

The care and treatment of young people in relation to their gender identity in the UK

Summary of exploratory meetings – autumn 2019

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Key points and recommendations

- The Nuffield Council on Bioethics organised a series of meetings to explore experiences, expertise and ethical challenges in the care and treatment of young people in the UK in relation to their gender identity.
- Engagement with a wider range of young people would have been desirable during this process but time and resources prevented this. We recommend that any review of policy in this area should listen to the views of young people directly.
- There was strong disagreement among the people we met on a number of issues, but there were some areas of agreement as well. For example, the participants were clear that the needs and well-being of young people should always be the central focus of any discussion about their care.
- There was broad agreement among participants that the current NHS model of care for young people in relation to their gender identity needs to develop to respond to the needs of young people today and changing social contexts.
- Many participants thought there is a need for good quality, up-to-date evidence on the long-term outcomes of using puberty suppressants and cross-sex hormones in young people with gender dysphoria. There was disagreement over what the current evidence base means for clinical practice.
- Some participants questioned the ability of young people to consent to the use of puberty suppressants for gender dysphoria, a question now being considered by the High Court. Concerns were expressed about the discriminatory nature of this claim and the wider implications of the case for young people's rights.
- There was disagreement among participants about whether young people should automatically be supported by parents and others to transition socially if they express a desire to do so.
- More work is needed to understand fertility issues in this area. We heard that most young people do not pursue fertility preservation before hormone treatment.
- Discrimination and prejudice against gender diverse young people was identified as having a significant impact on their lives.
- We heard media reporting in relation to gender identity in young people can be misleading and convey contradictory messages that can be upsetting and confusing for young people and others to hear. To improve accuracy, balance and sensitivity in reporting, we recommend that accessible summaries of any evidence reviews should be made available and a greater diversity of experiences should be represented in media accounts.
- Many people we spoke to called for more or different research to be carried out in order to fill gaps in the evidence base. We recommend that a broad review of existing evidence and ongoing research should be undertaken by healthcare commissioners, so that any significant gaps can be identified.

Introduction

- 1 Between September and December 2019, the Nuffield Council on Bioethics organised a series of meetings to explore experiences, expertise and ethical challenges in the care and treatment of young people in the UK in relation to their gender identity. We endeavored to hear from a range of different people, including medical practitioners, academics and researchers with expertise in this specific area, and people or representatives of people who have personal experiences of gender identity services. We decided that small group and one-to-one meetings would enable us to explore the issues in some depth and create a positive atmosphere for discussion. We held 15 meetings during which we talked and listened to 38 people. Participants were identified primarily through desk research and selected for the range of expertise the Council judged it would be helpful to include. The vast majority of people we contacted were willing to take part and went on to attend meetings. Participants included:
 - Clinicians working in NHS gender identity services for young people in England, Scotland, Northern Ireland, Belgium and The Netherlands.
 - Representatives of other professions that support young people in relation to their gender identity, such as GPs, psychiatrists, endocrinologists, counsellors, paediatricians, and telephone helplines.
 - Representatives of charities and organisations that support and advocate for gender diverse young people and their families.
 - Academics and researchers working in the fields of philosophy, medicine, sociology and bioethics, including gender critical feminists.
 - Regulators of clinical practice and research.

In addition, we were invited to observe a stakeholder meeting at the NHS England commissioned Gender Identity Development Service (GIDS), which was attended by four young users of the service and a parent.

- 2 Participants of the meetings organised by the Nuffield Council on Bioethics were asked for their views on the following questions:
 - Is the current approach to the use of puberty blocking and cross-sex hormones in young people, and the pathways that lead to this, ethically appropriate?
 - How can research in this area be supported and conducted ethically?
 - How should the Government ensure gender diverse young people receive the care and support they need in a timely manner?
 - How are broader debates about extending rights and promoting inclusion for gender diverse people affecting the care and support of gender diverse young people?
 - Can the Nuffield Council on Bioethics make a helpful contribution in this area?
- 3 This report provides a summary of what we heard from the participants of the meetings. All participants were given the opportunity to review an earlier draft of this report and 19 participants submitted comments, which were incorporated as

faithfully as possible. The views outlined below cannot be assumed to be representative of the wider population. The views do not represent the views of the Nuffield Council on Bioethics, except where this is clearly indicated.

