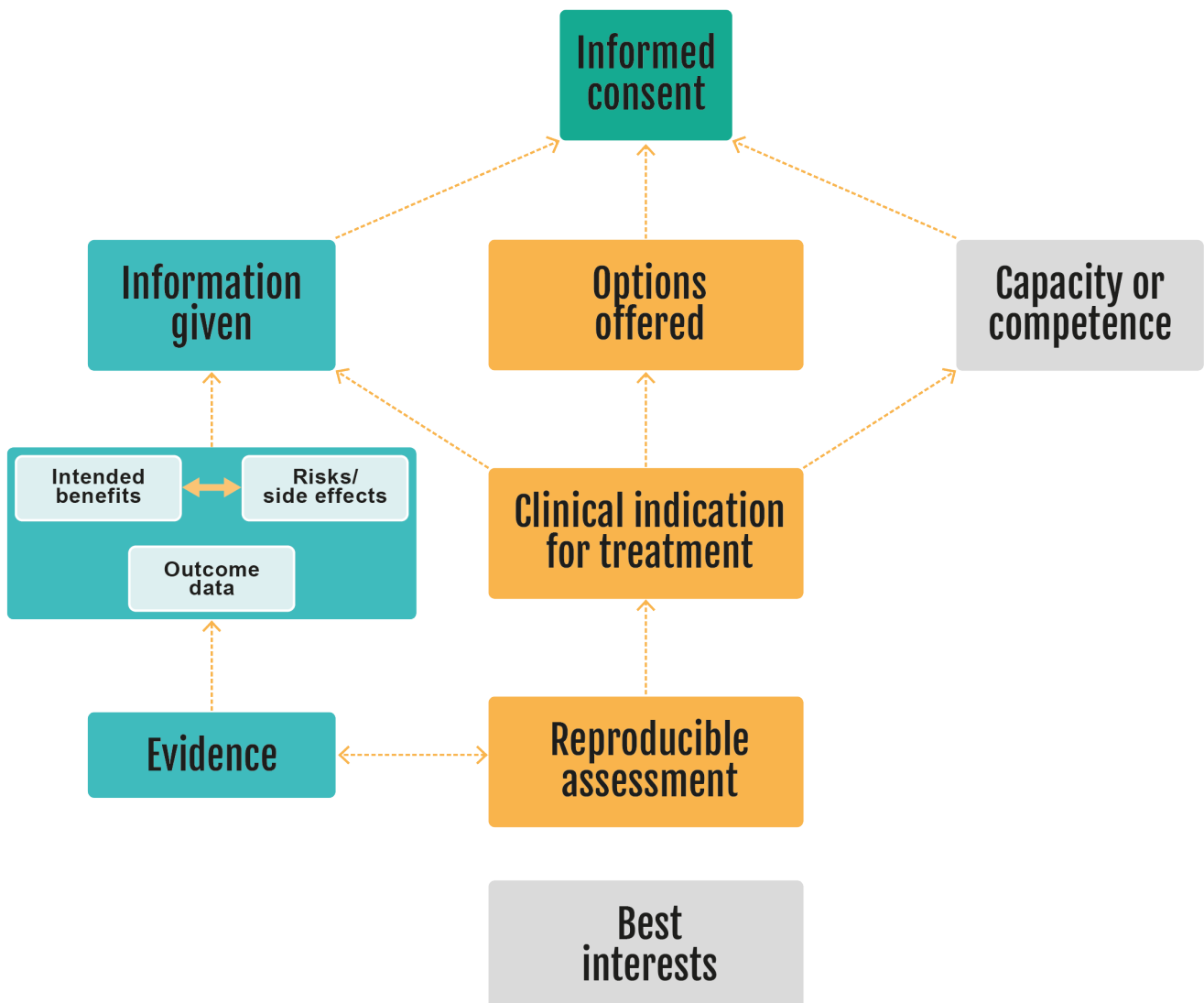
NHS England, working with DHSC should direct the gender clinics to participate in the data linkage study within the lifetime of the current statutory instrument. NHS England's Research Oversight Board should take responsibility for interpreting the findings of the research.

16. Challenges in clinical decision making

16.1 There was considerable public interest in the Bell v Tavistock case referenced in Chapter 2, which focused on competence/ capacity of the child or young person to consent to medical treatments. However, this is only part of the process of decision making about treatment options.

16.2 The clinician must first decide what treatments options are appropriate/clinically indicated, and then provide the information that the patient needs in order to make an informed decision about the options offered.

Figure 38: Informed consent



16.3 GMC guidance (GMC, 2021) makes it clear that doctors are responsible for any prescriptions they provide and accountable for their decisions and actions when supplying or administering medicines. ‘Prescribing’ is used to describe many related activities, not just prescription medicines. For example, it can also include activities such as exercise, and it may also be used to describe any written information or advice that is given to patients; thus, in the context of gender services, this could reasonably be deemed to apply to any advice ranging from social transition to hormone treatments.

16.4 General Medical Council (GMC) guidance (GMC, 2024) states that a doctor must “propose, provide or prescribe drugs or treatment (including repeat prescriptions) only when [they] have adequate knowledge of the patient’s health and are satisfied that the drugs or treatment will meet their needs”.

16.5 There are multiple problems in making these judgements in this complex area of healthcare.

Assessing whether a treatment is clinically indicated

16.6 As discussed in Chapters 9 and 10, international guidelines on assessment of children and young people with gender incongruence or dysphoria lack clarity about purpose, content or duration. Formal assessment tools have not been adequately validated.

16.7 Although the most cited reasons for carrying out an assessment are to inform a care plan or assess eligibility for endocrine treatment, few guidelines provide detail about operational criteria for eligibility for puberty blockers or masculinising/feminising hormonal prescriptions.

The Review was unable to obtain clear criteria from the GIDS team on their criteria for referral for endocrine intervention.

16.8 A formal diagnosis of gender dysphoria is frequently cited as a prerequisite for accessing hormone treatment. However, it is not reliably predictive of whether that young person will have longstanding gender incongruence in the future, or whether medical intervention will be the best option for them. Depending on what has caused their distress or dysphoria, it may be resolved by medical treatment, but it may also be resolved in other ways.

16.9 As discussed in Chapter 8, the nature and causes of gender dysphoria/incongruence are complex and poorly understood, and there is very limited understanding of the currently presenting population of predominantly birth-registered adolescent females. Each individual will have a different mix of biopsychosocial factors, but if potentially dynamic psychosocial or sociocultural factors predominate in a significant proportion of people, one of the most challenging ethical questions is whether and/or when medical intervention is the correct response.

16.10 As set out in the section on brain development, maturation continues into a person’s mid-20s, and through this period gender and sexual identity may continue to evolve, along with sexual experience. Priorities and experiences through this period are likely to change, and this was reflected in the differences in feedback from young adults compared to teenagers. Furthermore, the Review heard accounts from young adults and parents about young people who felt certain about a binary gender identity in teenage years and then became more fluid in young adulthood or reverted to their birth-registered gender.

16.11 For these reasons, many clinicians who the Review has spoken to nationally and internationally have stated that they are unable to reliably predict which children/young people will transition successfully and which might regret or detransition at a later date.

16.12 Some commentators suggest that since there is no evidence that gender assessments by clinicians can reliably predict or prevent detransition/regret any better than self-reported gender identity and embodiment goals, services should adopt an 'informed consent' model of care (Ashley et al., 2023). This model may be used to support proceeding with gender affirming interventions based primarily or solely on the person's own assessment of the risks and benefits of a treatment, rather than a decision by the doctor about the different treatment options that may meet the patient's needs. This would also be in line with the views of some service users who see the assessment process as intrusive and 'gatekeeping'.

16.13 In the opinion of the Review, this is inconsistent with the approach to joint decision making with patients set out in the GMC's professional standards. These standards highlight the importance of doctors recommending, prescribing, or providing treatments only when they have adequate knowledge of the patient's health and are satisfied that the drugs or treatment will meet their needs (GMC, Prescribing 2021, Good medical practice 2024). Doctors must make sure the patient has the information they need to make a well-informed decision about the options for treatment (GMC, Decision making and consent 2020).

Best evidence and information

16.14 The University of York's systematic reviews demonstrated poor study design, inadequate follow-up periods and a lack of objectivity in reporting of results. As a result, the evidence for the indicated uses of puberty blockers and masculinising/feminising hormones in adolescents are unproven and benefits/harms are unknown.

16.15 In addition to this making it difficult for clinicians to know whether these are appropriate treatments to offer, it is also challenging to provide children, young people and families with sufficient information on which to make an informed choice.

16.16 Montgomery makes it clear that clinicians must not merely disclose information but also take reasonable care to ensure that patients are aware of material risks ([2015] UKSC 11). This is an active responsibility that involves assessing what the patient has understood.

16.17 This duty applies not just to the recommended treatments but also to any reasonable alternatives or treatments. This means that it would not be enough to discuss endocrine options, but also other non-endocrine options, as well as the pros and cons of delaying endocrine intervention.

16.18 The duty of information disclosure is complicated by many 'unknown unknowns' about the long-term impacts of puberty blockers and/or masculinising/feminising hormones during a dynamic developmental period when gender identity may not be settled.

16.19 For example, when young people commence on the hormones of their identified gender after a period of puberty suppression, they start to experience a sense of libido and a change in their physical appearance. Many report a period of 'gender euphoria'. This makes it surprising that the observed improvements

in psychological functioning in the first year of masculinising/feminising hormones are relatively modest. Their experience of puberty will then be based on their identified gender, which may have permanent neuropsychological effects.

16.20 For birth-registered females, the impact of testosterone will give a higher sex drive than they might have experienced during their biological puberty, and after one year will result in robust increases in muscle mass and strength (while birth-registered males will maintain their muscle strength) (Wiik et al., 2020). In the absence of any experience as an adult cis-woman, they may have no frame of reference to cause them to regret or detransition, but at the same time they may have had a different outcome without medical intervention and would not have needed to take life-long hormones.

16.21 There is no information on the natural history (that is, untreated trajectories) of the current cohort of predominantly birth-registered females presenting in early adolescence because endocrine interventions have been initiated.

16.22 Tragically deaths by suicide in trans people of all ages continue to be above the national average, but there is no evidence that gender-affirmative treatments reduce this. Such evidence as is available suggests that these deaths are related to a range of other complex psychosocial factors and to mental illness.

16.23 This raises the question of whether, for those who are in late adolescence and not on puberty blockers, managing any mental health problems, ensuring participation in education or work, supporting social transition and organising fertility preservation if required are more pressing issues than commencing masculinising/feminising hormones.

16.24 All of these difficult questions make provision of sound information and properly informed consent very challenging.

Competency and capacity to consent

16.25 Over the age of 16, the Mental Capacity Act 2005 presumes that a patient is able to make their own decision about their medical treatment - that is, choosing among the options made available to them - unless it is shown that they are unable to do so because they cannot understand or retain or use/weigh the information relevant to that decision because of an impairment or disturbance in the functioning of their mind or brain. The Family Law Reform Act 1969 s8 set out that the consent of a person aged 16 is as effective as the consent of a patient aged 18.

16.26 Under the age of 16, the ability to make the decision means having sufficient maturity and understanding to make the relevant decision ('Gillick competence').

16.27 Although as described in Chapter 4, in the *Bell v Tavistock* judgment, the Court of Appeal rejected the High Court's guidance on whether particular age groups would be likely to be able to make such decisions, these decisions would be uniquely difficult for children to be able to make for themselves, for all the reasons set out above.

16.28 The age for starting puberty blockers varies between clinics. Many guidelines have removed a lower age limit as puberty is now starting earlier than it was previously. This means that children as young as 9 can be started on treatment. However, such early treatment has not been the practice in the UK ([2021] EWCA Civ 1363).

16.29 Even at Tanner stages 2-3, young people have had minimal experience of their own biological puberty, and such experience as they have had may have been distressing for a wide range of reasons.

16.30 Once on puberty blockers, they will enter a period when peers are developing physically and sexually whilst they will not be, and they may be experiencing the side effects of the blocker. There are no good studies on the psychological, psychosexual and developmental impact of this period of divergence from peers.

16.31 However, if a young person is already on puberty blockers they will need to make the decision to consent to masculinising/feminising hormones at a point when their psychosexual development has been paused, and possibly with little experience of their biological puberty.

Best interests of the child/young person

16.32 For children and young people there may also need to be an assessment of best interests when it comes to making a choice among the treatment options which are made available, if they cannot make that decision for themselves. This must take account of the views, culture and beliefs of the child or young person, the parents and/or other close carers, as well as the views of other healthcare professionals involved in their care, or professionals involved in their welfare. Account should also be taken of “which choice, if there is more than one, will least restrict the child’s or young person’s future options” (GMC, 2018).

16.33 Best interests decisions are especially difficult where the proposed treatment is very significant, not readily reversible and the outcome of treatment is less predictable.

Conclusion

16.34 In considering endocrine interventions, the large number of unknowns regarding the risk/benefits in any one individual and the lack of robust information to help them make decisions present a major problem in obtaining informed consent.

16.35 The more fundamental issue though is determining the circumstances under which such treatments should be offered to children and young people in the first place.

16.36 A trusted source of information is needed on all aspects of medical care, but in particular it is important to defuse/manage expectations that have been built up by claims about the efficacy of puberty blockers.

16.37 Although younger people experience a sense of urgency to access medical treatments, some young adults have suggested that taking time to explore options is preferable.

16.38 The Review has already advised that because puberty blockers only have clearly defined benefits in quite narrow circumstances, and because of the potential risks to neurocognitive development, psychosexual development and longer-term bone health, they should only be offered under a research protocol. This has been taken forward by NHS England and the National Institute for Health and Care Research (NIHR).

16.39 The option to provide masculinising/feminising hormones from age 16 is available, but the Review would recommend an extremely cautious clinical approach. There should be a clear clinical rationale for providing hormones at this stage rather than waiting until an individual reaches 18. This would keep options open during this important developmental window, allowing time for management of any co-occurring conditions, building of resilience and fertility preservation, if required.

16.40 A more fundamental problem that has become more apparent as the Review has progressed is that research on psychosocial interventions and longer-term outcomes of those who do not access endocrine pathways is as weak as research on endocrine treatment. This leaves a major gap in our knowledge about how best to support and help this growing population of young people with gender-related distress in the context of complex presentations.

16.41 The overarching conclusion from the evidence presented in this Review is that the puberty blocker trial, which is already in development, needs to be one part of a much broader research programme that seeks to build the evidence on all potential interventions, and to determine the most effective way of supporting these children and young people.

Recommendation 6:

The evidence base underpinning medical and non-medical interventions in this clinical area must be improved. Following our earlier recommendation to establish a puberty blocker trial, which has been taken forward by NHS England, we further recommend a full programme of research be established. This should look at the characteristics, interventions and outcomes of every young person presenting to the NHS gender services.

- The puberty blocker trial should be part of a programme of research which also evaluates outcomes of psychosocial interventions and masculinising/ feminising hormones.
- Consent should routinely be sought for all children and young people for enrolment in a research study with follow-up into adulthood.

Recommendation 7:

Long-standing gender incongruence should be an essential pre-requisite for medical treatment but is only one aspect of deciding whether a medical pathway is the right option for an individual.

Recommendation 8:

NHS England should review the policy on masculinising/feminising hormones. The option to provide masculinising/feminising hormones from age 16 is available, but the Review would recommend extreme caution. There should be a clear clinical rationale for providing hormones at this stage rather than waiting until an individual reaches 18.

Recommendation 9:

Every case considered for medical treatment should be discussed at a national Multi Disciplinary Team (MDT) hosted by the National Provider Collaborative replacing the Multi Professional Review Group (MPRG).

Recommendation 10:

All children should be offered fertility counselling and preservation prior to going onto a medical pathway.

Service model



This part looks at the service model for children and young people's gender services, clinical pathways, workforce and training, service improvement and research. It seeks to address the following aspects on which the Review has been asked to provide recommendations:

- pathways of care into local services, including clinical management approaches for individuals with less complex expressions of gender incongruence who do not need specialist gender identity services
- pathways of care into specialist gender identity services, including referral criteria into a specialist gender identity service and referral criteria into other appropriate specialist services
- current and future workforce requirements
- ongoing clinical audit, long-term follow-up, data reporting and future research priorities.

17. Existing service models

17.1 The interim report highlighted a number of issues in relation to the existing service model:

17.2 It is unusual for there to be direct referral into specialist services, as was the case for The Tavistock and Portman NHS Foundation Trust Gender Identity Development Service (GIDS). Early in the Review it became clear that referring a rapidly increasing number of children and young people into a single national service with insufficient links to local services was not working. The service did not have the ability to respond to the increasing demand and was not a safe or viable long-term option.

17.3 This has led to an increasingly long waiting list, which clinicians, young people and their parents/carers cite as the single biggest challenge in providing high quality care to gender dysphoric children and young people.

17.4 The long wait can further add to distress, result in deterioration of co-occurring mental health problems, and make it difficult for children and young people to explore the full range of options for addressing their gender-related distress.

17.5 Young people participating in the focus groups and the qualitative research study described how the lack of communication and support while waiting for specialist services meant they had to do their own research. They had often decided what they needed by the time they were seen by GIDS and had already taken steps to help manage how they felt, including social transition.

17.6 Parental and personal narratives described children and young people having more than one presenting issue, but services (for example, GIDS, CAMHS, general practice) dealing with

each issue in isolation, without considering the impact of different issues on each other. This may include the impact of neurodivergence or significant mental health issues, including past history of eating disorders, experiences of loss and/or trauma and bullying.

17.7 Parents described how an absence of support following referral left them worried and frustrated, not knowing where to get help. The University of York qualitative study (Appendix 3) found that: “Parents express continuing uncertainties and doubts about what was best for their child. They worry about getting it “wrong”. They also worry about the extent to which services can understand their child and respond appropriately”.

17.8 In addition, young people and their families have highlighted that referral into a service with a single focus on gender raises the issue of ‘diagnostic overshadowing’. They described children having more than one presenting issue, but different services (for example, GIDS, CAMHS, general practice), dealing with each issue in isolation, without considering how they might impact on each other.

17.9 Lack of clarity over clinical responsibility for a child/young person following referral, and the fact that there has often been little or no preliminary assessment of risk and safeguarding, is also a cause for concern.

17.10 Addressing these issues requires a system-wide response. The Review’s interim report concluded that a fundamentally different service model is required, and the Review subsequently undertook stakeholder testing of different service models that would:

- increase capacity both at tertiary and secondary care level

- allow initial assessment at an early point in the patient pathway
- approach clinical management through a broader paediatric and mental health lens
- have a multi-disciplinary workforce able to take a holistic view of children and young people
- skill-up a wider range of clinicians to work with gender-questioning children and young people, thus democratising knowledge and expanding capacity through the system.

17.11 The Review also considered the practicalities:

- care needs to be provided as close to home as possible
- roles need to be attractive for recruitment and tap into as broad a range of skills as possible
- recruitment to tertiary centres should not destabilise local services.

17.12 In July 2022, the Review wrote to NHS England expanding its advice in the interim report (Appendix 6). The letter set out the key components of a regional networked model of care to ensure this population of children and young people receive the holistic service described in Part 4 at appropriate levels within the NHS.

17.13 The aim of the proposed new regionalised NHS gender service for children and young people is to provide a comprehensive patient and family-centred service and package of care, supporting children and young people who are questioning their gender identity or experiencing gender dysphoria to get on the right pathway for them as an individual.

NHS England's interim service – establishing Phase 1 providers

17.14 Since receiving the Review's interim report, NHS England has taken steps to increase capacity and manage the closure of GIDS, establishing two new nationally networked services to be led by specialist children's hospitals. This is the first step in commissioning a network of regional services across the country over the coming years.

17.15 These Phase 1 service providers will take over clinical responsibility for seeing children and young people on the national waiting list, as well as providing continuity of care for the GIDS open caseload at the point of transfer as part of a managed transition of the service.

17.16 There have been delays due to the complexity of the programme and the phenomenal challenge of building the new service. This has meant designing and commissioning a new clinical and service model rather than simply transferring the existing model across to the Phase 1 providers. There has also been the need to recruit and train a clinical workforce to meet the requirements of the new service.

17.17 The Review had hoped to take learning from the clinicians seeing the patients in the interim services, about the characteristics of the patient cohort and optimum pathways of care. Instead, it has gained insight and learning from the considerable challenges faced in establishing the interim service. These have included: how best to manage the existing caseload and the recruitment to and training of staff for the new services.

Existing caseload

17.18 One of the key challenges in establishing the interim service has been the transfer of the open caseload. This has proven difficult in light of a lack of information on the patient cohort and the expectations of young people and their families/carers who have started care under a different clinical model.

17.19 Although representatives of GIDS have been involved in these discussions, the transfer of information to the new providers about the open caseload has proven challenging as the characteristics of the population have been difficult to ascertain. The situation is similar for those on the waiting list.

Recruitment and training

17.20 The reluctance of clinicians to engage in the clinical care of gender-questioning children and young people was recognised earlier in this report. Clinicians cite this stems from the weak evidence base, lack of consistent professional guidance and support, and the long-term implications of making the wrong judgement about treatment options. In addition, concerns were expressed about potential accusations of conversion practice when following an approach that would be considered normal clinical practice when working with other groups of children and young people.

17.21 Throughout the Review, clinicians working with this population have expressed concerns about the interpretation of potential legislation on conversion practices and its impact on the practical challenges in providing professional support to gender-questioning young people. This has left some clinical staff fearful of accepting referrals of these children and young people.

17.22 Clinical staff must not feel that discharging their clinical and professional responsibility may expose them to the risk of

legal challenge, and strong safeguards must be built into any potential legislation on conversion practices to guard against this eventuality. This will be of paramount importance in building (as opposed to diminishing) the confidence of clinicians working in this area. Any ambiguity could serve to further disadvantage these children and young people rather than support them.

17.23 Clinicians are being asked to work within a highly emotive and politicised arena. This, coupled with concerns about the weakness of the evidence base and a lack of professional guidance, has impacted on the ability of the new services to recruit the appropriate multi-disciplinary workforce.

17.24 For these reasons, whilst the Review welcomes the first step NHS England has taken to begin to establish a regional model of care, it maintains that a much more distributed model of care is needed to meet current demand and provide a more appropriate holistic, localised and timely approach to care for children and young people needing support around their gender identity.

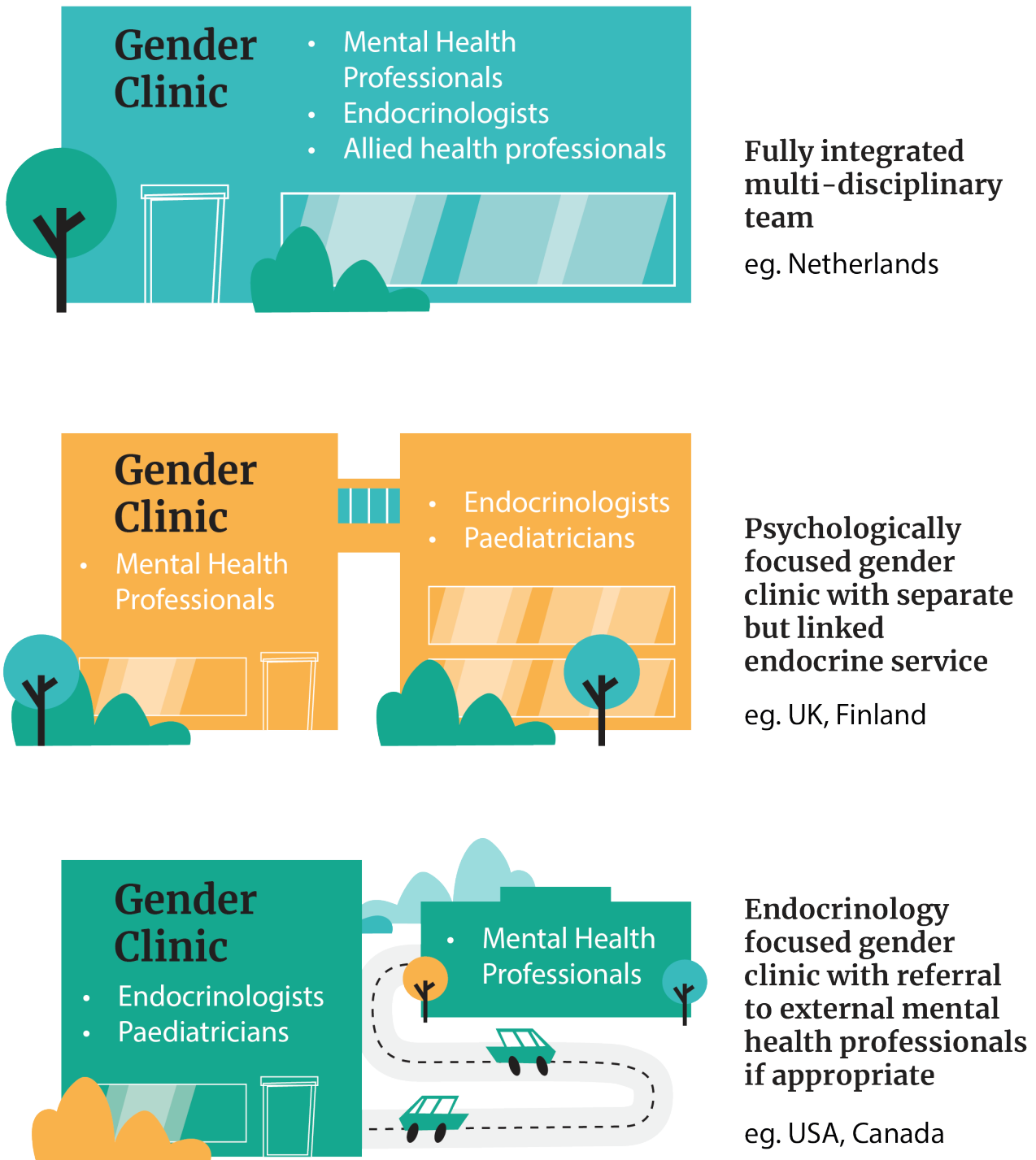
17.25 This means services should not be located solely in tertiary centres. A much broader based service model is needed with a flexible workforce working across a regional footprint in partnership with designated local specialist services.

International practice

17.26 The University of York looked at how services are organised in other health systems.

17.27 Each of these models considers the gender service in isolation. However, models of care that deliver a clinical service over multiple sites have the potential to maintain geographical access to services whilst improving quality of care and optimising the use of the workforce.

Figure 39: Variations in service models for specialist gender care



NB: These are just exemplars of models that have been described within different countries, but there is also considerable within-country variation.

Different service models in the NHS

17.28 A systematic review of ‘multiple site single service’ models of care was published by Public Health England (2019) and described a number of such models.

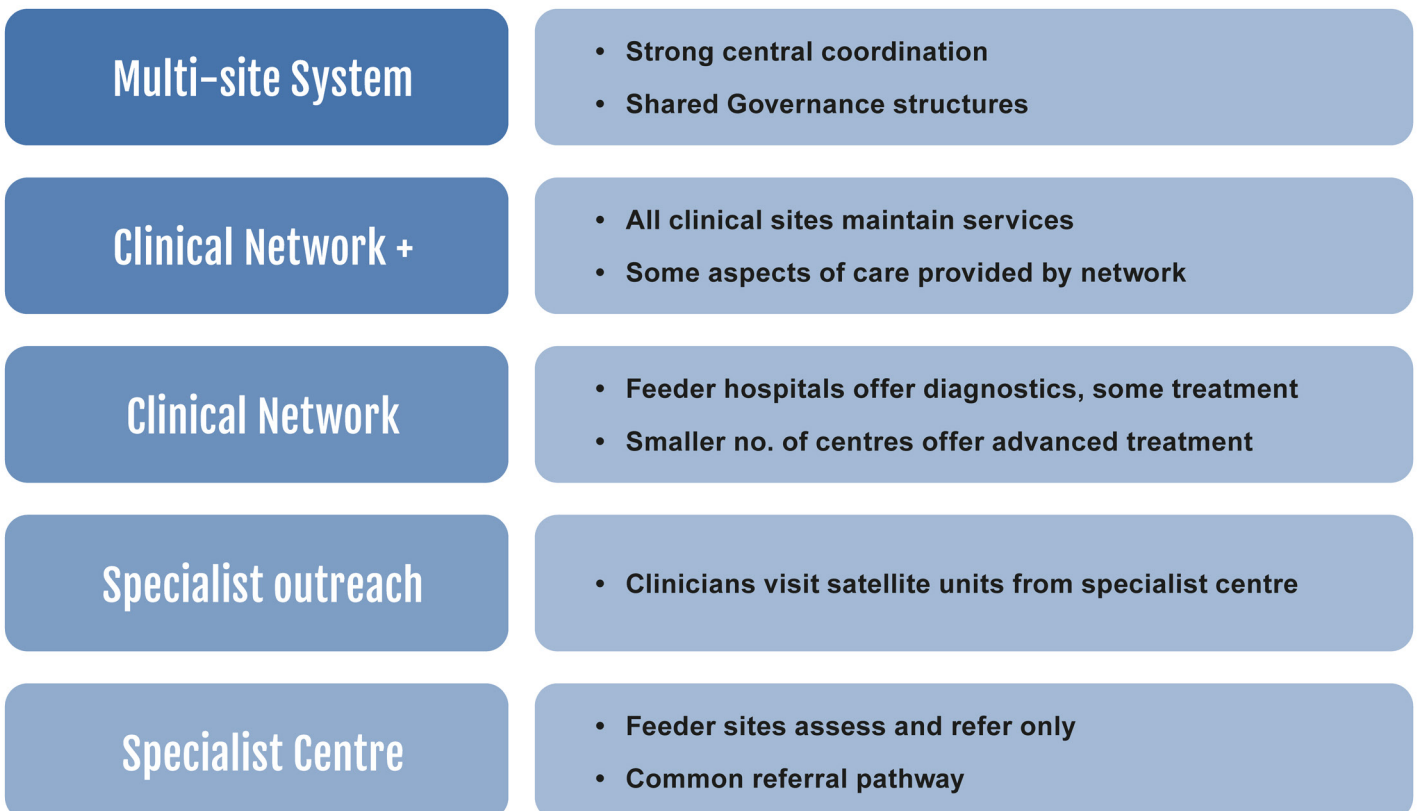
17.29 The interim service, with two initial hubs, is a ‘specialist centre’ model of care that involves a specialist (‘tertiary’) centre accepting referrals from feeder hospitals in a defined geographical area. This is intended as a step towards a clinical network approach.

17.30 ‘Specialist outreach’ involves clinicians from a specialist centre travelling out from the

centre to smaller sites to offer some elements of peer support, clinical advice and/or patient care. Many specialties in both paediatric and adult care deliver outreach clinics. GIDS operated this model, running outreach clinics in various locations around the UK.

17.31 ‘Clinical network’ describes a network in which a specialist centre provides specialist treatment to patients who reside in a defined area, but whose feeder hospitals complete some form of initial assessment, diagnostics and medical management before transferring the patient. This is the model NHS England consulted on for its interim services: secondary care provides initial assessment before referring a patient to the specialist centres.

Figure 40: Descriptive framework describing different types of multiple site, single service models of care



Source: Public Health England (October 2019)

17.32 ‘Clinical network plus’ describes a network in which all sites provide the same treatment to patients, but some aspects of care are restricted to a smaller number of sites at certain times. Within these models, some secondary-level services take an intermediate role between secondary and tertiary care and with additional staffing and training provide an additional level of care that is not routine in all secondary-level services (for example, different levels of neonatal care).

17.33 ‘Multi-site system’ describes a model of care in which all clinical sites provide the same level of care to patients, based on shared treatment pathways and clinical policies and with shared governance across the system.

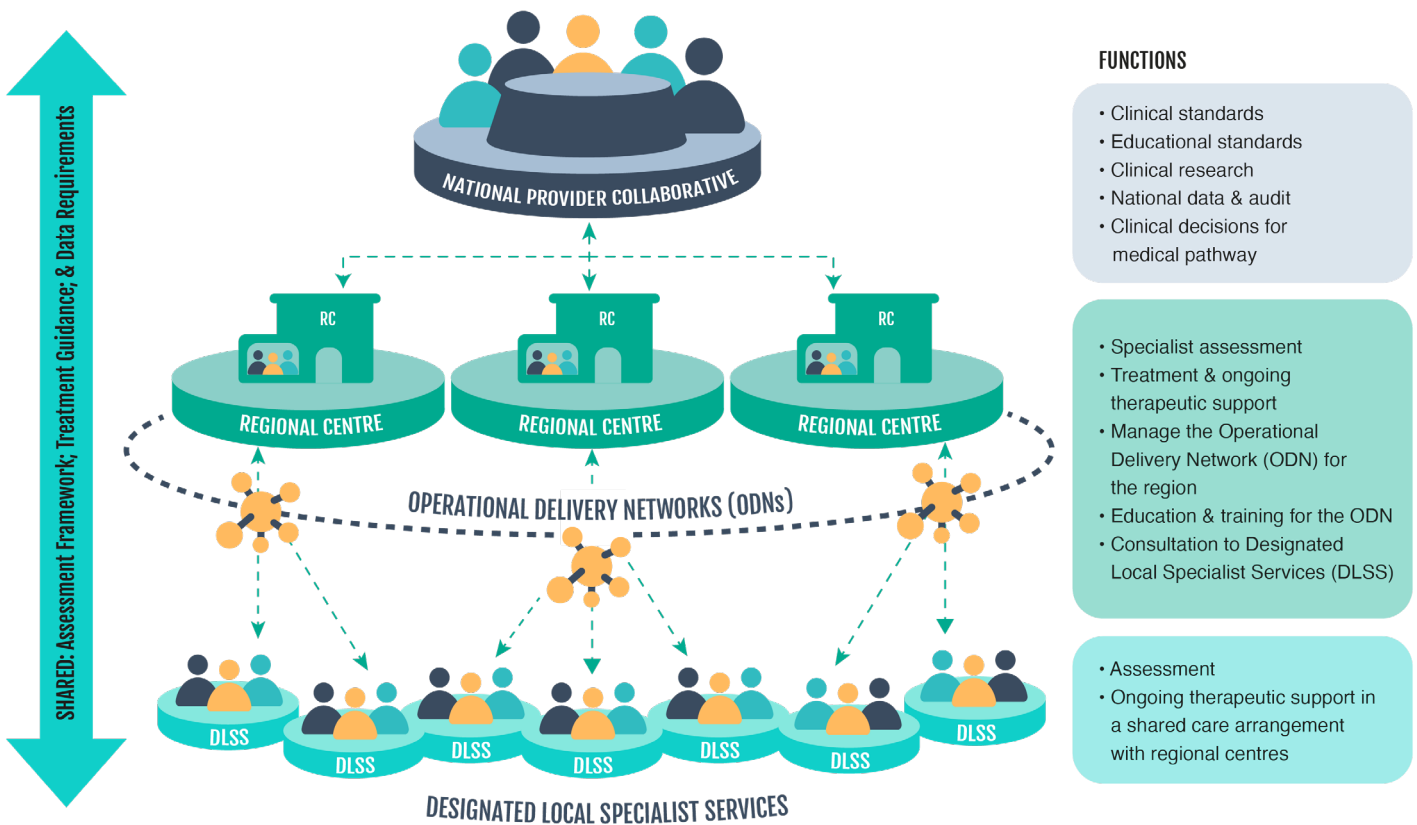
17.34 The clinical network plus and the multi-site system models are most closely aligned with the Review’s proposed model because:

- they provide better continuity of care, closer to home, and the ability for children and young people to move between components of the service at their own pace
- there is a finite workforce available to serve the needs of this population and the wider population of young people with complex needs. Therefore, partnerships with local services must be developed so that workforce can be shared across the network without destabilising local services.

17.35 Without this approach the challenges in recruitment experienced by both GIDS and the Phase 1 providers will continue.

18. A new model for gender services for children and young people

Figure 41: Proposed service model



Regional Centres

18.1 Despite the growth in the numbers of children and young people requiring support from the NHS for gender-related issues, the number remains relatively small and there will still be a need for specialist tertiary care for some of the cohort.

18.2 The regional centres will play a pivotal role in delivering the new services. They will be responsible for managing the caseload of individuals requiring support around their gender identity and hold responsibility for the assessment and treatment of those with more complex presentations and requiring more specialist care. They will oversee and work through an operational delivery network (ODN) within their region and will also provide consultation support and training to local providers.

18.3 The Review has advised that these centres be situated within experienced providers of paediatric tertiary care that have the ability to provide essential related services to support the broad range of presentations this group of children and young people may have (or be able to access such services through provider collaborations). These essential services should include, but not be limited to: mental health services, services for children and young people with autism and other neurodiverse presentations, and access to endocrinology services and fertility services, where appropriate for those seeking medical intervention.

18.4 It will also be essential that the regional centres have established academic and education functions to ensure that ongoing research and training is embedded within the service delivery model.

Designated Local Specialist Services

18.5 Although the Review recognises that much of the assessment described in Part 4 could be undertaken more locally by secondary care services, it recognised that not all local services will have the capacity, capability and/or aspiration to support this cohort, particularly given that Child and Adolescent Mental Health Services (CAMHS) services are already stretched, with a high threshold for referrals.

18.6 It is recommended that a smaller number of secondary services within CAMHS and paediatrics should be identified initially to act as Designated Local Specialist Services (DLSS) within each area. This would increase the available workforce through a flexible, multi-site staff group working between the DLSS and the regional centre, with the opportunity to provide targeted training and upskilling.

18.7 This mix of paediatric and mental health services is a fundamental change to the existing service model. In order to meet the wider needs of this population these services will need to demonstrate experience in working in child and adolescent health and with young people with complex needs, in addition to having access to mental health support. Among the workforce GPs with a special interest in adolescent health could be included.

18.8 Initially the Review advises the Regional Centres work within existing relationships to allow this provision to be established as quickly as possible with appropriate funding. Joint contracts between the Regional Centres and the DLSS should be used to support flexibility of the workforce.

