

The care and treatment of children and adolescents in relation to their gender identity: ethical issues

**Call for evidence** 

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### Introduction

#### About the Nuffield Council on Bioethics

The Nuffield Council on Bioethics is an independent body that examines and advises on ethical issues arising from developments in bioscience and health. We aim to inform policy and public debate through timely consideration of the ethical questions raised by biological and medical research so that the benefits to society are realised in a way that is consistent with public values.

In late 2019, the Nuffield Council on Bioethics held a series of exploratory meetings with people and representatives of people with experience of gender identity services, medical practitioners, academics, and researchers to understand the ethical challenges in the <u>care and treatment of young people in relation to their gender identity</u>. This exploratory work raised a number of ethical issues about how gender diverse and gender incongruent children and adolescents under the age of 18 should be cared for, which we believe warrant more discussion and consideration.

The aim of this project is to carry out a more in-depth review of some of those issues. Our conclusions will inform practitioners and policy-makers and, ultimately, help improve the well-being of gender diverse and gender incongruent children and adolescents by ensuring they receive ethical, appropriate, and high-quality care. We hope that, as the UK's independent ethics body, we can make a valuable contribution to how these issues are discussed and considered.

#### About this call for evidence

This call for evidence is an open call for views on some of the issues we want to explore in more detail, including:

- the nature of gender dysphoria and how this affects approaches to care and treatment;
- the social context within which gender dysphoria exists;
- whether there is adequate evidence on the safety and effectiveness of puberty blockers and cross-sex hormones to support treatment;
- current approaches to care and treatment, including the purpose of puberty blockers, the gender affirmative approach, and social transition;
- how to consider the benefits and harms of treatment and non-treatment in decision-making; and
- the ability of children and adolescents to consent to medical interventions for gender dysphoria.

This call for evidence is not concerned with the wider gender identity debate as it relates to questions of self-identification, nor issues about the care and treatment of young adults/adults aged 18 and over. A review of the current provision of gender

identity services for children and young people is the subject of a separate independent review commissioned by NHS England.

#### Who we want to hear from

We would like to hear from as many people and organisations as possible who have an interest in the care and treatment of children and adolescents in relation to their gender identity, and this call for evidence is open to anyone who wishes to respond. In particular, we would like to hear from anyone with personal experience of using gender identity services or supporting someone to use those services.

The responses to this call for evidence will form an important step in our evidence gathering and play a significant role in influencing this project and its final conclusions. We will also be undertaking a number of other evidence-gathering exercises to ensure we hear from a diverse range of people. Please contact us by emailing <a href="mailto:gender@nuffieldbioethics.org">gender@nuffieldbioethics.org</a> if you would like to be involved in any further opportunities to contribute, or to alert us to other people or organisations who may be interested in this work.

#### How to respond

Please complete and return the attached form to <a href="mailto:gender@nuffieldbioethics.org">gender@nuffieldbioethics.org</a> by Friday 14 May 2021. Responses will be handled confidentially, and we will not publish your name without express permission.

We have outlined questions grouped under six key themes, alongside a very brief overview of some of the views expressed in the literature. You are welcome to respond to as many, or as few, of the questions as you wish. You will have the opportunity to comment on any other relevant issues you would like to draw to the attention of the Council in the final open-ended section.

A note on terminology: We recognise that the language used in this area is complex, and that not everyone agrees on the 'correct' terminology or how it is used. Throughout this call for evidence we use 'trans' and 'transgender' interchangeably as an umbrella term for anyone whose gender identity does not correspond with their birth sex. We also use the phrase 'gender diverse' to refer to children and adolescents whose gender identity may be different in a variety of ways from their birth sex - this includes people who have been diagnosed with gender dysphoria and gender incongruence. The gender diverse young people we met with through our initial exploratory work told us they preferred this as a collective term.