- 4 'Gender diverse young people' is used throughout to refer to people under 18 who feel their gender identity is or might be different in a variety of ways to their assigned-at-birth gender or sex. This includes people who have been diagnosed with gender dysphoria and gender incongruence. The gender diverse young people we met told us they prefer this as a collective term.
- 5 We would like to extend our sincere thanks to all the participants for their willingness to engage with us, and their openness and honesty during meetings and other interactions.

What we heard

The views of young people

Several participants encouraged us to meet and talk to gender diverse young people directly. Although we were able to observe a small meeting of young people at GIDS, the time and resources required to undertake ethical review of and organise any activities of our own during this engagement exercise prevented us from doing so. Direct engagement with young people more generally would have also been desirable. This represents a limit of this report. We recommend that any review of policy in this area involves the very people it concerns, and that time and resources are allocated to gathering the views of a range of young people directly.

Areas of disagreement and agreement

- There was strong disagreement among the people we met on a number of issues. These include what kind of evidence on the long-term effects of puberty suppressants would provide ethical justification for their use in young people with gender dysphoria, and how young people who are questioning their gender identity should be supported by parents, schools and healthcare professionals. These disagreements often appeared to be based on differing conceptions of gender incongruence and gender dysphoria. For example, some view gender incongruence and dysphoria as symptoms of underlying mental or other health problems or social factors. For others, mental health problems are understood as a reflection of difficulties experienced by young people with gender incongruence or dysphoria, or as co-occurring issues.
- 8 There were also some areas of agreement. Participants broadly agreed that:
 - The needs and well-being of young people should always be the central focus of any discussion about their care and treatment. All participants wanted young people to have the care and support that would best support their health and happiness.

- The current NHS model of care for young people in relation to their gender identity needs to develop to respond to the needs of young people today and changing social contexts.
- Media reporting in relation to gender identity in young people can be misleading and convey contradictory messages that can be upsetting and confusing for young people and others to hear.

Increase in gender dysphoria among young people

- 9 There were different theories as to why there has been an increase in referrals to NHS gender identity services across the UK over the past few years. Some participants suggested that gender dysphoria was always as prevalent among young people but that it was repressed, ignored or not recognised in the past. Others suggested that a range of factors has led more young people to question their gender identity and to express their concerns about their gender identity to others. It was thought these factors might include there being more transgender people in the public eye and on social media, changes in the way gender is talked about in schools, and broader factors such as the sexual objectification of women. Some believed that many of the young people identifying as transgender or nonbinary today would, in the past, have identified as gay, lesbian or bisexual. Others pointed out the number of people who identify as gay, lesbian or bisexual in the UK has also increased, and that little is known about the sexual orientation of gender diverse young people. A study of adolescents referred to an Amsterdam clinic between 2000 and 2016 suggested that the increase in referrals may be due to feelings about gender dysphoria being more common than originally expected, rather than thresholds for referral becoming lower.1
- 10 Whether the increase in referrals is due to some kind of new phenomenon is a contested issue. Some of the participants at our meetings reported anecdotal accounts of adolescents and young adults expressing feelings of gender dysphoria apparently 'out of the blue', according to their parents. 'Rapid onset gender dysphoria' was described in an academic article in 2018 as when adolescents, particularly teenage girls, suddenly question their gender identity, often after being in contact with other gender diverse people.² The paper calls for more research to explore the roles of social influence, maladaptive coping mechanisms, parental approaches and family dynamics in the development and duration of gender dysphoria in adolescents and young adults. The paper drew both criticism and support. The journal later published a correction article that emphasised that it was a descriptive research study of parental observations which served to develop hypotheses, and that claims about causal associations cannot be made from such studies.³ Further research involving gender diverse young people themselves, and

¹ Arnoldussen M *et al.* (2019) Re-evaluation of the Dutch approach: are recently referred transgender youth different compared to earlier referrals? Eur Child Adolesc Psychiatry (Aug); doi: 10.1007/s00787-019-01394-6.

² Littman L (2018) <u>Parent reports of adolescents and young adults perceived to show signs of a rapid onset of gender dysphoria *PLoS ONE* 13: e0202330.</u>

³ Littman L (2019) Correction: Parent reports of adolescents and young adults perceived to show signs of a rapid onset of gender dysphoria *PLOS ONE* 14: e0214157.

their parents or carers, would be helpful to increase understanding of how best to care for and support young people.

