

Independent review of gender identity services for children and young people

boys who had demonstrated gender incongruence from an early age.^{51,52,53}

5.7. There is extensive literature discussing the possible aetiology of gender incongruence. Based on the available evidence, many authors would suggest that it is likely that biological, cultural, social and psychological factors all contribute. The examples in **Appendix 4** show that this is not an uncommon situation; many conditions do not have a single clear causation – they are in other words ‘multifactorial’.

5.8. Regardless of aetiology, the more contentious and important question is how fixed or fluid gender incongruence is at different ages and stages of development, and whether, regardless of aetiology, can be an inherent characteristic of the individual concerned. There is a spectrum of academic, clinical and societal opinion on this. At one end are those who believe that gender identity can fluctuate over time and be highly mutable and that, because gender incongruence or gender-related distress may be a response to many psychosocial factors, identity may

sometimes change or the distress may resolve in later adolescence or early adulthood, even in those whose early incongruence or distress was quite marked. At the other end are those who believe that gender incongruence or dysphoria in childhood or adolescence is generally a clear indicator of that child or young person being transgender and question the methodology of some of the desistance studies. Previous literature has indicated that if gender incongruence continues into puberty, desistance is unlikely.^{54,55} However, it should be noted that these older studies were not based on the current changed case-mix or the different socio-cultural climate of recent years, which may have led to different outcomes. Having an open discussion about these questions is essential if a shared understanding of how to provide appropriate assessment and treatment is to be reached.

⁵¹ Zucker KJ (2017). [Epidemiology of gender dysphoria and transgender identity](#). Sex Health 14(5): 404–11. DOI:10.1071/SH1.

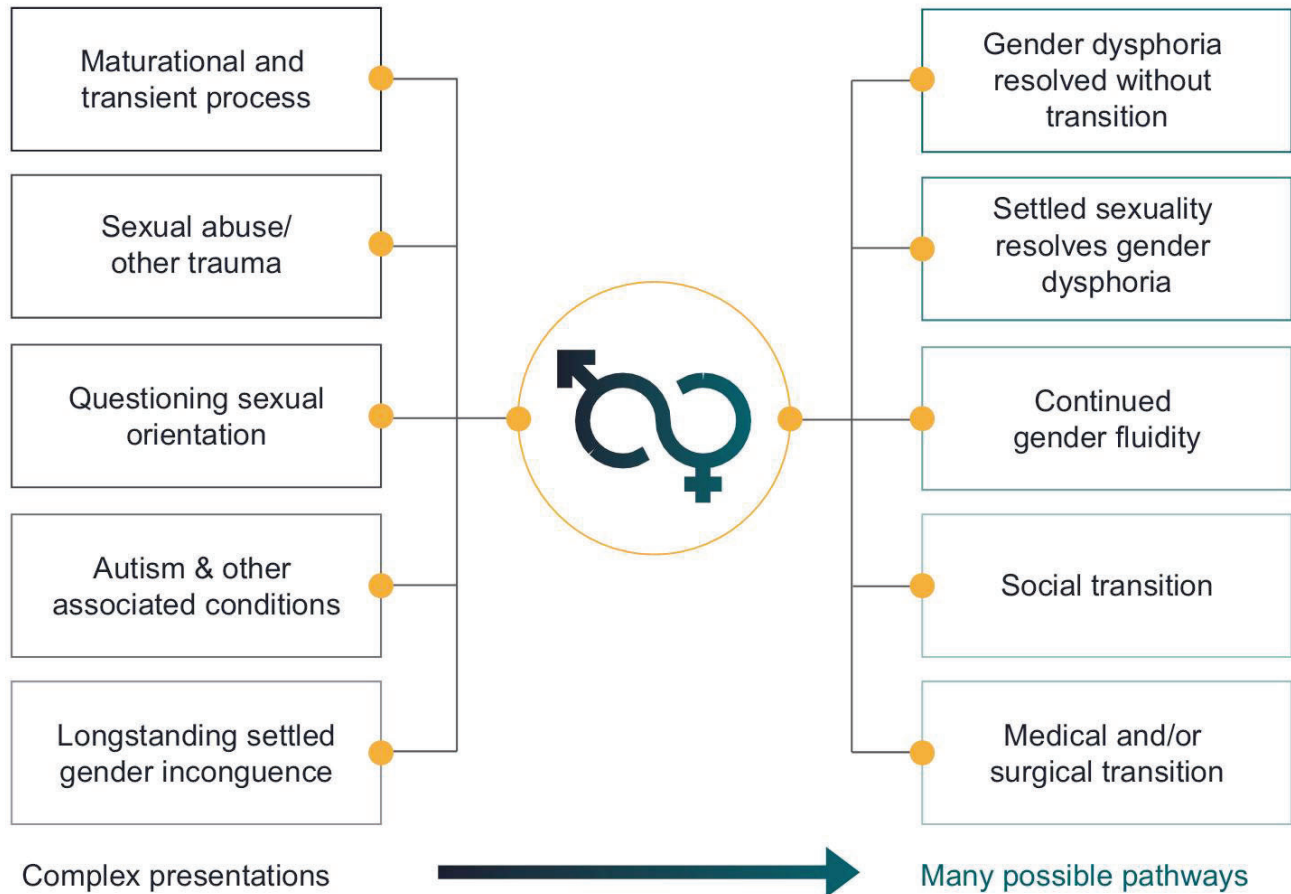
⁵² Zucker KJ, Lawrence AA (2009). [Epidemiology of gender identity disorder: recommendations for the Standards of Care of the World Professional Association for Transgender Health](#). Int J Transgend 11(1): 8-18. DOI: 10.1080/15532730902799946.

⁵³ de Graaf NM, Giovanardi G, Zitz C, Carmichael P (2018). [Sex ratio in children and adolescents referred to the gender identity development service in the UK \(2009-2016\)](#). Arch Sex Behav 47(5): 1301–4.

⁵⁴ Steensma TD, Biemond R, de Boer F, Cohen-Kettenis PT (2011). [Desisting and persisting gender dysphoria after childhood: a qualitative follow-up study](#). Clin Child Psychol Psychiatry 16(4): 485-97. DOI: 10.1177/135910451037803.