### Your details

⊠ Yes

Name: Dr Jonathan Leach OBE, MB, ChB, MSc(Med), FRCGP, DRCOG, DIMC, RCS(Ed) **Joint Honorary Secretary of Council** Organisation (if applicable): Royal College of General Practitioners Email: policy@rcgp.org.uk You do not need to provide an email address, but it would be helpful for us to be able to contact you should we have any queries about your response or wish to follow up on any of the points raised. Your email address will not be shared or published in the report. About your response Are you responding personally (on your own behalf) or on behalf of an organisation? □ Personal □ Organisation May we include your name/your organisation's name in the list of respondents that will be published in the final report? ▼ Yes  $\square$  No If you have answered 'yes', please give your name or your organisation's name as it should appear in print: **Royal College of General Practitioners** May we quote from your response in the report and make it available on the Council's website when the report is published?

□ No

☐ Yes, anonymously\*

<sup>\*</sup> If you select this option, please note that your response will be published in full (excluding this form). If you wish to remain anonymous, please make sure that your name and any other identifying information does not appear in the main text of your response. The Nuffield Council on Bioethics cannot take responsibility for anonymising responses in which you or your organisation may be identifiable from the content of your response. Please note that obtaining consent to publish a response does not commit the Council to publishing it. We will also not publish any response where it appears to us that to do so might result in detriment to the Council's reputation or render it liable to legal proceedings.

In what capacity are you responding to this call for evidence? Tick all that apply.
☐ Personal experience of using gender identity services for children and adolescents
$\hfill\square$ Personal experience of supporting a user of gender identity services for children and adolescents
☐ Healthcare professional
□ Policy maker
☐ Work for a charity or advocacy group
□ Academic interest
□ Researcher
□ Legal/regulatory interest
☐ Other professional interest
☑ Other (please state):
Royal College
□ Prefer not to say
We would like to send you a link to the report when it is published and keep you informed about other activities related to this project. If you would like us to do so, please tick here $\boxtimes$
If you would like to receive our newsletter on all the Council's activities, please tick here $\hfill\Box$
We will use your data to send you the newsletter, project updates, and for our internal reviews of our impact. We will not share your data with any third parties. You may unsubscribe from our newsletter at any time by clicking the unsubscribe link in any newsletter email or by emailing <a href="mailto:bioethics@nuffieldbioethics.org">bioethics@nuffieldbioethics.org</a> . For more information on our principles when dealing with personal data, please see our privacy policy at <a href="mailto:http://nuffieldbioethics.org/legal">http://nuffieldbioethics.org/legal</a> .

## Section 1: The nature of gender dysphoria

In carrying out our exploratory work, we found that disagreement about what gender dysphoria is underlies many of the disagreements about what the approach to care and treatment of young people should be. Some people think that gender dysphoria is a medical condition, and explain it as a genetic, hormonal, neurodevelopmental or psychiatric condition. Other people reject the idea that gender dysphoria is a medical condition, and understand it as either a social construct or a normal variant of gender expression.

In the absence of clear evidence as to what causes gender dysphoria, it is unlikely that a single agreed view will be reached. That being the case, we want to understand views on whether and how a lack of consensus on what gender dysphoria is, and what causes it, should affect the approach to care and treatment.

### 1. How should gender dysphoria be characterised?

The RCGP position statement on "The role of the GP in caring for genderquestioning and transgender patients", defines gender dysphoria as "distress or discomfort experienced due to a discrepancy between a person's gender identity and their biological sex observed at birth".<sup>1</sup>

# 2. In your view, how should young people with gender dysphoria be treated, cared for, or supported?

The role of GPs and their teams is to provide general holistic care for all individuals within the scope of their practice and expertise. GPs should support young people with gender dysphoria as they do every patient - openly, respectfully, sensitively and without bias.