The NHS model of care

- 11 There was broad agreement among participants that the current NHS model of care for young people in relation to their gender identity needs to develop to respond to the needs of young people and their families today, and changing social contexts. There is a relatively small workforce working within gender identity services and there has been significant and rapid increases in demand. There have also been demographic changes among the young people being referred, and changes in societal attitudes towards and debate around gender identity. The NHS England review of its service specification for gender identity development services for children and young people is timely.⁴
- 12 Various problems with the current model of care were highlighted by participants, including (these proposals came from different participants so do not represent a single coherent proposal):
 - Long waiting times to see gender identity services, particularly in England. Given that puberty will be progressing while waiting for an appointment, a waiting time of more than a few months was thought to be unacceptable.
 - An overly centralised service, whereby every young person is referred to a
 national gender identity service. This can involve people travelling long
 distances for appointments with little support in between and creates limited
 room for clinicians outside central services to contribute in the field.
 - A lack of knowledge, skills and confidence among GPs, mental health and other
 professionals in the care and support of young people in relation to their gender
 identity. Variability in the willingness of GPs to oversee prescribing of puberty
 suppressants and hormones that have been recommended by gender identity
 services.
 - The requirement that the young person does not have severe or deteriorating mental health problems before being prescribed medication.
 - The perceived pathologisation of gender dysphoria, which can involve intrusive questioning, unnecessary delays in accessing treatment, and a lack of trust or belief in the young person. Conversely, others thought the assessment process was not thorough or long enough, and more 'watchful waiting' should be taking place.
 - Variable levels of communication and collaboration between gender identity services and local Child and Adolescent Mental Health Services (CAMHS) and GP services.

⁴ NHS England (20 January 2020) <u>Update on gender identity development service for children and young people.</u>

- Shared responsibility for care and prescribing across several specialisms (e.g. psychiatry, endocrinology) which might diffuse accountability for outcomes.
- Difficult transitions to adult services. In some countries, for example Northern Ireland, adult services have a long waiting list and there is no effective continuity of treatment.
- 13 Suggestions that were put forward by participants for improving the system included (again, these proposals came from different participants so do not represent a single coherent proposal):
 - A more flexible and holistic model, whereby young people are cared for through pathways that are adapted for their individual needs by multidisciplinary teams.
 - A less centralised service, for example with more gender identity clinics around the country (such as the GIDS Leeds base, and the Birmingham, Bristol and Exeter outreach services), or where gender identity clinicians run clinics within local CAMHS services (such as the model in Northern Ireland), or a 'hub and spoke' model, where a central expert and learning centre co-ordinates a nationwide system and carries out research.
 - Use of puberty suppressants and hormones in adolescents only in the context of a clinical trial for the time being, while further evidence on their use is gathered.
 - Widespread evidence-based training and education for all health and social care professionals and others who might be involved in the care of young people in relation to their gender identity.
 - Continuing work to improve collaboration between, or even merging of, adult and adolescent gender identity services to remove arbitrary cut-offs and ensure continuity of care.
 - Information and training in schools by independent parties that cover the spectrum of views and theories on gender and gender identity.

Social transition

- 14 Some young people are supported by their family, school and healthcare services to live in accordance with their gender identity, including non-binary gender identities, in name, clothing and through other methods of self-expression. The support and advocacy groups we met want young people to be supported and nurtured in expressing their gender identity without judgment, which is sometimes described as the affirmative approach. We heard that social transition and a positive social environment can have a significant impact on well-being.
- 15 Conversely, some participants thought that always supporting young people to transition socially could be damaging to them, or that it could be doing them a disservice. There was concern that young people are currently receiving the message that if they feel like a girl/boy, then they are a girl/boy. This was thought by some to be misleading. Those participants were resistant to the idea that adults

should automatically affirm a young person's feelings of gender dysphoria, but rather the young person should be supported in context, with an understanding of the experiences of puberty, and that it should be acceptable to support the young person in different ways.