⁵⁵ Steensma TD, McGuire JK, Kreukels BPC, Beekman AJ, Cohen-Kettenis PT (2013). [Factors associated with desistance and persistence of childhood gender dysphoria: a quantitative follow-up study](#). J Am Acad Child Adolesc Psychiatry 52: 582-590. DOI: 10.1016/j.jaac.2013.03.016.

Complex presentations and complex pathways – exemplars, not comprehensive lists



Epidemiology: Epidemiologists collect data to find out how common a condition is, who is most likely to be affected, what the age distribution is and so on. This allows health service planners to work out how many services are needed, where they should be established, and what staff are needed.

They also report on changes in who is most affected, which may mean that either the disease is changing, or the susceptibility of the population is changing.

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5.9. As previously indicated, the epidemiology of gender dysphoria is changing, with an increase in the numbers of birth-registered females presenting in early teens.^{56,57} In addition, the majority of children and young people presenting to GIDS have other complex mental health issues and/or neurodiversity.⁵⁸ There is also an over-representation of looked after children.⁵⁹

5.10. There are several implications arising from the change in epidemiology:

- Firstly, the speed of change in the numbers presenting means that services have not kept pace with demand.
- Secondly, the cohort that the original Dutch Approach was based on is different from the current more complex NHS cohort, and also from the current case-mix internationally, and therefore it is difficult to extrapolate from older literature to this current group.
- Thirdly, different subgroups may have quite different needs and outcomes, and these must be built into any service design, so that it works for all children and young people.

5.11. At present we have the least information for the largest group of patients – birth-registered females first presenting in early teen years. Since the rapid increase in this group began around 2015, they will not reach late 20s for another 5+ years, which would be the best time to assess longer-term wellbeing.

⁵⁶ Steensma TD, Cohen-Kettenis PT, Zucker KJ (2018). [Evidence for a change in the sex ratio of children referred for gender dysphoria: Data from the Center of Expertise on Gender Dysphoria in Amsterdam \(1988-2016\)](#). Journal of Sex & Marital Therapy 44(7): 713–5. DOI: 10.1080/0092623X.2018.1437580.

⁵⁷ de Graaf NM, Carmichael P, Steensma TD, Zucker KJ (2018). [Evidence for a change in the sex ratio of children referred for Gender Dysphoria: Data from the Gender Identity Development Service in London \(2000–2017\)](#). J Sex Med 15(10): 1381–3. DOI: 10.1016/j.jsxm.2018.08.002.

⁵⁸ Van Der Miesen AIR, Hurley H, De Vries ALC (2016). [Gender dysphoria and autism spectrum disorder: A narrative review](#). Int Rev Psychiatry 28: 70-80. DOI: 10.3109/09540261.2015.1111199.

⁵⁹ Matthews T, Holt V, Sahin S, Taylor A, Griksaitis (2019). [Gender Dysphoria in looked-after and adopted young people in a gender identity development service](#). Clinical Child Psychol Psychiatry 24: 112-128. DOI: 10.1177/1359104518791657.

Assessment and diagnosis: Clinicians will usually take a history from (that is, of their symptoms) and examine the patient (that is, for signs and symptoms), and where appropriate undertake a series of investigations or tests, to help them reach an accurate diagnosis.

Sometimes the whole process of making a diagnosis through talking to the patient and asking them to complete formal questionnaires, examining them and/or undertaking investigations is called 'clinical assessment'.

As well as diagnosing and ruling out a particular condition, clinicians often need to consider and exclude other, sometimes more serious, conditions that present in a similar way but may need quite different treatment – this process is called 'differential diagnosis'.

5.12. For children and young people with gender-related distress, many people would dispute the notion that 'making a diagnosis' is a meaningful concept, arguing that gender identity is a personal, internal perception of oneself. However, there are several reasons to why a diagnostic framework is used:

- Firstly, the clinician will seek to determine whether the child or young person has a stable transgender identity, or whether there might be other causes for the gender-related distress.
- Secondly, the clinician will determine whether there are other issues or diagnoses that might be having an impact on the young person's mental health. The Dutch Approach suggesting that these should be addressed prior to or alongside initiation of any medical treatments.
- Thirdly, in any situation where life-altering treatments are being administered, the clinician holds the

responsibility for ensuring that they are being administered based on an appropriate decision making process. Therefore, it is usual practice for a diagnosis of gender dysphoria to be made prior to referring for any physical treatments.

5.13. When the word 'diagnosis' is used, people often associate this with the use of blood tests, X-rays, or other laboratory tests. As set out in the **Appendix 4**, the public is very familiar with diagnosis of Covid-19 and understands that there need to be tests that give a high degree of certainty about whether an individual is Covid-19 positive or not. False positive lateral flow tests are rare, but caused problems for schools, while PCR has been treated as the 'gold standard' test for accuracy.

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5.14. When it comes to gender dysphoria, there are no blood tests or other laboratory tests, so assessment and diagnosis in children and young people with gender-related distress is reliant on the judgements of experienced clinicians. Because medical, and subsequently possibly surgical treatments will follow, it may be argued that a highly sensitive and specific assessment process is required. The assessment should be able to accurately identify those children or young people for whom physical intervention is going to be the best course of action, but it is equally important that it identifies those who need an alternative pathway or treatment.

5.15. The formal criteria for diagnosing gender dysphoria (DSM-5) are listed in **Appendix 3**. However, there are two problems associated with the use of these criteria:

- Firstly, several of the criteria are based on gender stereotyping which may not be deemed relevant in current society, although the core criteria remain valid.
- Secondly, and more importantly, these criteria give a basis on which to make a diagnosis that a young person is clinically distressed by the incongruence between their birth-registered and their experienced gender, but they do not help in determining which factors may have led to this distress and how they might best be resolved.

5.16. At present, the assessment process varies considerably, dependent on the perceptions, experience and beliefs of different clinicians. There are some existing measurement tools, but it is suggested that these have substantial limitations.⁶⁰

5.17. The challenges are similar to the early difficulties in diagnosing autism, as set out in **Appendix 4**. As with autism, the framework for assessment needs to become formalised so there are clearer criteria for diagnosis and treatment pathways which are shared more widely. These should incorporate not just whether the child or young person meets DSM-5 criteria for gender dysphoria, but how a broader psychosocial assessment should be conducted and evaluated, and what other factors need to be considered to gain a holistic understanding of the child or young person's experience. Professional judgement and experience will still be important, but if the frameworks and criteria for assessment and diagnosis were more consistent and reproducible, there would be a greater likelihood that two different people seeing the same child or young person would come to the same conclusion. This would also mean that any research on interventions or long-term outcomes would be more reliable because the criteria on which a diagnosis was made, and hence the patients within the sample, would have the same characteristics.