In providing holistic care, GPs are able to contextualise a young person's presentation of gender dysphoria taking in to account their individual medical history, broader environment and issues including mental health and autism. The GP role includes consideration of sexual health, safeguarding and family relationships, the latter of which can be particularly challenging for young people with gender dysphoria. GPs will recognise that the family members of a patient experiencing gender dysphoria also face significant challenges and as appropriate refer these family members to further support services.

GPs are expert generalists and can often find that the provision of detailed advice about gender identity issues and associated treatment falls outside their area of competence. For children and young people particularly, treatment and care for gender dysphoria is a specialist service. Patients with possible or diagnosed gender dysphoria, or who self-define as trans,

<sup>&</sup>lt;sup>1</sup> https://www.rcgp.org.uk/policy/rcgp-policy-areas/transgender-care.aspx

should receive prompt and timely access to specialist services such as those provided by gender identity clinics.

3. Do you think that treatment and care of gender diverse young people should take into account the deep disagreement about the nature and causes of gender dysphoria? If so, how?

GPs will provide holistic care to patients regardless of the deep disagreements relating to gender dysphoria. However, addressing the needs of children and young people under the age of 16 who are experiencing gender dysphoria or are in the process of transitioning to another gender often presents particular challenges. These include the vulnerabilities of young people at this time and the heightened risk of self-harm and attempted suicide, as well as the concerns of parents who may not be accepting of what is happening to their child. Parental and carer involvement in the care of these patients is crucial and adds another layer of complexity to the GP role. This is exacerbated by an absence of a robust evidence base for interventions for children and young people.

#### Section 2: The social context

The number of young people being referred to gender identity services has increased significantly over the past ten years, both in the UK and internationally. There has been an increase in the number of referrals from girls (sometimes referred to as natal girls, biological females, or those assigned female at birth).

There are divergent views as to the reasons for this. Some think that gender dysphoria has always been prevalent among young people, but was often unrecognised or repressed. Others think it is a new phenomenon, specific to today's social context. Various social factors and societal changes have been suggested as playing a role in the number of those seeking treatment or contributing to how gender dysphoria is perceived and understood, including:

- shifting social attitudes towards sex and gender;
- intense sexualisation and objectification of women associated with female puberty and womanhood;
- increased visibility of transgender individuals in public life and coverage of trans issues in the media;
- social pressures to conform, or not conform, to gender norms;
- experience of homophobic or other types of abuse and bullying;
- the significant role that social media and the internet play in young people's lives - which, alternatively, upholds and enforces traditional gender norms; offers opportunities for self-expression and the chance to find supportive communities; or contributes to what some have called a 'social contagion' of gender dysphoria.
- 4. In your view, what social factors are most relevant to the discussion about gender identity in children and adolescents? How might these contribute to:

(a) the onset or expression of gender dysphoria in children and

adolescents; and	
(b) the way gender dysphor	ia is understood and perceived in society?

N/A
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5. How might the social factors you have identified affect whether, what, and how care and treatment is provided to children and adolescents?

N/A			

#### Section 3: Research evidence

There are differences of opinion as to what the existing evidence base on the use of puberty blockers (gonadotropin-releasing hormone agonists (GnRHas)) and cross-sex hormones means for clinical practice. Some believe that the existing evidence and clinical experience provides an ethical justification for the use of puberty blockers and cross-sex hormones in care, pointing to the literature which shows the potential risks of <u>not</u> providing that treatment (i.e. increased psychiatric morbidity, self-harming behaviours and suicide). They reject the claim that the use of these treatments is 'experimental', or argue that it is similar to other areas of paediatric practice where there are no licensed treatment options.

Others believe that the current state of research evidence provides an insufficient basis for treatment, and that puberty blockers should be considered experimental treatment and prescribed only in the context of a research study. This was the conclusion of the High Court in the recent *Bell v Tavistock and Portman NHS Foundation Trust* case, on the basis of the uncertainty over the short- and long-term clinical and life-course outcomes and ambiguity over their purpose.

6. In your view, does the available evidence support medical interventions in gender diverse children and adolescents? Please expand on your comments.