Puberty suppressants and cross-sex hormones

Research evidence

- 16 Many participants thought there is a need for good quality, up-to-date research evidence on the long-term clinical and life-course outcomes associated with the use of puberty suppressants in young people with gender dysphoria. However, there were differences of opinion on what the existing evidence base means for clinical practice. Some thought that existing evidence and international clinical experience provides ethical justification for the use of puberty suppressants in standard care, given the potential risks of not providing this treatment. They rejected the claim that the use of puberty suppressants is 'experimental', or at least not any more experimental than other areas of paediatric practice when there are no licensed treatment options. A small number of participants judged existing international evidence to be substantial and sufficient.
- 17 Other participants believed that the state of the existing evidence is such that offering puberty suppressants to young people is unethical unless this is part of a research study. Those critical of the research base highlighted that existing studies tend to be small and do not enable the effects of different treatment regimes (e.g. psychological therapy or therapeutic support, and medication) to be separated. Some refuted the claim that it is not possible to include control groups in this area of research. Participants highlighted a recent blog in *BMJ EBM Spotlight* which found a lack of relevant, high quality evidence on the use of puberty suppressants and cross-sex hormones and concluded that "the development of these interventions should, therefore, occur in the context of research, and treatments for under 18 gender dysphoric children and adolescents remain largely experimental".⁵
- 18 Some participants suggested that long-term evidence on the efficacy and safety of puberty suppressants for the treatment of precocious puberty⁶ provides relevant evidence for the same treatment in young people with gender dysphoria. Others felt that clinical and research evidence for any medicine cannot be transferred from one indication or condition to another.
- 19 A study was initiated in 2011 to explore the long-term impact of halting the progression of puberty through the prescribing of puberty suppressants to young adolescents, known as the Early Intervention Study.⁷ Forty-four adolescents with

⁵ Heneghan C and Jefferson T (2019) <u>Gender-affirming hormone in children and adolescents</u> *Blog: BMJ EBM Spotlight.*

⁶ Precocious puberty is when puberty begins before age 8 in girls and before age 9 in boys.

⁷ The study is called 'An evaluation of early pubertal suppression in a carefully selected group of adolescents with gender identity disorder' and was undertaken at the Tavistock and Portman NHS Foundation Trust and sponsored by the University College London Institute of Child Health.

persistent gender dysphoria were recruited. The study was subject to an investigation by the Health Research Authority in 2019. The investigation concluded that the researchers had worked in accordance with recognised practice for health research, including its decision not to include a control arm.⁸ At the time of writing, the findings of the Early Intervention Study had been submitted for publication.

- 20 An interim report from the Early Intervention Study in 2014 stated that all 44 adolescents wanted to continue on puberty suppressants. The Health Research Authority report states that the participants in the study have progressed to cross-sex hormones. This led some participants at our meetings to express concerns that using puberty suppressants does not, as suggested, provide young people with a 'breathing space', but instead sets them on course to transitioning later on. Other participants pointed out that the study participants were post-pubertal and selected for strong and persistent gender dysphoria, so would not be expected to desist later on. In our meetings, we heard anecdotally about young people under the care of gender identity services in the UK who have decided not to move on to cross-sex hormones, and where puberty suppressants had in fact provided a breathing space.
- 21 Interim results of the Early Intervention Study also led to media reports that there are links between the use of puberty suppressants and self-harm. OGIDS responded by stating that the sample was too small to draw any generalisable conclusions and that this was an inaccurate interpretation of the preliminary data.
- 22 We heard that the barriers to conducting large, long-term studies could include a lack of funding, small numbers of potential participants, and hard-to-measure outcomes. It was suggested that carrying out a randomised controlled trial on the effects of puberty suppressants would not be ethical or practical, given the effects of the treatment would be well known to participants, and families actively pursuing treatment would be unlikely to opt for a randomised study. Others suggested that clinicians working in the field are reluctant to interrogate current treatment regimes, that any studies emerging from gender identity centres would be biased, and that funders and institutions were cautious about supporting research in such a controversial area. There was thought to be no financial incentive for pharmaceutical companies to put resources into licensing puberty suppressants for this patient group.
- 23 We heard that research in this area is now receiving more support and there is a larger pool of potential study participants to recruit from. Two noteworthy studies that are underway include one being undertaken by Oxford University on the

⁸ Health Research Authority (2019) <u>Investigation into the study 'Early pubertal suppression in a carefully selected group of adolescents with gender identity disorders'.</u>

⁹ Report presented at a seminar at the WPATH Symposium, Bangkok 14-18 Feb 2014, see https://gids.nhs.uk/our-early-intervention-study.