⁶⁰ Bloom TM, Nguyen TP, Lami F, Pace CC, Poulakis Z, Telfer N (2021). [Measurement tools for gender identity, gender expression, and gender dysphoria in transgender and gender-diverse children and adolescents: a systematic review](#). *Lancet Child Adolescent Health*. 5: 582-588. DOI: 10.1016/s2352-4642(21)00098-5.

Principles of evidence based service development

5.18. As outlined above, it is standard clinical practice to undertake a process called differential diagnosis. This involves summarising the main points of the clinical assessment, the most likely diagnosis, other possible diagnoses and the reasons for including or excluding them, as well as any further assessments that may be required to clarify the diagnosis and the treatment options and plan. This is important when a medical intervention is being provided on the basis of the assessment, so the process

is robust, explicit and reproducible. These considerations need to be applied to the assessment of children and young people presenting with gender-related distress. In mental health services, practitioners may also undertake a diagnostic or psychological formulation, which is a holistic summary of how the patient is feeling and why, and how to make sense of it, and a plan for moving forward with management or treatment.

Developing and implementing new treatments: Clinicians and scientists work on developing treatments. This involves clinical trials and, where there are new treatments, comparing them to any existing treatments. Questions include: What are the intended outcomes or benefits of treatment? What are the complications or side effects? What are the costs? To initiate a new treatment, it must be both safe and effective. Questions of affordability can sometimes become controversial.

The best type of single study is considered to be the randomised controlled trial (RCT), but sometimes this is not feasible. Even where RCTs are not available, it is usual to at least have data on the outcomes of sufficient cases or cohorts to understand the risk/benefit of the treatment under consideration. As demonstrated in Fig. 4, the highest level of evidence is when the results of several different studies are pooled, but this is only useful if the individual studies themselves are of high quality.

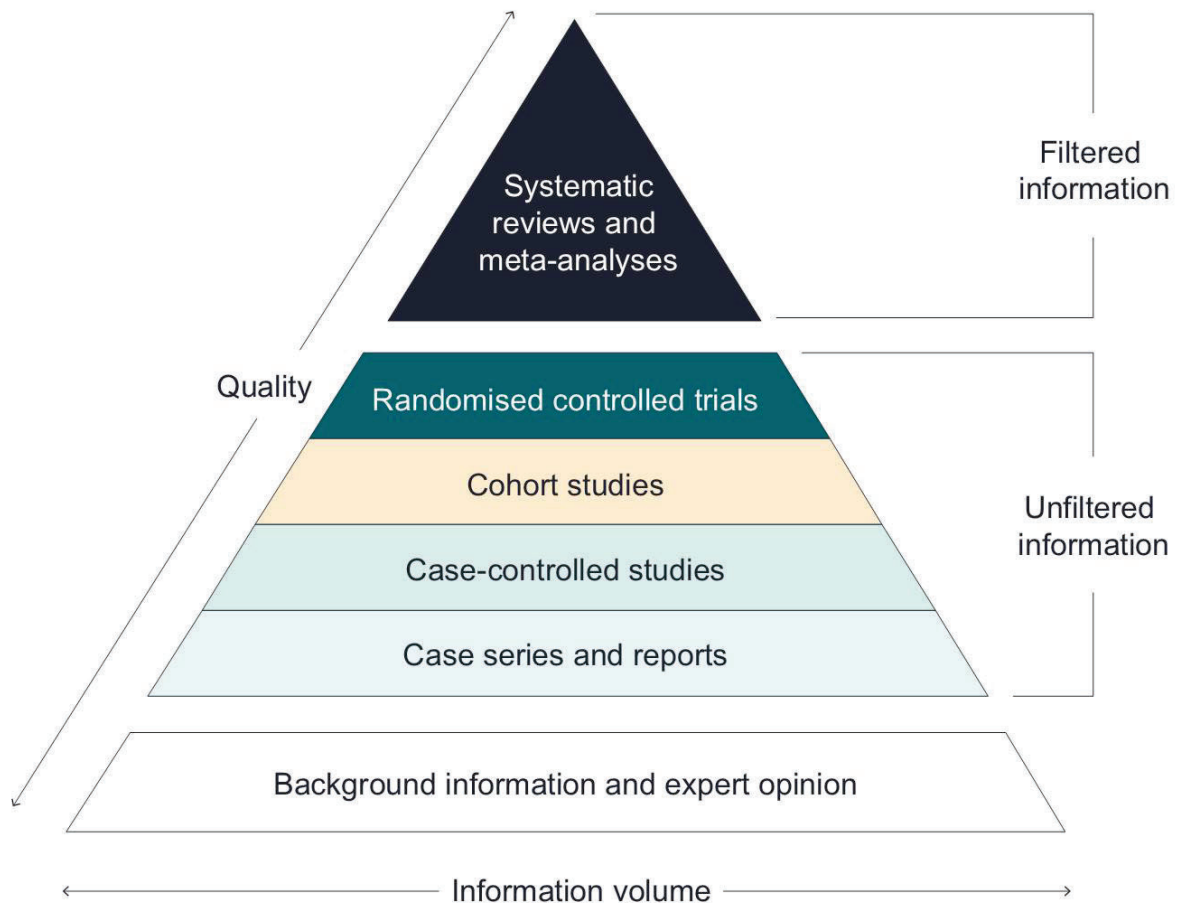
In many instances, evidence is not perfect and difficult decisions have to be made. Where treatments are innovative or life-changing, the whole multi-disciplinary team will usually meet to consider the available options, and how to advise the child or young person and family so that a shared decision can be made. Sometimes an ethics committee is involved. This is one of the most challenging areas of medicine and is underpinned by GMC guidance.^{61,62}

⁶¹ General Medical Council (2020). [Decision making and consent](#).

⁶² National Institute for Health and Care Excellence (2021). [Shared decision making](#).

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Figure 3: Pyramid of standards of evidence



Source: Levels of evidence pyramid, OpenMD. Reproduced with permission⁶³

5.19. There are three types of intervention or treatment for children and young people with gender-related distress, which may be introduced individually or in combination with one another:

- **Social transition** – this may not be thought of as an intervention or treatment, because it is not something

that happens within health services.