There are currently significant gaps in evidence for nearly all aspects of clinical management of gender dysphoria in youth. Urgent investment in research on the impacts of treatments for children and young people is needed. This should cover the effects of various forms of interventions (including 'wait and see' policies) for gender dysphoria. This lack of robust evidence prevents GPs from helping patients and their families to make informed decisions.

7. Does the use of puberty blockers in this context warrant a different standard of evidence to support decisions about treatment compared to other paediatric interventions? Please expand on your comments.

The use of puberty blockers should not be held to a higher evidential standard than other interventions, but this does not negate the significant need for further research and evidence in this field.

## **Section 4: Approaches to care and treatment**

The current approach to care and treatment in the UK is based on the World Professional Association for Transgender Health (WPATH) guidelines. It focuses on providing psychological and psychosocial support to patients and families and, if there are persistent signs of gender dysphoria upon reaching puberty, making a referral to a paediatric endocrine clinic for puberty suppression with the option of receiving cross-sex hormones to masculinise or feminise the body from the age of 16.

#### The purpose of puberty blockers

One of the current dilemmas in treatment decisions relates to the *purpose* of puberty blockers: whether it is to give young people time for reflection and exploration before proceeding with further, irreversible treatment, or whether it is intended as the first step towards other treatment and designed to facilitate more straightforward transition with cross-sex hormones and later surgical interventions.

There is also a broader question about whether the provision of puberty blockers at a young age opens up or closes down future choices, for example, whether it leaves room for gender identity to fluctuate or evolve over time, or whether it determines or fixes a particular identity which excludes exploration of other options. Evidence on the number of children and adolescents with profound and longstanding gender dysphoria who persist in their gender identities, and on those who desist and do not become transgender adults, illustrates the complexity of the situation.

# 8. What should be the purpose of puberty blockers? Does this match up with how they are used in practice?

These decisions are the remit of gender identity specialists rather than expert generalist GPs.

Puberty blockers are prescribed by GPs in other parts of medicine – for example the treatment of prostatic cancer. These medications are not initiated by a GP, and if prescribing is undertaken in primary care there are detailed shared care arrangements between hospital consultants and GPs. These agreements ensure the patient can be referred back into hospital for advice and specialist input as necessary.

Currently, there is concern that many of the shared care arrangements for transgender patients move too much clinical responsibility onto GPs, given the complexities and questions that may arise in this specialist area of prescribing and the very small number of patients that an individual GP will be caring for. It is vital that appropriate specialist care is commissioned, and robust shared care arrangements are in place, if this type of prescribing is to be undertaken in primary care.

The gender affirmative approach One current approach to care and treatment of children and young people is often referred to as the 'gender affirmative' approach. It seeks to affirm the gender identity expressed by young people without questioning it. This approach complements the idea that gender is innate, sometimes expressed as the view that gender diverse and gender incongruent young people are 'born this way'. According to the gender affirmative approach, refusing to acknowledge and affirm gender identity, or attempting to 'cure' gender dysphoria, would be an attack on the identity and dignity of children and young people.

Others note evidence that a number of young people will desist from questioning their gender identity and will not become transgender adults. They also note evidence that suggests the majority of gender-questioning young people later identify as homosexual or bisexual adults, and worry that it is not always easy for children or clinicians to distinguish early questions and feelings about gender identity from early questions and feelings about sexuality. On this basis, they question whether the presence of gender non-conforming feelings and behaviour provides sufficient basis to endorse, unquestioningly, a child's view of their gender.

Those who view gender dysphoria as a symptom of broader mental health or social problems may advocate psychological and therapeutic approaches which adopt a more enquiring approach to a young person's expressed gender identity. Finally, the high rates of autism spectrum disorders (ASD) and mental health conditions in gender diverse and gender incongruent children and adolescents, and whether they are interrelated or simply co-existing, may also influence views on the most appropriate approach.