18.9 Several children's hospitals operate community paediatric and/or mental health services. For example, Alder Hey Children's NHS Foundation Trust provides both acute, community and mental health paediatric services for its local population of children and young people. The range of mental health services includes Child and Adolescent Community Mental Health Services, Community Eating Disorder Service, 24/7 Crisis Care Service including Home Based Treatment Service, Mental Health in Schools Service, Enhanced Support Team and Tier 4 Children's Inpatient Regional Unit (Sunflower House). The services are located with Community and Neurodevelopmental Paediatric Services including autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD) assessment and diagnostic services, which ensures an integrated, holistic and supportive approach to the physical and emotional health needs of children and young people.

18.10 The Review has met with clinicians working in services established to support a wide range of adolescent health and wellbeing needs; for example, the Well Centre, a GP-led service in Lambeth, London, and the Onward Clinic in the Brandon Centre, a community-based service with secondary care staffing based in Kentish Town, London.

18.11 These centres provide a wide range of services, helping young people to overcome the psychological and social needs and challenges they might face, and providing support with mental health and physical and emotional wellbeing through GPs, mental health and wellbeing practitioners. There are also youth workers to support young people along their care pathway.

18.12 There is an opportunity for Regional Centres to partner with these types of services to provide the holistic needs assessment and some of the treatment pathways that might be identified through formulation and the individualised care plan. Such services may also provide parenting and broader family support.

18.13 The expansion of such models could support not only this population of young people, but also the wider population of children and young people presenting to the NHS, with gender being one component of the needs addressed. In the future, consideration could also be given to the inclusion of long-term physical care; for example, screening and supporting the public health needs of this population within a community setting.

18.14 There is considerable scope for local innovation and voluntary sector partnerships in developing these services in a range of settings. Yellow Door - Gender Identity Therapy Service, for example, is a voluntary sector Southampton-based service commissioned by the NHS that aims to provide a safe and supported thinking space for children and young people who are negatively affected by confusion, distress or interpersonal difficulties related to gender.

18.15 NHS provision for young people across the board requires service and workforce development and additional sustained investment. There is an opportunity to integrate investment and development of gender services with the ambitions set out in the NHS Long Term Plan (2019) for broader adolescent provision. In doing so, consideration should be given to integration across health, social care and other sectors, especially for young people with complex and/or multiple needs.

Operational Delivery Networks

18.16 Each Regional Centre should have an ODN. ODNs are network groups comprising representatives from the regional centre, DLSS and relevant agencies; for example, social care and education. The ODN should hold shared care agreements with DLSS to ensure this population has access to supportive care and appropriate treatment as close to home as possible.

18.17 An ODN board should be established with formal governance responsibility for children and young people in the region. An ODN is an established NHS England structure (NHS Commissioning Board, 2012). Its purpose is to:

- ensure effective clinical flows through the provider system with clinical collaboration for networked provision of services
- take a whole-system, collaborative provision approach, ensuring the delivery of safe and effective services across the patient pathway
- improve cross-organisational, multi-professional clinical engagement to improve pathways of care
- enable the development of consistent provider guidance and improved service standards, ensuring a consistent patient and family experience
- focus on quality and effectiveness through the facilitation of comparative benchmarking and auditing of services, with implementation of required improvements
- fulfil a key role in assuring providers and commissioners of all aspects of quality as well as co-ordinating provider resources to secure the best outcomes for patients across wide geographical areas.

18.18 In relation to this specific population the ODN Board will:

- support capacity planning and activity monitoring with collaborative forecasting of demand and matching of demand and supply
- ensure the DLSS meet data collection requirements and standards as established by the National Provider Collaborative
- establish sub-groups to manage the administrative functions around data, referrals and oversight of ongoing local training and CPD.

18.19 This approach should ensure clinical risk is held at the local level and help to facilitate access to and integration of local support services. The shared care arrangements will require organisations to use the same record system to allow joined-up working.

National Provider Collaborative

18.20 The Regional Centres will need to come together to form a National Provider Collaborative to ensure standards of care and equitable access is maintained. This governance role will be key to the success of the model and should include the following functions:

- the development of shared standards, operating procedures and clinical protocols, for example, for assessment and treatment
- updating the assessment framework in line with emerging evidence, audit and quality improvement
- the development of clear referral criteria and intake procedures to ensure equitable access to services

- a forum for discussion of complex cases and all decisions about medical care (a national multi-disciplinary team), ultimately subsuming the role of the Multi-Professional Review Group (MPRG)
- an ethics forum for cases where there is uncertainty or disagreement about best interests or appropriate care
- a process of peer review between Regional Centres
- development of a programme of ongoing continuing professional development (CPD) for staff at all levels, as well as educational standards for practitioners within the various tiers of service provision
- collation of the national dataset and conduct of national audit
- development of a quality improvement programme to ensure evolving best practice
- consideration of research requirements
- ongoing research in areas of weak evidence.

18.21 The National Provider Collaborative should consist of clinical and academic representatives from across the Regional Centres, as well as any external experts considered to be necessary for its work. This will require resourcing for a secretariat and time allocated in job roles to deliver the responsibilities.

Summary – service model

18.22 The aim is that no matter where in the country the child/young person is seen, they will receive the same high standards of evidence-based care and better information upon which to base their decisions, avoiding a so-called ‘postcode lottery’.

18.23 The proposed new service model with its formalised network structures at national and regional levels, and increased number of providers, should allow care and risk to be actively managed at different levels according to need, reducing waiting times for specialist care.

18.24 It is envisaged that this model will also support integration between different children’s services and facilitate early access to local services along flexible pathways that better respond to children and young people’s individual needs. Overall, this model should improve the experience of care for children and young people questioning their gender identity.

18.25 The new providers of these services should quickly develop their ODN and DLSS networks, utilising existing relationships in the first instance with those services that have the capacity, capability and interest in supporting this cohort to establish this vital level of service provision more quickly.

18.26 This approach would act as a stepping stone to ultimately skilling up all secondary-level services to provide assessment and psychological support for these children and young people, with medical intervention remaining at tertiary level.

Recommendation 11:

NHS England and service providers should work to develop the regional multisite service networks as soon as possible. This could be based on a lead provider model, where NHS England delegates commissioning responsibility to the regional services to subcontract locally to providers in their region.

Recommendation 12:

The National Provider Collaborative should be established without delay.

Workforce

18.27 The Review recognises that workforce shortfalls are one of the most challenging aspects of delivering this service.

18.28 Within the existing model of care, the vast majority of gender-questioning children and young people who seek help from the NHS have been referred to a highly specialised workforce working solely in gender care. A smaller number are successfully supported in local CAMHS or paediatric services. This approach has had the unintended consequence of de-skilling the rest of the workforce and generating unmanageably long waiting lists.

18.29 Given the increasing numbers of gender diverse and gender-questioning young people, it is important that all clinical staff are able to support them in a range of settings across the NHS. It is equally important that professionals who are involved in their ongoing care have broad-based skills in adolescent physical and mental health so that young people are treated holistically and not solely on the basis of their gender presentation.

18.30 Most international guidelines recommend that there should be a multi-professional team involved in assessment and care. The exact composition of the recommended team varies, but access to mental health professionals within the specialist team and/or within local teams is a common theme.

18.31 In line with international practice, the Regional Centres will need to have a broad multi-professional workforce. The skills of those working within the service need to reflect the needs of this heterogenous group and the service needs to include the appropriate skill mix to support both individuals who require medical intervention and those who do not.

18.32 This workforce should include paediatricians, psychiatrists, psychologists, psychotherapists, clinical nurse specialists, social workers, family therapists, specialists in autism and other neurodiverse presentations, speech and language therapists, occupational therapists and, for the subgroup for whom medical treatment may be considered appropriate, endocrinologists and fertility specialists. Social care should also be embedded and there should be expertise in safeguarding and support for looked-after children and children who have experienced trauma.

18.33 The role of paediatric and mental health professionals in this area is well recognised, but the role of allied health professionals has been under recognised. Speech and language therapists are particularly important given that a large subset of this population are neurodiverse or have other communication needs. Screening for these issues and/or advising on accessibility of written and verbal information for consent is essential. Some young people may need specialist voice intervention.

18.34 This group of young people may equally need access to occupational therapy support, again because of issues of neurodiversity and sensory distress, but also because they may experience a wide range of barriers to participation in school or other peer settings that may require assessment and advice.

18.35 Staff should maintain a broad clinical perspective by working across related non-gender services within the tertiary centre and as a multi-site staff group between tertiary and secondary centres in order to embed the care of children and young people with gender-related distress within a broader child and adolescent health context. This has the additional benefits of not destabilising existing services, supporting continuity and connection and sharing expertise and knowledge.

18.36 This is a highly challenging, complex and emotive area in which to work. Those working with this group should be given professional supervision and support to provide a place for exploration of their own approach and the range of emotions they may feel. There should be formal processes for raising concerns that sit outside immediate supervision. This should support consistency in approach and improve retention of the workforce.

18.37 The National Provider Collaborative should also explore running structured forums where all staff, clinical and non-clinical, come together regularly to discuss the emotional and social aspects of working within the service - supporting staff by giving them a safe place to raise issues and ask questions.

Recommendation 13:

To increase the available workforce and maintain a broader clinical lens, joint contracts should be utilised to support staff to work across the network and across different services.

Recommendation 14:

NHS England, through its Workforce Training and Education function, must ensure requirements for this service area are built into overall workforce planning for adolescent services.

Training and education

18.38 During the course of the Review, it has become clear that there is a general lack of confidence among the wider workforce to engage with gender-questioning children and adolescents. Many clinicians working with children and young people more generally have transferable skills and expertise, but there is a need for all clinicians across the NHS to receive better training about how to work sensitively and effectively with trans, non-binary and gender-questioning young people.

18.39 Clinicians working with children and young people and families/carers will need to have the skills to competently engage families/carers from a broad range of backgrounds, and be aware and informed of the range of priorities that young people and their parents/carers can present to services.

18.40 Young people have told the Review that they want clinicians to listen to them, respect how they feel and support them to work through their feelings and options. They expect clinicians to display compassion, understanding, and to treat them as an individual.

18.41 Training programmes should follow practice in other service areas (for example, safeguarding), where levels of competency and training needs depend on the staff group and clinical area.

18.42 In addition, providers should work with commissioners to realise the NHS Long Term Workforce Plan commitment that: “Additional specialist training in gender dysphoria will be provided to meet the workforce shortage in this specialist service; we will raise awareness of this patient group across the workforce and support healthcare professionals to signpost and support patients” (NHS England, 2023).

18.43 An effective approach would be to establish a consortium to include relevant Medical Royal Colleges, special interest groups and other professional bodies, including but not limited to:

- Association of Clinical Psychologists
- Association of Psychotherapists
- Royal College of Speech and Language Therapists
- Royal College of Occupational Therapists
- British Association of Social Workers.

18.44 The consortium should develop a shared skills and competency framework relevant to all clinical and social care staff working in this area at different levels within the system. This should include broader skills in adolescent care, as well as the more specific aspects relevant to gender care.

18.45 Individual professional organisations should determine which of the transferable skills and competencies are already embedded in the training curricula of their specific staff groups and where the gaps are.

18.46 The consortium should then develop a curriculum to cover topics that are deemed to be missing from existing training programmes and curricula, and necessary for top-up training/CPD/credentialing for individuals working within this area.

18.47 Training materials developed by MindEd and the induction materials developed for the Phase 1 providers will be helpful starting points for this work (MindEd, 2023).

18.48 The National Provider Collaborative will have responsibility to engage with the education consortium and ensure that new evidence and practice is integrated into teaching materials.

18.49 In addition to the development of national training resources, the National Provider Collaborative and individual Regional Centres/ODNs will have responsibility for ensuring a CPD programme comprising case presentations, research updates and other methods of shared learning as in all other specialty areas.

18.50 Service users and families have told the Review that there is not a single trusted source of information available from the NHS. The Provider Collaborative should work to develop regularly updated information for service users, families and other agencies such as schools and social care services.

Recommendation 15:

NHS England should commission a lead organisation to establish a consortium of relevant professional bodies to:

- develop a competency framework
- identify gaps in professional training programmes
- develop a suite of training materials to supplement professional competencies, appropriate to their clinical field and level. This should include a module on the holistic assessment framework and approach to formulation and care planning.

Recommendation 16:

The National Provider Collaborative should coordinate development of evidence-based information and resources for young people, parents and carers. Consideration should be given as to whether this should be a centrally hosted NHS online resource.

Service improvement

18.51 As set out in the interim report, central to any service improvement is the systematic and consistent collection of data on the outcomes of treatment.

18.52 Throughout the course of the Review, it has been evident that there has been a failure to reliably collect even the most basic data and information in a consistent and comprehensive manner; data have often not been shared, or have been unavailable. This has led to challenges in understanding the patient cohort, referral data and outcomes, all of which have hindered the work of the Review. More importantly, this has been to the detriment of young people and their families being able to make informed decisions.

18.53 There needs to be a cultural shift, with active leadership supporting all providers to adopt a proactive learning culture across the new services.

18.54 There should be a process of continuous service improvement and clinical reflection, with consideration to how services should evolve as the evidence base grows and care pathways are evaluated.

18.55 The Review has previously advised that the National Provider Collaborative should oversee this process, ensuring national treatment protocols and guidelines are in place to enable standardisation and consistency in practice, including for case management, assessment, consent and safeguarding.

18.56 Regional Centres should ensure these standards are disseminated and implemented through their networks and that the relevant workforce is recruited and trained, contingent on the type of support, therapy or treatment this population needs.

18.57 The National Provider Collaborative should have independent oversight of quality improvement (for example, through a Healthcare Quality Improvement Partnership commissioned approach) to ensure the highest possible standards of data management and utilisation. Regional Centres should also have oversight and reporting structures to monitor quality and improvement across their networks.

18.58 There remains the need for the collection of an agreed core dataset to inform service improvement and research, based on similar approaches already established in other specialties; for example, PICANet - Paediatric Intensive Care Audit Network for the UK and Ireland in paediatric critical care. This will be critical to informing current and future clinical practice and care for this population.

Recommendation 17:

A core national dataset should be defined for both specialist and designated local specialist services.

Recommendation 18:

The national infrastructure should be put in place to manage data collection and audit and this should be used to drive continuous quality improvement and research in an active learning environment.

Research capacity

18.59 The gaps in the evidence base regarding all aspects of gender care for children and young people have been highlighted, from epidemiology through to assessment, diagnosis, therapeutic support and treatment.

18.60 It is troubling that so little is known about this cohort and their outcomes. An ongoing programme of work is required if the new case-mix of children and young people and their needs are to be fully understood, as well as the short-, medium- and longer-term impacts of all clinical interventions.

18.61 Given the particular uncertainties regarding the long-term outcomes of medical and non-medical interventions, and the broader knowledge gaps in this area, the Review has previously advised on the need to build research capacity into the national network.

18.62 This research capacity is needed to:

- provide ongoing appraisal of new literature and rapid translation into clinical practice
- continue to identify areas of practice where further research is needed
- develop a research portfolio that will inform policy on assessment, support and clinical care of children with gender dysphoria, from presentation through to appropriate social, psychological and medical management.

18.63 The appropriate research questions and protocols will need to be developed with input from a panel of academics, clinicians, service users and ethicists.

18.64 In order to build on the work undertaken by the University of York and maintain an up-to-date understanding of this complex and fast-moving research area, a living systematic review approach should be considered. Through this approach the systematic reviews could be continually updated, incorporating relevant new evidence as it becomes available to inform the clinical approach of the new services, ensuring it remains up-to-date and dynamic.

18.65 As detailed in this report, priorities for research should include analysis of the characteristics of the population and formal research protocols underpinning both medical and non-medical interventions with follow-up into adulthood.

18.66 Without an established research strategy and infrastructure, the outstanding questions will remain unanswered, and the evidence gaps will continue to be filled with opinion and conjecture.

18.67 This is critical if the NHS is to provide reliable, transparent information and advice to support children, young people, their parents and carers in making potentially life-changing decisions.

Recommendation 19:

NHS England and the National Institute for Health and Care Research should ensure that the academic and administrative infrastructure to support a programme of clinically-based research is embedded into the Regional Centres.

Recommendation 20:

A unified research strategy should be established across the Regional Centres, co-ordinated through the National Provider Collaborative and the Research Oversight Board, so that all data collected are utilised to best effect and for sufficient numbers of individuals to be meaningful.

Recommendation 21:

To ensure that services are operating to the highest standards of evidence the National Institute for Health and Care Research should commission a living systematic review to inform the evolving clinical approach.

19. Pathways

19.1 The interim report set out that: “Clear criteria will be needed for referral to services along the pathway from primary to tertiary care so that gender-questioning children and young people who seek help from the NHS have equitable access to services”.

International practice

19.2 The University of York’s review of international guidelines (Taylor et al: Guidelines 2: Synthesis) and international survey (Hall et al: Clinic survey) found that:

- There is variability in whether services required that referrals come from child and adolescent mental health services or not. Several clinics specify that a referral must come from a clinician. Finland is unique in also having referral criteria related to co-occurring conditions, which need to be addressed prior to a referral being accepted.
- The care pathway for most guidelines is similar, starting with psychosocial care for pre-pubertal children, followed by puberty blockers then hormones for eligible adolescents.
- There is usually a separate pathway for pre-pubertal children, involving a one-off assessment followed by local management until eligible for puberty blockers.
- Denmark and Finland reported a different pathway for young people with psychosocial concerns or a short history of distress.
- Co-occurring mental health conditions or neurodiversity are usually managed by other providers, and sometimes have a longer assessment process.

- The approach among those countries that reported on their approach to non-binary individuals is generally cautious, usually delaying treatment until adulthood.
- Only one guideline mentioned transition [transfer] to adult services.

Current referral pathway

19.3 Usual practice in the NHS is that for patients to access tertiary (specialist) care, they need to be seen by a secondary care practitioner (for example, CAMHS, paediatrics) in the first instance. If, following an initial assessment, that practitioner felt that their case was sufficiently complex or the individual met the criteria for tertiary (specialist) care, they would make a referral.

19.4 When the Review commenced, access to the specialist GIDS service was unusual in that the service accepted referrals directly from primary care (a GP) and from non-healthcare professionals including teachers and youth workers.

19.5 The audit of GIDS discharge notes, undertaken by Arden & Gem CSU in spring 2023 (Appendix 6), found that 48.6% of patients referred to GIDS were referred by CAMHS and 40.68% were referred by their GP. Of the remaining, referrals were made by other healthcare providers (2.6%), local authorities (3.3%), the voluntary sector (3.1%) and schools (1.8%).

19.6 This created a number of problems:

- The information recorded on the referral was highly variable and often lacked even the basic information that the specialist team would need to screen and triage the patient.
- Patients who would not usually meet the threshold for a specialist service were being referred, meaning waiting times increased for everyone without a way to discern those who genuinely required specialist input from those who could be managed in secondary care or even primary or community care.
- Once referred, it was unclear who held clinical responsibility for the care of the young person.
- Usual assessments that would be undertaken by a secondary care practitioner (for example, safeguarding assessment, mental health assessment) were not being completed for these young people, particularly those referred through a non-healthcare route. This means that there is an unknown level of risk inherent in the legacy waiting list, that is, it is not known which young people may be at risk of self-harm or suicide, and which may be at risk due to family breakdown or other safeguarding issues.

19.7 Following the Review's interim report, NHS England consulted on a proposal for all referrals to the Regional Centres to come via secondary care. The Review supports this approach for the following reasons:

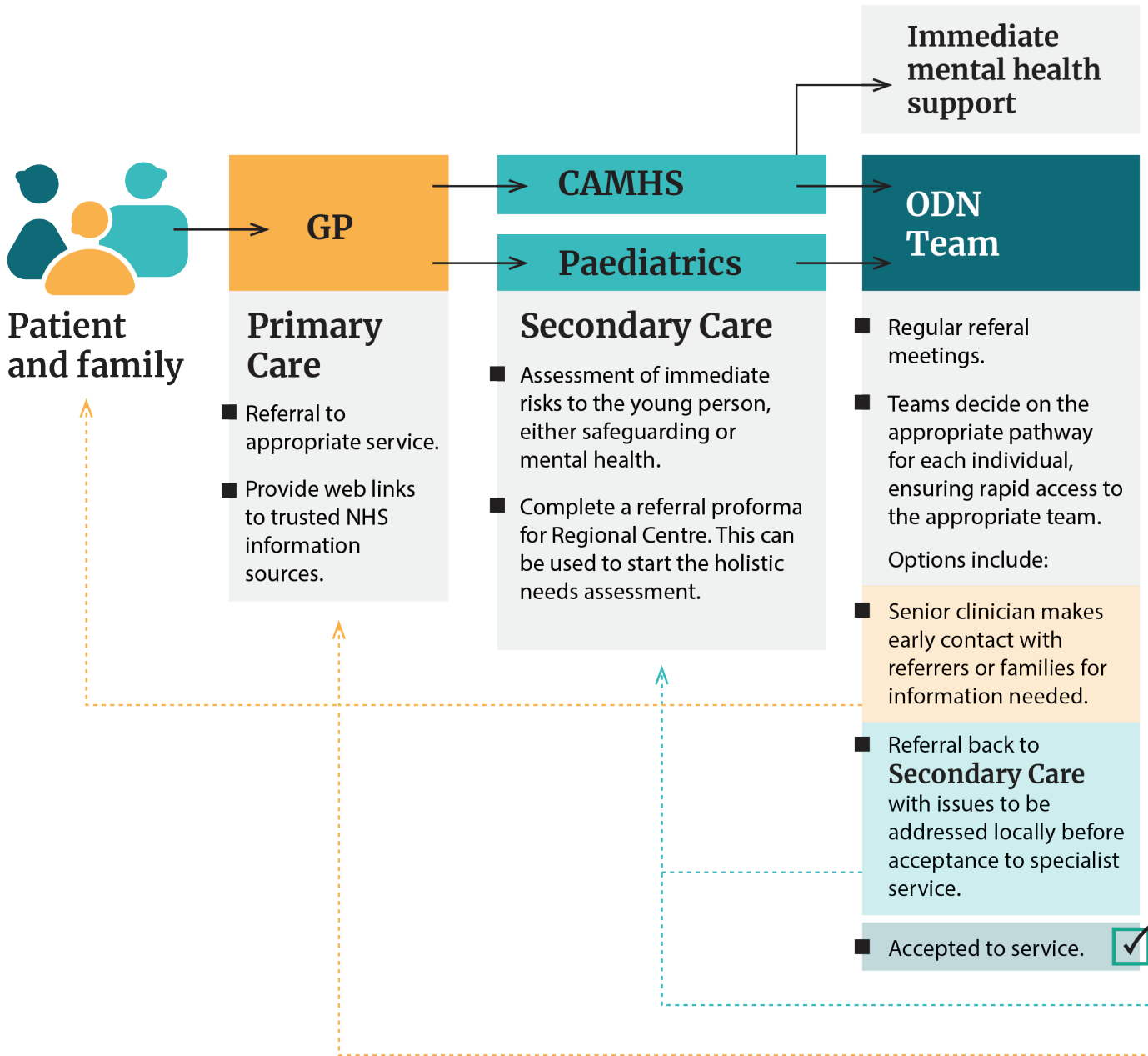
- The Regional Centres need to remain focused on the young people they can best support, and in common with other tertiary services, an initial local assessment ensures that referrals that reach the tertiary centre are appropriate, and are those whose needs cannot be met locally.
- Any immediate safeguarding or mental health risk issues can be identified and addressed, with ongoing local responsibility for this aspect of care.

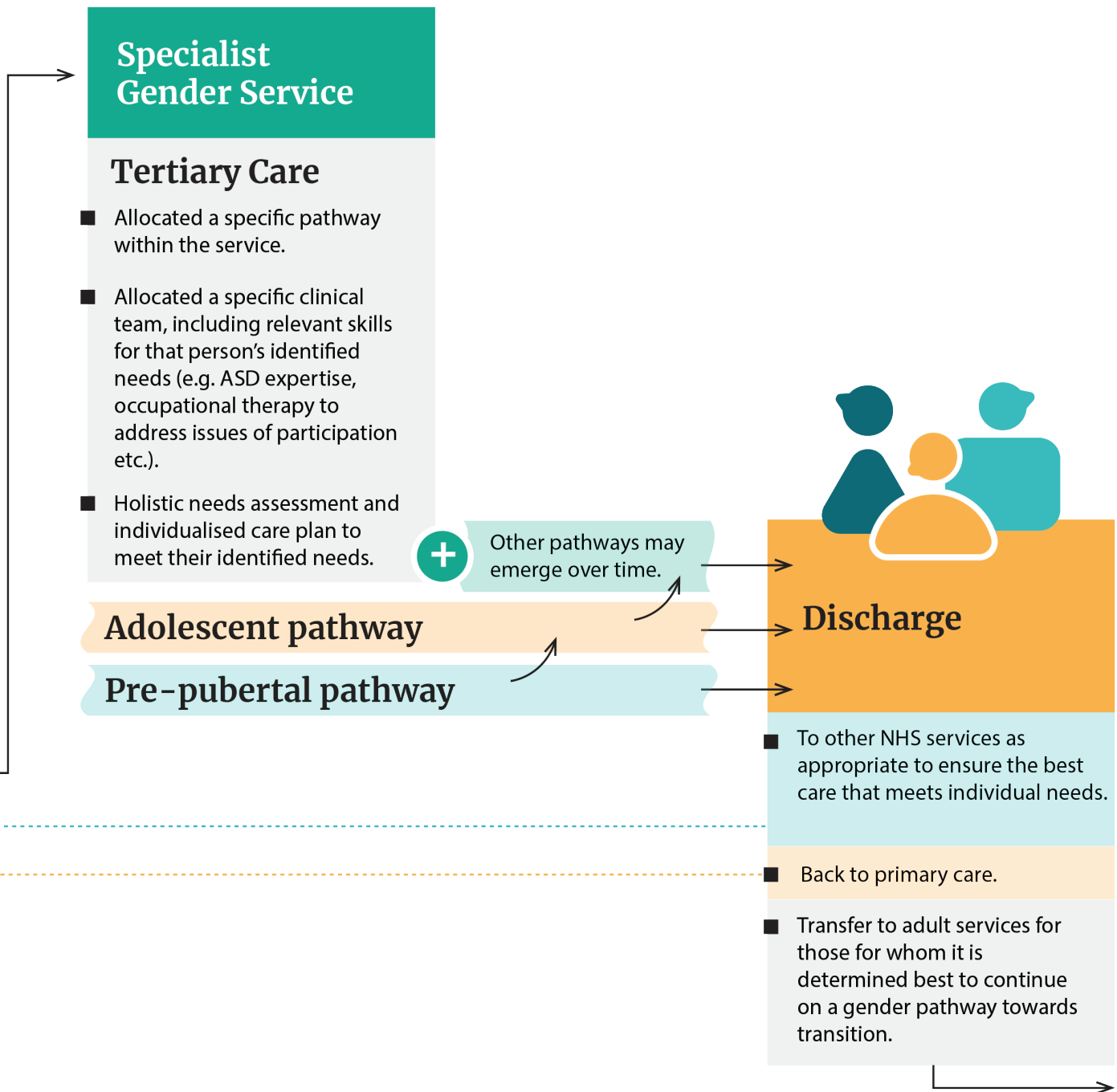


Recommended referral pathway

19.8 Taking the new service model, described previously, the process for referral would be as follows:

Figure 42: Referral pathway





Role of Primary Care

19.9 Initial consultation should be with the GP, who should make an initial assessment as they would with any other adolescent. They will have a record of any relevant past medical history and of family context.

19.10 If they consider that the young person may need to be referred to a Regional hub, they should make a referral in the first instance to a secondary Centre service. If the young person reaches the referral threshold for CAMHS, they should be referred to that service, or otherwise they should be referred to paediatrics. This should have an immediate effect on reducing the length of time children and young people are waiting to be seen by NHS services.

19.11 The GP should also share weblinks to trusted NHS information sources with the child or young person. In the longer-term these sources should be overseen by the National Provider Collaborative. In the interim, MindEd (2023) provides initial information for frontline staff, parents and teachers.

Role of Secondary Care

19.12 The responsibility of secondary care services is to make an assessment of immediate risks to the young person - either safeguarding or mental health. If there are significant concerns, these will need a local management plan.

19.13 The secondary care service will also need to complete a referral pro forma for the Regional Centre. This will document basic information including a brief history of the young person's gender presentation, family history, any co-existing conditions, and a list of any other services or agencies involved in the young person's care.

19.14 This information should be used to inform/start to complete the information for the

assessment framework described in Part 4, so that individuals are not repeating information unless necessary.

Role of the Operational Delivery Networks

19.15 The ODN should hold a regular referral management meeting. Members should include clinical staff from the tertiary service, as well as the DLSS. The team should also include a referral data manager, and may include representatives from social care, education and any other relevant team members at the discretion of the ODN.

19.16 It is essential that information about referrals be collected on a core database in order to improve understanding about the characteristics of the referred population, which is currently weak both nationally and internationally.

19.17 The referral management group will make a decision about the appropriate pathway of care for that young person, ensuring the fastest access to the appropriate team. This decision should be communicated to the young person/child's parents. The ODN should operate a 'transparent walls' approach between the tertiary centre and DLSS, so that initial assessment takes place with the most appropriate team. This will allow flexibility of capacity and skill mix between the DLSS and the tertiary team.

19.18 Options may be as follows:

- a senior clinician may make early contact with referrers or families to gain any further information needed to make decisions about the appropriate referral pathway
- referral to secondary care with advice about issues that may need to be addressed locally before the young person can be seen in the specialist service
- accepted to the specialist service.

19.19 This change should ensure that children and young people are appropriately engaged within the health system and that the NHS has clear responsibility for their care, including support whilst on the waiting list. It will need to be underpinned by access to support and information for referrers, so the whole health system better understands the needs of this population.

Pathways within the service

19.20 Discussions with clinicians have highlighted the importance of differentiating the subgroups within the referred population who may be at risk and/or need more urgent support, assessment or intervention; there may also be subgroups for whom early advice to parents or school staff may be a more appropriate first step.

19.21 If accepted to the specialist service the child/young person should:

- be allocated to the specific pathway within the service (for example, pre-pubertal pathway or adolescent pathway, other specific pathways may emerge over time)
- be allocated to a specific clinical team either within the DLSS or the tertiary team, to include relevant skills for that person's identified needs (for example, ASD expertise, occupational therapy to address issues of participation etc.).
- receive a full assessment and holistic plan to meet their identified needs.

19.22 Children and young people should be able to move flexibly between different elements of the service in a step-up or step-down model, allowing them and their parents/carers to make decisions at their own pace without requiring rereferral into the system. This could reduce the sense of urgency a young person may feel when first accessing the service.

19.23 The current evidence base suggests that children who present with gender incongruence at a young age are most likely to desist before puberty, although for a small number the incongruence will persist. Parents and families need support and advice about how best to support their children in a balanced and non-judgemental way.

19.24 In reviewing cases put forward for puberty blockers, the MPRG noted that children who had socially transitioned early and completely were likely to approach puberty in a fearful and anxious state because of living 'in stealth'. Helping parents and families to ensure that options remain open and flexible for the child, whilst ensuring that the child is able to function well in school and socially is an important aspect of care provision and there should be no lower age limit for accessing such help and support.

19.25 Importantly some children within this group who remain gender incongruent into puberty may benefit from puberty blockers and will be able to enter the specialist component of the service and access the puberty blocker trial in a timely way, if already under the supervision of the regional network.

Recommendation 22:

Within each regional network, a separate pathway should be established for pre-pubertal children and their families. Providers should ensure that pre-pubertal children and their parents/carers are prioritised for early discussion with a professional with relevant experience.

Discharge

19.26 Children and young people accessing gender services may be discharged as follows:

- to other NHS services according to their individualised care plan
- back to primary care
- a transfer to adult gender services.

Transfer to adult gender services

19.27 Currently, young people may transition [transfer] to adult gender services from the age of 17. These adult services are perceived to be quite different from GIDS, and young people presenting later may therefore not have access to the same holistic care as described in this report.

19.28 There is also concern about the impact on the young person of changing clinicians at a crucial point in their care, particularly for those with neurodiversity/special educational needs or other vulnerabilities.

19.29 The Review considered the wider implications surrounding transition [transfer] from children and young people's gender services to an adult Gender Dysphoria Clinic (GDC), which include:

- the clinical risk at the point of transfer, which includes increased suicidality, loss to follow-up, extended periods on puberty blockers
- that young people are ageing out whilst on the waiting list having not been seen by the children and young people's gender service
- the waiting list challenges within the adult services more generally
- the need for the long-term audit and follow-up research data that are currently lost at the point of transition [transfer] to adult services

- approaches taken by other NHS services: for example, adult congenital heart disease, which is an already established service; 0-25 oncology services, available in some parts of the country; and the aspiration within the NHS Long Term Plan (2019).

19.30 Currently, significant numbers of young people are being transferred from GIDS to adult services. Some will have been under the care of GIDS, but another group who have turned 17 will not have been seen by GIDS, but whose wait for GIDS is being counted towards the wait for adult services. This is increasing waiting lists for adult services and disadvantaging older adults seeking NHS support.

19.31 Taking account of all the above issues, a follow-through service continuing up to age 25 would remove the need for transition at this vulnerable time and benefit both this younger population and the adult population. This will have the added benefit in the longer-term of also increasing the capacity of adult provision across the country as more gender services are established.

19.32 This would be consistent with other service areas supporting young people that are selectively moving to a '0-25 years' service to improve continuity of care.

"Failure to achieve a safe transition can lead to disengagement, failure to take responsibility for their condition and ultimately poorer health outcomes. By 2028 we aim to move towards service models for young people that offer person-centred and age-appropriate care for mental and physical health needs, rather than an arbitrary transition to adult services based on age not need" (NHS Long Term Plan, 2019).

Recommendation 23:

NHS England should ensure that each Regional Centre has a follow-through service for 17-25-year-olds; either by extending the range of the regional children and young people's service or through linked services, to ensure continuity of care and support at a potentially vulnerable stage in their journey. This will also allow clinical, and research follow up data to be collected.

19.33 The Review requested data on the demographics of referrals into adult GDCs, and NHS England requested these data from the clinics on the Review's behalf. The dataset was incomplete (particularly for birth-registered gender) but demonstrates that the majority of referrals (around 70%) were birth-registered females under the age of 25. However, the data related to new referrals only and did not include direct referrals of GIDS patients who had reached the age of 17. Therefore, a conservative estimate would be that 17-25 year olds account for around 75% of referrals to adult gender clinics.

Table 11: Referrals received and referrals accepted by Adult Gender Dysphoria Clinics in England April 2023 - July 2023

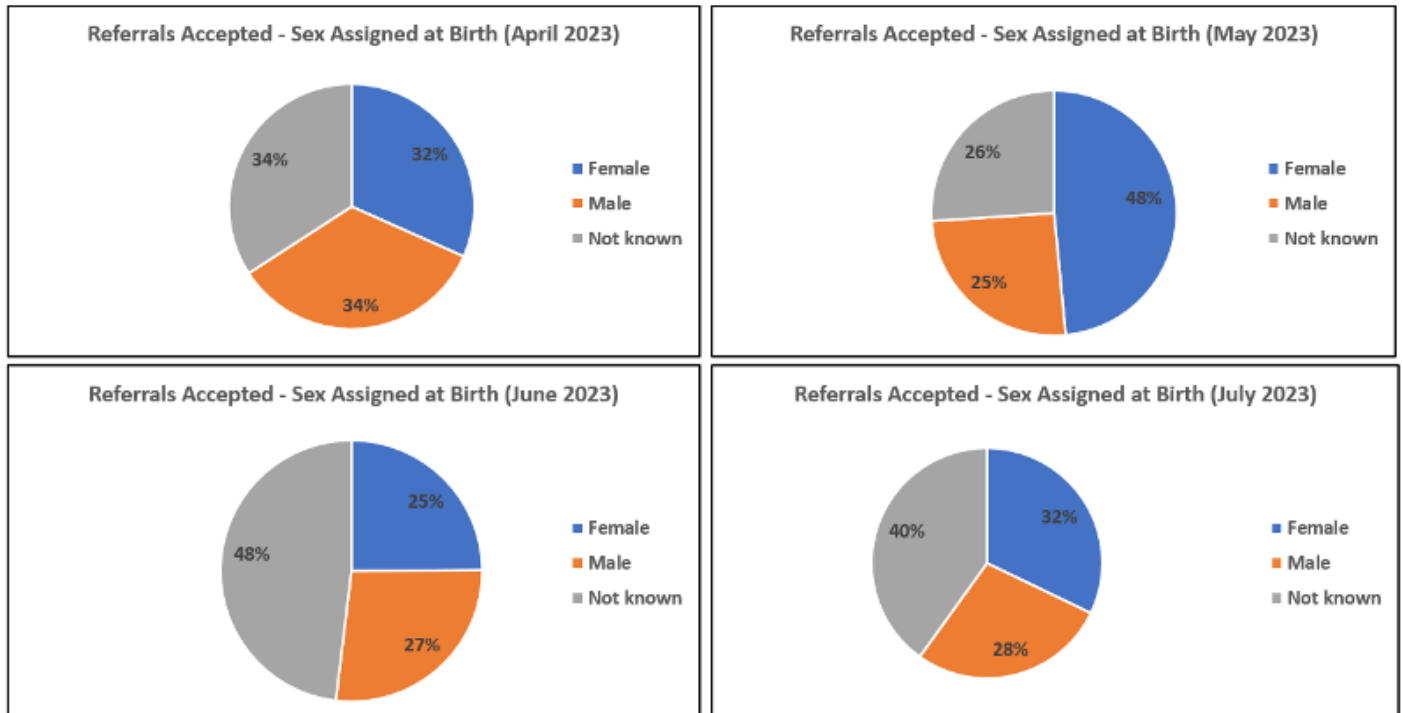
REFERRALS RECEIVED (AGE OF INDIVIDUALS)	APRIL 2023	MAY 2023	JUNE 2023	JULY 2023
Total Aged under 25 years	268	621	503	521
Total Aged 25-49 years	133	150	231	218
Total Aged 50 Years and over	21	21	28	38
Total	422	792	762	777

REFERRALS ACCEPTED (AGE OF INDIVIDUALS)	APRIL 2023	MAY 2023	JUNE 2023	JULY 2023
Total Aged under 25 years	245	603	447	496
Total Aged 25-49 years	125	145	218	213
Total Aged 50 Years and over	23	20	24	37
Total	393	768	689	746

Source: The Gender Identity Development Service Audit Report, Arden & GEM

NB: All data used has been provided to NHS Arden & GEM CSU by Adult Gender Dysphoria Clinics (GDCs). April 2023 was the first month the GDCs reported activity data using a new template/process. As such data collected/reported in April and May was experimental and data quality has improved since this period.

