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# Gender incongruence in children, adolescents and adults

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# Gender incongruence in children, adolescents and adults: General practitioners should apply usual basic compassion and full assessment despite existing uncertainties

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#### Introduction

More individuals are requesting medical assistance for gender uncertainty or dysphoria and provision of adult NHS gender identity services (GIS) is changing.(1) Despite minimal medical input to polarised debates, several issues are potentially concerning: reports of poor care; recent rapid rises in referrals of children and young people to GISs; (2) the public's conflation of biological sex with socially influenced gender roles; and extensive uncertainty in the evidence base to guide practice.(3)

Medical practice should happen within robust human rights frameworks where individual patients always have their concerns heard. Generalists, with expertise in whole-person care, handling uncertainty and complexity, have a key role when consulted by identity-questioning and transgender individuals for routine care, gender identity concerns, treatments recommended by private or NHS services, or for referral. Presentations with prior emotional trauma, co-existing mental or neurodevelopmental issues, or 'bridging hormones' requests may make primary care professionals uneasy. Without a considered approach to practice, high-quality evidence and guidance, a policy of active 'affirmation' and 'treat or refer' may lead to more people receiving medical interventions with uncertain outcomes.

# The changing landscape of gender identity

The characteristics of those seeking help are changing. Previously, mainly older biological males wanted medical interventions to gain a female appearance. Contemporarily, many younger people identify with a range of gender types (e.g. trans, fluid, non-binary, gender-queer) and there is greater difficulty distinguishing overlaps with imaginative processes. The majority presenting before puberty desist. Some, but not all, seek interventions with uncertain longterm outcomes. There is growing demand for GPs to prescribe cross-sex hormones before specialist assessments but GMC and BMA positions differ.(4,5) More definitive knowledge is needed about: the causes of rapid increased referrals, especially girls and young women;(2) the outcomes of interventions or 'wait and see' policies in this new demographic; and how to practice and organise services, especially anticipating longterm health implications.

The planned recommissioning of adult GIS in England provides an opportunity to develop best practice through integrated programmes of training, research and service redesign. Multidisciplinary approaches used within child and adolescent services might ensure that adults now being referred also receive whole person comprehensive support.(6)

# *Understanding the rise in referrals*

No robust analysis explains why referrals have risen so fast. Whilst some individuals will feel able to disclose earlier in a less stigmatised context, it is possible that gender identity uncertainty and dysphoria may be generated or exacerbated by societal (e.g. media and peers) and psychological factors, particularly during puberty. One study of concerned American parents reported their transidentifying children had previously identified as gay, had mental health or neurodevelopmental problems, recent onset dysphoria or came from friendship groups with other trans-identifying individuals.(7) The paper drew intense criticism despite acknowledging limitations including distinguishing cause and effect. Likely the rise is multifactorial: 35% of those seen in the Tavistock service have autism traits(1); some girls may favour traditional male roles; present female stereotypes and appearances may be rejected; some young women later identify as lesbians.

Doctors recognize social determinants influence distress and disease but deal with patients hereand-now rather than in utopias without sex oppression and infinite gender expression.

#### Intervention outcomes

While low quality observational studies of mainly older male-to-female full transition have shown high levels of satisfaction,(8) there are no robust contemporary cohort studies of younger female-to-male outcomes(1) nor of supportive, non-invasive interventions. Adolescents, who previously may have come to terms with changing bodies or emergent homosexuality, may be offered puberty-blocking drugs prior to psychoactive steroid hormones and irreversible surgery. We lack information whether these improve outcome, including reproductive consequences. Surgical deaths have been reported.(9) Improved mental wellbeing is the main rationale for intervention although one study shows high rates of suicide after surgery.(10) This could be due to ineffective treatment, ongoing prejudice or co-existent mental illness. Rates of persistence, benefits and complications, regret and detransition are unclear. Practitioners have been sued for not providing sufficient assessment or information.(11)

## Clinical practice and pathways to medical interventions

Gender questioning individuals need protection from discrimination, high quality services and clear information. Regulated professionals should be able to refer to bodies of evidence and guidelines, but there is no UK guidance designed for generalists. Some international guidelines advocate 'affirming' an individual's expressed gender. The 2017 UK Memorandum of Understanding, signed by the RCGP (but not RCPsych), rejects formal 'conversion therapy', also stating that actions which contribute to a change to gender identity could be seen as 'covert' conversion. So while 'affirmation' could indicate non-judgmental respect and compassion, practitioners might infer they should not explore wider issues or discuss harms of interventions. This would be counter to consultation models which encourage evidence sharing and leave room for differing views.