9. What is the best way to respond to a child or adolescent who expresses unhappiness or discomfort with their gender identity?

As outlined above, all GPs are expected to respond openly, respectfully, sensitively and without bias. GPs should offer a space for non-judgemental discussion with the child or young person and their family, and refer the patient promptly to appropriate specialist gender services. The best response may also include referral to mental health services and engaging with social care, safeguarding or sexual health colleagues.

### Social transition

Another approach to gender dysphoria is to support young people to live in accordance with their chosen gender identity, through choice of dress, changing names or pronouns - known as social transition. Some encourage early social transition as a way of exploring and expressing gender without the need for medical intervention, and note that it can help to reduce signs of distress and dysphoria. Recent trends in referrals indicate that a growing number of young people presenting to specialist gender clinics do so having already made a social transition.

Others have argued that social transition makes it difficult for young people to change their minds, and in fact increases the likelihood of later medical transition. Some raise concerns about external pressure to socially transition, perhaps from parents, mentors, or peers. They question whether social transition opens up or closes down future options. Some note that young people who later desist from identifying as trans may find this difficult it they have socially transitioned.

# 10. Should children and adolescents with gender dysphoria be encouraged or supported to transition socially? When should this occur?

This will be dependent on advice from gender identity specialists, and the individual circumstances of the child or young person. GPs will support patients to transition socially where this is consistent with the advice of specialist colleagues and within the scope of their work.

## Section 5: Understanding benefit and harm

As with other medical interventions, decisions about treatment can be seen through the lens of benefit and harm: what is most likely, given the available information, to prevent the greatest harm and yield the greatest overall benefit for a child? There are differences in opinion as to what those benefits and harms are, and the extent to which the available evidence can be used to draw conclusions. Some believe that the existing evidence base provides a definitive answer as to whether medical interventions are beneficial or harmful, while others believe that the long-term risks and benefits have not yet been fully established.

Some of the suggested benefits associated with medical interventions in relation to gender identity include:

- in the case of puberty blockers, the prevention of irreversible development of secondary sex characteristics, making any further surgical intervention easier or unnecessary;
- in the case of cross-sex hormones, the development of physical features which complement one's gender identity;
- the alleviation of distress associated with gender dysphoria;
- greater social acceptance and improved relationships;
- improved psychological functioning; and
- reduction of risks of suicidality and self-harming behaviours.

These need to be weighed against a number of suggested harms, which include:

- unknown or uncertain long-term adverse effects of puberty blockers;
- in the case of puberty blockers, the risk of decreased bone density and increased risk of osteoporosis;
- adverse effects on brain function by blocking puberty's normal role in cognitive development;
- loss of fertility;
- the negative consequences of disrupting physiological puberty, given the role it might play in the formation and development of a consistent gender identity;
- adverse impacts on social and emotional function for example, the feeling of being 'left behind' or 'out of sync' with peers who will be going through puberty;
- inhibition of age-appropriate sexual and romantic development and exploration;
- later regret and distress at an earlier decision; and
- for some individuals, a decision to desist or detransition if gender identity subsequently changes with no reliable way of distinguishing between those

individuals who will persist in their gender identities and benefit from treatment and those who will not.

11. How should the possible benefits and harms of treatment and non-treatment be weighed?

As above, further research is needed to enable the benefits and harms of different interventions including 'wait and see' approaches to be properly evaluated.

12. How should we balance the needs of young people who will become trans adults ('persisters') with those who will not ('desisters') if we cannot reliably distinguish between the two?

Given this challenge, research into the benefits and harms of different interventions is all the more important.

13. How should the evidence on desistence and detransitioning be factored into decisions on whether and when children and adolescents should be permitted to embark on different stages of treatment?

This evidence is an important element of research into benefits and harms of different interventions and should be considered as part of overall evaluation of interventions.

14. What are the ethical implications of providing treatment that children and adolescents might later regret or reconsider?