However, 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.^{64,65} There are different views on the benefits versus the harms of early social transition. Whatever position one

⁶³ OpenMD (2021). [New Evidence in Medical Research](#).

⁶⁴ Sievert EDC, Schweizer K, Barkmann C, Fahrenkrug S, Becker-Hebly I (2020). [Not social transition status, but peer relations and family functioning predict psychological functioning in a German clinical sample of children with Gender Dysphoria](#). *Clin Child Psychol Psychiatry* 26(1): 79–95. DOI: 10.1177/1359104520964530

⁶⁵ Ehrensaft D, Giammattei SV, Storck K, Tishelman AC, Colton K-M (2018). [Prepubertal social gender transitions: What we know; what we can learn—A view from a gender affirmative lens](#). *Int J Transgend* 19(2): 251–68. DOI: 10.1080/15532739.2017.1414649.

Principles of evidence based service development

takes, it is important to acknowledge that it is not a neutral act, and better information is needed about outcomes.

- **Counselling, social or psychological interventions** – these may be offered before, instead of, or alongside physical interventions. Again, they should be viewed as active interventions which require robust evaluation in their own right.
- **Physical treatments** – these comprise puberty blockers and feminising/masculinising hormones (administered by endocrinologists) and surgery. The latter is not considered as part of this Review since it is not available to those under age 18.

5.20. It should also be recognised that ‘doing nothing’ cannot be considered a neutral act.

5.21. The lack of available high-level evidence was reflected in the recent NICE review into the use of puberty blockers and feminising/masculinising hormones commissioned by NHS England, with the evidence being too inconclusive to form the basis of a policy position.^{66,67} Assessing treatments for gender dysphoria has many of the same problems as assessing treatment for children with autism – it can take many years to get a full appreciation of outcomes and there may be other complicating factors in the child or young

person’s life during this period. However, this of itself is not an adequate reason for the major gaps in the international literature.

5.22. It is still common that drugs are not specifically licensed for children because the trials have only taken place on adults. This does not preclude their use or make their use inherently unsafe, particularly if they are used very commonly in children. However, where their use is innovative, patients receiving the drug should ideally do so under trial conditions.

5.23. The same considerations apply to ‘off-label’ drugs, where the drug is used for a condition different to the one for which it was licensed. This is the case for puberty blockers, which are licensed for use in precocious puberty, but not for puberty suppression in gender dysphoria. Again, it is important that it is not assumed that outcomes for, and side effects in, children treated for precocious puberty will necessarily be the same in children or young people with gender dysphoria.

5.24. As outlined above, in other areas of practice where complex or potentially life-altering treatment is being considered for a child or young person, it is usual for the case to be discussed by an MDT including all professionals involved in their care. In gender services for children and young people in the Netherlands, as well as a number of other countries, there are full

⁶⁶ National Institute for Health and Care Excellence (2020). [Evidence Review: Gonadotrophin Releasing Hormone Analogues for Children and Adolescents with Gender Dysphoria](#)

⁶⁷ National Institute for Health and Care Excellence (2020). [Evidence review: gender-affirming hormones for children and adolescents with gender dysphoria.](#)

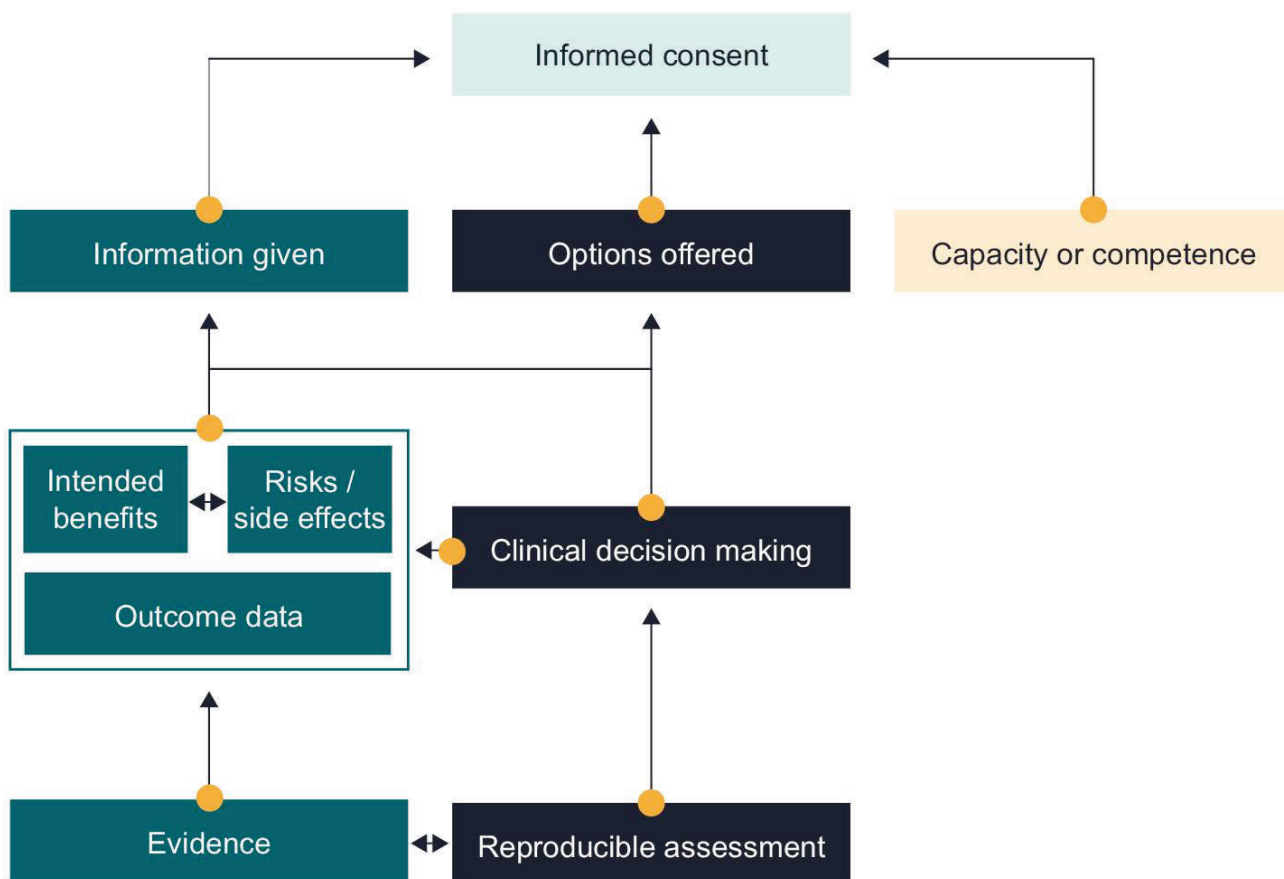
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MDT meetings, including psychiatrists and endocrinologists, to make decisions about suitability for hormone intervention and to review progress.^{68,69}