Figure 43: Referrals received and referrals accepted by adult Gender Dysphoria Clinics in England, April 2023 - July 2023



Source: The Gender Identity Development Service Audit Report, Arden & GEM

NB: All data has been provided to NHS AGEM CSU by GDCs. April 2023 was the first month the GDCs reported activity data using a new template/process. As such data collected/reported in April and May was experimental and data quality has improved since this period. No data was provided by Northampton, Newcastle, Nottingham or Exeter GDCs for referrals received/accepted (sex assigned at birth). AGEM CSU: Arden & GEM Commissioning Support Unit; GDC: Adult Gender Dysphoria Clinic.

19.34 While provision within the NHS adult gender services is outside the scope of this Review, a number of current and past GDC staff have contacted the Review in confidence with concerns about their experiences working in adult gender services. Their experiences covered clinics across different parts of the country, and the Review will set out the main points of concern to NHS England. The consistent messages are represented below.

- Clinicians confirmed the changing demographic as demonstrated by the data above. They described how this changed over a 2-year period between 2017 and 2019, from a mixed age range group with a majority of birth-registered males to 70-80% birth-registered females under the age of 25.
- In terms of complexity, clinicians described a large percentage of the patients having various combinations of confusion about sexuality, psychosis, neurodevelopmental disorders, trauma and deprivation, forensic issues and a range of other undiagnosed conditions.
- There was an expectation that patients would be started on masculinising/feminising hormones by their second appointment, which was a cause of concern given the complexity of presentations.
- Clinicians reported seeing an increasing number of detransitioners, describing how they often moved between clinics as they preferred not to return to the clinic that had originally treated them.

19.35 As the services for children and young people develop, a strategic approach will be needed to ensure that adult service provision takes account of different population needs and emerging evidence.

Recommendation 24:

Given that the changing demographic presenting to children and young people's services is reflected in a change of presentations to adult services, NHS England should consider bringing forward any planned update of the adult service specification and review the model of care and operating procedures.

19.39 The Review has heard that people experiencing regret may be hesitant to engage with the gender services that supported them through their transition. Consideration should be given to whether existing service specifications need to be adapted to specifically provide for detransition pathways, or whether this should be a separately commissioned service. This should be in consultation with people who have been through detransition.

Recommendation 25:

NHS England should ensure there is provision for people considering detransition, recognising that they may not wish to re-engage with the services they were previously under.

Detransition

19.36 The issues around de/retransition have been highlighted in Part 4 in relation to the outcomes of medical interventions and long-term follow-up. There is a need for better services and pathways for this group, many of whom are living with the irreversible effects of transition and no clear way to access services.

19.37 NHS gender services should support all those presenting with gender incongruence and dysphoria, whether that be to transition, detransition or retransition. Those who choose to detransition should be carefully monitored in a supportive setting, particularly when coming off hormone treatments.

19.38 It is also important that services understand and learn from those who choose to detransition as their experience can be used to inform understanding of what services are required earlier in the pathway. There is also the need for more research to understand what factors contribute to the decision to detransition.

Private provision

19.40 The Review has heard that a number of young people have sought private provision whilst on the waiting list for GIDS, and about families trying to balance the risks of obtaining unregulated and potentially dangerous hormone supplies over the internet with the ongoing trauma of prolonged waits for assessment. Feedback from the lived experience focus groups presents this as “a forced choice (because the NHS provision is not accessible in a timely way) rather than a preference”. The ongoing cost of this treatment and the subsequent monitoring can be prohibitive for some.

19.41 Additionally, GPs have expressed concern about being pressurised to prescribe puberty blockers or masculinising/feminising hormones after these have been initiated by private providers and that there is a lack of clarity around their responsibilities in relation to monitoring.

19.42 The Review understands and shares the concerns about the use of unregulated medications and of providers that are not regulated within the UK. Any clinician who ascertains that a young person is being given drugs from an unregulated source should make the young person and their family aware of the risks of such treatment.

19.43 In terms of shared care and prescribing responsibility, this should mirror other areas of practice. Specifically, no clinician should prescribe outside their competence, nor should GPs be expected to enter into a shared care arrangement with a private provider, particularly if that private provider is acting outside NHS guidance. Additionally, pharmacists are responsible for ensuring medications prescribed to patients are suitable (General Pharmaceutical Council, n.d.).

19.44 However, there should be an arrangement to carry out relevant investigations to ensure a young person is not coming to harm (for example, monitoring bone density).

19.45 In terms of funding, NHS England will normally only fund the treatment of a patient who has transferred from privately funded healthcare where their NHS clinician is content that the treatment is clinically indicated. This decision would usually require an individual to join the appropriate waiting list to be assessed by the NHS clinician within NHS protocols before the decision could be made. The prescription could then be continued if the clinician were satisfied that the treatment is clinically indicated and safe.

19.46 In the case of puberty blockers, NHS England has set out that these will only be available under a research protocol (NHS England, 2024). On entering the trial, the young person will have a number of tests to establish

their baseline levels for monitoring purposes; for example, in relation to bone density, as well as other initial assessments. If an individual were to have taken puberty blockers outside the study, their eligibility may be affected.

Recommendation 26:

The Department of Health and Social Care and NHS England should consider the implications of private healthcare on any future requests to the NHS for treatment, monitoring and/or involvement in research. This needs to be clearly communicated to patients and private providers.

Recommendation 27:

The Department of Health and Social Care should work with the General Pharmaceutical Council to define the dispensing responsibilities of pharmacists of private prescriptions and consider other statutory solutions that would prevent inappropriate overseas prescribing.

Changing NHS number and access to healthcare

19.47 Currently, when a person requests to change their gender on their NHS record, NHS guidance requires that they are issued with a new NHS number.

19.48 Clinicians have raised concerns about children and young people's NHS numbers being changed inconsistently, as there is no specific guidance for GPs and others as to when this should be done for this population and under what consent.

19.49 This has implications for safeguarding and clinical management of these children and young people, and could affect longer-term health management into adulthood (for example, in terms of screening).

19.50 Safeguarding professionals have described a range of situations where this has put children/young people at risk. These include young people attending hospital after self-harm not being identifiable as a child already on a child protection order; records of previous trauma and/or physical ill health being lost; people who do not have parental responsibility changing a child's name and gender; children being re-registered as the opposite gender in infancy; children on the child protection register being untraceable after moving to a new area.

19.51 The concerns with changing NHS number have also shone a light on the varied experiences and needs of transgender people who are often disadvantaged as they access healthcare (for example, screening services) and risk misdiagnosis.

19.52 It is unclear why an NHS number should need to be changed when the patient is under 18.

19.53 From a research perspective, the issuing of new NHS numbers makes it more difficult to identify the long-term outcomes for a patient population for whom the evidence base is weak.

Recommendation 28:

The NHS and the Department of Health and Social Care needs to review the process and circumstances of changing NHS numbers and find solutions to address the clinical and research implications.

20. Implementation

20.1 The Review recognises that delivery of the aspirations set out in this report will require significant changes. The move to the proposed service model will require a phased approach and it may be several years before the full model is operational across the country. Pragmatic strategic and operational plans are required that set out in a transparent way the steps that will be taken to realise the service transformation. This will be essential to build trust and manage expectations.

20.2 Governance needs to be put in place to oversee implementation of the required changes and provide system-wide leadership. This should be external to the Specialised Commissioning division and draw clinical leadership from professional bodies. Given the level of external interest in these services progress against the implementation plans should be reported.

Recommendation 29:

NHS England should develop an implementation plan with clear milestones towards the future clinical and service model. This should have board level oversight and be developed collaboratively with those responsible for the health of children and young people more generally to support greater integration to meet the wide-ranging needs of complex adolescents.

Recommendation 30:

NHS England should establish robust and comprehensive contract management and audit processes and requirements around the collection of data for the provision of these services. These should be adhered to by the providers responsible for delivering these services for children and young people.

20.3 While the Review has been focused on children and young people with gender incongruence and gender-related distress, the NHS needs to be ambitious in its provision for all children and young people seeking NHS support.

20.4 Consideration should be given to the need to integrate services across health, social care and other sectors, especially for young people with complex and/or multiple needs.

20.5 Through the work of the Review it is clear that the type of holistic service and structures described for gender services could work well for how the NHS supports children and young people more generally.

20.6 NHS provision for adolescents across the board requires greater service and workforce development and sustained investment. Without this we are letting down future generations. NHS England should use this opportunity to integrate investment and development of gender services with the ambitions set out in the NHS Long Term Plan for broader adolescent provision, with consideration given to a complex adolescent pathway.

Wider system learning

20.7 Clinical staff need support and guidance from their professional bodies to apply the evidence-based approaches described in this report. The consortium brought together to develop training resources should also be a vehicle for agreeing professional guidance for their respective clinical groups. This collaborative approach should include processes for listening to the community the service is built for.

20.8 Innovation is important if medicine is to move forward, but there must be a proportionate level of monitoring, oversight and regulation that does not stifle progress, but prevents creep of unproven approaches into clinical practice. Innovation must draw from and contribute to the evidence base.

20.9 Although the GIDS service had set up a research study to evaluate the use of puberty blockers, it failed to publish the results for four years, and continued to act outside of its own findings, and the limitations of the service specification.

Recommendation 31:

Professional bodies must come together to provide leadership and guidance on the clinical management of this population taking account of the findings of this report.

20.10 At a local level regulation of innovation should be integrated with regulation of clinical care. Responsible innovation requires anticipatory governance processes to be put in place, organisational safeguards and submission of innovation to external review. Reporting must include failure as well as success (Centre for Medical Ethics and Law HKU, 2024 [video]).

20.11 At a national level, systems are in place to ensure that any new drug is subjected to rigorous trials, appraisal and approval before unrestricted use on patients. Medical devices are also subject to scrutiny and approval. In response to the lack of such a system being in place for interventional procedures, in 1996 the Safety and Efficacy Register for New Interventional Procedures (SERNIP) was founded by the Royal colleges, and allowed voluntary registration for new procedures. Subsequently the National Institute for Clinical Excellence has taken responsibility for safety and efficacy of interventional procedures (Campbell & Maddern, 2003).

20.12 In the case of use of puberty blockers, there was another system weakness in that an off-label use went beyond the usual level of permissiveness in extending use to a very different indication. NICE may be well placed to lead work to address how this kind of innovation should be managed.

Recommendation 32:

Wider guidance applicable to all NHS services should be developed to support providers and commissioners to ensure that innovation is encouraged but that there is appropriate scrutiny and clinical governance to avoid incremental creep of practice in the absence of evidence.

Final thoughts from the Chair

20.13 It has been a privilege to undertake this important and very necessary Review, but it has, at times, been heartbreaking to hear the struggles that young people and their families face trying to navigate their way to care. Over a number of years, the children and young people at the heart of this review have been bypassed by local services and directed to a single national service that, whilst passionate and wholly committed to their care, had developed a fundamentally different philosophy and approach compared to other paediatric and mental health services.

20.14 While it will take a while to build the whole network of services, I very much hope that with this new approach, that brings these young people back into mainstream care, clinical staff will see this is an important and rewarding area of work. Most importantly I hope that the children and young people will benefit from access to a holistic multi-faceted model of care, along with a research infrastructure that will provide them with more robust evidence-based information on which to make decisions that may have long-term implications.

20.15 Finally, I am aware that this report will generate much discussion and that strongly held views will be expressed. While open and constructive debate is needed, I would urge everybody to remember the children and young people trying to live their lives and the families/ carers and clinicians doing their best to support them. All should be treated with compassion and respect.



Glossary



The glossary below sets out a description of some of the terms we have used in the Review.

At times, the Report covers complex scientific concepts and research; the glossary aims to support reader understanding and accessibility.

There is also sometimes no consensus on the best language to use relating to the topic of gender identity. Language changes rapidly and new generations develop varied ways of describing their experiences using different terms and constructs that are relevant to them. The Review tries as far as possible to use language and terms that are respectful and acknowledge diversity, but that also accurately illustrate the complexity of what we are trying to describe and articulate.

The terms we have used may not always feel right to some; nevertheless, it is important to emphasise that the language used is not an indication of a position being taken by the Review.

TERM	ABBREVIATION	DESCRIPTION
Affirmative model		A model of gender healthcare that originated in the USA, which affirms a young person's subjective gender experience while remaining open to fluidity and changes over time (Chen et al., 2021; Ehrensaft et al., 2018; Hidalgo et al., 2013; Olson-Kennedy et al., 2019). This approach is used in some key child and adolescent clinics across the Western world.
Assent		To agree to or approve of something (idea, plan or request), especially after thoughtful consideration.
<u>Attention Deficit Hyperactivity Disorder</u>	ADHD	A neurodevelopmental condition that affects people's behaviour - people with ADHD can seem restless, may have trouble concentrating and may act on impulse. They may also have sleep and anxiety disorders. ADHD is an example of neurodiversity (see below).
Autistic Spectrum Disorder	ASD	<p>The medical name for autism. ASD is a neurological and developmental disorder that affects how people interact with others, communicate, learn and behave.</p> <p>DSM-5 (see below) sets out people with ASD often have:</p> <ul style="list-style-type: none"> • Difficulty with communication and interaction with other people. • Restricted interests and repetitive behaviours. • Symptoms that affect their ability to function in school, work, and other areas of life. <p>ASD is known as a “spectrum” disorder because there is wide variation in the type and severity of symptoms people experience (National Institute of Mental Health, 2024).</p>

TERM	ABBREVIATION	DESCRIPTION
Autonomy		<p>Personal autonomy is the ability of a person to make their own decisions. In health this refers specifically to decisions about their care.</p>
Best interests		<p>Clinicians and the courts seek to act in the best interests of children and young people.</p> <p>The need to act in someone’s best interests is outlined in law.</p> <p>For the Mental Capacity Act (MCA) 2005, decisions for someone who cannot decide for themselves must be made in their best interests. Under the Children Act 1989, in any decision of the court about a child (under 18), the welfare of the child must be paramount. For these purposes, there is little or no material difference between the welfare and best interests, and we have used “best interests” throughout the report.</p> <p>Although there is no standard definition of “best interests of the child,” the General Medical Council advises that an assessment of best interests will include what is clinically indicated as well as additional factors such as the child or young person’s views, the views of parents and others close to the child or young person and cultural, religious and other beliefs and values of the child or young person (General Medical Council, 2018).</p> <p>The Mental Capacity Act, Section 4 and extensive Court of Protection case law, deals with the approach to best interests under that legislation. Whether in the Court of Protection or the High Court, when the Court is asked to make an assessment of a child or young person’s best interests, it will consider their welfare/best interests in the widest sense. This will include not just medical factors but also social and psychological factors.</p>
Binder		<p>A binder is a purpose-built undergarment used to flatten and reduce the appearance of breasts.</p>
Case-mix		<p>The mix of patients (cases) seen by a health service.</p>

TERM	ABBREVIATION	DESCRIPTION
Child and adolescent mental health services	CAMHS	<p>NHS children and young people’s mental health services. CAMHS is a secondary care service for children and young people under the age of 18, that assess and treat young people with moderate to severe mental health difficulties. There are local NHS CAMHS services around the UK, with teams made up of nurses, therapists, psychiatrists, psychologists, support workers and social workers, as well as other professionals (Young Minds, n.d.).</p>
Child and/or young person		<p>In law, everyone under 18 years of age is a child (Children Act 1989) but we recognise that it may be more appropriate to refer to those approaching the age of 18 as a young person, and that such young people may not recognise themselves as a “child”.</p> <p>In places, we have referred only to “young person”, or only to “child”, for example where treatment in question is only given towards the later stages of childhood, closer to the age of 18, or in reference to the parent/child relationship, in which they remain the parents’ child, regardless of their age.</p> <p>Otherwise, we have used the phrase “child and/or young person” throughout the report for this reason only, and do not intend there to be a material difference between them other than that.</p>
Cisgender		<p>Used to describe a person whose personal identity and gender identity is the same as their birth-registered sex.</p>
Cognitive		<p>Relating to, or involving, the process of thinking and reasoning.</p>
Confidence interval		<p>A range around a measurement that conveys how precise a measurement is.</p> <p>In statistics, a confidence interval is a range of values providing the estimate of an unknown parameter of a population. A confidence interval uses a percentage level to indicate the degree of uncertainty of its construction. This percentage, known as the level of confidence, refers to the proportion of the confidence interval that would capture the true population parameter if the estimate were repeated for numerous samples.</p>

TERM	ABBREVIATION	DESCRIPTION
Confounder		<p>Something that affects the result of an experiment in a way that makes it less clear that one thing causes another, because it has an effect on one of the things being measured (Cambridge Advanced Learner’s Dictionary & Thesaurus, n.d.).</p> <p>For example, mortality rates between two groups - one consisting of heavy users of alcohol, one consisting of teetotallers. You may conclude that heavy alcohol use increases the risk of death, however, in reality the situation may be more complex.</p> <p>Alcohol use may not be the only mortality-affecting factor that differs between the two groups, for example, those who consume less alcohol may be more likely to eat a healthier diet, or less likely to smoke, which may in turn affect mortality. These other influencing factors are called confounding variables. Ignoring confounding variables may mean that your results don’t reflect reality that well (Iloia, 2018).</p>
Consent		<p>Permission for a clinical intervention (such as an examination, test or treatment) to happen. For consent to be ‘informed’, information must be disclosed to the person about relevant risks, benefits and alternatives (including the option to take no action), and efforts made to ensure that the information is understood.</p> <p>In legal terms, consent is seen as needing:</p> <ol style="list-style-type: none"> 1. capacity (or Gillick competence under 16) to make the relevant decision 2. to be fully informed (i.e. the information provided about the available options, the material risks and benefits of each option, and of doing nothing, “material” meaning (per the Montgomery Supreme Court judgment in 2015) what a reasonable patient would want to know, and what this patient actually wants to know, NOT what a reasonable doctor would tell them) 3. to be freely given (that is, without coercion).

TERM	ABBREVIATION	DESCRIPTION
Contraindications		A condition or circumstance that suggests or indicates that a particular technique or drug should not be used in the case in question. For example, having a bleeding disorder is a contraindication for taking aspirin because treatment with aspirin may cause excess bleeding.
Court of Appeal		(England and Wales) The Court of Appeal hears appeals against both civil and criminal judgments from the Crown Courts, High Court and County Court. It is second only to the Supreme Court.
Detransition/ detransitioners		The process of discontinuing or reversing a gender transition, often in connection with a change in how the individual identifies or conceptualises their sex or gender since initiating transition (MacKinnon et al., 2023).
Diagnostic and Statistical Manual of Mental Disorders Fifth edition	DSM-5	The standard classification of mental disorders used by mental health professionals in the UK, and internationally, published by the American Psychiatric Association (2013). The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision (DSM-5-TR) (2022) is the latest version.
Diagnostic formulation		The comprehensive assessment that includes a patient's history, results of psychological tests, and diagnosis of mental health difficulties.
Divisional Court		(England and Wales) When the High Court of Justice of England and Wales hears a case with at least two judges sitting, it is referred to as the Divisional Court. This is typically the case for certain judicial review cases (as well as some criminal cases).

TERM	ABBREVIATION	DESCRIPTION
Dutch Approach		<p>Protocol published in 1998 by the Amsterdam child and adolescent gender identity clinic (de Vries & Cohen-Kettenis, 2012). The protocol set out that young people being considered for treatment for gender dysphoria with the use of puberty blockers must meet the following criteria:</p> <ul style="list-style-type: none"> • minimum age 12; • life-long gender dysphoria increased around puberty; • psychologically stable without serious comorbid psychiatric disorders that might interfere with the diagnostic process; and • have family support.
Endocrine treatment		<p>Sometimes referred to hormone treatment/therapy. In relation to this clinical area, this term is used to describe the use of gonadotropin-releasing hormones (see below) and feminising and masculinising hormones (see below).</p>
Endocrinologist		<p>An endocrinologist is a medical doctor specialising in diagnosing and treating disorders relating to problems with the body's hormones.</p>
Endocrinology		<p>The study of hormones.</p>
Epidemiology		<p>Epidemiology is the study of how often diseases occur in different groups of people and why. This includes the study of the distribution and determinants of health-related states or events in specified populations, and the application of this study to the control of health problems (Centers for Disease Control and Prevention, 2012).</p>
Exploratory approaches		<p>Therapeutic approaches that acknowledge the young person's subjective gender experience, whilst also engaging in an open, curious, non-directive exploration of the meaning of a range of experiences that may connect to gender and broader self-identity (Bonfatto & Crasnow, 2018; Churcher Clarke & Spiliadis, 2019; Di Ceglie, 2009; Spiliadis, 2019).</p>

TERM	ABBREVIATION	DESCRIPTION
Feminising and masculinising hormones (also known as cross-sex hormones, and gender affirming hormones).		Sex hormones given as part of a medical transition for gender dysphoric individuals (testosterone for transgender males and oestrogen for transgender females).
Gender dysphoria		Diagnostic term used by health professionals and found in DSM-5 outlined above (American Psychiatric Association, 2013). Gender dysphoria describes “a marked incongruence between one’s experienced/ expressed gender and assigned gender of at least 6 months duration” which must be manifested by a number of criterion.
Gender fluid		An experience of gender that is not fixed, but changes between two or more identities
Gender identity		This term is used to describe an individual’s internal sense of being male or female or something else.
Gender identity development		The developmental experience of a child or young person in seeking to understand their gender identity over time.
Gender Identity Development Service	GIDS	The service commissioned by NHS England for children and adolescents with gender dysphoria. NHS England decommissioned GIDS as part of a managed transition of the service, initially to two new nationally networked services (Phase 1 providers) based in specialist children’s hospitals.
Gender incongruence		<p>Diagnostic term used by health professionals, found in the WHO International Classification of Diseases ICD-11 (see below).</p> <p>Gender incongruence is characterised by “a marked and persistent incongruence between an individual’s experienced gender and the assigned sex”.</p>

TERM	ABBREVIATION	DESCRIPTION
Gender-questioning		A broad term used to describe children and young people who are in a process of exploration about their gender.
Gender-related distress		A way of describing distress that may arise from a broad range of experiences connected to a child or young person's gender identity development. Often used for young people whereby any formal diagnosis of gender dysphoria has not yet been made.
General Practitioner	GP	A doctor who provides general medical treatment for people who live in a particular area (Cambridge Advanced Learner's Dictionary & Thesaurus, n.d.). GPs deal with a whole range of health problems and manage the care of their patients, referring onto specialists as appropriate.
Gillick competence/ Fraser guidelines		A term derived from the legal case Gillick v West Norfolk And Wisbech AHA, 1984 that is used to decide whether a child or young person up to the age of 16 years is able to consent to their own medical treatment, without the need for parental permission or knowledge. A child or young person will be 'Gillick competent' for that decision if they have the necessary maturity and understanding to make the decision.
Gonadotropin releasing hormone analogues (also known as hormone blockers and puberty blockers)	GnRH	Taking these hormones stops the progress of puberty. The GnRH analogues (puberty blockers) act by competing with the body's natural gonadotrophin releasing hormone. This competition blocks the release of two gonadotrophin hormones important in puberty called Follicular Stimulating Hormone (FSH) and Luteinising Hormone (LH) from the pituitary gland.
High Court		The third highest court in the UK. It deals with all high value and high importance civil law (non-criminal) cases and appeals of decisions made in lower courts. When the High Court sits with more than one judge, as required for certain kinds of cases, it is called the Divisional Court.

TERM	ABBREVIATION	DESCRIPTION
International Classification of Diseases 11th Revision	ICD-11	<p>The International Classification of Diseases (ICD) is a globally used medical classification of anything that is relevant to health care and is used clinically for medical diagnosis. (https://icd.who.int/en).</p> <p>It is developed and annually updated by the World Health Organization (WHO) and is the mandatory global data standard for recording health information. It is currently in its 11th revision (ICD-11).</p>
Living in stealth		Used to describe a person who is living as a member of their identified gender without others being aware this is different from their birth-registered sex.
Looked after children		Children who are in the care of their Local Authority who may be living with foster parents or in a residential care setting.
Mega-analysis		An analytical process by which raw data is pooled across studies (Eisenhauer, 2020).
Meta-analysis		Meta-analysis is the statistical combination of results from two or more separate research studies that address a similar research question to generate an average result (Higgins et al., 2023).
Minority stress		Ongoing stress - including discrimination, exclusion, prejudice and violence - experienced by members of minority groups living in a society that stigmatises their identities (Meyer, 2003).
Multi-disciplinary-team	MDT	The identified group of professional staff who provide a clinical service. As a group they provide experience from diverse disciplinary backgrounds.
Neuro-developmental disorders		The World Health Organization criteria (2022b) defines neurodevelopmental disorders as “behavioural and cognitive disorders that arise during the developmental period that involve significant difficulties in the acquisition and execution of specific intellectual, motor, or social functions”.
Neurodiverse		“Neurodiversity” is a popular term that's used to describe differences in the way people's brains work. It is a combination of traits that are seen as both strengths and challenges. ADHD (see above) is an example of neurodiversity.

TERM	ABBREVIATION	DESCRIPTION
Non-binary		A gender identity that does not fit into the traditional gender binary of male and female (Twist & de Graaf, 2018).
Packer		A packer is an item (e.g. prosthetic device, fabric packer) worn to create the appearance of male genitalia.
Paediatrics		The branch of medicine dealing with children and their medical conditions.
Pass/passing		A person's gender being seen and read in the way they identify.
Precocious puberty		This is when a child's body begins changing into that of an adult (puberty) early - before age 8 in girls and before age 9 in boys.
Primary care		Primary care in the UK includes general practice, community pharmacy, dental and optometry (eye health) services. This tends to be the first point of access to healthcare.
Pseudonymised		<p>Patient confidentiality and anonymity is essential. Sometimes to maintain this, patient information and data needs to be presented in a format that ensures a person is not identifiable. This is called <u>pseudonymisation</u>.</p> <p>Pseudonymisation is the de-identification of identifiable patient-centric data item values through the use of substitute values. Pseudonymised data can be linked and used for secondary purposes, such as trend analysis and peer comparison, without using identifiable data items.</p>
Psychological formulation		A structured approach to understanding the factors underlying distressing states in a way that informs the changes needed and the therapeutic intervention for these changes to occur.
Psychosocial		Describes the psychological and social factors that encompass broader wellbeing.
Puberty blockers		See gonadotropin-releasing hormone analogues above.

TERM	ABBREVIATION	DESCRIPTION
Retransition		<p>Resuming a gender transition following detransition. Some people who have detransitioned may use this term to:</p> <ul style="list-style-type: none"> • indicate restarting hormone therapy for medical reasons, but without re-identifying as transgender • refer to re-identifying since initiating a gender transition such as moving from a binary transgender identity to non-binary • describe stopping or reversing transition (MacKinnon et al., 2023).
Secondary care		<p>Hospital and community health care services that do not provide specialist care and are usually relatively close to the patient. For children this will include Child and Adolescent Mental Health Services (CAMHS), child development and general paediatric services.</p>
Service specification		<p>A <u>service specification</u> clearly defines the standards of care expected from organisations funded by NHS England to provide specialised care. The specifications are developed by specialised clinicians, commissioners, expert patients and public health representatives to describe both core and developmental service standards. Core standards are those that all funded providers should be able to demonstrate, with developmental standards being those which may require further changes in practice over time to provide excellence in the field.</p>
Sex-of-rearing		<p>The gender-specific upbringing by which a child is brought up.</p> <p>In children with Differences in Sex Development (DSD) sex-of-rearing is decided by parents according to the child's biological birth sex (i.e. phenotype).</p>
Social contagion		<p>The spread of ideas, attitudes, or behaviour patterns in a group through imitation and conformity (Colman, 2014).</p>

TERM	ABBREVIATION	DESCRIPTION
Specialised services		<p><u>NHS specialised services</u> support people with a range of rare and complex conditions. Three factors determine whether NHS England commissions a service as a prescribed specialised service. These are:</p> <ul style="list-style-type: none"> • The number of individuals who require the service; • The cost of providing the service or facility; <p>The number of people able to provide the service or facility.</p>
Tanner Stage		<p>Tanner Staging, also known as Sexual Maturity Rating, is a classification of puberty by stage of development. This ranges from Stage 1, before physical signs of puberty appear, to Stage 5 at full maturity. The name originates from Professor JM Tanner, a child development expert, was the first to identify the visible stages of puberty.</p>
Tertiary care		<p>Tertiary care is the specialist end of the NHS. These services relate to complex or rare conditions. Services are usually delivered in a number of specialist hospitals/centres.</p>
Transgender	trans	<p>This is an umbrella term that includes a range of people whose gender identity is different from the sex they were registered at birth.</p>
Transition		<p>These are the steps a person may take to live in the gender in which they identify. This may involve different things, such as changing elements of social presentation and role and/or medical intervention for some.</p>
Watchful waiting		<p>An approach by which a child/young person's gender journey is observed (without intervention) to see how their gender identity and expression naturally evolves.</p>

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Appendix 1

Terms of reference

TERMS OF REFERENCE FOR THE REVIEW OF GENDER IDENTITY DEVELOPMENT SERVICES FOR CHILDREN AND ADOLESCENTS

INTRODUCTION

1. NHS England is the responsible commissioner for specialised gender identity services for children and adolescents. The Gender Identity Development Service for children and adolescents is currently managed by the Tavistock and Portman NHS Foundation Trust.
2. In recent years there has been a significant increase in the number of referrals to the Gender Identity Development Service, and this has occurred at a time when the service has moved from a psychosocial and psychotherapeutic model to one that also prescribes medical interventions by way of hormone drugs. This has contributed to growing interest in how the NHS should most appropriately assess, diagnose and care for children and young people who present with gender incongruence and gender identity issues.
3. It is in this context that NHS England and NHS Improvement's Quality and Innovation Committee has asked Dr Hilary Cass to chair an independent review, and to make recommendations on how to improve services for children and young people experiencing issues with their gender identity or gender incongruence, and ensure that the best model/s for safe and effective services are commissioned.

REVIEW SCOPE

The independent review, led by Dr Cass, will be wide ranging in scope and will conduct extensive engagement with all interested stakeholders. The review is expected to set out findings and make recommendations in relation to:

- i. Pathways of care into local services, including clinical management approaches for individuals with less complex expressions of gender incongruence who do not need specialist gender identity services;
- ii. Pathways of care into specialist gender identity services, including referral criteria into a specialist gender identity service; and referral criteria into other appropriate specialist services;
- iii. Clinical models and clinical management approaches at each point of the specialised pathway of care from assessment to discharge, including a description of objectives, expected benefits and expected outcomes for each clinical intervention in the pathway;
- iv. Best clinical approach for individuals with other complex presentations;
- v. The use of gonadotropin-releasing hormone analogues and gender affirming drugs, supported by a review of the available evidence by the National Institute for Health and Care Excellence; any treatment recommendations will include a description of treatment objectives, expected benefits and expected outcomes, and potential risks, harms and effects to the individual;
- vi. Ongoing clinical audit, long term follow-up, data reporting and future research priorities;
- vii. Current and future workforce requirements;
- viii. Exploration of the reasons for the increase in referrals and why the increase has disproportionately been of natal females, and the implications of these matters; and,
- ix. Any other relevant matters that arise during the course of the review.
- x. In addition, and with support from the Royal College of Paediatrics and Child Health and other relevant professional associations, the Chair will review current clinical practice concerning individuals referred to the specialist endocrine service. It is expected that findings and any recommendations on this aspect of the review will be reported early in 2021 with the review's wider findings and recommendations delivered later in 2021.
- xi. The review will not immediately consider issues around informed consent as these are the subject of an ongoing judicial review. However, any implications that might arise from the legal ruling could be considered by the review if appropriate or necessary.

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Appendix 2



The epidemiology, care pathways, outcomes, and experiences of children and adolescents experiencing gender dysphoria/incongruence: a series of linked systematic reviews and an international survey

The epidemiology, care pathways, outcomes, and experiences of children and adolescents experiencing gender dysphoria/incongruence: a series of linked systematic reviews and an international survey

Introduction

Increasing numbers of children and adolescents experiencing gender dysphoria or incongruence are being referred for care at specialist paediatric gender services. There are several clinical guidelines to support the clinical care of children and adolescents experiencing gender dysphoria or incongruence and their families, however, there are divergent clinical approaches to the management of these children and adolescents. Several countries have or are modifying referral and care pathways and provision in response to increasing numbers of referrals, changing demographics and ongoing uncertainty about the benefits, risks, and long-term effects of medical interventions for these children.

Overall aim: To systematically identify, collate and synthesise the existing evidence on the epidemiology, care pathways, outcomes and experiences for children and adolescents with gender dysphoria/incongruence.

We answered the following questions in the linked series of systematic reviews:

- What are the number of referrals and the characteristics of children and/or adolescents referred to specialist gender identity or endocrinology services that provide healthcare for those experiencing gender dysphoria/incongruence, and have these changed over time?
- What are the range of care pathways for children and/or adolescents referred to specialist paediatric gender or endocrinology services?
- What is the impact of social transition in relation to gender for children and/or adolescents?
- What is the effectiveness of psychosocial support interventions for children and/or adolescents experiencing gender dysphoria/incongruence?
- What is the gender-related, psychosocial, physiological, or cognitive outcomes of puberty suppression in adolescents experiencing gender dysphoria/incongruence?
- What is the gender-related, psychosocial, physiological, or cognitive outcomes of feminising/masculinising hormones in adolescents experiencing gender dysphoria/incongruence?
- What does published guidance on recommendations regarding the care of children and adolescents experiencing gender dysphoria/incongruence include, how were they developed and what is the quality?

The aim for the international survey was to understand the current provision of gender services for children and adolescents across the EU-15+ countries which have comparable high-income healthcare systems, to inform service development in the UK.

Systematic Review Methods

The protocol was registered on PROSPERO (CRD42021289659).

Search strategy

A single search strategy was used to identify studies comprising two combined concepts: 'children', which included all terms for children and adolescents; and 'gender dysphoria', which included associated terms such as gender incongruence and gender-related distress, and gender identity terms including transgender, gender diverse and non-binary. MEDLINE, EMBASE and PsycINFO through OVID, CINAHL Complete through EBSCO, and Web of Science (Social Science Citation Index) were searched (May 2021 updated in April 2022). Reference lists of included studies and relevant systematic reviews were also checked.

Overarching inclusion and exclusion criteria

Each individual review had its own inclusion and exclusion criteria, but studies were first screened against the following broad criteria:

Inclusion Criteria:

- Studies including children <18 years with gender incongruence, gender dysphoria / gender-related distress or referral to a paediatric or adolescent gender identity service.
- Primary studies (including those that involve secondary analysis of previously collected data) of any design, including experimental studies, observational studies, surveys, consensus studies and qualitative studies.

Exclusion Criteria:

- Studies about gender incongruence or gender dysphoria in adulthood.
- Studies of mixed populations unless the results for those with childhood gender incongruence, gender-related distress/dysphoria or those referred to a gender identity service in childhood are presented separately.
- Studies about individuals with differences in sex development (DSD)/ variations in sex characteristics (VSC).
- Single case studies, case series, editorials, or opinion pieces.
- Student dissertations.
- Systematic reviews or other literature reviews.
- Studies reported in conference abstracts.
- Studies not reported in English language.

Selection process

Search results were uploaded to Covidence and screened independently by two reviewers. Full texts for potentially relevant articles were retrieved and reviewed against the inclusion criteria for each review by two reviewers independently. Disagreements were resolved through discussion and involvement of a third reviewer where required.

Risk of Bias (quality) assessment

Where appropriate, the quality of studies included in the individual reviews were appraised using the most appropriate method. The tools used included the Mixed Methods Appraisal Tool (MMAT), modified versions of the Newcastle Ottawa Scale, and the Appraisal of Guidelines for Research and Evaluation (AGREE) II instrument. Two researchers rated the studies independently with discussion

to reach consensus. Study quality was not formally assessed in the systematic review that examined the characteristics of children and adolescents referred to paediatric gender services or in the review that examined their care pathways.

Data synthesis

A narrative approach to syntheses was used across reviews. The syntheses were performed by one reviewer and second-checked by another. Depending upon the specific review, proportions were combined in a random-effects meta-analysis using metaprop (Stata v18) with variances stabilised using the Freeman-Tukey double arcsine transformation. Graphs were used to display data visually where appropriate.

International Survey Methods

This was an e-survey of gender services for children and adolescents in the EU15+ countries which was open between September 2022 and April 2023. Contact details for the services were obtained from publicly available data, expert contacts and via snowball sampling. An email was sent to identified clinicians or managers, explaining the survey aims, confidentiality and data protection, and expected completion time. One reminder email was sent after three weeks. The survey contained 34 questions on service structure, care pathways, interventions, and data collection and an additional four questions on staffing and waiting lists. The questions were informed by a review of published papers describing service provision and the content of clinical guidelines. All responses were downloaded into Excel, descriptively analysed, and compared to assess similarity and variation among the services.

Results

Our searches yielded 28,147 records, 3,181 of which were identified as potentially relevant for the linked series of systematic reviews. Across all the reviews, 237 papers (214 studies and 23 guidelines/position statements) including 113,269 children and/or adolescents from 18 countries were reviewed (Figure 1). Included studies were published between 1978 and 2022, with 162 (68%) published from 2017 to the end date of the search in 2022.

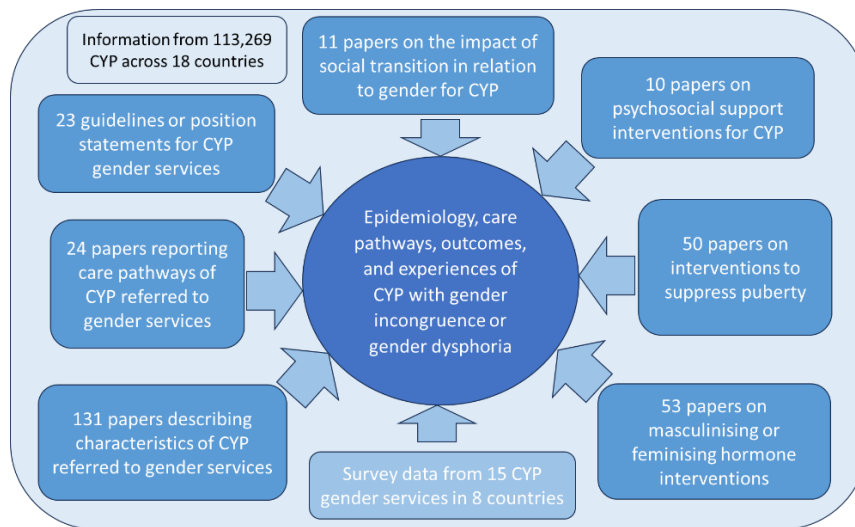


Figure 1: Overview of studies included in the individual reviews.