Somewhat paradoxically, calls for medical intervention refer to mental distress and suicide risk whilst psychiatric assessment is often rejected. This is worrying as there are no objective tests for gender dysphoria which has no agreed physical basis and is assessed by interview. It may be affected by social and cultural context and has the potential to change over time. In contrast to previous debates about de-pathologisation of sexual orientation which led to de-medicalisation, the opposite may occur here; while helping some, interventions can result in ongoing side effects and medical dependency. Medical intervention may, in effect, become another form of 'conversion therapy' whereby children who would otherwise have grown up gay or lesbian receive 'gender affirming' cross-sex treatments instead.

Much patient information does not fully express the known uncertainties of interventions. Many health care organisations and schools have been educated by pressure groups.(12) NHS material contains concepts that biological sex is assigned at birth (rather than observed) and that surgery can change sex. The medical profession has much to learn from transpeople, but it is essential to maintain both a societal and whole person perspective, considering the wide range of experiences including desistance.

A number of consultation approaches may be considered: use clear, respectful language and the patient's preferred form of address; allow a few appointments to explore issues which may be linked; explore the time frame of gender related distress, whether the individual is questioning or has firm beliefs, and how feelings of gender relate to sexuality; assess associated mental health issues such as self harm, anxiety or body dysmorphia, as well as autism traits; enquire about

relationships with family, friends, intimate partners and on-line groups and how these relate to the patient's views and wishes; remember sex is biological whilst gender relates to social roles; facilitate discussion of key controversies, such as whether it is possible to be 'born in the wrong body'; allow respectful space for differing views; share understanding of the uncertainties of long term treatment and outcomes; share literature from a variety of sources which the patient can read and discuss at future meetings.

Proposals for immediate action and research

Immediate actions could include: examination of NHS literature with regard to evidence and uncertainty; creation of coherent guidance for practitioners not specializing in gender identity; a national survey of doctors to understand views and concerns; and development of training to ensure practitioners feel competent to combine compassion and an understanding of the evidence.

Well-funded, independent, longterm research is required to ensure doctors meet their ethical and professional duties to 'first do no harm' and fulfill Good Medical Practice. Research could include: exploration of the interplays between gender dysphoria, mental health problems, autism spectrum disorders, sexual orientation, autogynephilia and unpalatable roles in our highly gendered society; exploration of the different assessment and diagnosis models; trials of different strategies, including wait-and-see versus intervention for young people, puberty-blocking, hormonal and surgical treatments.

The national reconfiguration of services is a one-off chance to integrate research, service redesign and training, with the creation of ongoing cohorts to monitor outcomes for all those referred and receiving different interventions.