5.25. Recent legal proceedings have examined the question of the competence and capacity of children and young people to consent to hormone treatment. However, there are some essential components that underpin informed consent; the robustness

of the options offered to the patient, the information provided to them about those options, and their competence and capacity to consider them. The courts have given consideration to competence and capacity, and it is incumbent on this Review to consider the soundness of the decision making which underpins the options offered, and the quality and accuracy of the information provided about those options.

Elements of informed consent



⁶⁸ Kyriakou A, Nicolaidis NC, Skordis N (2020). [Current approach to the clinical care of adolescents with gender dysphoria](#). Acta Biomed 91(1): 165–75. DOI: 10.23750/abm.v91i1.9244.

⁶⁹ Cohen-Kettenis PT, Steensma TD, de Vries ALC. [Treatment of adolescents with gender dysphoria in the Netherlands](#). Child Adolesc Psychiatr Clin N Am 20. 689–700. 2001. DOI: 10.1016/j.chc.2011.08.001.

Service development and service improvement: Central to any service improvement is the systematic and consistent collection of data on outcomes of treatment. There is a process of continuous service improvement as new presentations or variations on the original condition are recognised, diagnosis or screening improves and/or trials on new treatments or variations on existing treatments are ongoing.

There should be consistent treatment protocols or guidelines in place, in order to make sense of variations in outcomes. Where possible, these should be compared between and across multiple different centres.

As time passes, services need to be changed or extended based on patient need, and on what resources are needed to deliver the available treatments. They need to be accessible where the prevalence of the condition is highest. The relevant workforce to deliver the service needs to be recruited and trained, contingent on the type of treatments or therapy that is required.

5.26. When a pioneering treatment or specialist service starts, it is often delivered in a single centre. Thereafter, additional centres take on the work as increasing numbers of patients need to access the treatment. Current provision of NHS specialist gender identity services for children and young people has remained concentrated within a single organisation, but demand has grown dramatically.

5.27. The situation has been exacerbated because there are not many local services seeing gender-questioning children at an earlier stage in their journey, which means that GIDS is carrying an unsustainable workload of increasingly complex young people.

5.28. As a condition evolves, rigorous data collection and quantitative research is an essential prerequisite to refining understanding and treatment. Historically, The Tavistock and Portman NHS

Foundation Trust built its international reputation as the home of psychoanalysis, psychotherapy and family therapy, with a strong track record of publishing qualitative rather than quantitative research; consequently its approach to quantitative data collection about this important group of children and young people has been weak.

5.29. A further anomaly is a public perception that The Tavistock and Portman NHS Foundation Trust is the responsible organisation for leading the management of children receiving hormone treatment for their gender dysphoria. In reality, the hormone treatment is delivered by paediatric services in University College London Hospitals NHS Foundation Trust and The Leeds Teaching Hospitals NHS Trust.

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5.30. In practice, it is important that for children and young people who need physical intervention, paediatric and mental health services are seen as equal partners, with seamless joint working and shared responsibility. When there were very small numbers of patients, it was easier for this to be achieved, but cross-site working with a very large caseload has made this more difficult to achieve, despite the best intentions of the staff.

5.31. Over the last two years there have been strong efforts on the part of The Tavistock and Portman NHS Foundation Trust to make practice within GIDS more consistent, with tighter procedures for case management, consent, and safeguarding. However, although this has resulted in better documentation, variations and inconsistencies in clinical decision making remain. In responding to a changing legal framework, some processes have become more cumbersome and complex, and the team are working hard to streamline the process.

5.32. Overall, GIDS faces a daunting task as a single provider in managing risk on the waiting list, seeing new referrals, reviewing and supporting those on hormone treatment, undertaking an ongoing transformation programme, recruiting and training new staff and trying to retain existing staff. This suggests that the current model is not sustainable and that another model is needed.

6. Interim advice, research programme and next steps



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Dealing with uncertainty

6.1. As outlined throughout this report, there are major gaps 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.

6.2. As with any other area of medicine, where there are gaps in the evidence base and uncertainties about the correct clinical approach, three tasks must be undertaken:

- Clinical services must be run as safely and effectively as possible, within the constraints of current knowledge; treatment options must be weighed carefully; and treatment decisions must be made in partnership between the clinicians and the children, young people and their families and carers, based on our current understanding about outcomes.
- Consistent data must be collected by clinical services, for both audit and research purposes so that knowledge gaps can be filled, alongside an active research programme.
- Where there is not an immediate prospect of filling research gaps, professional consensus should be developed on the correct way to proceed pending clearer research evidence, supported by input from service users.

6.3. The additional problem with the current service model is that safety and access are further compromised by the pace at which referrals have grown and outstripped capacity at tertiary level, and the lack of service availability at local level.

6.4. The Review's approach to these tasks is as follows:

- Our **interim advice** focuses on the issues of capacity, safety, and standards around treatment decisions, as well as data and audit.
- Our **research streams** will provide the Review with an independent collation of published evidence relevant to epidemiology, clinical management, models of care, and outcomes, as well as delivering qualitative and quantitative research relevant to the Terms of Reference of the Review. This offers a real opportunity to contribute to the international evidence base for this service area.
- There will be an ongoing and wide-ranging **programme of engagement** to address areas on which we will not be able to obtain definitive evidence during the lifetime of the Review.

Interim advice, research programme and next steps

Interim advice

6.5. The Review considers that there are some areas where there is sufficient clarity about the way forward and we are therefore offering some specific observations and interim advice. The Review will work with NHS England, providers and the broader stakeholder community to progress action in these areas.

Service model

6.6. It has become increasingly clear that a single specialist provider model is not a safe or viable long-term option in view of concerns about lack of peer review and the ability to respond to the increasing demand.