Overview of the findings

There has been a two to three-fold increase in the number of referrals and an increase in the ratio of birth-registered females to males being referred to specialist paediatric gender services over time across countries. Very few studies report data on gender status (self-reported gender identity, gender dysphoria, age at onset, and social transition) but from the limited data reported, over 60% of those referred were described as having taken steps towards a social transition. The evidence base for outcomes (benefits or harms) of social transition in childhood and adolescence is both limited and of low quality.

Data published to date suggests that presence of mental health challenges such as depression, anxiety, suicidality, self-harm, and eating disorders may be higher in children and adolescents referred to gender services than population estimates. There is limited data reported for other co-occurring mental health conditions. Presence of autism spectrum condition (ASC) and attention deficit hyperactivity disorder (ADHD) may be higher in those referred to gender services than population estimates. It was not possible to make inferences about changes over time for the characteristics explored due to overlapping samples and data being reported over large time-periods in individual studies.

There is very little information about detail or type of psychological care received by children and/or adolescents under the care of a specialist gender service, and there is limited low quality evidence on the outcomes of psychosocial interventions for children and adolescents with gender dysphoria or incongruence. Most analyses of mental health, psychological and/or psychosocial outcomes showed either benefit or no change, with none indicating negative or adverse effects. Only three studies assessed interventions that were specifically designed for children and/or adolescents experiencing gender incongruence, but these interventions varied considerably in content and delivery.

Data published to date suggests that approximately two-thirds of adolescents referred to specialist gender services receive puberty suppression or hormones, although rates for each vary considerably across clinics. There is also variation in the rates of those receiving puberty suppression prior to

starting hormones compared to those receiving hormones alone. There is very little information about children/adolescents who do not complete the assessment process within a specialist gender clinic or who do not receive medical intervention. Studies consistently report small proportions of adolescents who discontinue medical treatment; however, systematic reporting and reasons for discontinuation are rarely provided and follow up periods are limited.

There were no high-quality studies identified that used an appropriate study design to assess the outcomes of puberty suppression in adolescents experiencing gender dysphoria or incongruence. There is insufficient and/or inconsistent evidence about the effects of puberty suppression on gender dysphoria, mental and psychosocial health, cognitive development, cardio-metabolic risk, and fertility. There is consistent moderate-quality evidence, albeit from mainly pre-post studies, that bone density and height may be compromised during treatment.

There is a lack of high-quality research assessing the outcomes of hormones for masculinisation or feminisation in adolescents with gender dysphoria or incongruence and few studies that undertake long-term follow-up. There is little evidence regarding gender dysphoria, body satisfaction, psychosocial and cognitive outcomes, and fertility. There is moderate-quality evidence from mainly pre-post studies that hormone treatment may in the short-term improve some aspects of psychological health. There is inconsistent evidence about the effect of hormones on height/growth, bone health and cardiometabolic effects.

Twenty-three guidelines or position statements were identified that contain recommendations about the management of children and/or adolescents with gender dysphoria or incongruence. Few guidelines are informed by a systematic review of empirical evidence and there is a lack of transparency about how recommendations were developed. Only two of them consulted directly with children and/or adolescents during their development. Most national and regional guidelines have been influenced by the World Professional Association for Transgender Health and Endocrine Society guidelines which themselves lack developmental rigour and are linked through co-sponsorship. There is consensus across guidelines that those requiring specialist gender care should receive a multi-disciplinary assessment, although there is a lack of clarity about who should be involved in this and any differences in assessment for children and adolescents. Similarly, there is consensus that children and adolescents should be offered psychosocial support, but there is limited guidance about the process or approach for this and different recommendations about whether specialist gender clinics or mental health services should provide this. There are differing recommendations about when and on what basis psychological and hormone interventions should be offered, and limited guidance about pre-pubertal children or those with a non-binary gender identity.

The international survey found similar results with areas of common practice across gender services for children and adolescents in eight countries, with most using DSM-V diagnostic criteria and a multidisciplinary team approach. The survey revealed key differences in the composition of teams, the management of co-occurring conditions, pre-pubertal children, and those with a non-binary gender identity, and in the criteria for accessing medical interventions. Referral pathways into gender services for children and adolescents varied, and services reported limited provision of psychological care and a reliance on local mental health services. The survey found a lack of routine

outcome data collection among clinics, and this was evident from the studies included across the systematic reviews.

How the results might affect research, policy, or practice

Services need to respond to the potentially co-occurring complexities of children and adolescents being referred into specialist gender and endocrine services. Information about provision of psychological care and consideration of how this should be delivered is urgently needed considering the higher prevalence of mental health and psychosocial difficulties in this population. Detailed guidance to support psychological care of children and adolescents experiencing gender incongruence/dysphoria, or gender diverse children with psychosocial or mental health difficulties is needed. A better understanding of the care needs and provision for children and adolescents who enter assessment in a gender service but do not go on to receive medical interventions is needed to inform service provision. Prospective studies that follow-up children into adulthood and report information about the range of pathways followed are needed to understand longer term outcomes for those referred to specialist paediatric gender services. There is a lack of evidence and guidelines for those children and/or adolescents identifying as non-binary.

Healthcare services and professionals should take into account the variable quality of published guidelines to support the management of children and young people experiencing gender dysphoria or incongruence. The lack of independence in many national and regional guidelines, and the limited evidence-based underpinning current guidelines, should be considered when utilising these for practice. Practice base guidelines should reflect the limited evidence of the outcome of social transition for children and adolescents. Services and professionals should communicate the limitations of the evidence base surrounding social transition to children and adolescents experiencing gender dysphoria or incongruence and parents/carers.

There is a lack of high-quality evidence to support recommendations for puberty suppression or hormones for masculinisation or feminisation in children/adolescents experiencing gender dysphoria or incongruence. There is a lack of evidence comparing outcomes of adolescents who receive puberty suppression followed by hormones for masculinisation or feminisation to those who receive hormones only. Future guidelines should report the methods of development in full, with greater transparency about the links between evidence and recommendations and how recommendations are made in the absence of evidence.

Robust research is needed to address the significant gaps in our understanding of the potential short- and long-term outcomes of social transition, the risks, and benefits of puberty suppression and hormone interventions, and the appropriateness and effectiveness of different psychosocial interventions. Identification and agreement of core outcomes would help to ensure that what is important to relevant stakeholders is being collected and this would support future aggregation of evidence. High-quality studies using an appropriate study design are needed as is robust reporting. High quality standardised data collection should be routinely undertaken in gender clinics to enable comparison in outcomes for children and adolescents accessing different services.

Strengths and limitations

Strengths include a published protocol with robust search strategies and comprehensive synthesis. A limitation is that the database searches were conducted up until April 2022 and as this is a rapidly evolving area more recent publications would not have been included in the syntheses. We attempted to draw the findings of papers published after April 2022 into the discussion of each review, however as a comprehensive search of this literature was not undertaken more recent publications may have been missed. Due to available resources, only studies published in English were included. The primary research included in the reviews were generally of low quality and there was often inadequate reporting of key information required for the reviews which limited the analyses and conclusions that could be reached. All data relevant to review questions presented within the studies were extracted, summarised, and synthesised.

Caution should be taken when interpreting any of the pooled estimates as they represent data for a wide period of time, reported data were averaged over a large number of years, studies included often overlapping samples from the same clinic, and there were often discrepancies in the individual studies between the referred numbers and those included in the summaries of characteristics, and inadequate and/or unclear reporting of follow-up. Additionally, different tools or instruments were used to measure outcomes which increased heterogeneity. Reliance on publicly available information and known experts may mean some clinics were not identified and contacted to take part in the international survey. The low response rate within the survey means that certain countries are not represented and other potential differences in gender services are still unknown.

Journal publications

There are nine journal articles published in the Archives of Disease in Childhood associated with this overarching summary:

- Impact of social transition in relation to gender for children and adolescents: a systematic review.
- Gender services for children and adolescents across the EU-15+ countries: an online survey.
- Psychosocial support interventions for children and adolescents experiencing gender dysphoria or incongruence: a systematic review.
- Clinical guidelines for children and adolescents experiencing gender dysphoria or incongruence: a systematic review of guideline quality (part 1).
- Clinical guidelines for children and adolescents experiencing gender dysphoria or incongruence: a systematic review of recommendations (part 2).
- Interventions to suppress puberty in adolescents experiencing gender dysphoria or incongruence: a systematic review.
- Masculinising and feminising hormone interventions for adolescents experiencing gender dysphoria or incongruence: a systematic review.
- Characteristics of children and adolescents referred to specialist gender services: a systematic review.
- Care pathways of children and adolescents referred to specialist gender services: a systematic review.



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Appendix 3

Qualitative Research Summary

Narrative accounts of gender
questioning



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Introduction

In 2020 NHS England appointed Dr Hilary Cass to review [gender identity services for children and young people in England](#). Dr Cass - through NHS England - commissioned independent qualitative research from the University of York to understand:

- children and young people's experiences of gender dysphoria, and the support they found helpful;
- parents' experiences of supporting their child;
- families' experiences of accessing services, including how they make decisions about care;
- experiences of young adults who questioned their gender when younger; and
- the experiences of care professionals who support children and young people, referred to the Gender Identity Development Service (GIDS).

We spoke to young people, aged between 12 and 18 years old (n=14), who sought support from the specialist NHS gender services in England. We also talked to parents (n=12), young adults aged between 19 and 30 years old (n=18) and care professionals (n=23). The research, conducted between March 2022 and August 2023, received NHS ethical approval (IRAS Project Id: 306023). The [research protocol](#) is available on the Cass Review website. This short summary introduces what our participants told us. We are currently preparing peer review publications on the basis of further, in-depth analysis. Thank you to everyone, who generously shared their experiences with us.

Doing the research

There is a human imperative to tell our stories and we wished to make use of this, especially as gender identity is a sensitive (and contested) topic, in which public debate can be unsympathetic to diverse experiences. We used narrative interviews, to hear participants' voices and engage with their biographical experiences. We explored how they defined, articulated and negotiated their gender, within the context of social networks.

To ensure we captured diversity, our sampling strategy used different ways of recruiting participants. We recruited 12 young people via the Gender Identity Development Service (GIDS) and two through voluntary organisations. We asked these young people for consent, before inviting their parents to take part. We also recruited three parents,

not related to the young people we spoke to, through private practice and voluntary organisations. Our sample of parents included seven mothers and five fathers.

When recruiting young adults, we contacted six community and voluntary organisations who, in addition to engaging with valuable discussions about the research, circulated invitations to take part in it. We also recruited young adults through an Adult Gender Identity Clinic and interviewed a small number, who had contacted the Cass Review team, asking to take part in the research.

Most care professionals interviewed worked at GIDS. They represented all regional teams; had a variety of different backgrounds (i.e., clinical psychologists, psychological and family therapists, social workers and specialist nurses); varied in the time spent working in the service; and included those with managerial responsibilities. In addition, we interviewed a youth worker and a therapist working in private practice.

When inviting participants to take part in our research, we made no assumptions about how they identify. Our sample of young people included nine young people registered female at birth and five registered as male. Four had begun a medical pathway. Three young people were neurodiverse. Most young people described themselves as trans, although one described themselves as non-binary and several continued to explore labels. Our sample of young adults included eight trans men and four trans women. Four young adults identified as non-binary or gender queer, or for whom labels were not important. Two participants identified as detransitioners. Five young adults were neurodiverse. Three belonged to an ethnic minority.

During our interviews we covered similar topics, to ensure we could compare responses, while creating an environment that enabled participants to reflect on their specific experiences. Topics were developed from relevant literature and through discussions with young gender diverse people as part of our Patient and Public Involvement (PPI) work. These young people also commented on the make-up of the sample and the focus of the study.

Interviews, held online using video conferencing software, lasted between sixty and ninety minutes. With consent, we audio recorded interviews and transcribed them verbatim. We interviewed most participants once but adjusted our approach to support their needs. Those with autistic spectrum conditions, for example, were able to meet with a researcher for shorter periods over several interviews.

Analysis explored the ways in which participants negotiated meaning, within normative expressions of gender identity. This generated narrative themes that enabled us to relate personal and cultural stories to their social context. These themes were then interrogated to highlight similarities and differences among participants.

Doing research on gender identity generates challenges. Some people, for example, expressed a reluctance to take part in research, because of what they regarded as hostile public discussions. We are sorry to miss their voices but understand their concerns. Our voluntary sector colleagues spoke of research fatigue, while the use of GIDS' clinicians to generate our sample of young people may have meant the research did not capture more complex cases. Despite this, our research represents a diverse range of experiences, pathways and outcomes, which provide valuable insights for those planning services.

What we found

Young people

Many young people described an initial sense of difference, which was difficult to explain. They did not fit in and gender norms confused them. Social interactions became fraught with uncertainty and anxiety:

“I had people telling me constantly, like, why are you acting like this, you're a girl not a boy. Like, I would just be thinking to myself like why are people trying to make me a girl when I'm genuinely not a girl? So yes, that was probably the most confusing time of my life”.

Young people explained that they were sometimes made to feel like “freaks” or “outcasts”. Many described experiences of bullying. The negative reactions of others caused distress.

They - and their families - initially sought support from primary care and mental health services. Discussing gender in these settings was not always positive. Young people and their parents described a lack of knowledge and understanding. Some also spoke of not being taken seriously:

“At first, [with a GP] it was not good. He literally had no idea what we were talking about, which was frustrating.”

Young people wanted support to help manage potential distress and explore what gender questioning meant for them and their body. Most young people, however,

experienced a long wait before accessing NHS gender services (around three years). Waiting times impact on young people and their families, and the work specialist services provide. Care professionals believe waiting lists represent the biggest challenge facing service delivery. Young people and their parents agree. Families describe the difficulties of understanding gender questioning and managing distress, without formal support. Young people (and their parents) wished professional support was available during the initial stages of gender questioning:

“Hearing nothing [...] was definitely a struggle [...] So maybe like in those waiting times [services should] try providing a bit of support, whether it’s just even online or something because you’re kind of completely left in the dark and that’s quite scary.”

Accessing reliable information, a young person could trust and find useful proved challenging for many. While some did find online content helpful, it was described by many as a “minefield”. Many expressed a need for balanced and informative online material.

Young people said the lack of support, when waiting, affected their mental health and well-being. They spent the time reflecting and researching. They also took steps to help manage how they felt and most socially transitioned while waiting. The process, although dynamic and flexible, was positively regarded by young people. Many parents, although initially hesitant, come to understand the value of social transitioning. A few, however, remained anxious about its impact. Families would have welcomed advice on how to negotiate social transitioning but many experienced difficulties in accessing support.

Several young people, while waiting, become aware of the ways in which medical pathways could help them. Waiting, they said, provided them with plenty of opportunity to understand how they felt. Many were confident about the next steps, when first accessing NHS gender services. Some young people regard their parents as more cautious. This could be a cause of tension.

Many of the young people we spoke to, however, had not accessed medical pathways. Most were in various stages of assessment, while others were waiting for referral to adult services. The few who had accessed medical pathways described them as having a positive impact.

Young people expressed a range of thoughts and feelings about beginning sessions at GIDS. When accessing specialist services, they learn that “a lot of talking” must be done:

“At first, it [talking] didn’t feel helpful. I didn’t really know why [...] because they can’t really give you a quick-fix [...] I feel like when you’re a kid, you just want everything to be fixed, and my mum is the same [...] so, that was frustrating, but I’ve, kind of, come to terms with the fact that it’s a slow, kind of, like, therapy process, and it’s not all about just medication and stuff like that.”

Young people respond in different ways, although their hopes remain consistent. They want to feel better about themselves. Some young people looked forward to talking with someone who understood them. Some, however, felt uncomfortable and initially found it difficult to talk about how they felt. Others expressed frustration, disappointment and at times, anger. They believed talking slowed down or prevented access to medical pathways. These young people believed their life was “on hold” and described how they felt unable to plan for the future. Waiting had created a sense of urgency:

“I expected to do the talking first but I didn’t think it’d take long [...] [that] they’d want to get me on puberty blockers as soon as possible [...] it was just really frustrating because obviously there was nothing I could do about it. Like, it’s my body but I have no control over it.”

Irrespective of expectations (and any initial frustration or hostility), many young people come to appreciate the opportunity to talk with specialist clinicians. Young people felt listened to and believed. Relationships with clinicians, although not without tension, come to be highly valued. Young people described having access to a relaxed, comfortable and non-threatening, safe space in which they could explore how they feel, as empowering:

“They give you a safe place to talk as personal as you want and it doesn’t go anywhere, you can trust them, and you feel validated and like what you’re saying really matters.”

Young people remain sensitive to any questioning of who they are. They may, however, become open to talking, when exploring what their gender questioning means for them. Talking, for example, enables them to relieve distress, consider different options

and plan for the future. For young people, successful clinical relationships establish respect, build trust and encourage an openness, when exploring experiences. Young people believe they have a right to be flexible, as they search for an identity, with which they feel comfortable.

Parents

The parents we spoke to represent a diverse range of responses. They support their child in a variety of ways. Parents conduct their own research before seeking support and guidance. They value and prioritise different pathways. Each without doubt, and even when in discord with their child (or with services), acted in what they understood to be the best interests of their child. Maintaining supportive family relationships remained a priority for them. Young people, although mentioning parents' initial confusion and a lack of understanding, felt "lucky" to have such caring parents, even if they do not always agree with them.

Some parents, clear about the next steps, support their child by advocating for access to medical pathways. They express concerns that specialists services are not sufficiently "affirmative" and may act as an inappropriate gatekeeper to medical pathways:

"[They] felt like the gatekeeper to the endocrinology service [...], so we knew that we had to jump through that hoop [assessment] but in terms of therapeutic support, that's not to say that the therapists weren't skilled because I've got immense amount of respect for [name of clinician] but I think it was just, it's flawed, isn't it, it's an immensely flawed service."

Other parents enter specialist services feeling less certain about what should happen next. These parents wanted help supporting their child, which they hoped would include exploring different options and outcomes. They wanted reliable information and a comprehensive assessment process:

"I was quite relieved when the counselling with GIDS went on [for] a long time [...] because that just slowed it all down a bit. I think [name of child] wanted to rush, rush, rush, get the diagnosis, get his testosterone, get his top surgery done and then his life would be brilliant again [...]. Whereas [...] I wanted it to slow right down and take that time talking, for GIDS to make a proper assessment

and yes, and for me to be able to trust their assessment, [...] which I felt I did at the end of it.”

Most parents remain cautious, but open-minded about medical pathways. A few, however, avoided or delayed a referral to GIDS because of worries about an “affirmative” approach, which they believed would rush or prioritise medical pathways.

Parents expressed continuing uncertainties and doubts about what was best for their child. They worry about getting it “wrong”. They also worry about the extent services could understand their child and respond appropriately. Some parents explained that healthcare practitioners had raised safeguarding concerns. This included parents advocating for medical pathways and those who adopted a more cautious approach.

Many parents expressed anxieties about the future, including the extent their child would be accepted by a society they regarded as hostile to difference. The long-term consequences of medical interventions also concerned some parents. Parents want their child to be happy but are not always sure how best to achieve this.

Several parents express worries about the extent services can meet holistic needs. Some worry, for example, that mental health and neurodiversity would not be appropriately considered, when exploring their child’s gender questioning and any associated distress. Parents of children with autistic spectrum conditions describe positive experiences of specialist support, especially when they help establish networks of support, although some remain unsure if clinicians had the skills or experience to understand and support their child.

Parents’ narratives understandably focused on their child’s needs. Irrespective of their expectations and hopes for their child, parents found care difficult to negotiate:

“I think that’s part of the problem with this, because the system would like there to be a clear problem to solve and a clear route in which to solve it and I’m afraid it just isn’t the case.”

They also found caring emotionally challenging and there are times when they feel overwhelmed:

“I think [we] just need us to swallow our own discomfort and stuff about it, and sit with theirs [their child], and not judge, and not, not tell them how to be or what to do, to just, to standstill with it. And that’s really hard for some people I think because it is mind blowing stuff if you let yourself dwell on it.”

Some explained that their own mental and physical health had deteriorated because of their caring responsibilities. They rarely received support for this.

Healthcare professionals and clinicians

Clinicians said negotiating assessment (including making decisions about the readiness for medical pathways), while also providing therapeutic support is a defining feature of their role. It was a source of tension too. They explained that before making any assessment, they encouraged the young person to reflect on - and understand - what their gender questioning meant for them. Clinicians worry that current changes, which involve considerable documenting of decision making, reduce the time available for talking to young people and their families.

Clinicians said that increased waiting times meant some young people and their parents come with "fixed" ideas about what they need from specialist provision. This sometimes made it difficult to build positive relationships, at least initially. Working with families, who felt confident in their decision making and wished to move forward quickly, created particular challenges. Clinicians understood that some families regarded them as "gatekeepers" to medical pathways. They believe this can be unhelpful as it could undermine therapeutic intent. Clinicians spent time in initial appointments apologising for the long wait and setting expectations. This may require them to "unpick" what had gone on before. Some families did not like this and it undermined trust.

Clinicians found current clinical language unhelpful. Labels such as "affirmative" or "exploratory", they said, did not reflect the complex and thoughtful work they did. Clinicians felt it possible to "validate" a young person's experience, while seeking to "open up a curiosity" about what this may mean for them. In explaining this, some clinicians said their role was not to make decisions for - or change the mind of - a young person but rather to encourage self-reflection on what would help them to flourish:

"I think it is really [...] taking a holistic look at the young people that come through the door and a very person-centred approach. I wouldn't claim that any young person that comes through the door would need the same thing as the person who came to the door the hour previous. So really taking that person-centred approach. Looking at what they need to live well, I suppose that's what I see my job as, what does this person need to live well, to be happy, to flourish in the world."

Clinicians say they are “not invested in particular outcomes”, when supporting young people. Their role may include facilitating access to medical and/or social pathways, alongside considering other possible outcomes. Successful therapeutic relationships, they say, require carefully listening to what the young person is saying, although this does not preclude a “gentle” questioning of what is said. Clinicians said enabling a young person to articulate an outcome and/or pathway appropriate to their needs, remained their priority:

“I suppose I see the main purpose of the job as being to develop kind of trusting therapeutic relationships with young people and their families that enable young people to be able to feel safe to explore their experiences [...] thinking about how we can best support people, and that might include physical interventions, it might involve talking, it might involve both, but I think all of that can only really happen if clinicians kind of provide that really like safe listening space.”

Some clinicians highlighted the challenges of working with clinical uncertainty and an evidence base that was not as strong as they would have liked, although a few noted that this was not unique to their specialism. More experienced clinicians were better able to negotiate these challenges. Clinicians agreed that puberty blockers and cross sex hormones provide an important pathway, alongside therapeutic support. Ensuring their safe use was important, in addition to understanding their long-term consequences.

Clinicians remarked that there is no agreed fixed point of reference on which to judge the success of an intervention, let alone a societal consensus on the appropriate response to young people who are gender questioning and/or experiencing distress. Responding to changing social and cultural expectations, political interference and regulatory scrutiny, they said, made for a difficult working environment. Clinicians, however, commented on “respecting the anxiety” generated by their role. They agreed, it is a privilege to work with young people. Their work is challenging. They believe it should be. It was also hugely rewarding.

The value of dysphoria as a diagnostic category provides an example of the challenges clinicians face. For many young people - and young adults - dysphoria is a useful medical label, helping to legitimise and explain experience. It also helped justify asking for support. Young people believed it created - at least initially - a possible shared language, which others could understand. Over time, however, some expressed

ambivalence. They continued to understand the value of dysphoria, but thought it could also represent an unhelpful diagnosis, in which their social experience could only be regarded as authentic if a medical label were attached. Young adults are especially sensitive to this. Parents commented on how a diagnosis of dysphoria helped legitimate their child's experiences, while facilitating access to medical pathways. It also helped them make sense of what they were going through, by making it "real". Clinicians understand the importance of diagnosis, particularly when justifying decision making, but remained sensitive to over-medicalisation, especially when a person's dysphoria was socially located.

Young adults

The young adults we spoke to described similar experiences to young people, when managing their distress and like young people, they struggled to access appropriate support. Young adults also spoke of supportive family relationships, although these are not without tension. Several who had initially experienced their parents' questioning as unhelpful, came to recognise its value in enabling them to understand their feelings. A few young adults, however, described less positive relationships, which had deteriorated over time, with both immediate and extended family. This increased their risk of social isolation.

Young adults expressed an incredibly diverse range of experiences and pathways. Many benefitted from access to medical pathways which, they said, enabled them to lead the lives they wanted. Others explored equally empowering options, such as social transitioning and more fluid and non-binary expressions of gender. Some young adults, as they grew older, questioned binary approaches, although for others, gender binaries remain an important reference point. Like young people, young adults highlighted the importance of having access to balanced information that reflected a diverse range of experiences and pathways, from a trusted source, such as the NHS.

Young adults explained how the discovery of gender diversity - and the possibility of transition - generated self-understanding. This included knowledge about the diversity and richness of transition. For many, understanding and expressing their gender occurred gradually and evolved over time:

"But actually I've learnt that you grow into it and you start to understand yourself more and you begin to love yourself because of it."

Many young adults found transitioning liberating and a source of euphoria. These young adults are proud of their journeys, which they say, have brought them fulfilment, joy and happiness:

“I started going, oh so what does your euphoria actually want? What are the things that make you happy? And exploring my gender in that way has been just such a joy.”

For some, initial gender questioning created a sense of urgency, much of which focused on accessing medical pathways. These young adults acknowledged that their original response was to “fix” the problem. This became less important to them as they grew older. Some explained that discovering different ways to express gender identity was one of the most important things they had learned. They wished this had been explained to them when younger but remain uncertain about the extent they would have listened to such advice.

Young adults believe opening up a space for - and acceptance of - a diversity of ‘transition’ that does not require them to prove they are “trans enough”, is the basis for the successful exploration of gender identity. What young adults dislike is when others try to define - or make assumptions about - who they are. They also dislike the imposition of labels. Young adults are clear. Their gender questioning is not a lifestyle choice or preference. It is who they are.

Two young adults, however, experienced regret. Physical transition had initially helped them. They now felt it was a mistake. Looking back, they would have liked more therapeutic support when considering transition (which they had done outside the NHS). They also described a lack of support available to those who wish to detransition:

“I felt like it wasn’t, you know, acceptable to go back. It wasn’t a thing to go back, you know. It wasn’t something that was talked about. It didn’t feel like an option that they wanted to discuss or even mention [...] I want detransition to be something that can be openly talked about, and regret to be openly talked about.”

Many young adults, when reflecting on their own experiences of transition, explain that while it can be difficult and uncomfortable, it is important for young people to take their time, ask for support when needed and make decisions that are right for them:

“Go slow, go calm, just don’t rush it. Go at your own pace.”

Care, they say, must be timely and validating. Young adults, however, spoke of the difficulties of accessing appropriate care at the time, when you realise you need it.

Young adults (and clinicians) emphasise that diversity should not be used to undermine trans and gender diverse people or the options available to them. Recognising diversity also requires providing access to support for people who may experience regret. Internalised and socially realised transphobia, homophobia and misogyny especially concerned young adults. Young adults feel endlessly judged and held accountable for their difference and believe this closes down discussion and makes it more difficult for a person to take the path that is right for them. Young adults believe a person's capacity to flourish is strongly influenced by the circumstances in which they live. Services should seek to understand and support this:

I would tell [services] to [...] make it more of a personalised process [that] is really important because not everybody, kind of, falls under this neat little umbrella [...] much like gender - it's not confined to little boxes - the service cannot be confined to little boxes because it will then exclude so many more people."

Young adults' experiences suggest that one outcome or pathway should not be prioritised over another. All, they believe, are equally valid. Services should offer opportunities to understand different pathways, consistent with the breadth of experience associated with gender questioning. This, they say, is the basis for the successful exploration of identity. Young adults highlight the need for services to sensitively support young people, reduce distress and help them live well. They recognise the value of open and honest discussions as long as it is done respectfully, in a trusting encounter, in which rapport has been established:

"It was very in-depth, about every aspect of my life [talking therapy]. In a way, it was good because I'd never really had the chance to talk [...] in-depth about what was going on and piece together why I was feeling the way that I was. Yes. It was difficult, at times, I suppose but I'm glad I had to go through it and I'm glad that they [clinicians] were thorough enough to make sure that transitioning was the right thing for me, at that time."

Concluding thoughts

The needs of those who question their gender identity are not that different from anyone seeking support from healthcare services. They require timely access to appropriate care, consistent with their preferences, in which they are able to make informed choices

about their future. This includes safe and effective treatments, alongside respectful therapeutic support, sensitive to the challenges they face.

Our participants' narratives present rich and varied experiences, although one consistent theme, emerging throughout their accounts, regarded the importance of individual and personalised care. Gender questioning requires an open-minded approach, in which no outcome is presumed or predetermined and where an individual is given space (and time) to reflect on - and understand - what questioning means for them and their bodies. There remains no agreed approach to medical or social transitioning among young people, their parents or young adults. This is perhaps not surprising, given the considerable diversity in how individuals make sense of - and express - their experiences. The range of possible outcomes is similarly diverse. Services are required to respond to this diversity, while respecting the voices of young people. This requires thoughtful and supportive discussions. Those we spoke express a range of hopes, priorities and expectations. This requires transparency when clinicians offer and negotiate support.

Accessing timely support, however, creates considerable challenges for young people, their families and young adults. Participants also reflected on the fraught and politicised nature of current debates. These impacted on their wellbeing and by closing down debate, made it more difficult to pursue options consistent with how they felt.

The possibility of diverse outcomes is refuted by some and not seen as helpful by others. Highlighting diversity, however, does not discredit or devalue those who wish to celebrate their transition and the euphoria it brings them. Nor should it exclude the voices of those who have doubts or regrets. We risk injustice if this diversity and multiplicity is not supported by service delivery. For young people and young adults, their priority is to establish a social context in which they can flourish and feel comfortable. Parents and clinicians share these aspirations. Social inclusion and positive relationships, free from discrimination and in which an individual is accepted, respected and valued, represent an important priority for those - and their families - who seek support from health and social care agencies

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Appendix 4



OVERVIEW OF STUDY DEVELOPMENT

Assessment, Management and Outcomes for
Children and Young People Referred to a National
Gender Identity Development Service

Assessment, Management and Outcomes for Children and Young People Referred to a National Gender Identity Development Service

Introduction

Some children and young people experience significant levels of gender related distress in their course of their development arising from a persistent mismatch between their gender identity and their registered sex at birth. The numbers of children and young people referred to the Tavistock and Portman's Gender Identity Development Service (GIDS) - the NHS funded service for young people with gender related distress in England and Wales - increased markedly during the 2010s, resulting in lengthy waiting times and uncertainty for young people and their families. There have also been significant changes in the characteristics of young people referred, including an increase in the number of birth registered females and an over representation of young people who have traits or a diagnosis of autistic spectrum conditions. There is therefore an urgent need to understand the characteristics, needs, management options and outcomes of this changing population.

The intention of this study was to use data collected within the NHS - including data from the Tavistock Gender Identity Development Service, hospital wards, outpatient clinics, emergency departments and adult gender identity clinics - to assess the intermediate and longer-term outcomes for children and young people referred to the GIDS service. It would have examined the changing features of these children (including age at referral, co-occurring diagnoses of autism and other mental health difficulties), assessed if some groups of children are more likely to follow a medical approach to managing their gender related distress, and explored patterns of longer-term outcomes including successful transition, detransition and mental health outcomes.

These data would have provided children and their families with vital information on the different options for managing gender related distress and provided evidence for clinicians and policy makers delivering services for these children and young people. Ultimately, the study was not carried out, as the cooperation of all adult gender identity clinics could not be secured.

Overall aim: To examine the changing epidemiology of gender related distress in children and young people, in addition to their appropriate social, clinical, psychological and medical management.

Objectives: 1) To describe the clinical and demographic characteristics of this population of children and their clinical management in the GIDS service; and 2) To assess the intermediate outcomes of this population of children using national healthcare data.

Methods

Patient and public involvement and stakeholder engagement

A series of six online consultation events were held from Feb to June 2022. These events were advertised via GIDS stakeholder groups, the Yellow Door young person's group, Stonewall, Trans Actual, Mermaids and Gendered Intelligence. Across the sessions we spoke to 22 individuals. This was a mix of trans and gender questioning adolescents and young adults (n=12) and the parents of children and young people (n=10) who have been seen, or were waiting to be seen, at GIDS. Two further sessions were held in Autumn 2022, with another 23 individuals attending. Further engagement was planned during the study, following initial data analyses.

A study specific opt out was planned, with patient and carer information produced in both written and animated form. This material would have been advertised via the Tavistock GIDS service, other support organisations, and the University of York websites for 3 months prior to data extraction, directing prospective study participants to contact the Tavistock or their adult clinic if they did not wish their data to be used in the study. Any existing national opt outs would also be upheld.

Research design, participants and sample size

- Retrospective secondary analysis of the Tavistock GIDS data and linked population level datasets available for children and young people referred to the GIDS service.
- All children, teenagers or young adults aged 18 years old or younger at the point of referral to GIDS, who were referred to GIDS between 2009 and 2020.
- A full population cohort (estimated 9,000 participants).

Data Sources

The primary data source is clinical data from the Tavistock GIDS service linked to:

1. Data from the paediatric endocrinology services at University College London Hospital and Leeds Teaching Hospitals Trust.
2. Data from the NHS Gender Identity Clinics for Adults in England:
 - The Tavistock and Portman NHS Foundation Trust, Gender Identity Clinic, London
 - Leeds Gender Identity Clinic, Leeds
 - Northampton Gender Identity Clinic, Daventry
 - Northern Region Gender Dysphoria Service, Newcastle
 - The Nottingham Centre for Transgender Health
 - Porterbrook Clinic Gender Identity Service, Sheffield
 - The Laurels Gender Identity Clinic, Exeter

3. Other healthcare data held by NHS Data and Analytics:

- Hospital Episodes Data – Accident and Emergency (pre 2019) and Emergency Care (from 2019) datasets
- Hospital Episodes Data – Admitted Patient Care
- Hospital Episodes Data – Outpatient
- Mental Health Minimum data set
- Community prescribing data
- Death Registration data

Data Extraction

Demographic data held at the Tavistock GIDS service would be extracted from electronic patient records. Additional clinical data would require manual extraction from paper and/or electronic records. For more recent referrals much of this information will be available on a summary assessment and discharge forms. A unique study ID (pseudonym) would be used to retain the link between the non-identifiable data collected and confidential patient data. The confidential patient data would be retained on the Tavistock system until required for transfer to NHS Data and Analytics for linkage with their datasets. Pseudonymised data would be securely transferred to the Department of Health Sciences server at the University of York.

For assessment of outcomes, confidential patient data required for linkage to other NHS datasets (date of birth, NHS Number, postcode and birth registered sex) would be extracted from electronic records held at the Tavistock clinic and the Adult GIC clinics. To reduce flows of confidential patient data, this would only include those aged up to age 30 years (the oldest young person referred to GIDS in 2009 would be 30 in 2020). All data linkages would be undertaken by NHS Data and Analytics. The University of York team would receive pseudonymised clinical data from the Tavistock, UCLH, NHS Digital and Adult GIC clinics and would be data controller for the study. For both objectives a successful application was made to the Confidentiality Advisory Group (under section 251 of the National Health Service Act 2006 and its current Regulations, the Health Service (Control of Patient Information) Regulations 2002). The NHS Act 2006 and the Regulations enable the common law duty of confidentiality to be temporarily lifted so that confidential patient information can be transferred to an applicant without the discloser being in breach of the common law duty of confidentiality.

Compliance with the Gender Recognition Act (GRA) is required for the second objective. Advice was therefore sought from the National Data Guardian and a request was made to the Secretary of State for Health to enact Section 22, Point 5 of the GRA as the legal basis for this study. A Statutory Instrument was laid by the Secretary of State for Health for the specific purposes of this study, coming into force on the 28th July 2022 for a duration of 5 years.

Data analysis

Objective 1

A population based retrospective cohort study would have been undertaken using data from electronic and paper records in the GIDS. The population would include all children and young people referred to the Tavistock GIDS resident in England referred from 2009 to 2020. These analyses would aim to:

- Describe the demographics of children referred to GIDS;
- Assess the treatment pathways, including endocrine treatment, of children in GIDS;
- Describe the referral sources of children referred to GIDS;
- Describe the destination of children after GIDS assessment.

The demographic profile of this cohort would be described using counts and percentages for categorical data (e.g., ethnic origin) and means and standard deviation for continuous data (e.g., age at referral). Demographic data would include whether children had begun puberty at the point of referral. Clinical activity data would include numbers of appointments and clinical assessments, source of referral and destination on discharge.

Treatment pathways are an important outcome for this population, so log-binomial or robust (modified) Poisson regression models would be used to assess clinical and demographic associations with likelihood of referral for endocrine treatment. Statistical models would use binary outcomes (referred or not referred to endocrine clinics) with independent variables selected from demographic data (ethnic group, deprivation group, birth sex) and other clinical data (e.g. co-occurring conditions such as autism) and puberty status at referral, based on model fit as assessed by Akaike's Information Criterion and the Bayesian Information Criterion.

Objective 2

Following data linkage, an assessment of data quality and completeness would be undertaken for key clinical and demographic variables. Key outcome data derived from the linked healthcare data would include: surgical and medical management of gender dysphoria; mental health diagnoses and treatment; and co-occurring diagnoses of autistic spectrum disorder. Destinations of young people referred to the Tavistock clinic would be described in terms of the proportion: accessing assessment and psychosocial support only; prescribed hormone blocking treatment only; prescribed hormone blocking treatment followed by cross sex hormone treatment; accessing sex reassignment surgery in adulthood; appearing to have de-transitioned; with a co-occurring mental health diagnosis; with a diagnosis of autistic spectrum disorder; self-harming. Appropriate statistical models would be used to assess whether any clinical or demographic features, including puberty status at referral, are associated with these outcomes.