## **Section 6: Consent and capacity**

There are differences of opinion as to the capacity of children and adolescents to consent to medical interventions in relation to gender identity. Some believe that decisions about capacity should be made on an individual basis, and that with appropriate consultation, discussion, and the provision of detailed and age-appropriate information, many young people reach the standard of competence to make such decisions. They may hold that there is no reason for treating this decision differently from other types of medical treatment to which - if found to have capacity young people can consent themselves.

Others express doubts about whether children and adolescents have reached an appropriate state of cognitive development and emotional maturity to be able to make this sort of decision. They emphasise the uncertainties surrounding the long-term effects of medical treatment for gender identity; the (in)ability of young people to properly understand how treatment will affect future decisions and desires; and the uniqueness of treatment for gender identity as lifelong and life-changing in a way that few other treatments are.

There are differences of opinion too as to whether the consent of a young person alone should be sufficient, or whether there is a role for those with parental responsibility in addition to, or instead of, that young person's consent. In the UK, a young person is deemed to have capacity if they are able to weigh the information required and arrive at a decision; understand the nature and purpose of the proposed intervention; understand the risks of any proposed intervention as well as any alternatives; and are free from undue pressure or influence. This is often referred to as the standard of 'Gillick competence'. If the young person is not deemed to have capacity, the normal position would be that someone with parental responsibility must consent to medical treatment on their behalf. In the context of medical interventions in relation to gender identity the policy of the Gender Identity Development Service (GIDS) in England and Wales has always been that it would be inappropriate to administer puberty blockers to any patient without their consent and on the basis of parental consent alone.

A recent High Court judgement in the UK held that there will be 'enormous difficulties' in a child under 16 understanding and weighing the necessary information and being able to give consent to puberty blockers or cross-sex hormones. The Court concluded that it was 'highly unlikely' that anyone aged 13 or under could be deemed competent to give consent and 'doubtful' that anyone aged 14 or 15 could do so. Furthermore, in respect of young people aged 16 and over, clinicians 'may well regard these' as cases requiring consideration by the court. This decision is currently on appeal.

15. Do you think that children and adolescents under the age of 16 have the capacity to consent to puberty blockers and cross-sex hormones? Please expand on your answer.

GPs will be mindful of the December 2020 Bell vs Tavistock court judgement which ruled that it is 'highly unlikely' that a child aged 13 can competently consent to the use of puberty blockers and 'doubtful' that such consent could be given at the ages of 14 or 15. GPs will consider legal advice and advice from gender identity specialists and only prescribe where this is consistent with specialist advice and a robust shared care agreement is in place.

16. Who should have the authority to consent to and make decisions about medical intervention in relation to gender identity? (E.g. a competent young person alone; a competent young person and those with parental responsibility; those with parental responsibility should be able to consent on behalf a young person who lacks capacity; a court)?

As outlined above GPs will follow legal guidance and advice from specialist colleagues with regard to capacity to consent.

17.Is there anything distinctive about the use of puberty suppressants and cross-sex hormones such that they warrant a different standard of consent compared to other paediatric medical decisions?

The fact that some of the effects of cross-sex hormones can be irreversible along with the possibility of desisting may set puberty suppressants and cross-sex hormones apart from other paediatric medical decisions. Decisions over the standard of consent remain a matter for legal experts and gender identity specialists.

## **Section 7: Other**

Please use this section to share any other thoughts and comments which you have not been able to make in response to earlier questions.

Finally, we are also interested in understanding people's views and experiences of how this topic is debated and discussed more broadly. Many people have highlighted how polarised and hostile the debate around issues of gender identity and trans rights has become, and noted that this may inhibit open discussion about some of the clinical, legal and ethical complexities of this issue.

Are there any other ethical issues which arise in the context of the care and treatment of children and young people in relation to their gender identity that you would like to draw to our attention?
N/A
More generally, have you felt able to engage in talking about these issues openly in your personal or professional life?
N/A