6.7. Additionally, children and young people with gender-related distress have been inadvertently disadvantaged because local services have not felt adequately equipped to see them. It is essential that they can access the same level of psychological and social support as any other child or young person in distress, from their first encounter with the NHS and at every level within the service.

6.8. A fundamentally different service model is needed which is more in line with other paediatric provision, to provide timely and appropriate care for children and young people needing support around their gender identity. This must include support for any other clinical presentations that they may have.

6.9. The Review supports NHS England's plan to establish regional services, and

welcomes the move from a single highly specialist service to regional hubs.

6.10. Expanding the number of providers will have the advantages of:

- creating networks within each area to improve early access and support;
- reducing waiting times for specialist care;
- building capacity and training opportunities within the workforce;
- developing a specialist network to ensure peer review and shared standards of care; and
- providing opportunities to establish a more formalised service improvement strategy.

Service provision

6.11. The primary remit of NHS England's proposed model is for the regional hubs to provide support and advice to referrers and professionals. However, it includes limited provision for direct contact with children and young people and their families.

1: The Review advises that the regional centres should be developed, as soon as feasibly possible, to become direct service providers, assessing and treating children and young people who may need specialist care, as part of a wider pathway. The Review team will work with NHS England and stakeholders to further define the proposed model and workforce implications.

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2: Each regional centre will need to develop links and work collaboratively with a range of local services within their geography to ensure that appropriate clinical, psychological and social support is made available to children and young people who are in early stages of experiencing gender distress.

3: 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.

4: Regional training programmes should be run for clinical practitioners at all levels, alongside the online training modules developed by Health Education England (HEE). In the longer-term, clearer mapping of the required workforce, and a series of competency frameworks will need to be developed in collaboration with relevant professional organisations.

through the service. Standardised data collection is required in order to audit service standards and inform understanding of the epidemiology, assessment and treatment of this group. This, alongside a national network which brings providers together, will help build knowledge and improve outcomes through shared clinical standards and systematic data collection. In the longer-term, formalisation of such a network into a learning health system⁷⁰ with an academic host would mean that there was systematised use of data to produce a continuing research programme with rapid translation into clinical practice and a focus on training.

5: The regional services should have regular co-ordinated national provider meetings and operate to shared standards and operating procedures with a view to establishing a formal learning health system.

6: Existing and future services should have standardised data collection in order to audit standards and inform understanding of the epidemiology, assessment and treatment of this group of children and young people.

Data, audit and research

6.12. A lack of routine and consistent data collection means that it is not possible to accurately track the outcomes and pathways children and young people take

⁷⁰ Scobie S, Castle-Clarke S (2019). [Implementing learning health systems in the UK NHS: Policy actions to improve collaboration and transparency and support innovation and better use of analytics](#). Learning Health Systems 4(1): e10209. DOI:10.1002/lrh2.10209.

Interim advice, research programme and next steps

7: Prospective consent of children and young people should be sought for their data to be used for continuous service development, to track outcomes, and for research purposes. Within this model, children and young people put on hormone treatment should be formally followed up into adult services, ideally as part of an agreed research protocol, to improve outcome data.

8: There needs to be agreement and guidance about the appropriate clinical assessment processes that should take place at primary, secondary and tertiary level.

9: Assessments should be respectful of the experience of the child or young person and be developmentally informed. Clinicians should remain open and explore the patient's experience and the range of support and treatment options that may best address their needs, including any specific needs of neurodiverse children and young people.

Clinical approach

Assessment processes

6.13. We have heard that there are inconsistencies and gaps in the assessment process. Our work to date has also demonstrated that clinical staff have different views about the purpose of assessment and where responsibility lies for different components of the process within the pathway of care. The Review team has commenced discussions with clinical staff across primary, secondary and tertiary care to develop a framework for these processes.

Hormone treatment

6.14. The issues raised by the Multi-Professional Review Group echo several of the problems highlighted by the CQC. It is essential that principles of the General Medical Council's Good Practice in Prescribing and Managing Medicine's and Devices⁷¹ are closely followed, particularly given the gaps in the evidence base regarding hormone treatment. Standards for decision making regarding endocrine treatment should also be consistent with international best practice.^{72,73,74}

⁷¹ General Medical Council (2021). [Good practice in prescribing and managing medicines and devices \(76-78\)](#).

⁷² Hembree WC, Cohen-Kettenis PT, Gooren L, Hannema SE, Meyer WJ, Murad MH, et al (2017). [Endocrine treatment of gender-dysphoric/gender-incongruent persons: an Endocrine Society clinical practice guideline](#). J Clin Endocrinol Metab 102(11): 3869–903. DOI: 10.1210/jc.2017-01658.

⁷³ Cohen-Kettenis PT, Steensma TD, de Vries ALC (2001). [Treatment of adolescents with gender dysphoria in the Netherlands](#). Child Adolesc Psychiatr Clin N Am 20: 689–700. DOI: 10.1016/j.chc.2011.08.001.

⁷⁴ Kyriakou A, Nicolaidis NC, Skordis N (2020). [Current approach to the clinical care of adolescents with gender dysphoria](#). Acta Biomed 91(1): 165–75. DOI: 10.23750/abm.v91i1.9244.

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10: Any child or young person being considered for hormone treatment should have a formal diagnosis and formulation, which addresses the full range of factors affecting their physical, mental, developmental and psychosocial wellbeing. This formulation should then inform what options for support and intervention might be helpful for that child or young person.

11: Currently paediatric endocrinologists have sole responsibility for treatment, but where a life-changing intervention is given there should also be additional medical responsibility for the differential diagnosis leading up to the treatment decision.

6.15. Paediatric endocrinologists develop a wide range of knowledge within their paediatric training, including safeguarding, child mental health, and adolescent development. Being party to the discussions and deliberations that have led up to the decision for medical intervention supports them in carrying out their legal responsibility for consent to treatment and the prescription of hormones.

12: Paediatric endocrinologists should become active partners in the decision making process leading up to referral for hormone treatment by participating in the multidisciplinary team meeting where children being considered for hormone treatment are discussed.

6.16. Given the uncertainties regarding puberty blockers, it is particularly important to demonstrate that consent under this circumstance has been fully informed and to follow GMC guidance⁷⁵ by keeping an accurate record of the exchange of information leading to a decision in order to inform their future care and to help explain and justify the clinician's decisions and actions.