Regulatory requirements, data protection and patient confidentiality

The ethical aspects of this study were reviewed and approved by a Research Ethics Committee of the Health Research Authority (REF 22/HRA/3277). The use of confidential patient data without consent was approved by the Confidentiality Advisory Group (CAG) of the Health Research Authority. CAG is an independent body which provides expert advice on the use of confidential patient information (REF 22/CAG/0129).

All investigators and research staff would comply with the requirements of The Data Protection Act 2018, the UK's implementation of the General Data Protection Regulation (GDPR), with regards to the collection, storage, processing, and disclosure of personal information. Data storage and handling would comply with data controllers, processors, and University of York policies, including locked storage, password protection, and encryption of the pseudonymised data. Data would be archived for 5 years following the end of the project. Data would be stored in the University of York in accordance with GDPR and the University of York guidelines. At the end of the default retention period (5 years) all data would be confidentially destroyed by a secure method.

Steering group

A Study Steering Committee was established with an independent chair and representation from topic experts and academics. This panel would meet three times per year to assess progress of the study against the defined milestones and deliverables and provide advice and expertise to the Study Management Team.

Stopping the study

Conduct of the study was contingent on gaining access to the relevant patient data and securing the full cooperation of the gender identity clinics. Following study approval by the Health Research Authority, the research team contacted clinical leads at GIDS and each of the Adult Gender Identity Clinics to establish collaborative links and confirm capacity and capability to support the study. Systematic steps were taken to clarify the aims and motivations of the research, understand and address any concerns of clinic staff, and to propose alternative approaches and solutions where appropriate. Negotiations took place between August and November 2023, after which six of the seven adult clinics declined to support the study. Common reasons given by the clinics for non-participation are summarised in **Table 1**. Clinics also rejected the option to conduct the initial data-linkage phase of the study only (i.e. to provide patient name, date of birth and NHS number but no other clinical data). The decision to stop the study was therefore taken on November 30, 2023.

Table 1: Adult gender identity clinics' reasons for non-participation in the data linkage study

Area of concern	Specific issue	University of York response
Accessing patient records	<ul style="list-style-type: none"> • Paper records started to be replaced by electronic records in 2012, but were still in use in 2020. Identifying eligible patients and extracting data would therefore be labour intensive. • Where available, electronic records may not contain all the required data, and searches of paper records may still be required. • Only a minority of attendees at the adult clinics will have previously attended GIDS, potentially making them more difficult to identify. 	<ul style="list-style-type: none"> • Support is in place to cover clinics' workload in relation to research studies, including extraction of clinical data (see resource provision). • The study could be conducted in two phases, with the first phase only requiring clinics to provide patient name, date of birth and NHS number for the purposes of linkage. This would not require an extensive search of paper records. • Clinics would not have to identify patients who previously attended GIDS themselves, as attendance would be established through the data linkage process conducted by NHS Data and Analytics.
Resource provision	<ul style="list-style-type: none"> • Clinics lack resources and knowledge to answer patient queries in relation to the study. • Some clinics felt obliged to contact all eligible patients directly to inform them of the study (see ethical considerations). • Extracting clinical data from notes, even when performed by external researchers, would require supervision by a clinician with epidemiological research experience and local knowledge of the current and historical formatting and archiving of notes. 	<ul style="list-style-type: none"> • Queries about the study would be referred to the dedicated study website, which includes infographics, patient information, opt-out arrangements, a full study protocol and a contact e-mail. • Rigorous patient data safeguards are in place (see ethical considerations). • Research support is available to clinics through the Clinical Research Network to cover costs associated with basic data extraction, and researchers employed by the University of York would carry out the most labour-intensive activities relating to detailed data extraction (retrieval of clinical activity data from patient notes). Negotiations between the clinics and the funder (NHS England) could identify additional research support funding to cover the cost of local supervision where appropriate, although it is acknowledged that long-standing workload and recruitment pressures present significant challenges to the provision of support for research in this area.
Data completeness and linkage	<ul style="list-style-type: none"> • Changes to NHS numbers, postcodes and/or gender would make record linkage between GIDS and adult clinics extremely challenging. 	<ul style="list-style-type: none"> • These are standard challenges for health services research in general and data linkage studies in particular. University of York researchers and analysts based at NHS Data and Analytics have extensive experience in conducting complex

	<ul style="list-style-type: none"> • Data missingness is likely to be not-at-random, particularly for people who de-transition/re-transition. • Changes in clinical protocols, differences in protocols between clinics and (mis)understanding of those protocols (e.g. whether hormone treatment is required prior to surgery) may confound the study when attempting to associate treatments with outcomes. • Neurodiversity is likely to effect outcomes but may not be well recorded in clinical records, leading to potential confounding. 	data linkage studies, addressing issues of missingness and dealing with confounding variables.
Study methodology	<ul style="list-style-type: none"> • The study outcomes focus on adverse health events, for which the clinics do not feel primarily responsible. • Detailed definitions for study variables were not provided in the protocol, including the conceptualisation and measurement of detransition. 	<ul style="list-style-type: none"> • The purpose of the study is not to audit quality of care but to assess patterns of outcomes in the population. Inevitably, this will include adverse outcomes as these are of concern to both patients and providers. • Detailed definitions would be developed in line with the literature and clinical guidelines, and in consultation with clinic staff.
Ethical considerations	<ul style="list-style-type: none"> • There was insufficient involvement of clinic staff and service users in study design and development. • People with additional vulnerabilities may be less likely to opt out or may need more support to opt out from the study. • Trust data responsibilities and governance of patient data requires clinics to actively seek consent from all service users before sharing any information, and therefore an opt out (rather than an opt in) was not appropriate. 	<ul style="list-style-type: none"> • The final protocol was developed in consultation with clinicians, service users and international experts in the field. The research team liaised with the adult clinics at the study development stage but there was a general reluctance on the part of the clinics to engage. • Public and patient engagement sessions were conducted in the early stages of protocol development, and participants were generally supportive of the study and the use of their data. Many expected their data to be routinely collated and analysed by the NHS and associated researchers as part of its quality improvement work. • The UK has a stringent series of safeguards covering the use of patient data in research (including Health Research Authority approval, anonymisation of patient data, and General Data Protection Regulations). Additional specific safeguards (including the Statutory Instrument, and the 3 month opt-out period) were put in place for this study. Additional support for vulnerable patients would be discussed with clinics and patient groups.

<p>Concerns about funder motivation and political interference</p>	<ul style="list-style-type: none"> • The unintended outcome of the study is likely to be a high-profile national report that will be misinterpreted, misrepresented or actively used to harm patients and disrupt the work of practitioners across the gender dysphoria pathway. • Taking part in a study of this kind could bring into question the integrity of clinic staff and the relationships they have with patients. • The study may not be fully independent, and may suffer from interference by NHS England, the Cass Review Team and Government ministers whose interests do not align with those of providers and users of gender identity services. 	<ul style="list-style-type: none"> • Given that there are no existing national level assessments of longer-term outcomes in this patient group, the potential for misinterpretation or misuse of study findings is insufficient reason for not conducting research in this area. • The research team is mindful of the context for the research, having previously conducted systematic reviews and qualitative interviews with service users, and in some cases having direct clinical experience of working with patients. Although it is not possible to control all public responses to published research, the research team would take all reasonable steps to avoid misinterpretation and to ensure study outputs carried clear messaging that reflected the sensitivities surrounding this issue. • Although the study is funded by NHS England, the research team is fully independent and not subject to interference by the Cass Review, NHS England or any other external agency. The research team is experienced in handling sensitive research topics and in publishing research which is critical of funding bodies and government policy.
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Appendix 5



PRELIMINARY REPORT

Epidemiology and Outcomes for Children and
Young People with Gender Dysphoria:
Retrospective Cohort Study Using Electronic
Primary Care Records

Epidemiology and Outcomes for Children and Young People with Gender Dysphoria: Retrospective Cohort Study Using Electronic Primary Care Records

Introduction

The number of children and young people referred to the Tavistock and Portman's Gender Identity Development Service (GIDS) - the NHS funded service for young people with gender related distress in England and Wales - rose markedly during the 2010s, resulting in lengthy waiting times and uncertainty for young people and their families. Additionally, there has been a marked increase in referrals of adolescent birth-registered females and an over-representation of children with autism or autism spectrum traits. Recent reviews by the National Institute for Health & Care Excellence (NICE) on the medical treatment of these children highlighted a lack of evidence of effectiveness and low quality of the published literature. There is also a lack of evidence on outcomes for these children and adolescents, and their presentation in primary care.

Overall aim: To use electronic primary care records to describe the epidemiology of gender dysphoria in people aged 18 and under in England from 2009 to 2021.

Objectives: To estimate for people aged 18 and under with gender dysphoria:

- Changes in incidence and prevalence over time.
- Prevalence of co-occurring autistic spectrum disorders.
- Frequency of primary care prescribing and duration of treatment with puberty blockers and hormones.
- Prevalence of obesity, smoking, self-harm and common mental health conditions compared with people with autism spectrum disorders, eating disorder and no long-term condition.

This preliminary analysis covers the first two objectives; subsequent reports will cover prescribing and co-occurrence of other conditions.

Study population: People aged 18 and under with gender dysphoria and age matched controls with autism and an eating disorder. The final study population consisted of:

- 3,782 people with gender dysphoria;
- 18,740 matched controls with autism spectrum disorder;
- 13,951 matched controls with eating disorder;
- 18,871 matched controls with no recorded long-term condition.

Methods

Data were derived from the Clinical Practice Research Datalink (CPRD), a database of anonymised patient data from general practices across the UK linked to other health-related data, including routine and emergency hospital attendance and Office for National Statistics mortality data. The database holds data for over 18 million currently registered patients. The study population was identified using primary care code lists (READ and SNOMED) covering clinical activities (including diagnosis, symptoms, treatment and referrals) and secondary care codes (Hospital Episode Statistics) indicative of relevant conditions. Co-existing conditions (for example, anxiety and depression) were identified using similar methods. Key covariates included age and local area deprivation (based on the Index of Multiple Deprivation for the postcode of residence). Patient inclusion criteria included:

at least one year of registration with a practice with research-standard data; primary care record linked to secondary care data; and postcode of residence available.

People with gender dysphoria were matched by age to three groups of controls: people with autism spectrum disorders; people with eating disorder; and people with no recorded long-term condition. We aimed to match cases to 5 controls with each condition, but due to low numbers an average of 3.7 controls with eating disorder were matched. Matching was performed on year of birth and index date for controls, on or before index date of cases (i.e. matches must have been diagnosed with the relevant condition before the case was diagnosed with gender dysphoria). Controls were not matched on recorded gender in part due to limitations in the categorization of gender within CPRD. The gender data category allows options of 'male', 'female' and 'other'; as people are first registered at birth if born in the UK, this category generally refers to registered sex, but can subsequently be changed at the patient's request to reflect their gender identity (see **strengths and limitations**). In this study, we use the category term recorded in the CPRD database.

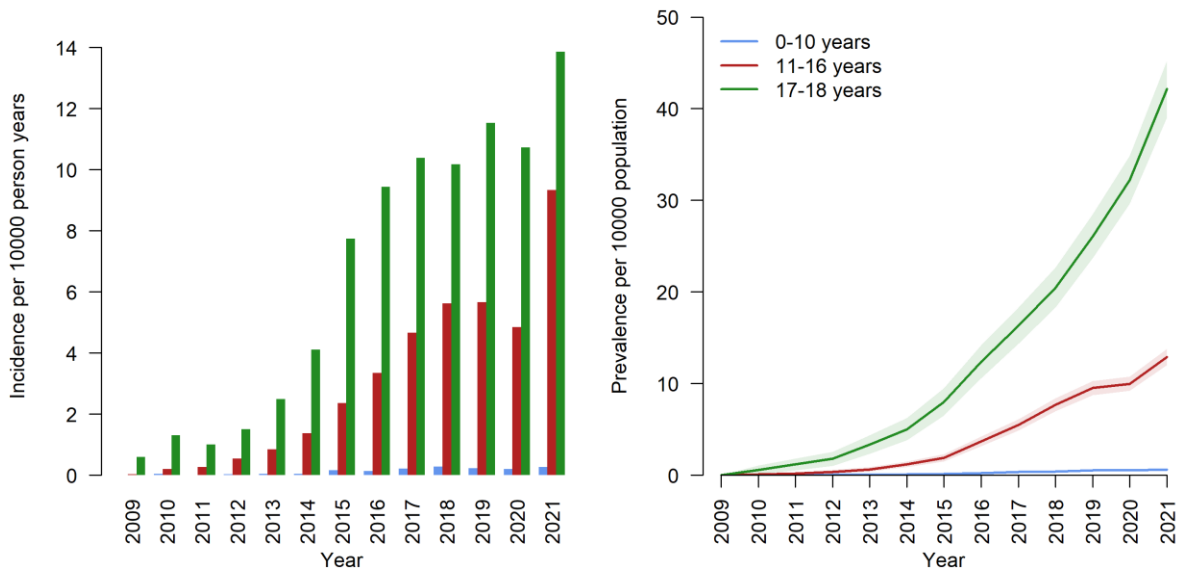
Incidence rates were calculated by dividing the number of new cases in a given year by the person-time at risk. Prevalence was calculated by counting the number of individuals in the dataset registered with practices on 1 July in each year with a diagnosis code recorded on or before that date. This number was divided by the total number of individuals in the dataset registered on 1 July and multiplied by 10,000 to give prevalence per 10,000 people. This method produces an upper limit estimate of recorded prevalence (see **strengths and limitations**). Prescribing data in CPRD were used to assess the proportion of cases and controls receiving relevant medications at each point in time. Comparative analyses of incidence of co-existing conditions and outcomes were calculated using incidence rate ratios, adjusting for common confounders (for example, age and local area deprivation).

To protect patient anonymity, published results are subject to small number suppression and no results for fewer than 10 people are reported. There were few missing data except for month of birth (year of birth was used to calculate age). No attempt was made to impute missing data for demographic information due to the low numbers of missing data (under 1% missing for the deprivation category; zero missing for gender) and the lack of relevant information on which to build an imputation model.

Results

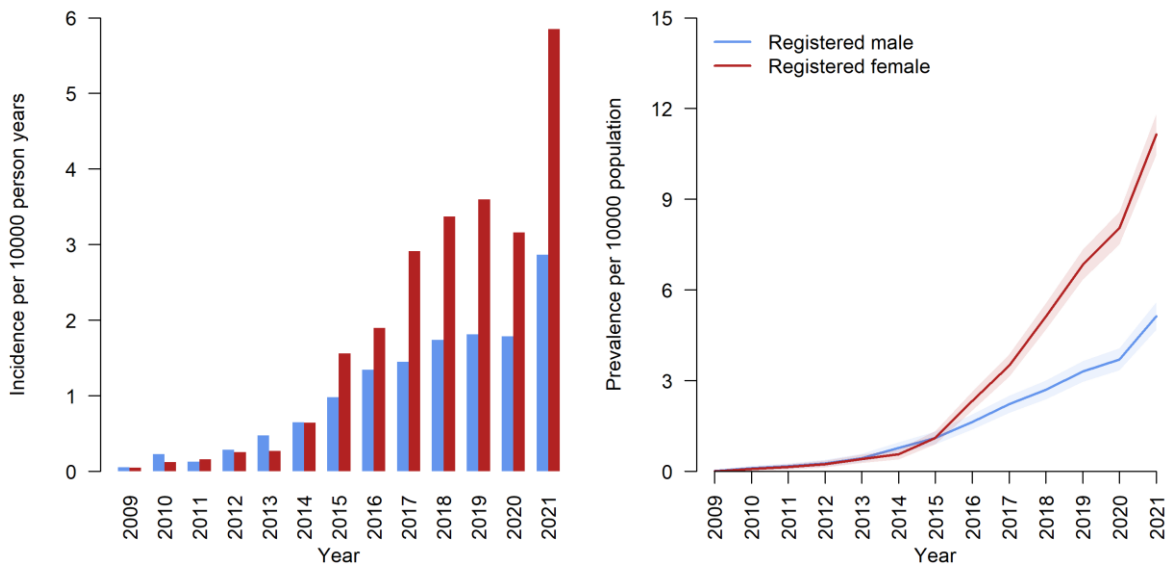
Recording of gender dysphoria was rare before the age of 10, increasing in frequency with each additional year up to age 16, the most common age at diagnosis. New cases for ages 18 and under increased from <0.1 per 10,000 person years in 2009 to 4.4 (95%CI 4.1-4.7) per 10,000 in 2021, with a decline in 2020, the first year of the COVID-19 pandemic (**Figure 1**). Overall recorded prevalence increased from <0.1 per 10,000 persons in 2009 to 8.3 (95%CI 7.9-8.7) per 10,000 in 2021, with the highest recorded prevalence in the 17-18 age group (42.2, 95%CI 39.1-45.2 per 10,000 in 2021). Incidence of new cases was similar for patients registered as male and female up to 2014, after which incidence increased at up to twice the rate for patients registered as female (**Figure 2**).

Figure 1: Incidence and recorded prevalence of gender dysphoria by age group



Note: shaded areas on prevalence graph denote 95% confidence intervals.

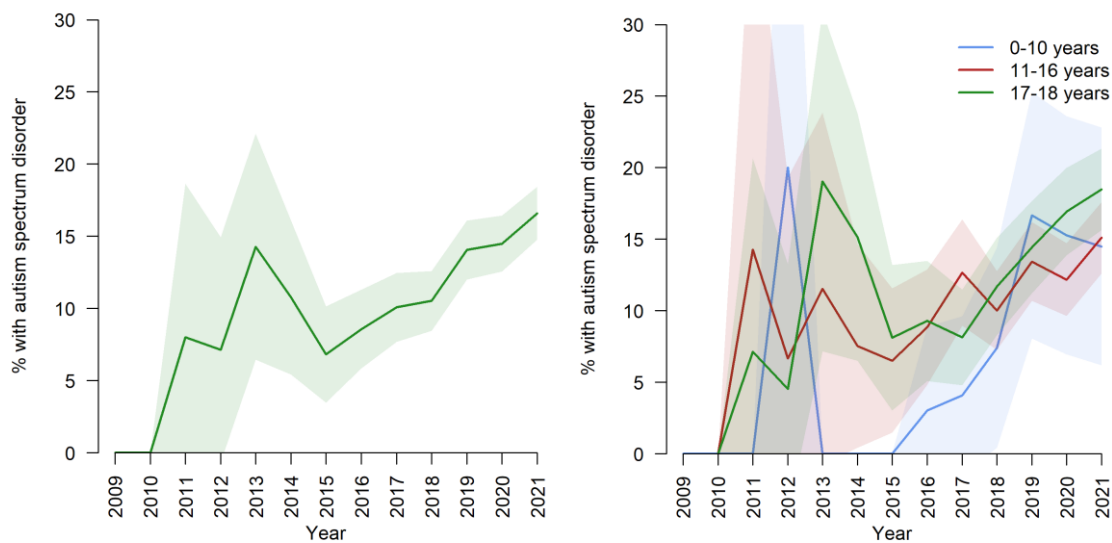
Figure 2: Incidence and recorded prevalence of gender dysphoria by registered gender



Note: shaded areas on prevalence graph denote 95% confidence intervals.

Patients can request to have their recorded gender changed on their clinical records without undergoing gender reassignment treatment, and CPRD reports the latest recorded gender only.

Figure 3: Co-occurrence of gender dysphoria and autism spectrum disorder, overall and by age group



Note: shaded areas denote 95% confidence intervals.

Due to low numbers of people with gender dysphoria, estimates of the prevalence of co-occurring conditions before 2014 are imprecise, as indicated by the wide confidence intervals.

Figure 4: Co-occurrence of depression, anxiety and gender dysphoria



Note: shaded areas denote 95% confidence intervals.

Due to low numbers of people with gender dysphoria, estimates of the prevalence of co-occurring conditions before 2014 are imprecise, as indicated by the wide confidence intervals.

In 2015, 6.8% (95%CI 3.5-10.1%) of people with gender dysphoria also had a diagnosis of autism spectrum disorder, increasing to 16.6% (95%CI 14.8-18.4%) by 2021. Trends in recorded prevalence did not vary substantially by age group (**Figure 3**). Recorded co-occurrence of depression and anxiety increased over time, reaching 15.0% (95%CI 13.3-16.8%) and 13.8% (95%CI 12.1-15.5%) respectively in 2021 (**Figure 4**).

Overview of the findings

In our sample of general practices, recorded prevalence of gender dysphoria in people aged 18 and under increased over a hundred-fold between 2009 and 2021. This increase occurred in two phases; a gradual increase between 2009 and 2014, followed by an acceleration from 2015 onwards. Increases in this second phase were more rapid for people registered as female, although clinical records do not indicate whether their recorded gender had been changed (see **strengths and limitations**).

Throughout the study period, presentations predominantly occurred in the teenage years, and over half of people with a recorded history of gender dysphoria were in the 17-18 age group. A substantial minority of people with a history of gender dysphoria also had a recorded diagnosis of autism spectrum disorder, and the proportion of people with such a diagnosis increased over time. Depression and anxiety were also more frequently reported over time, approaching 15% of people with gender dysphoria by 2021.

Strengths and limitations

These analyses draw on the complete primary care records of 3,782 children and young adults with a record of gender dysphoria derived from the Clinical Practice Research Datalink database, linked to other relevant health-related datasets. CPRD provides a large, comprehensive and nationally representative cohort covering all aspects of primary care and (through general practices' gatekeeping and care coordination role) secondary and tertiary care. The database facilitates investigation of rare exposures and events, such as gender dysphoria, and minimises selection and information bias as almost all residents in England are registered with a general practitioner soon after birth and practices collect data prospectively.

CPRD data also has several limitations, however, leading to risks of both under-reporting and over-reporting of gender dysphoria. Data are recorded by general practice staff for the purpose of clinical care and not primarily for research, hence key information may be inconsistently recorded, particularly for uncommon conditions such as gender dysphoria, with which individual practitioners may be less familiar. Practices may also not record that a long-term condition has resolved, hence our results report the proportion of people at a given point in time with a record of gender dysphoria *at any point* in their history. This will be higher than the proportion of people who currently have gender dysphoria. Conversely, for co-occurring conditions such as anxiety and depression, the analyses presented in this preliminary report are restricted to those with a recorded diagnosis, which may underestimate the number of people with symptoms of anxiety and depression, or receiving treatment.

Studies based on primary care records also face challenges with respect to classifying patient sex and gender, and this presents a particular problem for studies of gender dysphoria. Patients can request

to have their recorded gender category changed on their clinical records without undergoing gender reassignment treatment, and are then registered as a new patient with their previous medical information transferred to their new record. CPRD reports the latest recorded gender category only, so it is not possible to assess complete gender histories or to make definitive statements about patient sex. In our results, 'male' and 'female' refer to the gender recorded by the practice.



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Appendix 6



Independent review
into gender identity
services for children
and young people

Dr Hilary Cass
Chair
Independent Review of Gender Identity
Services for Children and Young People

John Stewart
National Director
Specialised Commissioning
NHS England

Sent by email

19 July 2022

Dear John

INDEPENDENT REVIEW OF GENDER IDENTITY SERVICES FOR CHILDREN AND YOUNG PEOPLE – FURTHER ADVICE

In my interim report I provided advice that in order to meet current demand and provide a more holistic and localised approach to care, gender identity services for children and young people need to move from a single national provider to a regional model.

I have since met with potential providers, Royal Colleges and support and advocacy groups to discuss the essential components of the proposed new model. I will continue with these conversations, including a programme of engagement with service users and their families, but wanted to share the outcome of discussions to date.

Essential components of a new model

A comprehensive patient and family centred service and package of care is needed to ensure children and young people who are questioning their gender identity or experiencing gender dysphoria get on the right pathway for them as an individual. A shared care arrangement is needed to enable children and young people to receive supportive care and appropriate treatment as close to home as possible. This would also improve integration between different children's services, facilitate appropriate access to local community support services, improve the experience of care, and support the transition between children's and adult services that are appropriate for the individual.

Regional centres

Regional centres should be commissioned as specialist centres to manage the caseload of children requiring support around their gender identity. The regional centres should be experienced providers of tertiary paediatric care to ensure a focus on child health and development, with strong links to mental health services. They should have established academic and education functions to ensure that ongoing research and training is embedded within the service delivery model. The centres should have an appropriate multi-professional workforce to enable them to manage the holistic needs of this population, as well as the ability to provide essential related services or be able to access such services through provider collaborations. These should include, but not be limited to: mental health services; services for children and young people with autism and other neurodiverse presentations; and for the subgroup for whom medical treatment may be considered appropriate, access to endocrinology services and fertility services. There should also be expertise in safeguarding, support of looked-after children and children who have experienced trauma. Staff should maintain a broad clinical perspective by working across related services within the tertiary centre and between tertiary and secondary centres in order to embed the care of children and young people with gender-related distress within a broader child and adolescent health context.

Designated local specialist services

The regional centres will need to work collaboratively with local services within their geography. However, recognising that not all local services will have the capacity, capability and/or aspiration to support the care of children and young people with gender-related distress, I would recommend initially identifying a smaller number of secondary services within Child and Adolescent Mental Health Services (CAMHS) and paediatrics to act as **designated local specialist services** within each area. This would give the opportunity to provide targeted training, upskilling and additional staffing to a more manageable number of centres within a geography. Similar models exist in the provision of children's cancer services where there are designated Paediatric Oncology Shared Care Units (POSCUs)¹ and in neonatal care where there are designated Local Neonatal Units (LNUs).²

Operational delivery network

The regional centres should be responsible for overseeing the shared care model, working through an **operational delivery network (ODN)** or similar mechanism that can fulfil the stated purposes of ODNs³ which include:

- ensuring effective clinical flows through the provider system through clinical collaboration for networked provision of services
- taking a whole system, collaborative provision approach to ensure the delivery of safe and effective services across the patient pathway

¹ [NHS England \(2021\). Service Specification: Children's Cancer Network - Principal Treatment Centres](#)

² [NHS England. Service Specification: Neonatal Critical Care \(Intensive Care, HDU and Special Care\)](#)

³ [NHS Commissioning Board \(2012\). Developing Operational Delivery Networks: The Way Forward](#)

- improving cross-organisational, multi-professional clinical engagement to improve pathways of care
- enabling the development of consistent provider guidance and improved service standards, ensuring a consistent patient and family experience
- focusing on quality and effectiveness through the facilitation of comparative benchmarking and auditing of services, with implementation of required improvements
- fulfilling a key role in assuring providers and commissioners of all aspects of quality as well as coordinating provider resources to secure the best outcomes for patients across wide geographical areas
- supporting capacity planning and activity monitoring with collaborative forecasting of demand, and matching of demand and supply

Key to this model is the governance role of the network in maintaining standards of care and ensuring equitable access.

Pathways of care

I would recommend that consideration is given to **intake procedures** that ensure that children and young people referred to these services are able to access the most appropriate package of support at the earliest feasible point in their journey. One model might be that each regional centre would host a regular **intake meeting** involving multi-professional staff from the tertiary centre, the designated local specialist services and other relevant local children's services. Discussions with Gender Identity Development Service clinicians have highlighted the importance of differentiating different subgroups within the referred population who may be at risk and/or need more urgent support, assessment or intervention; there may also be subgroups where early advice to parents or school staff may be a more appropriate first step. Given that it is not always possible to make these judgements based on written referral information, consideration should be given to ring-fencing senior clinical time to make early contact with referrers or families in order to ensure that children and young people are allocated to an appropriate pathway.

There should be a whole system approach to care across the network so that children and young people can access a broad range of services relevant to their individual needs, including supportive exploration and counselling. This is important both for those who go on to medical transition and those who resolve their gender distress in other ways. There should be the ability to move flexibly between different elements of the service in a step-up or step-down model, allowing children and young people and their families/carers to make decisions at their own pace without requiring rereferral into the system.

Stakeholders have raised the need for individuals who are distinct from the professionals that they view as 'gatekeeping' access to the medical treatment to provide support and a safe space for questioning. There is considerable scope for local innovation and partnerships with voluntary sector organisations in developing these services in a range of settings.

The appropriate age for transition to adult services will need further discussion, balancing the workload and capacity of services for children and young people with the need to provide ongoing holistic family-centred care during a critical point in the young person's gender care, particularly for those with neurodiversity/special educational needs or other vulnerabilities.

National provider collaborative/research network

I have already stated that the regional centres should have regular co-ordinated national provider meetings and operate to shared standards and operating procedures. The development of protocols for assessment and treatment to ensure such consistency is an important strand of the work of the Review, and this will be based on best available evidence, the findings from our commissioned research, and expert opinion.

There should also be agreement regarding collection of a core dataset to inform service improvement and research, based on similar approaches already established in other specialities, for example, in paediatric critical care.⁴

To achieve this end, I would recommend that a formal **national provider collaborative** with an **integral research network** is established, bringing together clinical and academic representatives from the regional centres. The national provider collaborative should undertake a range of functions including:

- a forum for discussion of complex cases and/or decisions about medical care, and ultimately subsuming the role of the Multi-Professional Review Group
- an ethics forum for cases where there is uncertainty or disagreement about best interests or appropriate care
- providing opportunities for peer review between regional centres
- development of a programme of ongoing Continuing Professional Development for staff at all levels, as well as educational standards for practitioners within the various tiers of service provision
- collation of the national dataset and conduct of national audit
- development of a quality improvement programme to ensure evolving best practice
- ongoing research in areas of weak evidence

Independent oversight of data collection, audit and quality improvement (for example, through a Healthcare Quality Improvement Partnership-commissioned approach) will ensure the highest possible standards of data management and utilisation.

Embedding research in clinical practice

My interim report highlighted the gaps in the evidence base regarding all aspects of gender care for children and young people, from epidemiology through to

⁴ [PICANet – Paediatric Intensive Care Audit Network for the UK and Ireland](#)

assessment, diagnosis, support, counselling and treatment.⁵ NHS England asked me to give some further thought as to how these gaps may be addressed.

The Review has already commissioned a research programme which includes a literature review and both qualitative and quantitative research components. However, I recognise that this programme will not provide all the answers that are needed, and an ongoing programme of work will be required.

Given the particular uncertainties regarding long-term outcomes of medical intervention, and the broader knowledge gaps in this area, there is an imperative to build research capacity into the national network. This research capacity is needed to provide ongoing appraisal of new literature and rapid translation into clinical practice, to continue to identify areas of practice where further research is needed, and to develop a research portfolio that will inform policy on assessment, support and clinical care of children with gender dysphoria, from presentation through to appropriate social, psychological and medical management.

As already highlighted in my interim report, the most significant knowledge gaps are in relation to treatment with puberty blockers, and the lack of clarity about whether the rationale for prescription is as an initial part of a transition pathway or as a 'pause' to allow more time for decision making. For those who will go on to have a stable binary trans identity, the ability to pass in later life is paramount, and many will decide that the trade-offs of medical treatment are a price that is fully justified by the ability to live confidently and comfortably in their identified gender. The widely understood challenge is in determining when a point of certainty about gender identity is reached in an adolescent who is in a state of developmental maturation, identity development and flux.

It is the latter option regarding a 'pause' for decision making about which we have the least information. The rationale for use of puberty blockers at Tanner Stage 2 of development was based on data that demonstrated that children, particularly birth-registered boys who had early gender incongruence, were unlikely to desist once they reached early puberty; this rationale does not necessarily apply to later-presenting young people, including the predominant referral group of birth-registered girls. We do not fully understand the role of adolescent sex hormones in driving the development of both sexuality and gender identity through the early teen years, so by extension we cannot be sure about the impact of stopping these hormone surges on psychosexual and gender maturation. We therefore have no way of knowing whether, rather than buying time to make a decision, puberty blockers may disrupt that decision-making process.

A further concern is that adolescent sex hormone surges may trigger the opening of a critical period for experience-dependent rewiring of neural circuits underlying

⁵ [Olson-Kennedy, J, Cohen-Kettenis, P. T, Kreukels, B. P, Meyer-Bahlburg, H. F, Garofalo, R, Meyer, W, & Rosenthal, S. M. \(2016\). Research priorities for gender nonconforming/transgender youth: gender identity development and biopsychosocial outcomes. *Current opinion in endocrinology, diabetes, and obesity* 23\(2\), 172–179. DOI:10.1097/MED.000000000000236.](#)

executive function⁶ (i.e. maturation of the part of the brain concerned with planning, decision making and judgement). If this is the case, brain maturation may be temporarily or permanently disrupted by puberty blockers, which could have significant impact on the ability to make complex risk-laden decisions, as well as possible longer-term neuropsychological consequences. To date, there has been very limited research on the short-, medium- or longer-term impact of puberty-blockers on neurocognitive development.

In light of these critically important unanswered questions, I would suggest that consideration is given to the rapid establishment of the necessary research infrastructure to prospectively enrol young people being considered for hormone treatment into a formal research programme with adequate follow up into adulthood, with a more immediate focus on the questions regarding puberty blockers. The appropriate research questions and protocols will need to be developed with input from a panel of academics, clinicians, service users and ethicists.

Without an established research strategy and infrastructure, the outstanding questions will remain unanswered and the evidence gap will continue to be filled with polarised opinion and conjecture, which does little to help the children and young people, and their families and carers, who need support and information on which to make decisions.

I hope this further advice is helpful as you look to develop a detailed service specification. I appreciate you will want some time to consider my advice and am happy to discuss both the longer-term ambition and any interim arrangements that may be necessary, particularly in relation to the development of the clinical and research protocols.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Hilary Cass', with a stylized flourish at the end.

Dr Hilary Cass
Chair, Independent Review of Gender Identity Services for Children and Young People

⁶ [Sisk C L \(2017\). Development: Pubertal Hormones Meet the Adolescent Brain: Current Biology. 27\(14\): 706-708. DOI: 10.1016/j.cub.2017.05.092.](#)

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Appendix 7



Independent review
into gender identity
services for children
and young people

Dr Hilary Cass
Chair
Independent Review of Gender Identity
Services for Children and Young People

National Director
Specialised Commissioning
NHS England

Sent by email

31 January 2023

Dear John

As the Review moves into its final phase, I thought it would be helpful to provide an update on progress since my last letter, to outline the Review timetable going forward, and highlight some areas in which NHS England (NHSE) and colleagues across the system may be able to help achieve the Review's objectives.

Over the last few months, the Review has continued to engage with key stakeholders across the statutory and voluntary sectors, as well as leaders of professional organisations, and I have had ongoing listening sessions with individuals who have direct service experience. The Review's commissioned research team is making excellent progress with the systematic reviews, a review of existing guidelines, an international survey of services in countries with comparable healthcare systems, and the qualitative research. We will have outputs from these pieces of work by the spring. I have also established a Clinical Expert Group, including representatives of professional bodies, NHSE's phase one provider units, gender experts and others with expertise in children and young people's care, to help us interpret the findings of this research. Alongside this, the Review is engaging with service users to gain insight into their perspectives on these initial findings.

We have discussed previously the fact that the commissioned data linkage study (part of our quantitative research programme), which represents a unique opportunity to collect longer-term outcome data on this population, has been much more complex than initially envisaged, and is taking longer to establish. However, I am pleased to say that we have now received provisional approvals and will soon be moving into the next phase of the work, which will involve detailed information for service users and the option to opt out before commencement of any data collection. The full protocol will be published on our website.

I anticipate that by the summer, in addition to the strands of work described above, we will have some information on the intermediate outcomes for children and young people with gender dysphoria, as well as the changing characteristics of this group, using data which is already routinely collected within the NHS. However, the complexities encountered in establishing the data linkage study means that the full results of this element will likely not be available before the Review is concluded. As you know, we have already had discussions about the logistics of establishing a formal research network (as described in my [letter of July 2022](#)) to receive the results of this study, oversee a clinically informed future research programme and ensure translation into clinical practice.

In the interim, I would like to ask for your help in obtaining some existing data which is of more immediate importance to understanding the needs of this population:

- Firstly, to-date the Review has been working on the understanding that around 20% of children and young people seen by the Gender Identity Development Service (GIDS) enter a hormone pathway. At this stage, it is crucial for us to verify that this is an accurate assumption as it has significant bearing on getting a fuller understanding of the outcomes of the existing clinical approach. I anticipate that it should be relatively straightforward to clarify this through an audit of discharge summaries and would be grateful if this could be arranged as swiftly as possible with colleagues at GIDS.
- Secondly, I understand from discussions with clinicians, that there has been a significant change in the demographic of referrals to adult NHS Gender Dysphoria Clinics (GDCs) - from a more mixed group in terms of age and birth-registered gender to a population base where a significant majority are under 25, with a higher proportion of birth registered females. This obviously comprises a mix of referrals from GIDS and direct referrals to adult clinics. I would be grateful if more robust data on this could be obtained since it is relevant for thinking about both the transition of young people to adult services and potential unmet need within the children and young people's service.

In terms of broader support, there are a number of strands of work which are outside our control, but are crucial to the successful delivery of the Review:

- I would particularly like to thank NHS-Digital for their help to-date in moving forward on the data linkage and look forward to continuing to work with them on this.
- I also look forward to working with the adult NHS GDCs, which are a vital part of understanding the patient journey.

The Review will continue to share information as it becomes available, and I anticipate submitting a final report to NHSE by the end of the year. Within that, I will be making clear those issues we consider to be the sole responsibility of the healthcare system and signposting other issues which fall outside the responsibility of the NHS and require the input of other agencies and organisations and I will make recommendations accordingly.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Hilary' with a stylized flourish at the end.

Dr Hilary Cass
Chair, Independent Review of Gender Identity Services for Children and Young People

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Appendix 8

The Gender Identity Development Service Audit Report

June 2023



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Background

An independent review of gender identity services for children and young people ([The Cass Review: Interim Report](#)), has identified a gap in the understanding of treatment pathways once patients are within the Gender Identity Development Service (GIDS) at the Tavistock and Portman NHS Foundation Trust.

As a result of this, a request by the Cass Review team was submitted to NHS England to undertake an audit of discharge notes for patients over a defined period.