¹⁰ BBC News (22 July 2019) <u>Transgender treatment: Puberty suppressants study under investigation.</u>

¹¹ GIDS (23 July 2019) Recent reporting about our Gender Identity Development Service.

perspectives and experiences of young people, families and gateway professionals in gender identity health services, ¹² and a study being undertaken by collaborators from a number of UK universities and the Tavistock and Portman NHS Foundation Trust on the experiences of all young people under 14 years who access GIDS and how the decisions they make affect their quality of life, physical health and psychological wellbeing later in life.¹³ These studies will take several years to complete. We also heard about forthcoming qualitative research being carried out in The Netherlands that will explore the experiences of young people who were taking puberty suppressants, had discontinued suppressants, and had never had any further medical treatment.¹⁴

Clinical experience

- 24 The clinicians we spoke to said their aim is to reduce distressing feelings of gender dysphoria in young people, improve well-being and quality of life, and not cause harm. They accepted that there is a level of uncertainty about the long-term outcomes associated with puberty suppressants and cross-sex hormones. Their approach attempts to balance this uncertainty with the potential risks of not prescribing medication in highly distressed young people, and the chances of improving their quality of life and well-being. We heard that fewer than half of young people seen by GIDS are referred to the endocrine clinic for a discussion about medical intervention. All service users receive ongoing psychosocial support. The approach in the UK broadly aligns with international guidelines and the approaches of other European countries.¹⁵
- 25 We heard that clinicians at GIDS were originally motivated to consider prescribing puberty suppressants to younger adolescents in a research context because a) their peers across Europe were doing so, with apparently good outcomes, b) gender diverse young people and their families were seriously dissatisfied with the situation in the UK, with some seeking treatment privately or going abroad, and c) bioethicists suggested that if it was likely to improve the child's quality of life, then it would be unethical to defer treatment. ¹⁶ GIDS considered the clinical and ethical issues for around a decade before embarking on the Early Intervention Study in 2011 with partners at University College London Institute of Child Health. ¹⁷

¹² NIHR project summary: <u>Meeting the transgender challenge: improving the experience of health services for gender diverse young people and their families.</u>

¹³ NIHR project summary: Outcomes and predictors of outcome for children and young people referred to uk gender identity development services: a longitudinal investigation.

¹⁴ Interview with Annelou de Vries, Child and Adolescent Psychiatrist, Amsterdam University Medical Center, The Netherlands.

¹⁵ For example: World Professional Association for Transgender Health (2012) <u>Standards of care for the health of transsexual, transgender and gender nonconforming people, 7th version; Hembree WC *et al.* (2017) <u>Endocrine treatment of gender-dysphoric/gender-incongruent persons: an endocrine society clinical practice guideline *J Clin Endocrinol Metab* **102**:3869-3903.</u></u>

¹⁶ This paper was particularly influential: Giordano S (2008) <u>Lives in a chiaroscuro</u>. <u>Should we</u> suspend the puberty of children with gender identity disorder?

¹⁷ GIDS An evaluation of early pubertal suppression in a carefully selected group of adolescents with 'Gender Identity Disorder'. <u>A statement and update on the Early Intervention Study</u> (accessed 14 May 2020).

- 26 Questions were raised by some participants about why changes were made to the NHS England Service Specification in 2016, which describes the prescribing of puberty suppressants for post-pubertal adolescents as 'established practice', before the full findings of the Early Intervention Study were known. Prior to this, puberty suppressants were only available to people aged 16 and over in the UK, apart from the participants of the Early Intervention Study. As mentioned above, there was disagreement among participants at our meetings about how evidence and other factors should be interpreted and weighed in clinical practice.
- 27 The requirement by GIDS that a young person must have been on puberty suppressants for a year before they can be prescribed cross-sex hormones is viewed as an inappropriate criterion by some, given some young people will first see GIDS when they are in an advanced stage of puberty. Services in Scotland do not have this requirement people presenting at 16 can be prescribed cross-sex hormones straight away if this is deemed to be the best course of action. Some in the medical community are discussing whether cross-sex hormones could be made available to people earlier than 16 years, in situations where an adolescent has been on puberty suppressants for several years and there are concerns about bone density. Some participants called for robust research to be carried out before any such changes were made to clinical practice.
- 28 Clinicians and others highlighted that puberty suppressants, when started in the earlier stages of puberty, keep young people from developing into adults while their peers are progressing through puberty and developing sex characteristics. The effects of this on well-being and mental health are not well understood.