13: Within clinical notes, the stated purpose of puberty blockers as explained to the child or young person and parent should be made clear. There should be clear documentation of what information has been provided to each child or young person on likely outcomes and side effects of all hormone treatment, as well as uncertainties about longer-term outcomes.

⁷⁵ General Medical Council (2020). [Decision making and consent](#).

Interim advice, research programme and next steps

14: In the immediate term the Multi-Professional Review Group (MPRG) established by NHS England should continue to review cases being referred by GIDS to endocrine services.

Research programme

6.17. The Review's formal academic research programme, comprising a literature review, quantitative analysis and primary qualitative research, has been based on the identified gaps in the evidence and the feasibility of filling them within the lifetime of the Review.

6.18. Initial work has identified the existing evidence base on epidemiology, natural history, and the treatment and outcomes of children and young people with gender dysphoria/gender-related distress. It has also assessed the feasibility of linking data between local, regional or national datasets in order to assess intermediate and longer-term outcomes.

Literature review

6.19. A literature review is being undertaken, which will interface with evidence gathering from the professional community (see qualitative research section below). Its aim is to systematically identify, collate and synthesise the existing evidence on the changing epidemiology of gender-related distress in children and young people and the appropriate social, clinical,

psychological and medical management of that distress.

6.20. The literature review will capture primary studies of any design, including experimental, observational, survey and qualitative, and is looking to answer the following questions:

1. How has the population of children and young people presenting with gender dysphoria and/or gender-related distress changed over time?
2. What are the appropriate referral, assessment and treatment pathways for children and young people with gender dysphoria and/or gender-related distress?
3. What are the short-, medium- and long-term outcomes for children and young people with gender dysphoria and/or gender-related distress?
4. How do children and young people and their families negotiate distress, present this distress to services, and what are their expectations, following presentation?
5. How do children, young people and their families/carers experience referral, assessment and treatment? And how are these negotiated among children and young people, parents/carers, families and healthcare professionals?

6.21. A separate synthesis for each question will be undertaken. The systematic review has been registered on PROSPERO [ID:289659].

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Quantitative research

6.22. The National Institute for Health and Care Excellence (NICE) recently published two evidence reviews.^{76,77} These highlight shortcomings in the follow-up data collected about children and young people, when they are referred to a specialist gender identity service. The quantitative research will therefore focus on the collection and analysis of data to uncover patterns and quantify problems, thereby helping the Review to address some of these shortcomings.

6.23. The aim of the quantitative study is to supplement the material collected by the literature review, further examining the changing epidemiology of gender-related distress in children and young people, in addition to exploring the appropriate social, clinical, psychological and medical management. Its objectives are to:

- a) describe the clinical and demographic characteristics of this population of children and young people and their clinical management in the GIDS service; and

- b) assess the intermediate and longer-term outcomes of this population of children and young people utilising national healthcare data.

6.24. This research will provide an evidence base to facilitate informed decision making among children and young people and their families. It will also provide an evidence base for those responsible for commissioning, delivering and managing services.

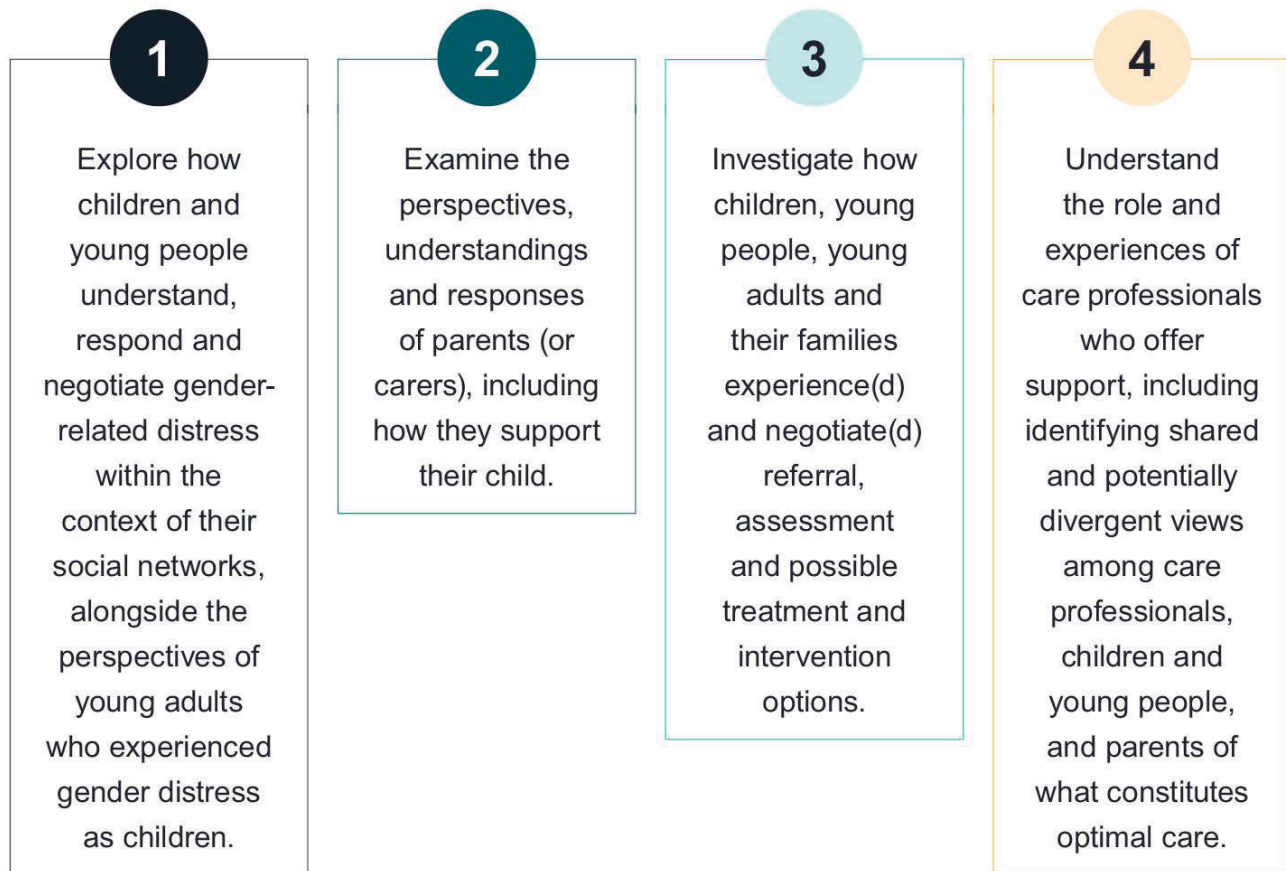
Qualitative research

6.25. The qualitative research will capture a diverse range of trajectories experienced by gender-questioning children and young people, exploring a range of different experiences and outcomes. This will include talking to children and young people and their families/carers who are currently negotiating gender-related distress, young adults who have gone through the process of resolving their distress and care professionals.