NHS England approached NHS Arden and Greater East Midlands Commissioning Support Unit (the CSU) to undertake this audit on behalf of the Cass Review team.

Audit aims and objectives

The aim of the audit was to understand the treatment pathways that children and young people who have entered the GIDS service have received and explore if there are any inconsistencies between GIDS providers.

The key objectives of this study were to:

- Develop a suitable audit template to gather the required information from patients' medical records
- Identify if there are any variations in referrals to endocrinology across the GIDS teams
- Capture information about the proportion of patients entering the GIDS who are subsequently discharged on hormone therapy
- Understand what care patients have received at the point of discharge.

The evidence from this audit will be used to support the next steps of the Cass Review.

Audit scope

The following patients were included in the data collection

- Patients who have attended at least 2 appointments to Tavistock & Portman NHS Foundation Trust GIDS
- Patients who have been discharged from the GIDS between 1 April 2018 and 31 December 2022
- Responsible commissioner is NHS England or NHS Wales

Introduction to methodology

To fulfil the aims and objectives of the study, the CSU developed an audit template in Microsoft Excel® (see Appendix 1) in collaboration with key clinicians at the Tavistock and Portman NHS Foundation Trust, to capture key information that would be extracted from individual patient records. Drop-down lists were utilised where possible to enable standardised information to be captured.

The sections of the audit were grouped into the following themes:

- Patient demographic profile
- Initial referral information
- Endocrinology referral and care pathway
- Discharge information
- Other comments

The CSU identified a clinical workforce to undertake the audit. This ensured that the audit would be to utilise a clinical workforce who:

- 1) Were bound by their professional registration for patient confidentiality
- 2) Can understand clinical terminology
- 3) Can interpret information to undertake the audit
- 4) Can limit the scope of their tasks to achieve the audit aims

Carenotes system training was provided by the Tavistock and Portman NHS Foundation Trust and individual log-in details were provided to the team. Recognising staff will be required to work within clinical systems at the GIDS which contains highly sensitive confidential patient identifiable information, honorary contracts were put in place between the individual and the trust.

Data extraction methodology



The Tavistock and Portman NHS Foundation Trust provided the CSU with a list of 3466 patients who had been discharged from the service between 1 April 2018 and 31 December 2022, covering the following regional GIDS teams

- GIDS Midlands (incl. Birmingham)
- GIDS Leeds
- GIDS Southeast (incl. London)
- GIDS Southwest (incl. Exeter and Bristol)

The patient list was grouped according to the GIDS team and allocated in batches of between 20-50 patients to the audit team who then reviewed each patient record within Carenotes.

Analysis methodology



To support analysis of the data from the audit, expertise was drawn from across the CSU.

Data from each individual auditor was cleansed and combined into a master Microsoft Excel® spreadsheet. Any patients who did not meet the criteria defined within the audit scope, were excluded from the analysis

Where information was captured as 'other', details were provided in the comments section of the audit template, and these were further grouped where possible. For example, several patients had been discharged because they had moved outside of the NHS England and NHS Wales geography.

In context of the [Bell v Tavistock High Court Judgement](#), the date of the judgement, 1st December 2020 was used to undertake the analysis. The terms pre-Bell and post-Bell are used through this report.

Introduction to results

Out of the 3499 patients audited, 3306 were included within the analysis. Of the 193 who were excluded, patients included those who were outside of the NHS England or NHS Wales footprint, non-gender dysphoria patients (for example a patient receiving support due to a family member undergoing gender reassignment), patients who had less than 2 appointments at GIDS and patients who had not been discharged from the service.

The results from the audit are separated into the following themes:

1. Patient demographic profile and referral to GIDs
2. Endocrinology referral and care pathway
3. Discharge from GIDs

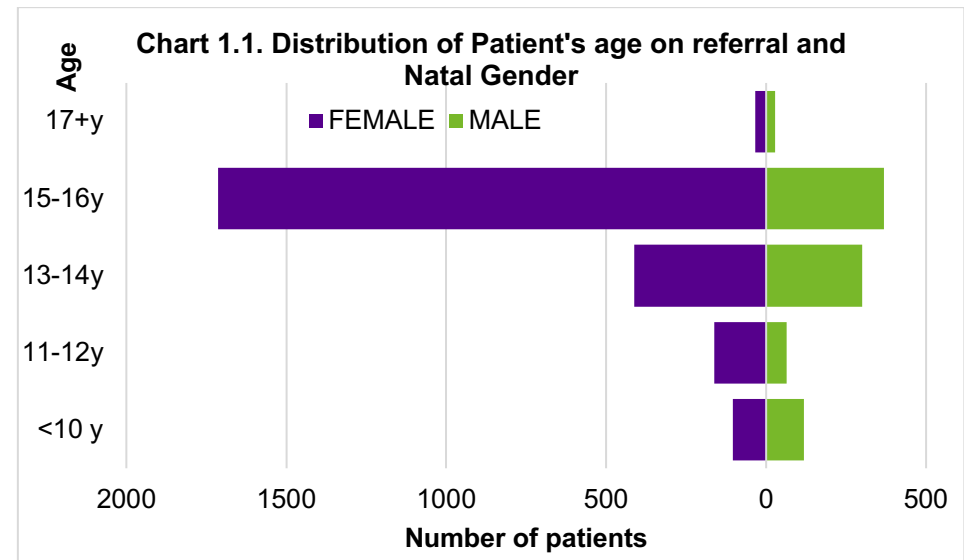
Theme 1. Patient demographic profile and referral to GIDs

Gender and age profile

The overall natal and current gender of the patients who were audited is detailed within table 1.1. Upon referral into the service, 73% of referrals were for natal female patients, and 27% for those with a natal gender of male. At the point of discharge from the GIDS, the current gender listed within the patients Carenotes record identified a larger proportion, 61% of patients who identified as male.

	Natal Gender (%)	Current gender (%)
Female	73%	22%
Male	27%	61%
Trans-unspecified/Gender Identity unknown	Not applicable	10%
Non-Binary	Not applicable	5%
Gender questioning	Not applicable	2%

The distribution of patients natal gender and age at the point of referral into the GIDS service is shown in chart 1.1. The minimum age of patients being referred into the GIDS service was 3years, the maximum age was 18years, with a mean and median of 14years.



Referral source

48.6% of patients referred to GIDS were referred by CAMHS/CYP Mental Health Services and 40.68% were referred by their GP practice (see table 1.2). The largest proportion of referrals from CAMHS/CYP Mental Health Services were consistent across the GIDS teams and a full breakdown of the referral source by the GIDS team is provided in appendix 2.

Referral Source	% of patients
CAMHS / CYP Mental Health	48.6%
GP Practice	40.7%
Children's or Council Service/Local Authority	3.3%
Voluntary sector	3.1%
School	1.8%
Paediatrics	1.6%
Healthcare provider - other	X
Healthcare provider - private	X
Other	X

GIDS team

Table 1.3 shows where patients were assigned their GIDS primary team as identified in the original patient list received from the Tavistock and Portman NHS Foundation Trust.



GIDS Team	% of patients
GIDS Leeds	35.27%
GIDS Southeast/London	28.31%
GIDS Midlands/Birmingham	19.87%
GIDS Southwest/Bristol/Exeter	16.55%

Limitations of analysis

- The CSU audit identified that although patients were assigned to a primary GIDS team, often based upon the patient's location, the GIDS team where they received their main assessments and care may have been different to the primary team which has not been analysed.
- There were variations in recorded information between clinics, for example inconsistencies in the information contained within the closing summaries, patient contract information, spells and referral letters. Whilst the CSU team tried to adopt as much consistency as possible, it is recognised that there may be slight variations or inaccuracies in the information that was obtained, such as referral and discharge dates.



Key findings

- 73% of patients are natal female, and 27% natal male when referred into the GIDS.
- The largest proportion of referrals into the GIDS are from CAMHS/CYP Mental Health (48.6%) and GP Practices (40.7%).



Theme 2. Endocrinology referral and care pathway

Across the patients audited, 27% were referred to endocrinology. Analysis against the Bell judgement was not possible due to the methodology of the data collection (refer to limitations within this section). The breakdown of patients by GIDS team is provided in table 2.1.

Table 2.1. Percentage of patients under the care of each GIDS team, referred to endocrinology	
GIDS Team	% of patients
All teams	27.0%
GIDS Leeds	32.7%
GIDS Midlands/Birmingham	11.1%
GIDS Southeast/London	20.9%
GIDS Southwest/Bristol/Exeter	11.7%

Excluding patients who did not attend/engage with the GIDS, the referral rate to endocrinology was 28%. Excluding this same cohort or patients along with those who refused the service, the referral rate to endocrinology was 31%.

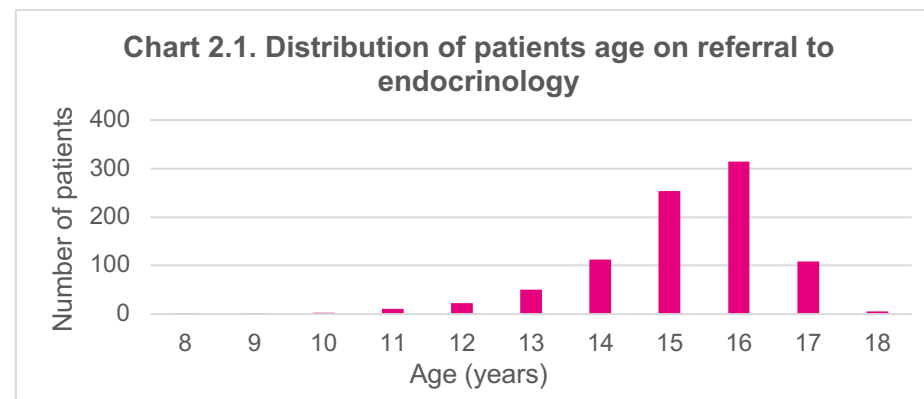
Gender profile on referral to endocrinology

34.6% of natal males were referred to endocrinology, compared to 24.2% of natal females.

Of the total patients referred into endocrinology, 34% were natal male, and 66% natal female.

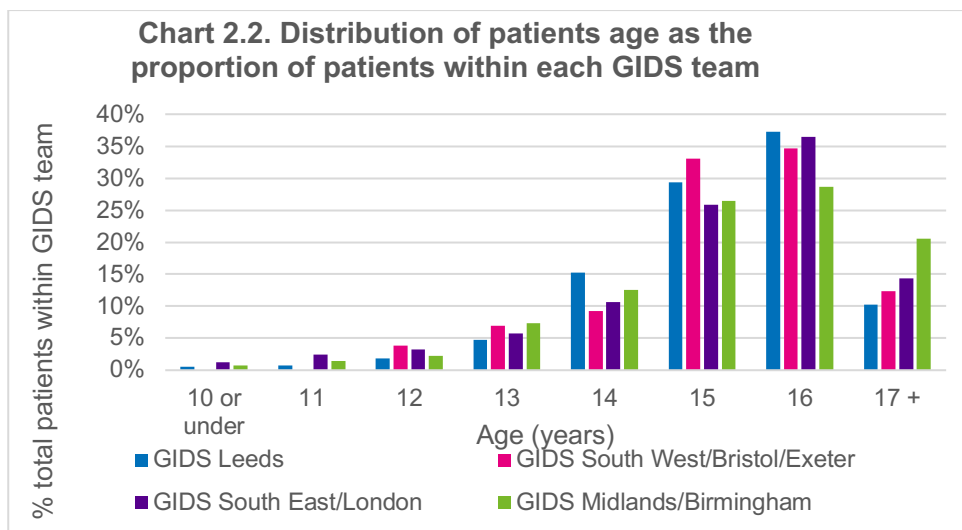
Age profile on referral to endocrinology

Patients were referred to endocrinology between the ages of 8 years and 18 years, although the <10 patients referred post-Bell were all 17 years. The mean and median age of referral was 15 years. Chart 2.1 shows the distribution of patients age on referral.



The distribution of age broadly similar across the GIDS as shown in chart 2.2. Excluding patients who did not attend/engage or who refused the service had no impact on the distribution of the ages.





<10 patients seen by the GIDS Leeds team were referred to endocrinology after the first appointment due to transfer of care and were already receiving puberty blocker treatment.

The distribution of appointments is shown in chart 2.3. There was a similar distribution of appointments according to the GIDS team, full details are provided in appendix 3.

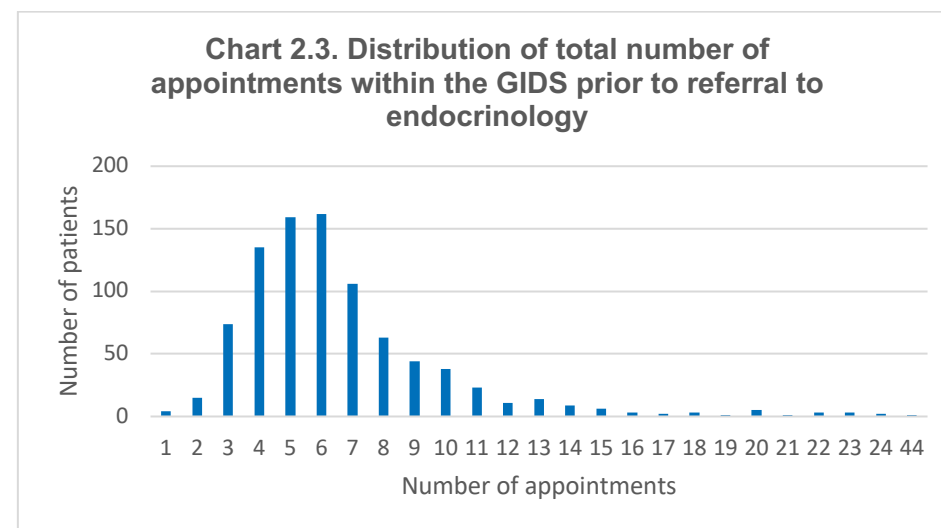
Post-Bell, <10 patients were referred to endocrinology had 12 or more appointments with the GIDS prior to the referral.

Appointments with the GIDS prior to referral to endocrinology

Patients received on average a total of 6.7 appointments with GIDS prior to referral to endocrinology. Analysis against the Bell judgement identified that patients received an average of 6.6 appointments pre-Bell, and 15.8 appointments post-Bell before being referred to endocrinology.

Table 2.2 provides a breakdown of appointments by the GIDS referral team.

GIDS Team	Average	Minimum	Maximum
All teams	6.7	1	44
GIDS Leeds	6.3	1	23
GIDS Midlands/Birmingham	6.4	2	22
GIDS Southeast/London	7.8	1	44
GIDS Southwest/Bristol/Exeter	5.8	1	14



Limitations of analysis

- The date of referral to endocrine was captured as part of the audit collection tool. The audit did not capture the date which the patient was then seen by endocrinology. Recognising the waiting times into the service, it was not possible to undertake analysis against the Bell judgement upon referral into endocrinology.
- The audit criteria focussed on patients who had been discharged from the GIDS. Therefore there is potentially a cohort who have not been considered as part of this audit and thereby referrals into endocrine could be higher than indicated in this audit.



Key findings

- Overall, 27% of patients were referred to endocrinology. This was slightly increased when excluding patients who did not attend/engage with the service or declined the service.
- The largest proportion of patients referred to endocrinology are seen by GIDS Leeds (32.7%) and GIDS Southeast/London (20.9%).
- 34.6% of natal males were referred to endocrinology, compared to 24.2% of natal females.
- A higher proportion of patients referred to endocrinology are aged 15-16years.
- Patients receive an average of 6.7 appointments prior to referral to endocrinology, with a range of 1 to 44.



First interventions within endocrinology

• First intervention type overview

Table 2.3 shows the first interventions received by patients upon referral to endocrinology. Please note, the first intervention was not necessarily the first appointment, where treatment was recommended there were often a number of appointments required to determine the patients' suitability for treatment (e.g., DEXA scans and blood tests prior to commencing puberty blocker treatment).

There was little variation in the first intervention following endocrinology referral when analysed by GIDS team (see appendix 4).

Of the <10 patients referred post-Bell, X received a puberty blocker only, X patients were discharged to the Gender Identity Clinic (GIC) and the other patients decided to access treatment privately. These patients were aged 16 to 17years of age upon referral.

First intervention type	% of patients
Puberty Blockers ONLY	81.5%
Patient declined treatment	7.1%
Puberty assessment ONLY	5.6%
Other*	X
DNA	X
Accessed treatment outside NHS protocols	X
Puberty blockers AND cross-sex hormones	X
Puberty Blocker not started due to JR	X
Did not access physical treatment	X
Cross-sex hormones ONLY	X

Puberty blocker (NHS before GIDS) AND cross-sex hormones	X
Puberty blockers (privately before GIDS) AND cross-sex hormones	X

***Other** – first interventions captured as other represent a small proportion of patients for reasons which include; referral on hold, other opinion required, discharged to GIC, notes incomplete, puberty blocker advised but unclear if started, treatment not advised on professional advice, patient moved from abroad on puberty blocker and referred on first appointment, puberty blocker not started due to patient misunderstanding about treatment regime, treatment recommended but supply issues (GP prescribing or pharmacy).

- **First intervention type by natal gender**

The first intervention patients received according to their natal gender was broadly similar (see appendix 5).

- **Treatment type and patients' age**

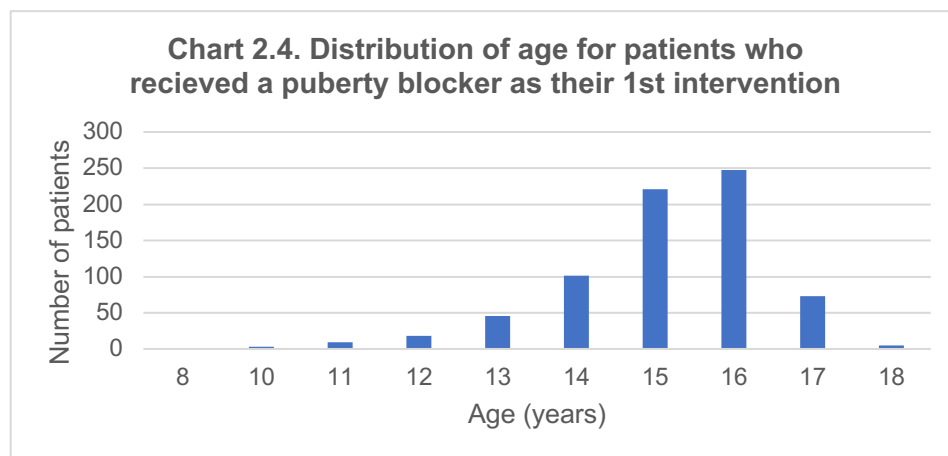
Appendix 6 shows the intervention types by age at the point of referral, against the total proportion of patients referred into endocrinology. 52.5% of patients between 15-16 years received puberty blockers, followed by those aged 13-14 years of age (16.5%).

For patients receiving puberty blockers and/or cross-sex hormones upon referral to endocrinology (excluding those who have received clinical treatments outside of the GIDS), table 2.4 provides information about the age at which the patients were upon referral, although the patient may have been older at the point of receiving treatment due to waiting times to be seen by endocrinology.

Puberty-blockers ONLY			
	Average age	Minimum age	Maximum age
All teams	15	8	18
GIDS Leeds	15	8	18
GIDS Midlands/Birmingham	15	10	17
GIDS Southeast/London	15	10	18
GIDS Southwest/Bristol/Exeter	15	12	17
Cross-sex hormones ONLY			
GIDS Leeds	N/A	N/A	N/A
GIDS Midlands/Birmingham	N/A	N/A	N/A
GIDS Southeast/London	<10 patients aged 15 years		
GIDS Southwest/Bristol/Exeter	<10 patients aged 17 years		
Puberty-blocker and cross-sex hormones			
GIDS Leeds	<10 patients aged 15 years <10 patients aged 16 years		
GIDS Midlands/Birmingham	<10 patients aged 14 years		
GIDS Southeast/London	<10 patients aged 16 and 17 years		
GIDS Southwest/Bristol/Exeter	N/A	N/A	N/A



Chart 2.4 shows the distribution of patients ages for those who received a puberty blocker as their first intervention.



Limitations of analysis

- The date that the patient started treatment as part of their first intervention whilst under the care of the endocrinology team was not captured, as it was difficult to capture this accurately and was not part of the audit tool design. The age of the patient upon referral into endocrinology was therefore used for the analysis.



Key findings

- 81.5% of patients referred into endocrinology received puberty blockers, of which 52.5% were between 15-16 years old.
- A small number of patients received cross-sex hormones (<10 patients) or both puberty blockers and cross-sex hormones (<10 patients), as their 1st intervention within the endocrinology service.
- <10 patients who were initially advised to start puberty blockers did not start treatment due to the Bell judgement. All patients were aged 16-17 years on referral.
- Post-Bell, <10 patients received a puberty blocker, <10 patients were discharged to the GIC and <10 patients decided to access treatment privately.
- Patients were on average 15 years old when referred for puberty blocker treatment.



Final interventions within endocrinology upon discharge from the GIDS

Table 2.5 shows the end point intervention upon patients discharge from the GIDS, with 54.8% ending up on both puberty blockers and cross-sex hormones.

Of the <10 patients who were referred to endocrinology post-Bell, <10 patients who subsequently received puberty blockers remained on the puberty blocker, but treatment was withdrawn for other patients on professional advice due to side effects. <10 patients was discharged to the GIC and did not access physical treatment whilst under the care of the GIDS, and the final patients decided to access treatment privately.

First intervention type	% of patients
Puberty blockers AND cross-sex hormones	54.8%
Puberty Blockers ONLY	19.9%
Patient declined treatment	11.4%
Accessed treatment outside NHS protocols	3.9%
Did not access physical treatment	3.3%
Puberty assessment ONLY	2.0%
Treatment withdrawn - DNA	1.5%
Detransitioned/detransitioning	X
Unknown/unclear	X
Puberty Blocker not started due to JR	X
Treatment recommended but supply issues (GP prescribing or pharmacy)	X
Treatment withdrawn - professional advice/side effects	X
Cross-sex hormones ONLY	X
Puberty blockers AND cross-sex hormones (privately)	X

Appendix 7 shows the final intervention types by age against the total proportion of patients referred into endocrinology.

The final intervention patients received according to their natal gender as shown in appendix 8 shows that a higher proportion of natal females (57.9%) ended up on both puberty blockers and cross-sex hormones compared to natal males (47.7%). A higher proportion of natal males (24.7%) ended up on puberty blockers alone compared to natal females (17.4%).

- First intervention puberty blockers: Final intervention type**

As shown in table 2.6, 64% of patients who were initially started on a puberty blocker at their first intervention pre-Bell, ended up on both a puberty blocker and cross sex-hormone through the GIDS (this does not include 1 patient who was on both interventions however was accessing cross-sex hormones privately). 23% of patients remained on a puberty blocker alone.

First intervention type	% of patients
Puberty blockers AND cross-sex hormones	64.0%
Puberty Blockers ONLY	23.0%
Patient declined treatment	7.3%
Accessed treatment outside NHS protocols	2.1%
Treatment withdrawn - DNA	1.4%
Unknown/unclear	X
Detransitioned/detransitioning	X
Treatment withdrawn - professional advice/side effects	X
Puberty blockers AND cross-sex hormones (privately)	X
Treatment recommended but supply issues (GP prescribing or pharmacy)	X

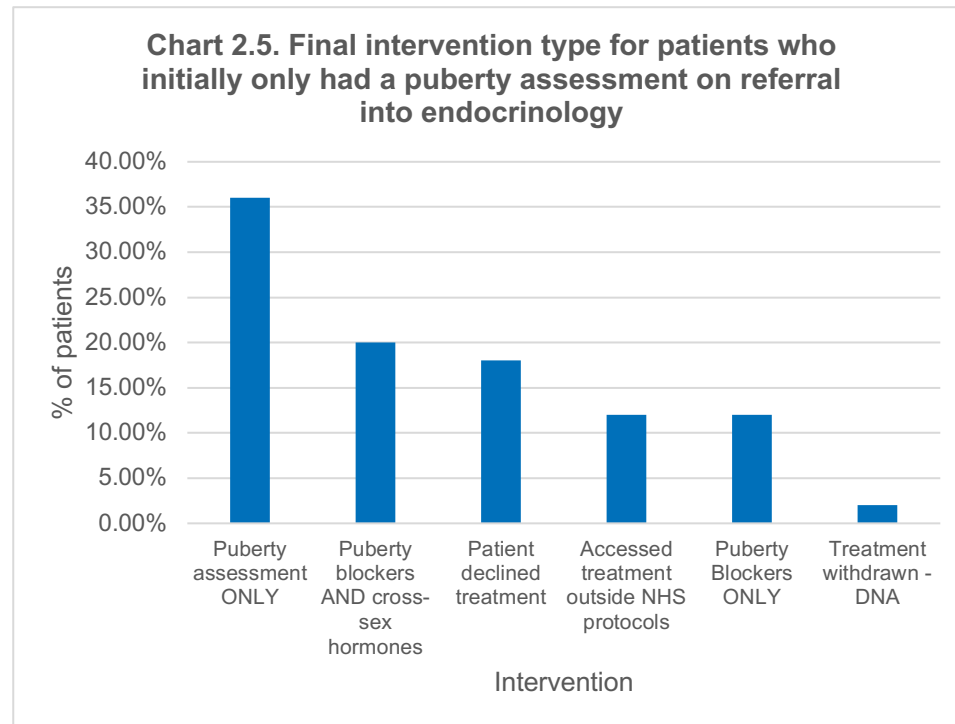


- **First intervention puberty blockers and cross-sex hormones: Final intervention type**

100% of pts (n=<10) who were started on a puberty blocker and cross-sex hormone, remained on the same treatment

- **First intervention initial assessment only: Final intervention type**

Where patients were referred to endocrinology and only received a puberty assessment at their first intervention, chart 2.5 shows the final intervention that the patient had following discharge from the GIDS.

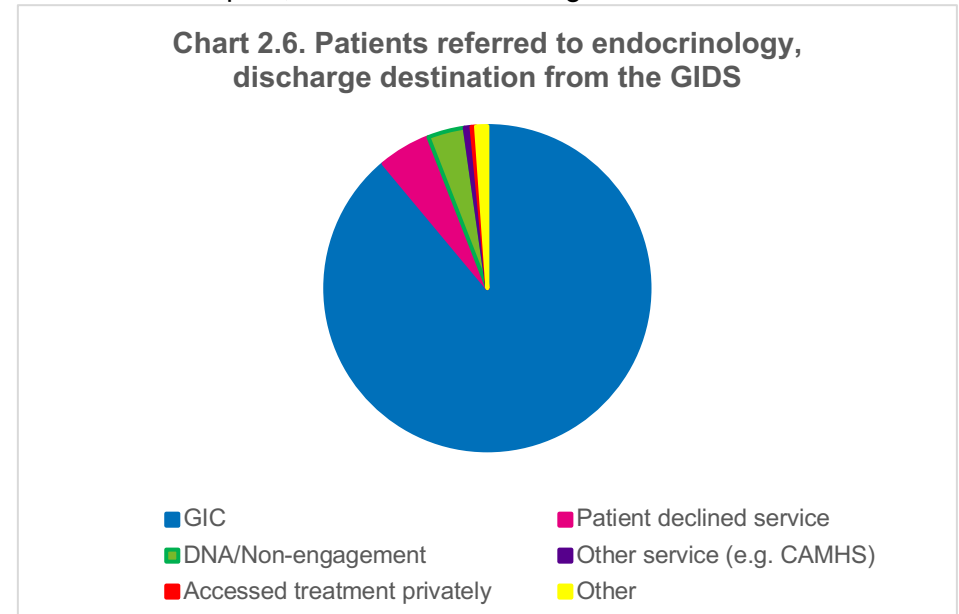


- **Detransitioned/detransitioning patients**

<10 patients who went on to detransition back to their natal gender, all were female. <10 patients had received puberty blockers as their first intervention following endocrinology referral, however it was not clear from the records of the final patient what interventions they had received. They had received an average of 6.5 appointments prior to referral to endocrinology (range 3-10 appointments).

Discharge destination for patients referred to endocrinology

For patients who were referred to endocrinology, 89% of patients were referred to a GIC following discharge from the GIDS (see chart 2.6), 5% of patients declined the GIDS, and 3% did not attend or engage with the service. Other reasons for discharge included to different services, accessed treatment privately, moved outside of the NHS England or NHS Wales footprint, or where the discharge destination was unknown.



Limitations of analysis

- Although first intervention and final intervention at discharge from the GIDS was captured, the audit did not gather any information about any interventions which the patient may have received between these time periods.



Key findings

- 54.8% of patients referred to endocrinology ended up on both puberty blockers and cross-sex hormones.
- 57.9% of natal females ended up on both puberty blockers and cross-sex hormones compared to 47.7% for natal males.
- 24.7% of natal males ended up on puberty blockers alone compared to 17.4% of natal females.
- For patients who initially received a puberty blocker upon referral to endocrinology, 64% went on to receive both a puberty blocker and cross-sex hormone.
- All patients who started on both a puberty blocker and cross-sex hormone, remained on the same treatment upon discharge from the GIDS.
- Of the patients who only initially had a puberty assessment, 12% went on to have puberty blockers and a further 20% went on to have both puberty blockers and cross-sex hormones.
- 89% of patients were discharged to a GIC.
- 9% of patients declined, did not attend or engage with the service.
- <10 patients detransitioned back to their natal gender, all of whom were female, and <10 patients were confirmed as having received puberty blockers as their first intervention.

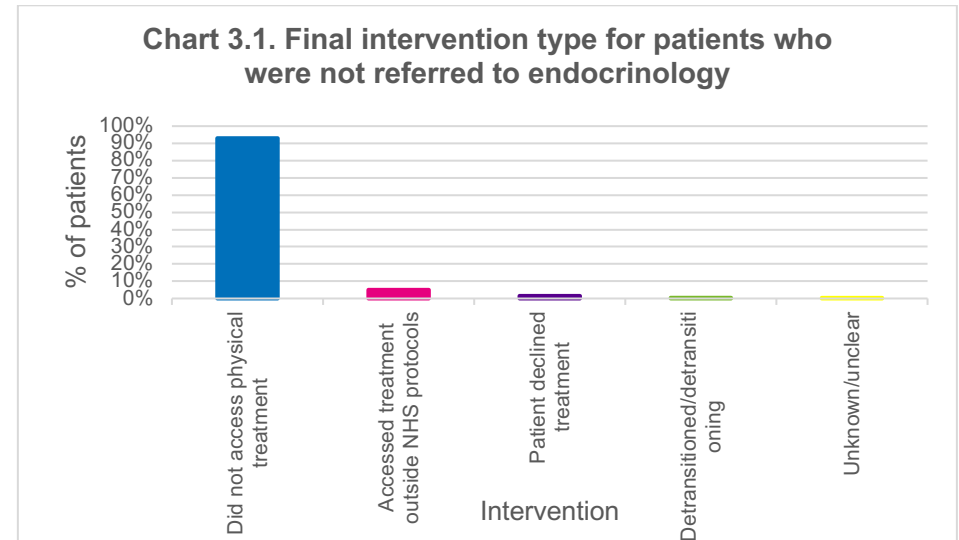


Theme 3. Patients not referred to endocrinology pathway

Across the 3306 patients' audits, 2415 patients were not referred to endocrinology by the GIDS team.

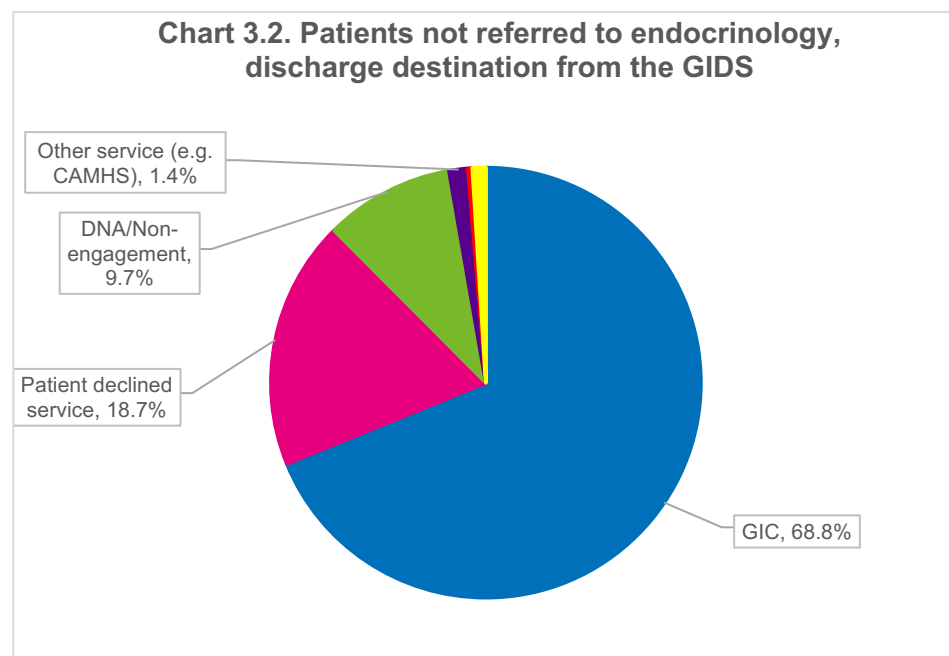
Final interventions for patients not referred to endocrinology

Chart 3.1 shows final intervention patients received upon discharge from the GIDS. 93.0% of patients did not access any physical treatment whilst under the GIDS. 5.0% of patients accessed treatment outside of NHS protocols, 1.5% declined treatment and 0.5% of patients detransitioned or were detransitioning back to their natal gender.



Discharge destination for patients not referred to endocrinology

For patients who were not referred to endocrinology, 69% were referred to a GIC following discharge from the GIDS (see chart 3.2), 19% of patients declined the GIDS, and 10% did not attend or engage with the service. Other reasons for discharge included to different services, patient death, or where the discharge destination was unknown.



Key findings

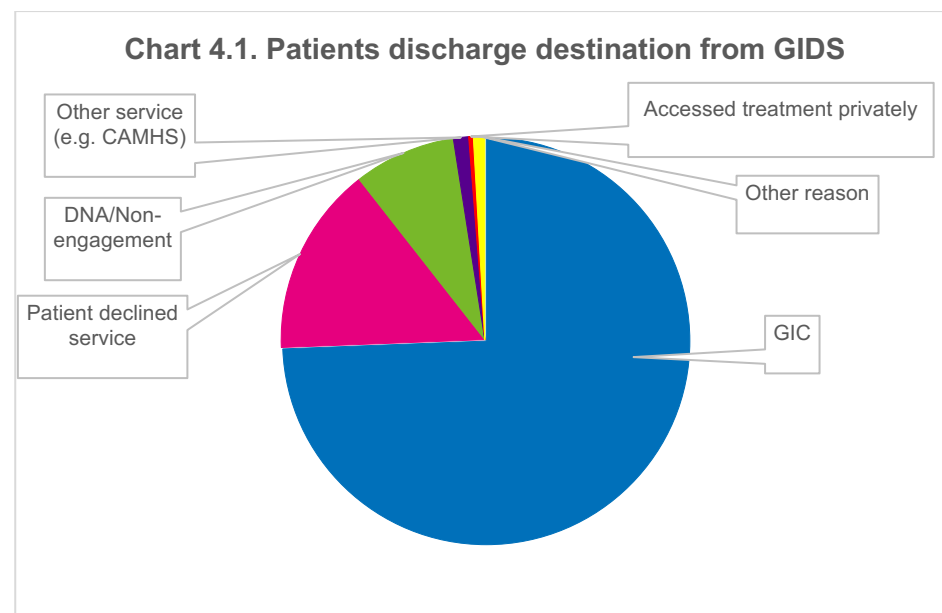
- 93% of patients who were not referred to endocrinology did not access any physical treatment, and 5% accessed treatment outside of NHS protocols.
- 69% of patients were referred to a GIC.
- 29% of patients declined, did not attend or engage with the service.



Theme 4. Discharge from GIDs – all patients summary

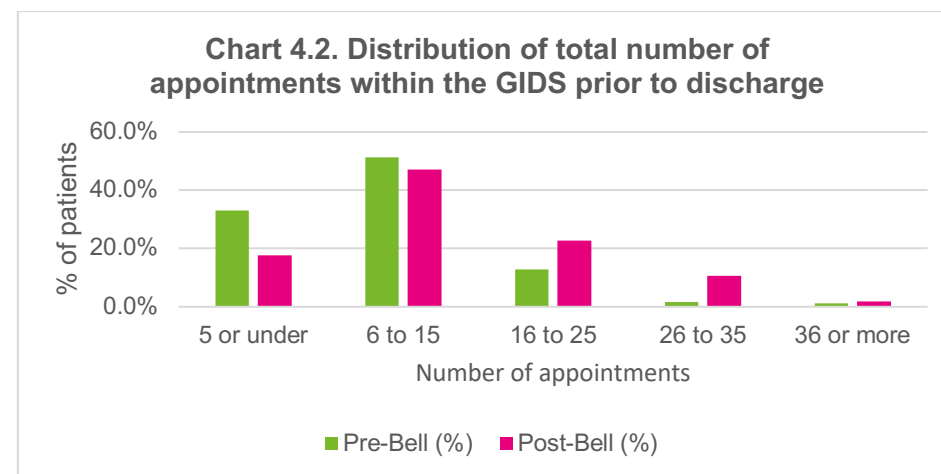
Discharge destination

Over 70% of patients were referred to a GIC following discharge from the GIDS (see Chart 4.1). Approximately 15% of patients declined the GIDS, and 8% did not attend (DNA) or did not engage with the service. This was similar when comparing the discharge destination pre-Bell and post-Bell. Other reasons for discharge included discharge to other services, moving outside of the NHS England or NHS Wales geographies, patient deaths or where the discharge destination was unknown.



Appointments with the GIDS prior to discharge

Patients received on average a total of 11 appointments with GIDS prior to discharge, with an average of 10 appointments pre-Bell and 14 appointments post-Bell, which included any relevant endocrinology appointments where the patient was under the care of the endocrinology team. The distribution of appointments pre-Bell and post-Bell are shown in Chart 4.2.