Consent to medical treatment

- 29 The clinicians we spoke to said they were always very clear in conversations with young people and their families about the uncertainties surrounding the use of puberty suppressants and hormones, and the potential effects of these treatments on, for example, future fertility, genital growth in assigned males, and the trajectory of gender identity development.
- 30 Some participants questioned the ability of young people, particularly those aged 16 and under, to consent to having medical treatment for gender dysphoria, given their developmental stage and the uncertain and potential long-term effects of the treatments. A case has been brought to the High Court that seeks to clarify whether people under the age of 18 are of sufficient maturity and capacity to understand the consequences of taking puberty suppressants. Those pursuing this case have asked the court to consider whether 'Gillick competence' (when a person aged under 16 years is able to legally consent to their own medical treatment without the need for parental permission) applies in this area of medicine. A judge gave permission in March 2020 for a hearing on this matter which is expected to take place in October 2020. Some participants suggested that the claim that young people with gender dysphoria are not legally able to consent to treatment, despite

¹⁸ The Guardian (5 Jan 2020) High court to decide if children can consent to gender reassignment.

being able to take decisions about other types of medical treatment, could be considered discriminatory, and that there are potential wider implications of this case for young people's rights to make decisions about their care.

- 31 The clinicians we spoke to emphasised the shared nature of decision making, whereby the young person, their parents or carers, and the doctors decide together on the care plan, focusing on what is in the best interests of the young person. In most cases agreement is possible. In some cases, agreement is not possible and clinicians will work with families to find a way forward. For under 16s, it is considered necessary for the parents or carers to support the young person's feelings and wishes before the proposed treatment can begin. Treatment would be offered to over 16s without parental or carer agreement only in exceptional circumstances, for example, if the young person is under the care of a local authority. This raised the serious question for some participants of what happens to those young people who do not have parental or carer support to begin medical treatment, or to seek professional help in the first place.
- 32 Some of the clinicians we spoke to said that social media and interactions with transgender support groups mean that the young people and families they see tend to have clear ideas about the medical treatments they want and how they believe they need to behave to qualify for treatment.

Association with autism spectrum disorders (ASD)

- 33 Young people with gender dysphoria are more likely to have ASD than the general population. The reasons for this are not well understood. Some participants suggested that the affirmative approach to care and treatment of gender dysphoria is not appropriate for people with ASD because of the language and communication difficulties associated with ASD. Others were of the view that people with ASD, just like anyone else, should be listened to and believed if they are questioning their gender identity.
- 34 There was general uncertainty among participants about how to care for and support young people with ASD and gender dysphoria. Resources have been developed by gender identity services in Scotland and England to facilitate discussion of puberty and the role of puberty suppressants to help people who struggle to describe how they feel.

Fertility

35 There is no evidence to suggest that puberty suppressants damage or do not damage fertility. It was broadly agreed that young people should be aware that taking puberty suppressants is frequently associated with taking cross-sex hormones or having surgery later on, which can affect fertility. Clinicians said they

¹⁹ Estimates vary but young people with ASD have been found to be roughly four times as likely as young people in the general population to have gender dysphoria: eg see Hisle-Gorman *et al.* (2019) Gender dysphoria in children with autism spectrum disorder LGBT Health Apr 2019: 95-100. http://doi.org/10.1089/lgbt.2018.0252; National Autistic Society (2017) Gender dysphoria and autism: Challenges and support (accessed 14 May 2020).

discuss fertility issues with young people before prescribing puberty suppressants or hormones, and some would refer the young person to a fertility clinic. There is a separate assessment and consent process for the prescribing of cross-sex hormones, when fertility issues can be discussed again. Questions were raised by some participants about the ability of young people to fully understand the implications of medical interventions for fertility later in life.

- 36 We heard anecdotally that most young people do not pursue fertility preservation before undergoing hormone treatment. Reasons suggested for this include that fertility preservation would delay or pause hormone treatment, long waiting lists for or lack of access to NHS fertility clinics, costs of private treatment, and the unpleasant process of egg extraction. For those who do pursue gamete freezing, it is not known how often people return to use them as part of fertility treatment.
- 37 It is possible to stop taking cross-sex hormones after a period of treatment and go on to have children. We heard that oestrogen has more complicated effects on fertility than testosterone. It can take a long time for sperm production to begin again following cessation of oestrogen. It is possible to become pregnant while on testosterone and we heard that some unexpected pregnancies have occurred. Some transgender support groups would like to see better information being given about other options for having a child, such as adoption and surrogacy. More research is needed to understand the decisions and experiences of gender diverse young people in relation to their fertility. Some work in this area is already underway.²⁰

Private treatment

38 We heard anecdotally that young people and their families are seeking psychosocial and medical care privately in the UK and abroad because of the barriers to accessing care in the NHS. It was also suggested that fear of litigation and referral to the GMC is preventing private practitioners in England from prescribing puberty suppressants. Some young people and their families are seeking prescriptions from doctors in other countries and buying medicines online, without ongoing psychosocial support. There are no data available on the extent or outcomes of private care for gender diverse young people in the UK. Participants suggested it would be helpful to know more about the breadth of experiences of gender diverse young people who have received care from private providers in the absence of access to NHS care.