### References

- 1. Butler G, De Graaf N, Wren B, Carmichael P. Assessment and support of children and adolescents with gender dysphoria. Arch Dis Child 2018
- https://adc.bmj.com/content/early/2018/04/26/archdischild-2018-314992 (last accessed 17 Nov 2018)
- 2. Tavistock and Portman NHS Trust. GIDS referrals increase in 2017/18. 17 May 2018 <a href="https://tavistockandportman.nhs.uk/about-us/news/stories/gids-referrals-increase-201718/">https://tavistockandportman.nhs.uk/about-us/news/stories/gids-referrals-increase-201718/</a> (last accessed 17 Nov 2018)
- 3. Byng R, Bewley S, Clifford D, McCartney M. Redesigning gender identity services: an opportunity to generate evidence. BMJ 2018;363:k4490
- 4. General Medical Council. Trans healthcare <a href="https://www.gmc-uk.org/ethical-guidance/ethical-hub/trans-healthcare#trans-health">https://www.gmc-uk.org/ethical-guidance/ethical-hub/trans-healthcare#trans-health</a> (last accessed 17 Nov 2018)
- 5. British Medical Association. Gender incongruence in primary care. <a href="https://www.bma.org.uk/advice/employment/gp-practices/service-provision/prescribing/gender-incongruence-in-primary-care">https://www.bma.org.uk/advice/employment/gp-practices/service-provision/prescribing/gender-incongruence-in-primary-care</a> (last accessed 17 Nov 2018)
- 6. Gender Identity Development Service Assessment <a href="http://gids.nhs.uk/about-us#main-content">http://gids.nhs.uk/about-us#main-content</a> (last accessed 17 Nov 2018)
- 7. Littman L. Rapid-onset gender dysphoria in adolescents and young adults: A study of parental reports <a href="https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0202330">https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0202330</a> (last accessed 17 Nov 2018)
- 8. Mural MH, Elamin MB, Garcia MZ, Mullen RJ, Mural A, Erwin PJ, Montori VM. Hormonal therapy and sex reassignment: a systematic review and meta-analysis of quality of life and psychosocial outcomes. Clinical Endocrinology 2010. https://doi.org/10.1111/j.1365-2265.2009.03625
- 9. Dhejne C, Lichtenstein P, Boman M, Johansson ALV, Långström N, Landén M. Long-Term Follow-Up of Transsexual Persons Undergoing Sex Reassignment Surgery: Cohort Study in Sweden

https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0016885 (last accessed 17 Nov 2018)

10. de Vries AL, McGuire JK, Steensma TD, et al. Young adult psychological outcome after puberty suppression and gender reassignment. Pediatrics 2014;134:696–704.doi:10.1542/peds.2013-2958 http://pediatrics.aappublications.org/content/134/4/696

11. 'I Wanted to Take My Body Off': Detransitioned

https://www.theatlantic.com/video/index/562988/detransitioned-film/ (last accessed 17 Nov 2018)

12. Kate Hutchinson: Wrexham to Euston – my journey to meet the General Medical Council <a href="http://www.allabouttrans.org.uk/kate-hutchinson-wrexham-euston-journey-meet-general-medical-council/">http://www.allabouttrans.org.uk/kate-hutchinson-wrexham-euston-journey-meet-general-medical-council/</a> (last accessed 17 Nov 2018)





Table 1. Medical uncertainties and our response to children, young people and adults with gender dysphoria

Medical Uncertainties	Response
What are the causes of gender dysphoria?	The causes of feeling uncomfortable with one's biological sex are unclear but likely to be multifactorial and include society's expectations of gender roles. For young people, especially, new forms of group identity, the need to belong and the influence of social media also need exploration.
Is there a biological basis for the concept of 'being born in the wrong body'?	Humans are sexually dimorphic; male and female sex characteristics are not on a spectrum, with the rare exceptions of some intersex conditions. It is not possible to change biological sex. There is no agreed scientific basis for brain sex or anyone with any concern being born in the wrong body.
How should a child or young person questioning their sexuality or gender identity be supported?	Questioning is a normal part of growing up, as is discomfort during puberty. Young people are fantastic, and should be encouraged to talk and ponder. If they experience rejection from family and services or cannot find a safe space to explore their feelings they are more likely to go online which may be risky.
What do shared decision making (including agreements to differ) and bio-psycho-social encounters look like in the absence of evidence?	Generalists should feel confident and supported to explore the potential links between gender questioning, emotions and cognitions, and the cultural context. Differences in views are likely to occur and provide the basis for each party to shift position.
How should we advise patients about the outcomes of medical treatments given the paucity of evidence?	Medical practitioners should be open and clear that, while satisfaction has been high for previous cohorts, we know little about the impact on physical (e.g. fertility), emotional (e.g. sustained reductions in distress) and social (e.g. future intimate relationships) outcomes for the current younger and mainly female group presenting.