Limitations of analysis

- There was inconsistency in the date recorded for discharge within the patients notes, with there being a delay in the processing of the discharge for the patient. The CSU audit team attempted to have consistency in the date used by utilising the closing summary as the first reference point, however this was not always possible where closing summaries were incomplete.



Key findings

- 70% of patients are referred to a GIC upon discharge from the GIDS.
- 8% of patients did not attend/engage or declined the service and were therefore subsequently discharged.
- Patients received an average of 11 appointments with the GIDS prior to discharge.



Arden & GEM CSU would like to thank colleagues at the Tavistock and Portman NHS Foundation Trust for their support provided during the audit process.

References

Dr Hilary Cass. (2022, February). The Cass Review: *Independent review of gender identity services for children and young people: Interim Report*. Retrieved from <https://cass.independent-review.uk/wp-content/uploads/2022/03/Cass-Review-Interim-Report-Final-Web-Accessible.pdf>

Dame Victoria Sharp P., Lord Justice Lewis, Lieven J. (2020, December). Bell v Tavistock Approved Judgement.. Retrieved from <https://www.judiciary.uk/wp-content/uploads/2020/12/Bell-v-Tavistock-Judgment.pdf>

Appendices

Appendix 1a. Audit Template questions: Patient demographics and initial referral information

Patient ID	Date of Birth	Natal gender (sex assigned at birth)	Current gender	Date of Referral to the GIDS	Referral Source	Gender Identify Development Service (GIDS) team	Lead clinician at initial assessment	Current Lead Clinician
Do not enter NHS number	Date (01/01/2023)	Male (M) or Female (F)	Male, Female, Non-Binary or other	Date (01/01/2023)	CAMHS / CYP Mental Health, Childrens or Council Service/Local Authority, GP Practice, Paediatrics, Private Healthcare, School, Voluntary sector, Other	London/Leeds/ Birmingham/Midlands Bristol/ Exeter, South East, South West, Other	Full Name	Full Name

Appendix 1b. Audit Template questions: Endocrinology referral and care pathway

Has the patient been referred to the endocrine clinic	If YES (Y), what was their 1st intervention?	If YES (Y), date of referral to endocrine?	If YES (Y), Number of appointments patient has attended pre referral to endocrine	Is patient discharged from the GIDS on referral to endocrine clinic
Yes or No If No - move to column U	<ol style="list-style-type: none"> 1. ONLY Puberty Blockers ONLY (PB), 2. ONLY x-sex hormones /gender affirming hormones (SH/GAH) 3. BOTH PB and SH/GAH (PB + SH/GAH) 4. Puberty assessment ONLY 5. Pt declined treatment 6. Other 	Date (01/01/2023)	<p>5</p> <p>(INCLUDE: 1-2-1 appts with clinicians, network/professional meetings, Child Protection/Children in Need meetings</p> <p>EXCLUDE: Support meetings such as summer groups, family days, parents and siblings groups)</p>	Yes or No If No - move to column T

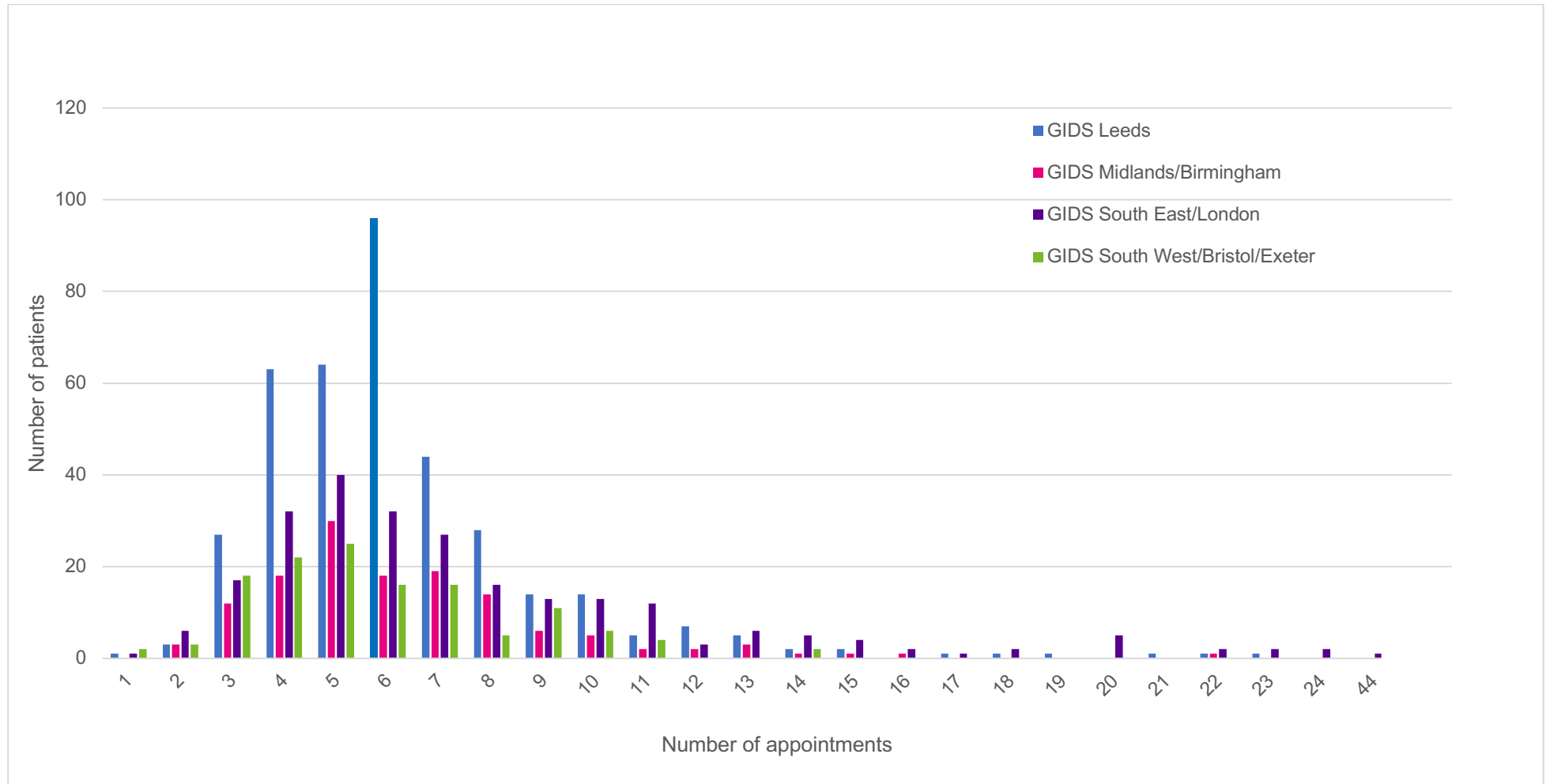
Appendix 1c. Audit Template questions: Discharge information and other comments

Has the patient been discharged for any other reason?	If YES (Y), Discharge reason on patients case file	If YES (Y), Number of appointments patient has attended at GIDS before discharge	If YES (Y), Date of discharge	Does the patient remain on the following at the point of discharge?	Other comments
Yes or No (If No, data capture for this patient is complete)	Select drop down (GDC, patient declined service, other service e.g. CAMHS, patient deceased, other reason)	5 (INCLUDE: 1-2-1 appts with clinicians, network/professional meetings, Child Protection/Children in Need meetings EXCLUDE: Support meetings such as summer groups, family days, parents and siblings groups)	Date (01/01/2023)	1. ONLY Puberty Blockers ONLY (PB), 2. ONLY x-sex hormones /gender affirming hormones (SH/GAH) 3. BOTH PB and SH/GAH (PB + SH/GAH) 4. Puberty assessment ONLY 5. Pt declined hormonal treatment 6. Other	Please do not include PID Ensure any relevant information is captured. Where you have selected 'other' in a column, please indicate the specifics along with which column question it related to. e.g. Column V - patient moved abroad

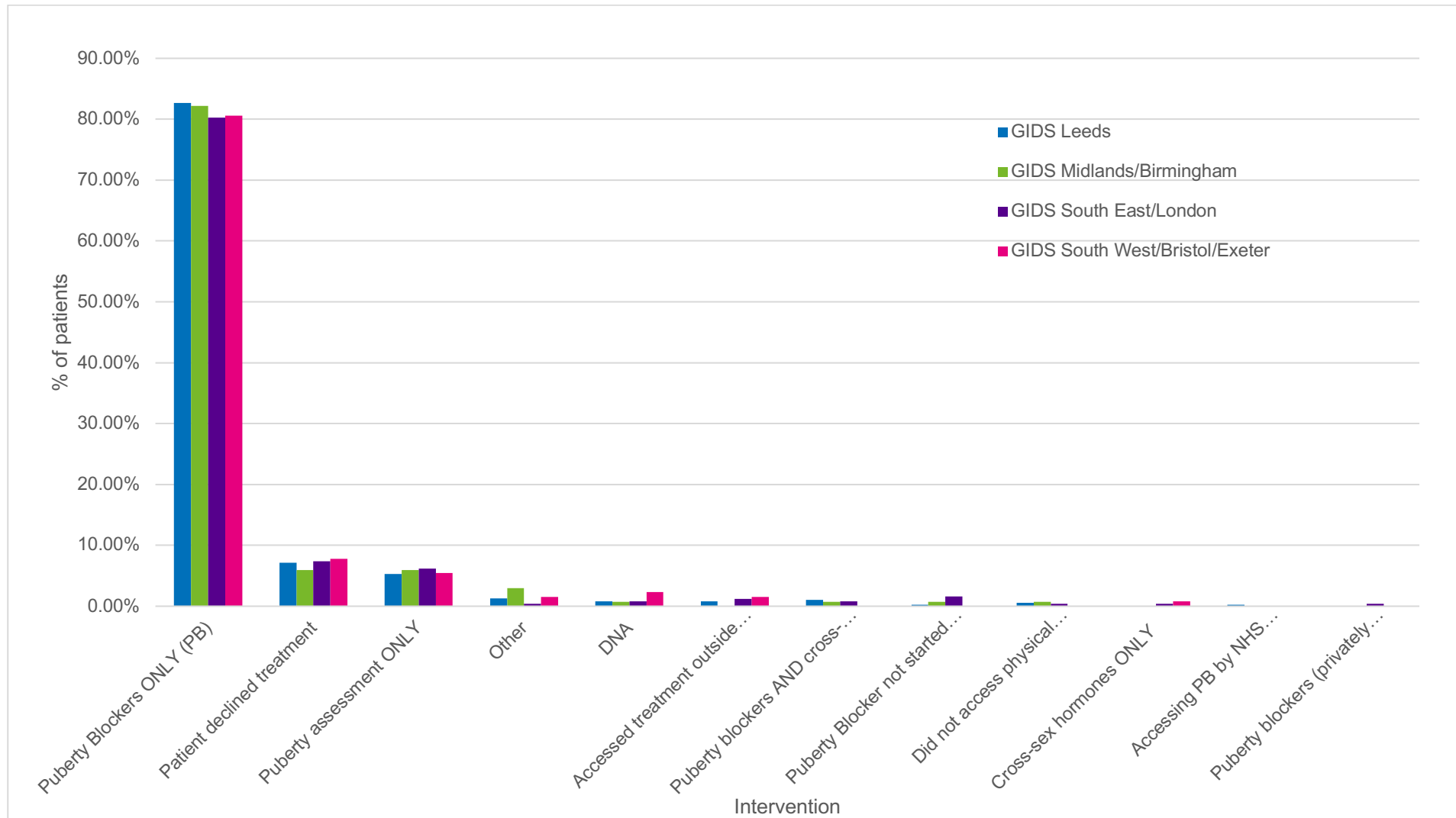
Appendix 2. Breakdown of referral source by GIDS team

	GIDS Leeds	GIDS Midlands/Birmingham	GIDS Southeast/London	GIDS Southwest/Bristol/Exeter	Grand Total
CAMHS / CYP Mental Health	47.34%	44.44%	50.43%	53.02%	48.58%
GP Practice	41.85%	46.27%	37.93%	36.20%	40.68%
Children's or Council Service/Local Authority	X	X	X	X	3.27%
Voluntary sector	X	X	X	X	3.09%
School	X	X	X	X	1.85%
Paediatrics	X	X	X	X	1.57%
Healthcare provider - other	X	X	X	X	X
Healthcare provider - private	X	X	X	X	X
Other	X	X	X	X	X

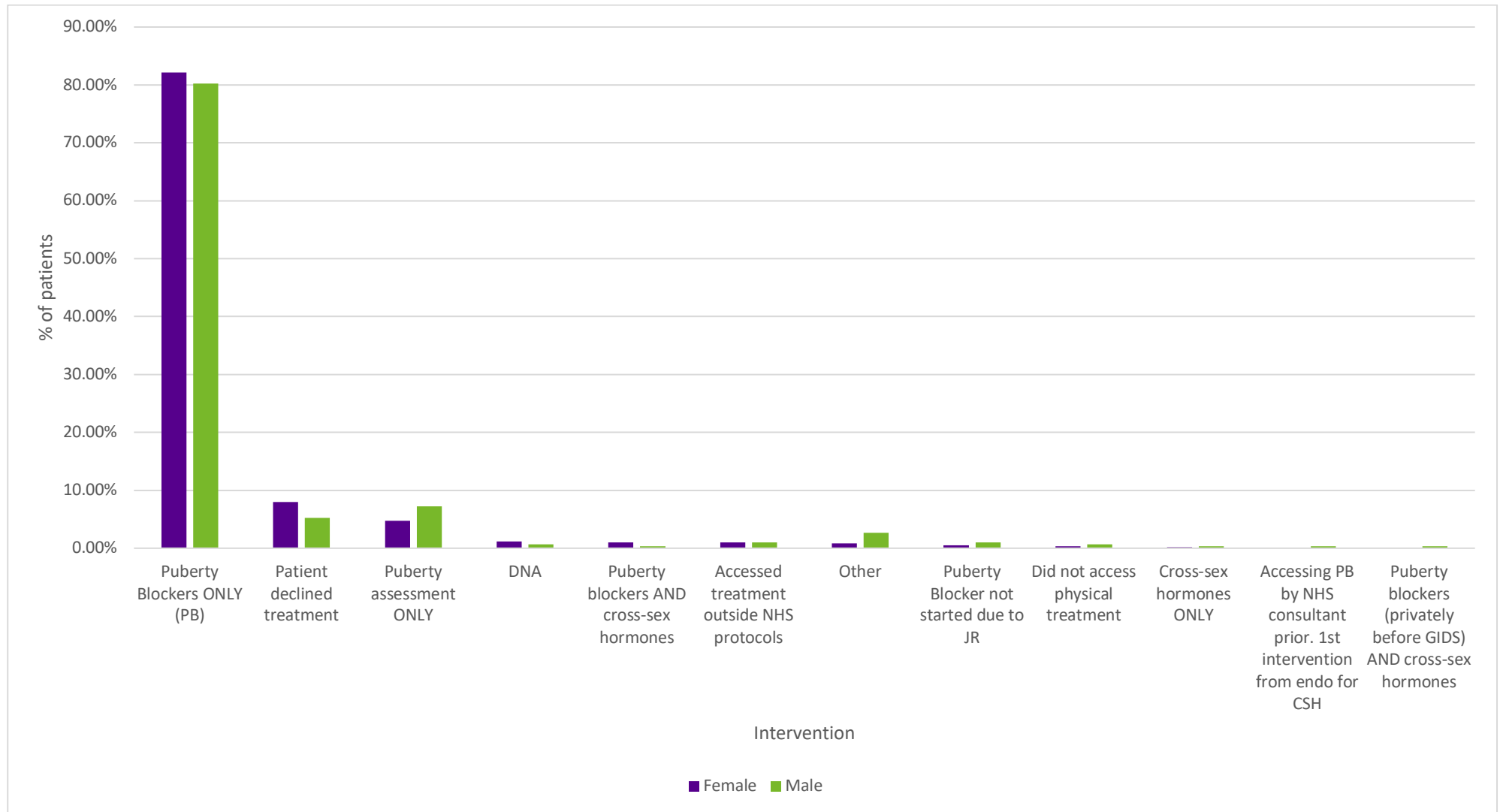
Appendix 3. Distribution of total number of appointments within the GIDS prior to referral to endocrinology, by GIDS team



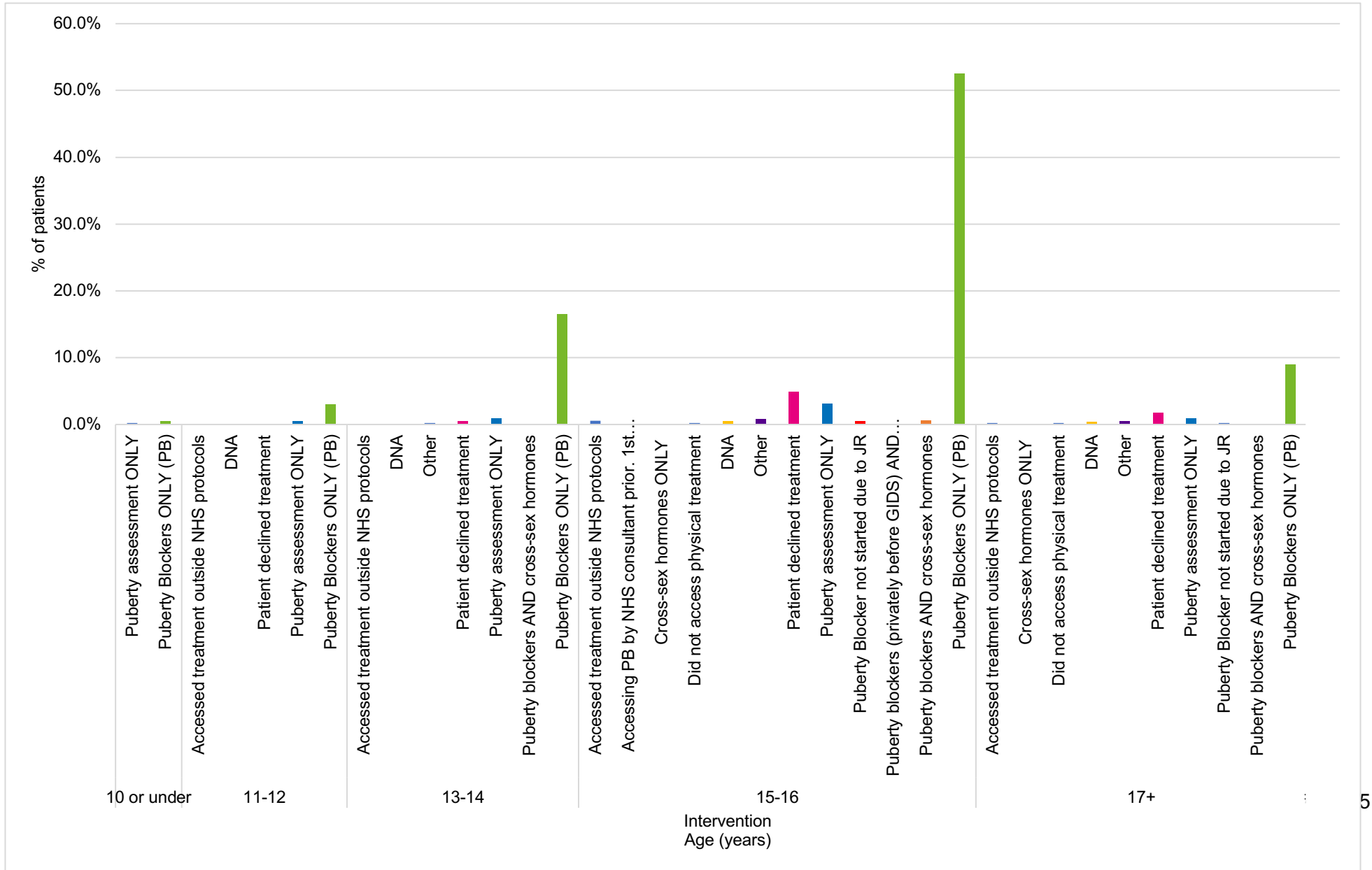
Appendix 4. First intervention for patients referred to endocrinology, by GIDS team



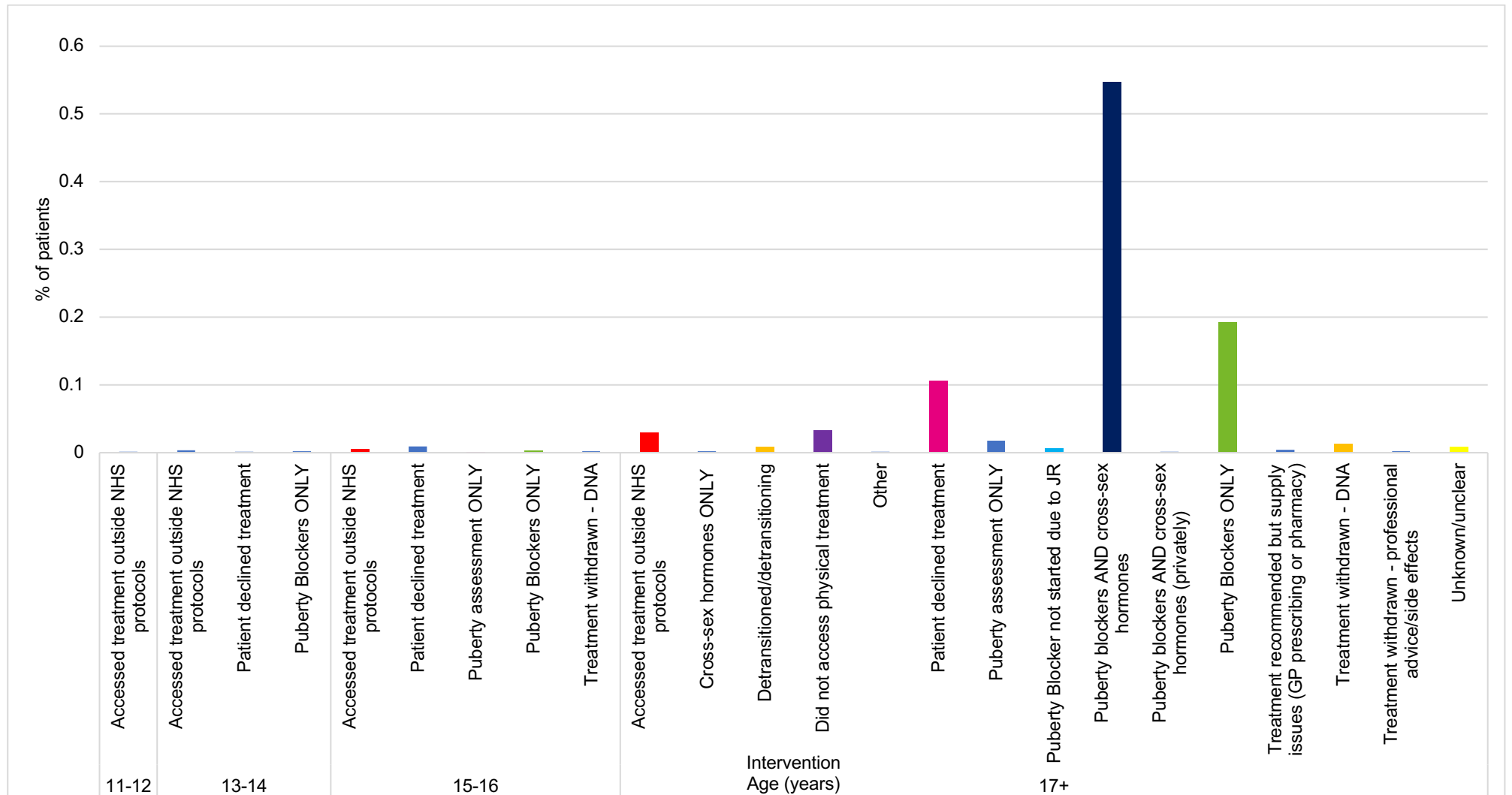
Appendix 5. First intervention following endocrinology referral by natal gender



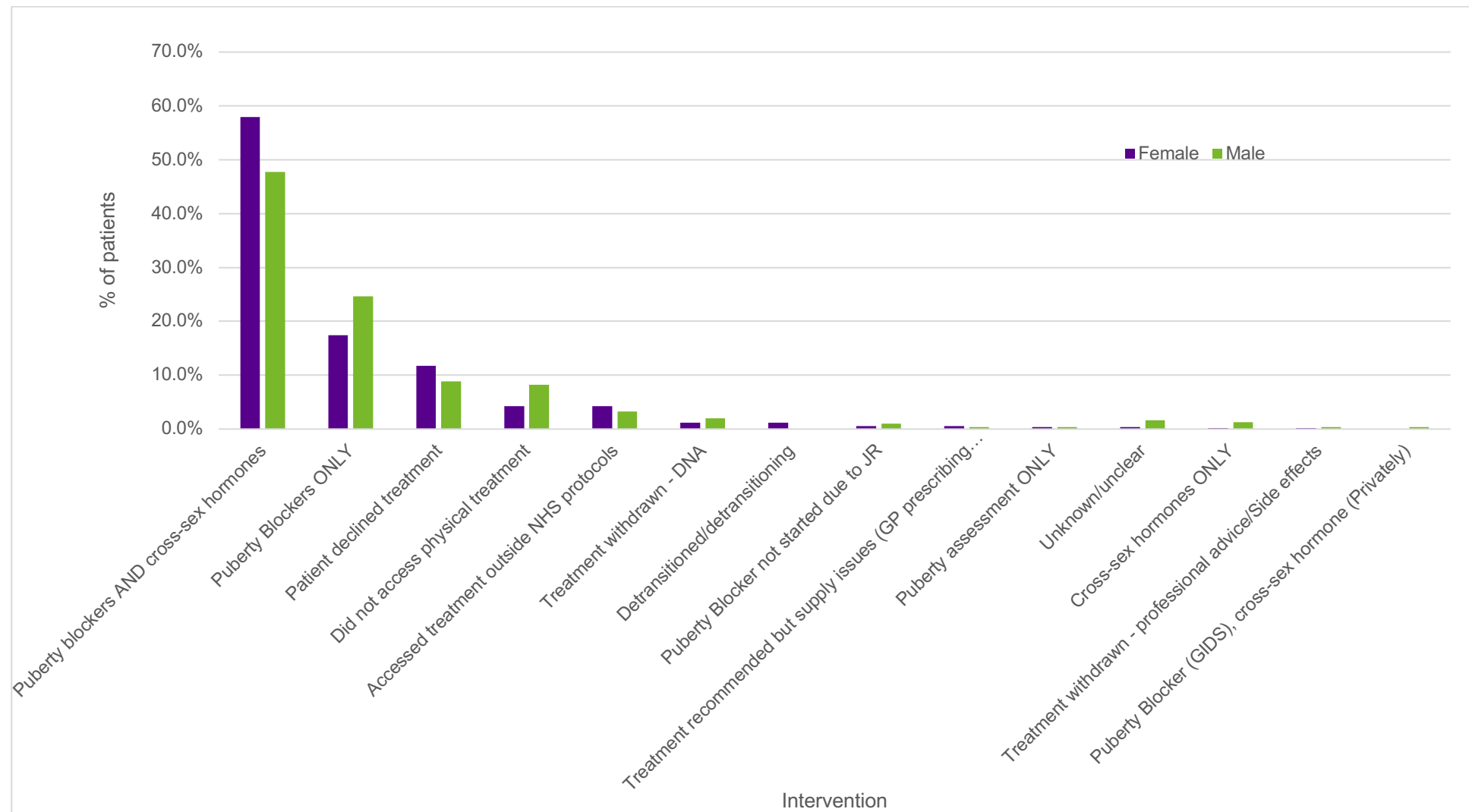
Appendix 6. First intervention following endocrinology referral by age as percent of all patients referred



Appendix 7. Final intervention at discharge from GIDS following endocrinology referral by age as percent of all patients referred



Appendix 8. Final intervention at discharge from GIDS for patients referred to endocrinology, by natal gender



Appendix 9

Date:

Summer 2023

Report:

Learning points from the Gender Dysphoria Multi-Professional Review Group (MPRG).

Provided by: Professor Judith Ellis OBE, Chair MPRG and all members of the MPRG.

Submitted to: John Stewart

Section	<u>Topic</u>	Page numbers
A	Background	2
B	MPRG	2-3
C	MPRG Outcome Options	3
D	MPRG Membership	3
E	MPRG Model of work	3-4
F	MPRG Activity	4
G	Outcomes	4-5
H	GIDS, Tavistock & Portman NHSFT Response	5
I	MPRG Reflections	5-14
J	MPRG Impact	15
K	Moving Forward	15
L	MPRG Summary learning points	15-16

A. Background:

MPRG was established in August 2021 on an interim basis following CQC and NHSE concerns about GIDS.

CQC concerns included:

- Lack of clearly demonstrated and validated assessment tools for staff
- Lack of structured plans for care,
- Decision-making records unclear,
- Teams not always including all specialists necessary for good care,
- Informed child consent procedures not in line with NHS & GMC requirements
 - Consistency of records on competency, capacity and consent
- Inadequate safeguarding

B. MPRG:

B. i: GIDS review

In summer 2021 a decision was taken for NHSE to establish a Multi-Professional Review Group to decide, if assured, whether appropriate process (according to the NHSE Standard Operating Procedure (SOP)) had been followed in order for the requesting clinician to arrive at a request to refer a child (under 16 years) for consideration of endocrine treatment. This included assurance that:

- the assessment and diagnosis are compliant with requirements of the Service Specification
- the child meets the eligibility criteria for referral to the endocrine clinic
- there is a written record of consent by those with parental/guardian responsibility
- clinicians have explained all necessary information to the parents/guardians, in a balanced way, with opportunity for discussion, and parental/guardian concerns have been addressed appropriately, with evidence that they have understood
- there has been opportunity for parents/guardians to discuss with GIDS clinicians without the child being present
- the capacity or ability of a child's parents/guardians to give consent has been explored and confirmed
- there is a written record of consent by the child
- clinicians have explained all necessary information to the child, in an appropriate and balanced way (tailored to developmental needs (e.g. age, ASD, ADHD, etc)), with opportunity for discussion, and the child's concerns have been addressed appropriately, with evidence that they have understood
- there has been opportunity for the child to discuss with GIDS clinicians without the parents/guardians being present
- the capacity or ability of the child to give consent has been explored and confirmed
- child safeguarding and child protection issues have been fully considered by the Tavistock clinicians in line with their statutory and professional duties.

B ii Endocrine Audit:

For the endocrine clinics, which were rated 'good' by the CQC, the MPRG retrospectively undertook a 'light touch' audit of a sample of endocrine assessments (puberty rating and baseline hormone profiles), to confirm confidence in the whole pathway of care.

This supports assurance to Trust executives that a consistent decision-making process is being followed.

C. MPRG Outcome Options:

There are two outcome options available to the MPRG:

- agree that the appropriate process has been followed and assurance given on all counts
- agree that there is insufficient information on which to be assured on one or all of the elements (see 2.1)

If not fully assured, the MPRG seek and the GIDS team are asked to provide, further information. Where this is the case the MPRG via the Chair clearly outlines the information required /action to be taken and the timeline for receipt of the additional information. Further information supplied is considered by the Chair and if necessary, by specific or all MPRG members, and a decision re assurance taken and communicated to GIDS.

N.B. MPRG reports an assurance that a process has been followed – it does not endorse or refuse treatment.

D. MPRG Membership:

- Chair
- Consultant Child & Adolescent Mental Health Psychiatrist
- Senior Paediatric Nurse with Safeguarding experience
- Professor of Paediatric Endocrinology
- Consultant Paediatrician
- Consultant Psychologists x 2
- Senior Social Worker
- Youth Development Worker (In initial cases)

Management and administrative support and Secretariat are provided by the Clinical Effectiveness, Specialised Services team at NHSE

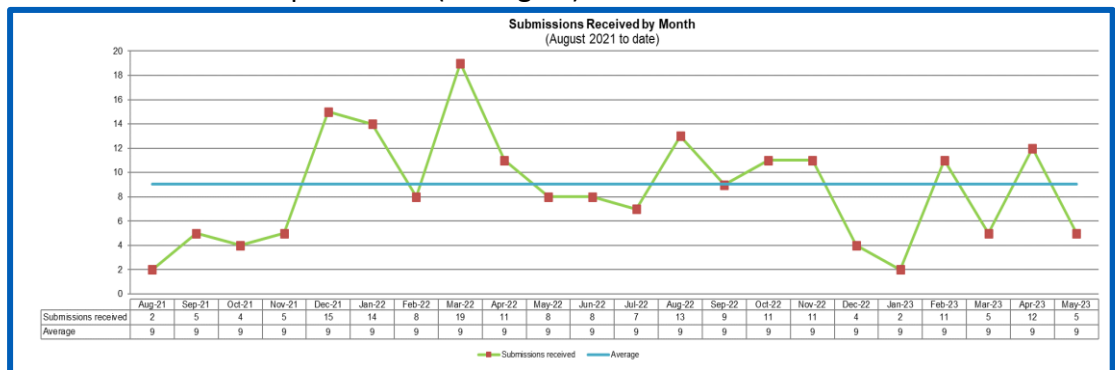
E. MPRG Model of work:

- MPRG meet via an online meeting platform for 4 hrs each week.
- Meetings require 4 members to be quorate (Meetings have never been cancelled due to being inquorate)
- All received documentation is redacted for family names and personal identifiable information
- Meetings are cancelled if no cases have been submitted by the Tavistock or if the NHSE secretariat identify that further redaction or clarification is required before the case is presented to the MPRG for consideration
- Submissions to MPRG have for each case been between 90 to 210 pages in length and vary in quality, from succinct to disorganised and repetitive.
- One MPRG member leads on each case but all members read and consider the complete file.

- Discussions are challenging and probing, remaining professional, respectful, and sympathetic to both the children, families and professional colleagues. As the clinical material can be distressing, the Chair and group seek to maintain psychological safety for participants during the discussions.
- Discussions/ decision documents are typed up by NHSE Admin team and direct quotes from the documentation are used to illustrate points made.
- The Chair reviews and signs off all decision documents.
- All case documentation received is deleted by MPRG members after the weekly discussion and by the Chair once the decision document is signed off.
- N.B. Although in their terms of reference the MPRG are allowed to meet the children and their families, in addition to accepting the importance of client confidentiality and the need for members anonymity, the MPRG have never considered that it would be appropriate or helpful to request a one-off face to face meeting between the young people/family and unfamiliar MPRG members. MPRG have however occasionally required GIDS staff to have additional meetings with the child/family to provide assurance required, particularly around assurance that the child's voice has been heard.

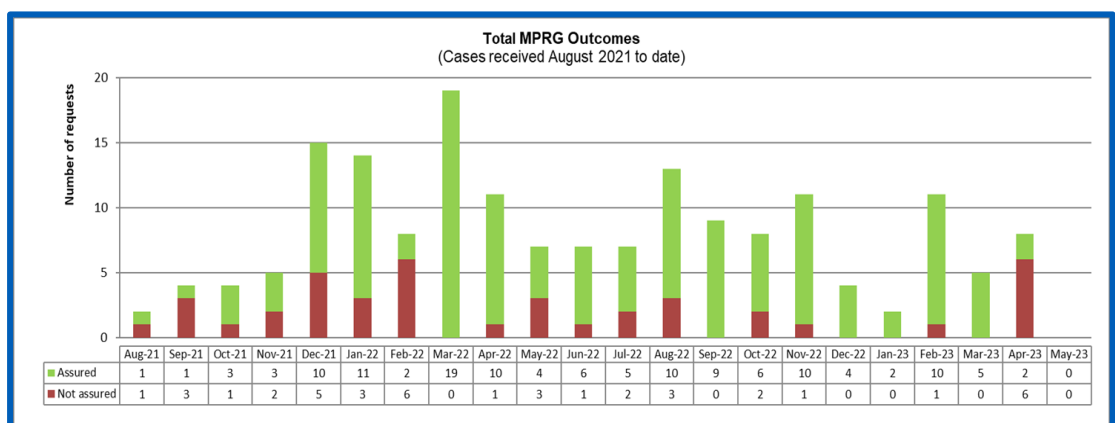
F. MPRG Activity:

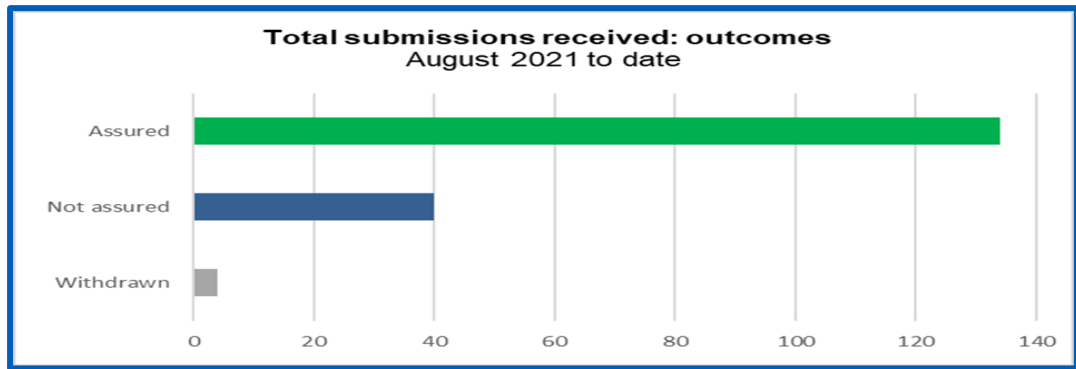
- Submissions received per month (average 9)



G. Outcomes:

- By July 2023 there have been 179 outcome decisions.





- N.B. The MPRG have always met the 20-day review timeline (100%) with a mean time of 10 days.

H. GIDS, Tavistock & Portman NHSFT Response

There have been mixed responses from the GIDS and T & P NHST leadership to the role of the MPRG, shared directly and indirectly with NHSE and the Chair.

Some responses were of expressed relief and indicated that the MPRG process is supportive and that an independent review is valued.

Some responses have, however, included:

- annoyance, due to the increased workload (preparing submissions)
- feeling professionally insulted and not accepting of the need for independent professional review
- the view, sometimes directly shared with children and families, that the MPRG process introduces an additional unnecessary and delaying step in the process of referral to Endocrinology.
- rejecting the need to improve safeguarding practice

I. MPRG reflections

(This section provides overall reflections from the MPRG with no numerical analysis possible as all documents are deleted immediately after a decision document is signed off by the Chair). It is worth noting that the vast majority of documentation provided appears disjointed and unstructured and this makes it vital for the MPRG to examine every page submitted to ensure vital points are not overlooked.