Detransitioning

39 People who transitioned during adolescence and decided to detransition later in life to their assigned-at-birth gender or sex have received attention in the media. Articles and programmes have described people's regret about transitioning during

²⁰ For example, 'An international exploration of transmasculine practices of reproduction' will explore the sociological and health care implications of the reproductive practices of people who become pregnant and/or give birth after transitioning, see https://transpregnancy.leeds.ac.uk/.

- adolescence and their belief that the assessment process for adolescents with gender dysphoria is inadequate.²¹
- 40 The clinicians we spoke to told us that there can be many outcomes for gender diverse young people who attend gender identity services. Many young people detransition without having undertaken any medical treatment. For others, living in accordance with their gender identity or non-binary status proves too difficult and detransition can be a temporary response to discrimination. Some decide they do not wish to compromise their fertility prospects. Research studies suggest that feelings of regret about medical or surgical intervention are uncommon among transgender people, and that regretful outcomes can result from a complex interplay of social factors.²²
- 41 There was disagreement among participants about whether people who detransition in adulthood provide evidence that the care and support they received earlier was not in their best interests. Some suggested that a process of exploration or a 'gender journey' might be necessary for some people before they are able to settle on what feels right.²³ Participants thought research on the experiences of people who have detransitioned would be helpful.

Social context and media debate

- 42 Although gender diverse young people are not a homogenous group, experiences of discrimination and prejudice were identified as often having a significant impact on their lives. Some gender diverse young people have strong support from friends and others at school. Others feel judged, for example, for wavering over their gender identity. Some are very open about being gender diverse. Others are open with some people in their lives and not with others. Being open often comes with the expectation they will support other young people who are questioning their gender identity. Some know lots of gender diverse people. Others talked about not having wide access to people going through the same experiences as them.
- 43 Some of the participants we spoke to criticised what they described as our highly gendered society and worried that affirming a young person's transgender identity reinforces gender stereotypes and binary genders. There were concerns that young people are being led to believe that they are transgender if they defy gender stereotypes. Some questioned whether so many young people would feel the need to change gender if they were supported to act and behave in whatever way they wish, regardless of their gender.

²¹ For example, see BBC Newsnight (26 Nov 2019) <u>Detransitioning: Reversing a gender transition</u> and Sky News (5 Oct 2019) <u>'Hundreds' of young trans people seeking help to return to original sex.</u>
²² Wiepjes CM (2018) <u>The Amsterdam cohort of gender dysphoria study (1972-2015): Trends in prevalence, treatment, and regrets</u> *J Sex Med* 15:582-590. doi: 10.1016/j.jsxm.2018.01.016; Vincent B (2016) <u>Non-binary gender identity negotiations: Interactions with queer communities and medical practice</u> PhD thesis, University of Leeds.

²³ Giordano S (2019) <u>Importance of being persistent. Should transgender children be allowed to transition socially? *J Med Ethics* **45**:654–661.</u>