⁷⁶ National Institute for Health and Care Excellence (2020). [Evidence Review: Gonadotrophin Releasing Hormone Analogues for Children and Adolescents with Gender Dysphoria](#).

⁷⁷ National Institute for Health and Care Excellence (2020). [Evidence review: gender-affirming hormones for children and adolescents with gender dysphoria](#).

The objectives of the qualitative research are to:



Progress

6.26. The literature review is already underway and is identifying relevant studies. Initial meetings have also taken place with voluntary organisations and other researchers working in the area to ensure there is no duplication and in recognition of research fatigue among this population.

6.27. Children and young people and young adults who have experienced gender-related distress are involved in the research programme. Their advice has been, and will continue to be, sought throughout this work, including in relation to the focus of the research and interpretation

of findings and the design and content of dissemination materials.

6.28. Three research protocols have been produced setting out how the research will be undertaken, and the research team is currently gaining the necessary ethical and governance approvals to progress the study. The systematic review is published on the PROSPERO website and will be published on the Review website in due course, along with the qualitative and quantitative research proposals once ethical and governance approvals have been received.

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6.29. The research findings will be subject to peer review through the publication process and various summaries, aimed at different audiences, will be available on the project website and distributed via support organisations. These summaries will also be made available on the Review website.

Ongoing engagement

6.30. In recognition that not all the published evidence is likely to be of high enough quality to form the sole basis for our recommendations, a consensus development approach will be used to synthesise the published evidence and research outputs of the academic work with stakeholder submissions and expert opinion.

6.31. Over the coming months, the Review will build on its engagement to date and, alongside the academic research programme, will continue informal and structured engagement with service users, their families, support and advocacy groups and professionals to test emerging thinking, provide opportunities for challenge and further develop the evidence base.

6.32. This review is an iterative process and we will share important findings when they become available. For the latest updates, please visit our website: <https://cass.independent-review.uk/>

6.33. We thank those who have participated in the Review to date and welcome engagement with us as work progresses towards final recommendations.

Glossary



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Glossary

There is sometimes no consensus on the best language to use relating to 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 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. The glossary below sets out a description of some of the terms we have used in the Review.

Term	Description
Affirmative model	A model of gender healthcare that originated in the USA ^{78,79,80,81} which affirms a young person's subjective gender experience while remaining open to fluidity and changes over time. 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.
Autonomy	Personal autonomy is the ability of a person to make their own decisions. In health this refers specifically to decisions about their care.

⁷⁸ Hidalgo MA, Ehrensaft D, Tishelman AC, Clark LF, Garofalo R, Rosenthal SM, et al (2013). [The gender affirmative model: What we know and what we aim to learn](#) [Editorial]. *Human Dev* 56(5): 285–290. DOI:10.1159/000355235.

⁷⁹ Chen D, Abrams M, Clark L, Ehrensaft D, Tishelman AC, Chan YM, et al (2021). [Psychosocial characteristics of transgender youth seeking gender-affirming medical treatment: baseline findings from the trans youth care study](#). *J Adol Health* 68(6): 1104–11.

⁸⁰ Olson-Kennedy J, Chan YM, Rosenthal S, Hidalgo MA, Chen D, Clark L, et al (2019). [Creating the Trans Youth Research Network: A collaborative research endeavor](#). *Transgend Health* 4(12): 304–12. DOI: 10.1089/trgh.2019.0024.

⁸¹ Ehrensaft D, Giammattei SV, Storck K, Tishelman AC, Colton K-M (2018). [Prepubertal social gender transitions: What we know; what we can learn—A view from a gender affirmative lens](#). *Int J Transgend* 19(2): 251–68. DOI: 10.1080/15532739.2017.1414649.

Term		Description
Best interests		<p>Clinicians and the courts seek to act in the best interests of children and young people. 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.⁸²</p>
		<p>The MCA s4,⁸³ 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>
Case-mix		The mix of patients within a particular group.
Child and adolescent mental health services	CAMHS	NHS children and young people’s mental health services. ⁸⁴

⁸² General Medical Council (2018). [0-18 years – guidance for all doctors](#).

⁸³ Mental Health Law Online. [MCA 2005 s4](#).

⁸⁴ Young Minds. [Guide to CAMHS: a guide for young people](#).

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Term		Description
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>
Cognitive		Relating to, or involving, the process of thinking and reasoning.
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 <i>Gillick</i> competence under 16) to make the relevant decision; 2 – to be fully informed (ie 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); and 3 – to be freely given (that is, without coercion).
Contraindications		A condition or circumstance that suggests or indicates that a particular technique or drug should not be used in the case in question.

Term		Description
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		Population of individuals who experienced gender dysphoria, chose to undergo medical and/or surgical transition and then detransitioned by discontinuing medications, having surgery to reverse the effects of transition, or both. ⁸⁵
Diagnostic and Statistical Manual of Mental Disorders Fifth edition	DSM-5	The American diagnostic manual used to diagnose mental health disorders, and commonly used in UK practice. See Appendix 3 .
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).
Dutch Approach		Protocol published in 1998 by the Amsterdam child and adolescent gender identity clinic. ⁸⁶
Endocrine treatment		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).
Endocrinologist		An endocrinologist is a medical doctor specialising in diagnosing and treating disorders relating to problems with the body's hormones.
Endocrinology		The study of hormones.

⁸⁵ Littman L (2021). [Individuals treated for gender dysphoria with medical and/or surgical transition who subsequently detransitioned: a survey of 100 detransitioners](#). Arch Sex Abuse 50: 3353–69. DOI: 10.1007/s10508-021-02163-w

⁸⁶ de Vries ALC, Cohen-Kettenis PT (2012). [Clinical management of gender dysphoria in children and adolescents: The Dutch approach](#). J Homosex 59: 301-320. DOI: 10.1080/00918369.2012.653300.