Once documentation is received the MPRG consider the following:

1. Age:

NHSE have analysed the age of children referred to MPRG, at various stages of the patient journey:

	Youngest	Oldest	Average
Age at time of referral to GIDS	4 years 1 month	12 years 5 months	8 years 5 months

Age at first GIDS appointment	5 years 1 month	14 years 6 months	9 years 9 months
Age at submission to MPRG	12 years 0 months	15 years 9 months	14 years 3 months

	Shortest	Longest	Average
Time from initial referral to GIDS to submission to MPRG	3 years 1 month	9 years 1 month	5 years 6 months

- 1.1 The MPRG are fully aware of the difficulties and delays children and their families experience accessing health services, the prolonged GIDS patient journey, including time from initial referral to GIDS to a case being considered by the MPRG. Frustration is evident in the statements received from children and families
- 1.2 MPRG work as a team to try and ensure that the MPRG review does not unduly add to their frustration. The MPRG have always met the 20-day review timeline (100%) with a mean time of 10 days.
- 1.3 The MPRG have noted that assigned girls present to GIDS, and therefore to MPRG later than assigned boys, with the start of menses often the main contributing factor for the increase in desire for medical intervention
- 1.4 Where sexuality was discussed, most cases are of same sex, opposite-gender attracted children. An increasing number of young people described themselves as 'straight' or 'not trans', just a boy/girl.
- 1.5 All cases referred had met or surpassed the 6 GIDS sessions required in the SOP and in many cases children and families had been seen far more frequently.
- 1.6 What has not been clearly evidenced is how thoroughly '*gender identity and consideration of different options for gender expression*' and '*different treatment options/choices*' (SOP) were explored.
- 1.7 MPRG also have a concern that the period between referral and first appointment at GIDS (early-stage delay), has resulted in children and parents having already adopted an affirmative approach. In all but one case, social transition had commenced or completed. There is inconsistent evidence of the individual impact of social transition being explored with children and their families with GIDS tending to affirm the presenting social transition.

1.8 It appears to MPRG from the submissions, that in most cases children and parents were asking to progress on to puberty blockers from the very first appointment with GIDS (see section 3).

2. Physical Medical history:

The GIDS notes supplied to the MPRG rarely provide a structured history or physical assessment, however the submissions to the MPRG suggest that the children have a wide range of childhood, familial and congenital conditions. MPRG has not identified prevalence of specific physical diagnoses in the cohort, including differences in sex development (DSD).

2.1 In a small number of cases parents/ guardians were notably disappointed when an 'intersex' (DSD) diagnosis was not applicable to the child.

3. Gender journey

3.1 Assigned and current gender are identified to the MPRG.

3.2 It is noted by the MPRG that although the Cass interim report shows a large increase in assigned female to male cases this has not been reflected in the cases referred to the MPRG, which remain predominantly assigned male to female cases (NHSE analysis: From August 2021 to April 2023 MPRG had considered 49 Assigned Female cases and 117 Assigned Male cases).

3.3 Information about the child's gender journey is provided by GIDS and it is notable that until the child and family's first appointment at GIDS they have received little, if any, support from health, social care, or education professionals. Most children and parents have felt isolated and desperate for support and have therefore turned for information to the media and online resources, with many accessing LGBTQ+ and GD support groups or private providers which appear to be mainly affirmative in nature and children and families have moved forward with social transition.

3.4 Evidence of adequate exploration of gender identity journey is, therefore, difficult to assure as prior to MPRG consideration, many children have already fully socially transitioned. Most children have changed their names by deed-poll, attend school in their chosen gender and some have changed NHS numbers and passports. (See section 1.4). This history/journey is rarely examined closely by GIDS for signs of difficulty, regret or wishes to alter any aspect of the child's gender journey trajectory.

3.5 Using the documents presented by GIDS to the MPRG it is difficult to assess whether GIDS clinicians have taken an exclusively affirmative stance with the child and family.

3.6 Although a diagnosis of gender dysphoria *DSM-5* (children with consideration of adolescent and adults criteria for older children) is required by the SOP, the MPRG acknowledges that the *DSM-5* diagnostic criteria for gender

dysphoria has a low threshold based on overlapping criteria, and is likely to create false positives, i.e. young people who do not go on to have an enduring cross-sex gender identity may have met the criteria in childhood and early – mid childhood social transition may be influential in maintaining adherence to the criteria. Sex role and gender expression stereotyping is present within the diagnostic criteria e.g., preferred toys, clothes etc., not reflecting that many toys, games and activities for children and young people are less exclusively gendered than in previous decades. Retrospective assessment of distress and poor social functioning in a child or young person is fraught with difficulty.

3.7 As stated in 1.4 and 3.4 in the cases considered by the MPRG social transition has occurred. The MPRG is concerned that some children are continuing to live in stealth, with a common, genuine fear of “being found out”, suffering rejection either due to having not taken friends into their confidence (with holding personal information regarding biological sex or specific sex based experiences), or due to trans-prejudice or phobia. MPRG observe that living in stealth appears to increase a child’s level of stress and anxiety with resultant behaviour and mental health problems, including social withdrawal, with children becoming increasingly isolated, including resorting to home-schooling or tutoring, with some distressing descriptions of children rarely leaving their house.

3.8 MPRG have noted both excellent examples of good practice by families and schools in supporting children as they socially transitioned and some worrying examples of unhelpful practices and restrictions.

4. Mental Health:

4.1 Some of the children have had contact with CAMHS at some stage on their GD journey or are on a long waiting list for a CAMHS review (mention of 2-6 year waiting times). In most cases once GIDS were engaged in care, CAMHS were no longer involved. However, MPRG note some examples of great quality collaborative parallel working with CAMHS, school-based therapists or private counsellors.

4.2 The most prevalent mental health issues appear to be social anxiety and the threat of self-harm (including children threatening to cut off their penis), with many families reporting actual self-harm behaviour and injuries having occurred (e.g. eating disorders, cutting, etc.).

4.3 A considerable number of children appear to express suicidal thoughts, particularly at the first signs of puberty, but there has been limited evidence in the MPRG cases of suicidal behaviour.

5. Neurodevelopmental:

5.1 In the majority of cases considered by the MPRG, there is mention of possible ASD or ADHD traits or diagnoses.

5.2 Confirmation of appropriate and complete assessment is rarely available, and there remains some confusion as to how or whether formal diagnosis has been made and whether formal assessments have used sex or gender related psychometric tools to assess children with gender dysphoria and neurodevelopmental concerns. For example, the continuous performance test (Qb) used as part of the ADHD assessment has a sample of children identified at birth as male and a sample identified at birth as female. While the correct use of pronouns and names is key, this is a computer-based programme which does not provide a sample of children with gender dysphoria.

5.3 There appears to be a prolonged waiting time from identification of neurodivergent traits to formal assessment (2- 4 years).

5.4 It is of most concern that where a neurodevelopmental disorder is suspected, but not confirmed because a formalised assessment is not available, there is often limited evidence of GIDS professionals ensuring that options and care has been explained to ensure the child's understanding so that valid consent can be obtained. There was often insufficient evidence of how GIDS make decisions made about the use of appropriate assessment tools for children with additional needs.

6. Psychosocial

6.1 No genograms / family trees were made available and it was difficult to ascertain family structure and relationships from the documentation provided due to redaction.

6.2 The psychosocial background of the children considered by MPRG was rarely uncomplicated and usually complex. MPRG were frequently concerned about the lack of evidence of professional curiosity as to how a child's specific social circumstances may be impacting on their Gender Dysphoria journey and decisions, for example; physical or mental illness within the family, abusive or addictive environments, bereavement, cultural or religious background, etc..

6.3 The children in many of the cases reviewed by the MPRG were residing with one parent but in most cases, there was shared parental responsibility and GIDS had made marked effort to engage with both parents.

6.4 MPRG members considered the impact that each child's home psychosocial situation may have been having on their gender journey, for example, their exploration of options, affirmative or transphobic beliefs and experiences and any possible coercion, family to child or child to family.

6.5 MPRG found it extremely useful to receive external organisation reports, for example from a child's school, that gave some indication of a child's social and psychological state e.g. peer group interactions and relationships and

acceptance, expression of gender identity and wellbeing, school attendance, academic achievement. Furthermore, there were frequent occasions where school reports were significantly out of date.

6.6 MPRG were particularly concerned and interested to understand why a child might be living in stealth and/or was socially isolated, for example being home schooled, taking into account the difficulties enhanced by Covid restrictions. The evidence provided by GIDS frequently failed to provide adequate explanation.

7 Multi-professional Teams

7.1 The Multi-professional nature of the MPRG is a definite benefit with all professionals approaching consideration of the same case from a particular expert standpoint, with constructive challenge from interested and supportive colleagues leading to comprehensive clarity in overall MPRG decision making.

7.2 The Pre MDCR meetings introduced by GIDS over the last year has gone some way to provide this multi-professional consideration of cases and notes from this meeting often identify the same concerns as are raised by the MPRG. The meeting notes from MCDR frequently show that questions or actions were raised, but it is very rare that evidence of answers or resolution of the action is documented.

7.3 It was rare to see appropriate referral of cases for consideration at Complex Case Panels and where this occurred the multi-professional membership, conclusions and actions were unclear.

7.4 A recurrent problem noted by the MPRG was the lack of routine endocrinology involvement during the GIDS process.

7.4.1 A paediatric endocrinologist would have been able to ascertain whether the child has entered puberty and if the Tanner stage reached met the SOP requirement for referral to endocrinology.

In most cases puberty staging depended upon child and family reported changes being interpreted by professionals with no endocrine training. Essentially, the GIDS team was undertaking the layperson's approach to when puberty starts. In summary: Male puberty was based on voice 'breaking' (in reality this occurs between Tanner stages 3-4), some hair 'down below', spontaneous erections described by a variety of terminology, squaring of the shoulders, some facial hair growth, height growth spurt. A key early sign of the onset of male puberty is the increase in testis volume from 3ml to 4ml. Clearly this can only be confirmed by examination. Female puberty was based on 'chest development', aka breast development which an early sign of puberty in girls (equivalent to the testis volume sign in boys). However, the 'chest development' may not represent true breast enlargement but be due to fatty tissue from obesity. Hair 'down below' is akin to pubic hair growth. The definitive marker of puberty well advanced in girls is the onset of menses. This is a late event female puberty, occurring after the growth spurt and equivalent to Tanner stage 4. There is no equivalent in boys, although

nocturnal 'wet dreams' would be approximately the same puberty state i.e., late, and well beyond the Tanner 2 stage.

The GIDS members were also involved in counselling about puberty blockers work, their potential side effects, and the need to be judicious in their use in assigned males in order to optimise penile growth to use for subsequent genitoplasty. The team was also involved in detailed discussions about future fertility and technical aspects of gamete preservation.

- 7.4.2 A recurrent concern for the MPRG was the inadequacy and on occasions inaccuracy of answers given to children and their families by GIDS and their failure to correct child and parental misconceptions about puberty, puberty blockers and hormones. These misconceptions were often evident in the Child and parental statements made at the end of the period of assessment after which the GIDS service had deemed the child appropriate for referral for physical intervention. Examples included:
- a. Failing to explain that puberty blocker use in GD cases is unlicensed and off label
 - b. Correcting parents when they quoted use in GD to be the same as licensed use in precocious puberty
 - c. Covering known side effects but minimising that a lot is still unknown about short- and long-term side effects,
 - d. Discussing the permanent and reversible impact of puberty blockers on fertility,
 - e. Not sharing figures around how many children who start puberty blockers go on to hormone treatment.
 - f. Rarely is a possible pause or slowing of psychosocial development discussed in relation to the use of puberty blockers.

7.5 MPRG were always provided with a copy of a completed Hormone Blocker Checklist and a Hormone Blocker Referral consent form signed by the child, parent/guardian and GIDS clinician. It was noted that although counterintuitive in most cases the checklist was completed after the consent form.

It would have been far more reassuring if in all cases an endocrinologist had been involved in the completion of this checklist, and early involvement of an endocrinologist would streamline the patient journey as currently after referral a further checklist is completed and a further consent for treatment form is signed by the child and parents and the prescribing endocrinologist. An endocrinologist as a member of the GIDS multi-professional team could ensure informed consent in relation to puberty blockers as well as assuring themselves as the prescriber, of the gender dysphoria diagnosis.

8 Private Puberty Blockers (PPB)

- 8.1 An increasing concern for the MPRG is the number of children who have commenced private puberty blockers (PPB).

- 8.2 Private providers do not follow the prescribing, administration and investigation/ monitoring protocols agreed and followed by the NHS.
- 8.3 It is apparent that children and parents seek this option due to their frustration with NHS delays and that parents believe that they are acting in the 'best interest' of their child.
- 8.4 When the MPRG was established in 2021 the GIDS team negated their responsibility to discuss any clinical concerns about private treatment with children and families but have since accepted their responsibility as stated in the SOP to discourage families from accessing treatment that is not being delivered according to NHS protocols. GPs have also been advised against prescribing these unlicensed, off label drugs and PPB's are more likely to be delivered by post from overseas.
- 8.5 As children and families face the increasing worry of further delay due to changes to GIDS provision, MPRG are now having cases presented where parents have, or are threatening to commence PPB's even though the treatment is not as identified in NHS protocols, the families have received no information about side effects or the impact on fertility, and no or limited baseline tests (e.g. bloods, dexamethasone scan) have been done. It is suspected that this is an attempt by parents/guardians to put pressure on the MPRG and NHS that for the child's safety they should be immediately referred for NHS treatment. This safety argument is particularly challenging in cases where PPB's were commenced with temporary charity funding which has now been withdrawn, and the cessation of treatment that the child believes is helping would potentially cause the child significant distress.

9 Consent

- 9.1 MPRG confirm that consent for referral to endocrinology has been signed and dated by the child, parent/guardian and clinician and generally this has been easy to locate in the documentation, with the MPRG required to accept redacted signatures are the child's and the signature of the parent/s/guardian/s who hold parental responsibility, and the unknown professional's signature.
- 9.2 For assurance the MPRG consider all information provided to confirm that: Clinicians have explained all necessary information, giving opportunities for discussion, confirming understanding, and that concerns have been addressed appropriately including:
- Exploration/ consideration gender identity/ expression and treatment options
 - Purpose and nature PBs: advantages and disadvantages
 - Evolving research and understanding of the known implications and short and long term consequences of treatment' PLUS many unknowns.
 - Fertility treatment options
 - 98% expectation progress to hormone treatment, surgery, etc
- 9.2.1 For children, clinicians are required to explain the information in an appropriate and balanced way, tailored to the child's developmental needs, which includes neurodevelopmental needs.

This was an area carefully considered by the MPRG and although the range of approaches to explain information and to confirm understanding directly used by GIDS in sessions has generally been impressive, in a number of cases additional information was requested by the MPRG.

- 9.2.2 As described in 1.4 and 3.4 due to the delay in access to GIDS, and the affirmative stance already evident at first appointments, the MPRG carefully sought evidence of consideration of gender identity and treatment options.
- 9.2.3 Fertility treatment options were generally well covered, with appropriate consideration of age-related decision making but by non-specialists in this area. However, the discussion of childhood interruption of the development of organs that reach mature function in adulthood is rarely evidenced.
- 9.2.4 Advantages and disadvantages of PB's were generally covered but the MPRG often requested further confirmation that evolving research, unknown consequences and the 98% expectation of progress to hormone treatment had been adequately discussed and understood.
- 9.2.5 As stated in 7.4 there was concern from MPRG that the absence of endocrinology input did raise concerns about adequacy of some of the information given and handling of questions and the addressing of concerns before the signing of the consent for referral form although it is acknowledged that a further consent form is signed once a child is under endocrinology and this consent is audited as part of the MPRG light touch endocrine audit

9.3 The MPRG looked for confirmation of the child and parent/guardian's capacity and ability to consent, that the parents/guardians and children:

- Understood and retained relevant information long enough to make a decision
- Used the information as part of the process of making a decision
- Were able to communicate decision to others
- And that there was no evidence of coaching /coercion of parents/child

9.3.1 MPRG were mainly reliant on the GIDS clinicians' assessment of the parent guardians' capacity and ability to consent.

9.3.2 Written statements from parents were provided. Many were moving and helpful, but some were used by parents to praise GIDS staff and to complain about the MPRG process. Many betrayed grave misunderstandings of the nature of gender dysphoria and the outcome of physical treatments.

9.3.3 MPRG occasionally had concerns that parents were being encouraged to move forward to consent by others, but this was difficult to confirm.

9.3.4 There were occasional cases where the parents appeared to be fearful of what they anticipated might be their child's response if they did not consent, (for example child threats of self-harm, suicide, or aggressive behaviour). On these occasions the MPRG carefully considered the notes of meetings when parents were seen alone.

9.3.5 MPRG were provided with an impressive array of resources to demonstrate the children's understanding and exploration of information including verbatim transcripts of discussion with children. While noting that

clinical practice evolves over time and many of the cases presented were seen over an extended period, MPRG were sometimes surprised to see the marked differences in approach and clinician choice of assessment and information giving materials.

9.3.6 In an attempt to hear the child's voice children were asked to write a short statement for MPRG. A few were extremely helpful and informative, but most were extremely brief and unhelpful and on occasions there was suspicious concern due to the language used that they had been rehearsed, written, or dictated by others. Often they included worrying misunderstanding of the outcome of physical interventions.

9.3.7 School reports, when thoughtfully completed were extremely useful in confirming whether the child had capacity and ability to consent.

9.3.8 If the MPRG were unconvinced that they were hearing the child's voice, or if there was concern that there may be coercion from others, the notes from the meetings when the child had been seen alone were carefully considered and on a number of occasions, especially if the child had not been seen alone for some time (e.g. for over a year), the GIDS team were requested by MPRG to organise a 1:1 review and update with the child and resubmit notes from this meeting to the MPRG.

10 Safeguarding & Child protection

When the MPRG began reviewing cases the Tavistock team were unwilling to comply with MPRG safeguarding reporting requirements, but this situation has been partially resolved.

10.1 The MPRG now see Confirmation from Social Services as to whether at the point of referral to the endocrine clinic the child is the subject of a statutory order e.g. a current Child Protection Plan or a Child in Need Plan.

10.2 A Tavistock Risk and Safeguarding assessment form is included in documentation received by the MPRG which is meant to indicate if GIDS are aware of any non-statutory safeguarding concerns including any that have been raised by any health, education, police or social care professionals involved in the child's care.

Although very occasionally a TRSA form is continuously and comprehensively completed, in most cases it has been completed just before the submission is sent to the MPRG and is incomplete when considered alongside issues noted by the MPRG whilst reviewing documentation received. Examples of issues identified by the MPRG include increased psychosocial vulnerability (including complex family relationships/situations/illness/addiction/domestic abuse), transphobic bullying, online abuse/ grooming, isolation, self-harm, suicidality, etc.)

Incomplete forms are returned to GIDS for reconsideration and resubmission.

10.3 MPRG continue to be very concerned about the GIDS teams lack of apparent professional curiosity or concern in relation to risk and safeguarding.

J. MPRG Impact

Positives:

- When established it was estimated that around 4,000 cases were being prepared by Tavistock GIDS for referral to the endocrine service. The MPRG have only received around 180 cases for review, and it is likely that these were cases that the GIDS team considered ready for referral. As shown in section G MPRG were not assured on all counts in 42 of these cases and additional information and action was requested prior to reconsideration. 2 of the 42 cases were withdrawn, 5 are still awaiting resubmission but in the remaining cases further information provided was found to be sufficient to provide assurance on all counts, allowing referral to endocrinology. The figure unknown to MPRG is the number of the remaining 3,820 cases originally stated to be in the system were not submitted to the MPRG due to MPRG requirements for assurance.
- Safeguarding practice has been transformed and strengthened.
- Vast amount of learning to inform Cass Review and support establishment of new centers

Perceived negatives:

- Further perceived delay due to MPRG process (NB MPRG achieved 100% compliance with NHSE agreed timeline)
- GIDS clinicians spending time preparing documentation for the MPRG, time that could have been spent with patients
- NHSE budget required for MPRG activity

(These were all unavoidable as required to deliver the NHSE brief)

K. Moving forward

The MPRG assure GIDS compliance with the SOP in place in 2021. When a new SOP and Service Specification are agreed and new services are established MPRG will be stood down. MPRG members envisage that the service provider's internal governance structures will have the oversight and be responsible for monitoring the quality and functioning of the service against the new service specifications standards and KPI's, with the opportunity for internal and cross-provider safe, respectful and supportive peer review.

The MPRG team members could be called upon to provide a supportive, advisory role as new services are developed and stabilised.

L. MPRG summary learning points:

- a. Essential need for early outreach, including possible direct and indirect support to parents with flexible support for the gender dysphoric child**
- b. Develop first point of access support to help explore *gender identity and consideration of different options for gender expression*'.**
- c. Improve on *DSM-5* diagnostic criteria Acknowledgement that a child meeting diagnostic criteria (DSMV or ICD 11) may reject a cross sex gender identity in later years**
- d. Need A full psychosocial assessment**

- e. **Need to increase the availability of ASD or ADHD assessments appropriate for age and gender identity, and for the powerful platform developed in this process to be used to ensure that wording and tools can fit all gender and sexual identities.**
- f. **Prioritise hearing child's voice with facility for a developing supportive conversation as the child learns about the complexities of cross-sex gender expression**
- g. **Liaise with schools, directing them to information and offer consultation/support to staff**
- h. **Adequate safeguarding and risk management**
- i. **Each professional act within their area of expertise**
- j. **Endocrinologist part of GIDS MDT**
- k. **Different treatment option/choices explored 'including the advantages and disadvantages of treatments, risks and complications of management options including medical intervention. .**
- l. **Ensure the child, parents and guardians understand Information on the purpose, nature and physical consequences of puberty blockers (e.g., menopause, osteoporosis and impact on fertility) including consideration of unknowns (to include for example: wellness during period without sex hormones, sexual function, fertility, Psychosocial development and cognitive function), 'evolving research and understanding of the implications and long-term physical consequences of treatment', and that 98% of children would progress to taking sex hormones.**
- m. **parents/guardians should periodically meet GIDS clinicians without the child being present'**
- n. **child should periodically meet with GIDS clinicians without the parents/guardians being present'**
- o. **the capacity or ability of child and parents/guardians to give consent are adequately explored**
- p. **Standard Operating Procedures should be agreed and implemented, clearly outlining the decision-making process / pathways that need to be followed to lead to a referral decision, with built in check points.**
- q. **A structured decision-making framework should be followed and documented when considering each case**

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Appendix 10

Diagnostic criteria for gender dysphoria

DSM-5-TR diagnostic criteria for gender dysphoria

Gender Dysphoria in Children

The DSM-5-TR defines gender dysphoria in children as a marked incongruence between one's experienced/expressed gender and assigned gender, lasting at least 6 months, as manifested by at least six of the following (one of which must be the first criterion):

- A strong desire to be of the other gender or an insistence that one is the other gender (or some alternative gender different from one's assigned gender)
- In boys (assigned gender), a strong preference for cross-dressing or simulating female attire; or in girls (assigned gender), a strong preference for wearing only typical masculine clothing and a strong resistance to the wearing of typical feminine clothing
- A strong preference for cross-gender roles in make-believe play or fantasy play
- A strong preference for the toys, games or activities stereotypically used or engaged in by the other gender
- A strong preference for playmates of the other gender
- In boys (assigned gender), a strong rejection of typically masculine toys, games, and activities and a strong avoidance of rough-and-tumble play; or in girls (assigned gender), a strong rejection of typically feminine toys, games, and activities
- A strong dislike of one's sexual anatomy
- A strong desire for the physical sex characteristics that match one's experienced gender

As with the diagnostic criteria for adolescents and adults, the condition must also be associated with clinically significant distress or impairment in social, occupational, or other important areas of functioning.

Gender Dysphoria in Adolescents and Adults

The DSM-5-TR defines gender dysphoria in adolescents and adults as a marked incongruence between one's experienced/expressed gender and their assigned gender, lasting at least 6 months, as manifested by at least two of the following:

- A marked incongruence between one's experienced/expressed gender and primary and/or secondary sex characteristics (or in young adolescents, the anticipated secondary sex characteristics)
- A strong desire to be rid of one's primary and/or secondary sex characteristics because of a marked incongruence with one's experienced/expressed gender (or in young adolescents, a desire to prevent the development of the anticipated secondary sex characteristics)
- A strong desire for the primary and/or secondary sex characteristics of the other gender
- A strong desire to be of the other gender (or some alternative gender different from one's assigned gender)
- A strong desire to be treated as the other gender (or some alternative gender different from one's assigned gender)
- A strong conviction that one has the typical feelings and reactions of the other gender (or some alternative gender different from one's assigned gender)

In order to meet criteria for the diagnosis, the condition must also be associated with clinically significant distress or impairment in social, occupational, or other important areas of functioning.

ICD-11: HA60 Gender incongruence of adolescence or adulthood

Gender Incongruence of Adolescence and Adulthood is characterised by a marked and persistent incongruence between an individual's experienced gender and the assigned sex, which often leads to a desire to 'transition', in order to live and be accepted as a person of the experienced gender, through hormonal treatment, surgery or other health care services to make the individual's body align, as much as desired and to the extent possible, with the experienced gender. The diagnosis cannot be assigned prior the onset of puberty. Gender variant behaviour and preferences alone are not a basis for assigning the diagnosis.

Exclusions:

Paraphilic disorders. Independent review of gender identity services for children and young people

ICD-11: HA61 Gender incongruence of childhood

Gender incongruence of childhood is characterised by a marked incongruence between an individual's experienced/ expressed gender and the assigned sex in pre-pubertal children. It includes a strong desire to be a different gender than the assigned sex; a strong dislike on the child's part of his or her sexual anatomy or anticipated secondary sex characteristics and/or a strong desire for the primary and/ or anticipated secondary sex characteristics that match the experienced gender; and make-believe or fantasy play, toys, games, or activities and playmates that are typical of the experienced gender rather than the assigned sex. The incongruence must have persisted for about 2 years. Gender variant behaviour and preferences alone are not a basis for assigning the diagnosis.

Exclusions:

Paraphilic disorders.

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Appendix 11

To: Dr Hilary Cass

NHS England
Wellington House
133-155 Waterloo Road
London
SE1 8UG

By Email

17 January 2024

Dear Hilary

INDEPENDENT REVIEW OF GENDER IDENTITY SERVICES FOR CHILDREN AND YOUNG PEOPLE – QUANTITATIVE RESEARCH PROGRAMME

With the Review now entering its final stages, I wanted to confirm an approach for handing over to NHS England certain aspects of the Review's research programme which will need to continue beyond delivery of your final report.

The Review's interim report highlighted that one of the challenges with understanding how best to improve NHS services for this group of children and young people is the lack of high quality data. A good example is that little is known about the medium and longer-term outcomes for children and young people who were seen by the Gender Identity Development Service (GIDS) at the Tavistock and Portman NHS Foundation Trust.

The Review's quantitative research programme, led by the University of York, aimed to improve the evidence and provide a better understanding of the treatment approaches for this population of children and young people. The research aimed to do this by tracking the journeys of young people who were seen by GIDS into NHS adult gender dysphoria clinics and the wider health system, to provide a population-level evidence base of the different pathways.

The Secretary of State for Health and Social Care granted an order under s22(5) of the Gender Recognition Act to enable data to be disclosed for a time-limited period for the sole purpose of the study. Like all NHS research, the study was subject to strict ethical and legal controls with an 'opt out' option for individuals who did not wish to have their data used as part of the study.

NHS England was fully supportive of the proposed approach; and the research received full approval from the Health Research Authority.

As you know, the study relied upon the seven NHS trusts in England that host adult Gender Dysphoria Clinics and the GIDS fully cooperating with the University of York in support of the research and NHS England wrote to the Chief Executives and Medical Directors of those organisations accordingly. Regrettably, it is now clear that despite the best efforts of the research team, the necessary cooperation from the clinical leads within those services has



not been forthcoming, and consequently the University of York has advised that as things currently stand, it is not appropriate to yet begin the next stage of the study.

This is clearly very disappointing and if left this way would represent a missed opportunity for the NHS to lead the way internationally in gathering high quality evidence that can, for the first time, present a better understanding of the longer-term outcomes for individuals who have received clinical or medical intervention for gender dysphoria / gender incongruence in childhood or adolescence.

I am sure you will agree that the NHS should not lose the opportunity to make further use of the statutory instrument that was passed by Parliament, which enables the collection of the data for use in an approved research study until 2027. As such, I am writing to confirm that NHS England will take over responsibility for realising the ambitions of the study and the NHS National Research Oversight Board for Children and Young People's Gender Services, chaired by Professor Sir Simon Wessely, is well placed to support us in this task. In your letter of 31st January 2023 you flagged that there would be a need for continued oversight of this work beyond the life of the Review, so I hope this approach reassures you that this aspect of the Review's work will not be lost.

As part of the handover process, I would be grateful if you could carefully document the work completed so far, including the circumstances that led the University of York to reach the conclusion that it was not yet possible to move ahead with the next stages of the research study. I would also welcome any specific recommendations you might wish to make for NHS England's consideration as we look to regain momentum with this important study.

I want to thank you for your vitally important ongoing work in improving services for this group of children and young people, and I look forward to receiving your final advice early in 2024.

Yours sincerely



John Stewart
National Director, Specialised Commissioning

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Appendix 12



Independent review
into gender identity
services for children
and young people

Dr Hilary Cass
Chair
Review of GIDS for Children and Young People

John Stewart
National Director
Specialised Commissioning
NHS England and NHS Improvement

Sent by email

20 March 2024

Dear John

INDEPENDENT REVIEW OF GENDER IDENTITY SERVICES FOR CHILDREN AND YOUNG PEOPLE – QUANTITATIVE RESEARCH PROGRAMME

I am writing in response to your letter of 17 January regarding the Review's commissioned quantitative research programme, advising that, despite your welcomed efforts to obtain cooperation, most of the NHS gender clinics have refused to take part in this research.

It has not been at all straightforward trying to get this research off the ground. It has absorbed a considerable amount of time and attention from the Review and the researchers at the University of York, as well as from NHS England and the Department of Health and Social Care, all of which has delayed our work.

The study follows usual NHS research practice, it is only novel because of the sensitivity of the subject matter and the issue of changing NHS Numbers, which was overcome by the Statutory Instrument. It is therefore hugely disappointing that the NHS gender services have decided not to participate with this research. I am frustrated on behalf of the young people and their families that the opportunity to reduce some of the uncertainties around care options has not been taken.

Ultimately, the NHS is an evidence-based service with a responsibility to maintain the safety of those in its care. Understanding more about what support people who attended the Gender Identity Development Service (GIDS) received, and whether this helped them, will provide vital evidence to assist young people, their families, and the clinicians working with them to make informed decisions about the right pathway for them. As a single integrated

health service, which for the period in question had one provider of care for children and young people, this was a world leading opportunity to look at outcomes for c.9000 young adults and add to the evidence base.

We had hoped to have some early findings to inform the Review. However, as outlined in my letter to you of 31 January 2023, it had become evident that the full outputs from the study, including resulting peer-reviewed papers, would not be available in time to be published alongside my final report.

I asked that NHS England give consideration as to how the ambitions of this study could be realised beyond the life of the Review. I am grateful for your confirmation that the National Research Oversight Board will support this going forward.

To assist the Oversight Board, I attach detail on the circumstances that led the University of York to reach the conclusion that it was not yet possible to move ahead with the next stages of the research study (Annex A).

I look forward to submitting my final report and recommendations in the coming weeks. In the meantime, my recommendations on this specific issue are that NHS England:

1. Work with the University of York to take forward phase one of the data linkage study without delay.
2. Work with Department of Health and Social Care to mandate the data exchange from the clinics to facilitate this.
3. Undertake a case note audit of record keeping in the adult clinics to assess the feasibility of phase 2 of the data linkage study.

Yours sincerely



Dr Hilary Cass
Chair, Independent Review into Gender Identity Services for Children and Young People

Annex A - Data linkage study: Assessment, Management and Outcomes for children and young people referred to a National Gender Identity Development Service

- 1.1. Little is known about what happens to the children and young people who have accessed the Gender Identity Development Service (GIDS) in relation to the support and interventions they have received and their outcomes.
- 1.2. Whilst a considerable amount of research has been published in this field, systematic reviews conducted for this Review and internationally have demonstrated the poor quality of the published studies, meaning there is not a reliable evidence base upon which to base clinical decisions.
- 1.3. The Review has tried to plug this gap through its commissioned research programme, which included an ambitious data linkage study. The study approach was proposed by the University of York as part of its response to a national open procurement process.
- 1.4. The research study plans to use existing data held by the NHS - including data from GIDS, hospital wards, outpatient clinics, emergency departments and adult Gender Dysphoria Clinics (GDCs) - to track the journeys of all young people (approximately 9,000) referred to the GIDS service through the system to provide a population-level evidence base of the different pathways people take and different outcomes people experience.
- 1.5. This study aims to improve the level and quality of evidence on the treatment and care of this population of children and young people:
 - enabling the Review and the NHS to have a better understanding of the best treatment approaches for this population of children and young people;
 - ensuring clinicians had the best possible evidence when providing care; and
 - supporting children and young people and their parents/carers in making better informed decisions.
- 1.6. This research study offers a real opportunity to contribute to the international evidence base for this service area as it would access what is thought to be the single largest data set available for the presenting population.
- 1.7. Healthcare data on populations of children, young people and adults are routinely used to determine outcomes of care for the purpose of improving NHS services. This has not been the case for gender questioning children and young people – the aim is that this research would go some way to address this imbalance.
- 1.8. As with the other studies, [the study protocol](#) was subject to Research Ethics Committee (REC) and Confidentiality Advisory Group (CAG) processes prior to achieving full Health Research Authority (HRA) approval. These approvals were required before the study could commence.

- 1.9. It took over a year to gain the necessary approvals from the Health Research Authority's Research Ethics Committee and Confidentiality Advisory Group. While the methodology proposed for the research is not particularly unusual, the robust scrutiny and consideration the committees applied to the study was entirely appropriate given the sensitivity of the subject matter.
- 1.10. The approach to governance, data protection and confidentiality was consistent with other research undertaken by the NHS or when using NHS data. In addition, the research team was careful to ensure compliance with any special rules and sensitivities that may apply to information about transgender people, including those with Gender Recognition Certificates (GRCs), as in some cases the individuals whose data would have formed part of the research would have obtained a GRC.
- 1.11. The Gender Recognition Act (GRA) creates an offence of unlawfully disclosing information about individuals who have obtained a GRC. To ensure an offence could not be inadvertently committed, a 'statutory instrument' was passed through Parliament, permitting the handling of information about people with GRC for the very limited purpose of this research. This was required before REC and CAG would consider the research protocol, and before NHS England and the NHS Data and Analytics team would support the research.
- 1.12. While the Statutory Instrument took some time to pass, and the public reporting of this caused some concern among the trans and gender diverse community, it was important to do this so that as full a picture as possible was established through the study, and the data of people, who potentially have some of the most successful outcomes, was not automatically excluded.
- 1.13. In addition, the ethics approval process required the researchers to seek the views of those affected to show that there was a need for the study and that patients were content with the planned approach.
- 1.14. The PPI sessions found that, while some participants were initially sceptical about the research based on what they had heard in the press or on social media, when the study was explained the majority understood the approach, the reason for the research and how their data would be used. Some participants were surprised that outcomes were not routinely collected and measured, and there was generally a high level of support for the research.
- 1.15. Another important consideration was the need to provide the opportunity to opt out for those that did not wish for their data to be included. Because the University of York needed to look at a large number of records, it was not feasible to get individual consent. Instead, individuals not wishing to take part in the study would have been able to opt out via their clinical team, based at GIDS or one of the seven adult NHS Gender Dysphoria Clinics (GDCs). The opt out period was to be the first step in the study, to be followed by a standard secure transfer of basic demographic data.

- 1.16. Despite the rigor applied in meeting HRA requirements, the University of York received significant opposition from all but one of the adult GDCs including refusal to facilitate the initial opt out stage of the study. The concerns cited by the adult GDCs included:
- ethical considerations, which had already been considered and met through the stringent and lengthy HRA process to achieve the relevant approvals;
 - availability of/access to data, although the initial stage of the study asked for basic demographic data, which would not be an unusual request for NHS research and raises questions in relation to GDC record management; and
 - resource impacts, even though the GDCs are contractually required to take part in research and appropriate costs would have been met by NHS England.
- 1.17. This was disappointing as at an early stage of protocol development, the research team had met with representatives from three of the clinics to discuss the proposed approach.
- 1.18. Additionally, prior to final REC and CAG approval, a workshop was held with the adult gender clinics to talk through the study, data requirements and technical aspects and to identify any logistical challenges, where some concerns were highlighted. Following the workshop, the University of York met with the clinics to discuss the issues raised.
- 1.19. It was agreed to phase the project, building in feasibility steps, which would be overseen by a further National Institute for Health and Care Research (NIHR) independent panel. Additionally, NHS England was willing to discuss resource implications to address provider concerns about the potential impact on clinical services.
- 1.20. The team had developed the patient notifications and communications resources to explain the research and provide information about how to opt-out of the study should an individual chose to do so. It was at the point of trying to launch the three-month opt-out period that the clinics confirmed their unwillingness to participate.
- 1.21. In January 2024, NHS England wrote to inform the Review that it had written to the Chief Executives and Medical Directors of the NHS trusts that host adult GDCs and GIDS to ask them to fully cooperate with the University of York in support of the research. Despite this, the necessary cooperation from the services has not been forthcoming and as a consequence, the University of York advised that it was not appropriate to begin the next stage of the study.
- 1.22. The Review is disappointed that the study has not progressed to even the first stage during its lifetime. Despite this setback, it is pleasing that NHS England has stated a clear commitment to realising the ambitions of this study beyond the life of the Review.
- 1.23. The statutory instrument is in place until 2027, and oversight of the study will transfer to the NHS National Research Oversight Board for Children and Young People's Gender Services.



The Cass Review

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