- 44 Social media plays a significant role in the lives of young people. For many it provides an important source of information and channel of communication to likeminded people and peer support. Those critical of the affirmative approach to the gender identity of young people thought that messages coming through social media are akin to propaganda.
- 45 The messages being conveyed in the news media about gender diverse young people were upsetting and disturbing to many of the participants. There was broad agreement that media reporting on this topic can be misleading and can convey contradictory messages.²⁴ This might be due in part to the fact that academic and other literature can be contradictory and difficult to navigate. Participants also suggested there has been an element of 'moral panic' in media reporting over the past few years.
- 46 Some participants had heard first-hand that messages in the news media can be upsetting and confusing for gender diverse young people to hear. It was suggested that increases in negative media reporting might be contributing to an increase in abuse and discrimination experienced by transgender people, although there is no evidence for this association. It was pointed out that the voices of young people themselves are largely missing from mainstream media reporting of these issues, particularly the voices of young people who have socially transitioned and not sought medical intervention. Those who have questioned current approaches to the care and treatment of gender diverse young people, such as gender critical feminists, also experience negative and hurtful media coverage.
- 47 Clinicians working in gender identity services, particularly in England, reported feeling under immense public scrutiny. They felt they were criticised by two communities coming from opposite poles. While they recognised they should be accountable and had a role in informing public conversations, the intense and often polarised debate and the demands of contributing to this significantly impacts on their daily working lives.
- 48 Some participants suggested that recent heightened media activity and campaigning in this area could be partly a result of the Government's delay in completing its review of the Gender Recognition Act 2004. A consultation on the Act was held in 2018 which drew strong views on how people can have their gender identity legally recognised. Political leaders have not settled the issue, which, it was suggested, has created space for the media to portray both those who oppose and those who support changes to the Act in negative ways. The participants who are involved in this debate expressed regret that the debate has become so polarised and hostile.
- 49 To improve accuracy, balance and sensitivity in reporting, we recommend that accessible summaries of any evidence reviews should be made

²⁴ For example, see GIDS (23 July 2019) <u>Recent reporting about our Gender Identity Development</u> Service.

²⁵ For example, see Mermaids (13 Nov 2019) 'Give transgender children like Emily a voice'.

available and a greater diversity of experiences should be represented in media accounts.

International context

- 50 The current UK approach to the care and treatment of young people in relation to their gender identity was originally pioneered in Europe, particularly in The Netherlands. In the early 2000s, UK clinicians were influenced by practices in Europe, for example the prescribing of puberty suppressants to adolescents in the early stages of puberty. The UK approach aligns with guidelines set out by the World Professional Association for Transgender Health and the Endocrine Society. Some participants criticised these guidelines for being biased towards a particular ideology and for being based on clinical experience rather than research evidence.
- 51 Similar increases in referrals to adolescent gender identity clinics have been seen in The Netherlands and Belgium, but appointment waiting times are not as long as in England. A stepped-care model is being explored in The Netherlands, and further gender identity services are being opened across the country. In Belgium, clinicians have recently considered whether prescribing cross-sex hormones to 15-year-olds might be justified in some cases.
- 52 Public debate about the care and treatment of young people in relation to their gender identity is less extreme in The Netherlands and Belgium than it is in the UK. Discussions tend to focus on access and barriers to care. The clinicians we spoke to accepted there was uncertainty around long-term outcomes of treatment and cited similar barriers to carrying out research as their UK counterparts, such as lack of funding and small patient populations.

Research gaps

53 Many people we spoke to called for more or different research to be carried out in order to fill gaps in the evidence base. It was suggested that, in a contentious area such as this, it would be important for researchers to involve appropriate external people in the design of their research (with an awareness of the interests of those people) and to ensure their research is highly rigorous and transparent.

54 Examples of gaps in the current evidence base identified by participants include:

- The reasons for the rapid increase in referrals to NHS gender identity services across the UK.
- The long-term clinical and life-course outcomes associated with the use of puberty suppressants and cross-sex hormones in young people with gender dysphoria.

²⁶ World Professional Association for Transgender Health (2012) <u>Standards of care for the health of transsexual</u>, <u>transgender and gender nonconforming people</u>, 7th <u>version</u>; <u>Hembree WC et al.</u> (2017) <u>Endocrine treatment of gender-dysphoric/gender-incongruent persons: an endocrine society clinical practice guideline</u> *J Clin Endocrinol Metab* **102**:3869-3903.

- The interactions between adolescent brain development, mental health and feelings of gender dysphoria.
- The decisions and experiences of gender diverse young people in relation to their fertility.
- How gender diverse young people with different needs, e.g. those with ASD, should be supported.
- The experiences of gender diverse young people who have received care from private providers in the UK and abroad.
- The experiences of people who have detransitioned.

We are aware that research in some of these areas is already underway. It was suggested by some participants that setting up an international registry could be helpful for sharing research protocols and data. We welcome the establishment by NHS England of an independent expert group to make recommendations on the evidence on the use puberty suppressants and cross-sex hormones.²⁷ We recommend that a broader review of existing evidence and ongoing research should be undertaken by healthcare commissioners, so that any significant gaps can be identified.

²⁷ NHS England (20 January 2020) <u>Update on gender identity development service for children and young people.</u>