



Government
Equalities Office

VARIATIONS IN SEX CHARACTERISTICS*

TECHNICAL PAPER

JANUARY 2019

* Sometimes referred to as intersex, differences of sex development or by using the name of a specific variation.



Government
Equalities Office

Variations in Sex Characteristics*

Technical Paper

January 2019

*Sometimes referred to as intersex, differences of sex development or by using the name of a specific variation.

Contents

Introduction.....	3
What does it mean to be someone who has variations in sex characteristics?	6
Chapter 1: Terminology	9
Chapter 2: Health	10
Chapter 3: Education	13
Chapter 4: Support services/organisations	15
Chapter 5: Workplace, Benefits, Sport and Leisure Services	17
Chapter 6: Sex Assignment, Birth registration and Correcting Birth Certificates	19
Chapter 7: Conclusion	22
References	23
Annex A: International Approaches and Wider Evidence	24

Introduction

1. The Government Equalities Office (GEO) is launching a call for evidence in order to help us better understand the experiences and needs of people in the United Kingdom who have variations in sex characteristics. This is an emerging and complex area of social policy and is the first time Government has produced a piece of work specifically looking at a range of issues experienced by this particular group.
2. As part of this call for evidence, we have published two documents. The first is a document/online form containing the questions we are asking as part of our evidence gathering process. The questions are designed to help address the existing evidence gaps across a range of key issues.
3. The second is this document. It is a technical paper that sets out some background information on the questions we have asked and why we are asking them, some technical information on relevant policy and legislation and our review of the current evidence base. We also describe the main findings from the extensive stakeholder engagement process that we have undertaken over the past year, in preparation for producing this call for evidence.
4. It is important to stress that this call for evidence is not a proposal from Government to change any particular policy and/or to introduce new laws. We may decide, having considered the evidence that is provided, to bring forward policy proposals at a later stage.

Evidence gathering so far

5. Over the last 12 months we have reviewed relevant research from the UK and internationally. We have also gathered evidence on the everyday experiences of people who have variations in sex characteristics through multiple stakeholder meetings. As well as this, we have looked at the data obtained through the National LGBT Survey 2017, although we recognise that the scope and design of the survey was specifically aimed at understanding the experiences of those who identified with a minority sexual orientation and/or gender identity. Additionally, in the recent consultation on reforming the Gender Recognition Act we included a question asking respondents about what changes were necessary to the legal gender recognition system in order to benefit people with variations in sex characteristics. Responses to this consultation will be analysed and published later this year.
6. To help us understand the issues faced by individuals and their families of this group, the GEO held meetings with a range of stakeholders. This included people with variations in sex characteristics, support organisations, academics and Parliamentarians, as well as clinical professionals such as psychologists and endocrinologists. Additionally, we met with international academics in Belgium, the Netherlands and Australia and attended a conference at the University of Bologna. We also learned about Malta's approach by meeting with Maltese civil society organisations and Maltese Government officials.

7. We gathered useful insights on people's experiences of interacting with the healthcare system, views on terminology and the role of support groups through this process but we have not been able to explore these and a range of other issues in depth. This is important to do if we are to determine whether Government has a role to play in addressing any issues.
8. That is why we are publishing this call for evidence. The call for evidence will provide everyone, especially people with variations in sex characteristics, with an opportunity to engage with Government and to tell us in detail about their experiences and what they think Government could or should be doing to improve their lives in society. It allows us to ask questions about the issues that we know matter to people with variations in sex characteristics.

Scope

9. The call for evidence focuses on the following areas:
 - **Terminology** – we know there are a wide range of views on the terms used to describe people who have variations in sex characteristics. Therefore, the first chapter invites respondents to share their views on what terminology Government should use in the future.
 - **Healthcare and medical intervention** – we are interested in whether people have undergone medical interventions/procedures, people's perceptions and experiences of accessing or considering healthcare services and how healthcare services could be improved to work better for people with variations in sex characteristics.
 - **Experiences in education** – there is little evidence in this area and we want to understand whether respondents have disclosed their variation to their educational institution, their experiences throughout life in education and how the education system could be improved.
 - **Support services** – we recognise that support services play a vital role. We want to understand the kind of support people who have variations in sex characteristics access, their experiences of doing so and whether the services could be improved.
 - **Workplace, benefits, sport and leisure services** – we want to gather evidence of people's experiences in the workplace, of claiming benefits and of using sport and leisure services. Stakeholders have raised concerns in these areas and we want to understand more about the issues they have raised.
 - **Sex assignment, birth registration and correcting birth certificates** – some stakeholders have raised concerns with the process for amending sex markers on birth certificates where these were incorrectly assigned/registered because of their variation. We want to understand what people's experiences have been of this process and their views on whether this needs to be improved.

- **Other issues** - there is an opportunity in the final section of the call for evidence for respondents to provide further information on any other issues that they might feel to be relevant.

What does it mean to be someone who has variations in sex characteristics?

10. Sex is assigned at birth, based on sex characteristics. It is usually easy to determine whether a newborn is male or female. Male newborns typically have a penis, testes, XY chromosomes and higher levels of testosterone. Female newborns typically have a vagina, uterus, XX chromosomes and higher levels of oestrogen. However, on occasion, the child's sex at birth may not be recognisable as male or female. The child may have a congenital variation, which means their sex characteristics, including their chromosomes, hormone responses, genitalia and/or gonads may develop differently to that typically expected of a male or female child. For example, some girls might have an enlarged clitoris or have a vagina but no uterus. Some boys may not produce enough testosterone to develop secondary male sex characteristics at puberty, such as increased muscle mass and body hair. To describe people who experience this form of sex development, the umbrella term we have used is 'variations in sex characteristics'.
11. Our working definition of the term 'variations in sex characteristics', adapted from research in the Netherlands is:

an umbrella term used to describe physical sex development which differs from what is generally expected of 'males' or 'females'. These variations are congenital and may be chromosomal, gonadal, anatomical or hormonal.¹
12. A variation in sex characteristics can be identified at different stages. For example, some chromosomal differences can be screened by optional tests during pregnancy. Where this occurs, a chromosomal difference may be identified before birth. If there is a difference in the child's genital appearance, the variation is often diagnosed at birth. Some people may only learn about their variation at puberty, for instance when girls do not menstruate or because secondary sex characteristics do not develop as typically expected. In other cases, puberty may not begin within the typical timeframe; for instance, some boys may continue to have underdeveloped testes from puberty into adulthood. Other people learn about their variation when they experience fertility issues. Some people may never know about their variation if they do not have a physical difference or any symptoms.
13. Some people's variations are associated with an underlying medical diagnosis. Most diagnoses do not have long-term health consequences, but some do and can require regular medical attention. Some diagnoses only affect females, others only affect males, whilst some affect both sexes. The following table summarises some of these diagnoses

¹ This definition has been adapted from van Lisdonk, J. (2014) *Living with intersex/DSD: an exploratory study of the social situation of persons with intersex/DSD*. The Netherlands Institute for Social Research. Available at: https://www.scp.nl/english/Publications/Publications_by_year/Publications_2014/Living_with_intersex_DSD

and includes descriptions from research in the Netherlands.²

Table 1 – Medically Classified Diagnoses³

Diagnoses	Description
Congenital Adrenal Hyperplasia (CAH)	<p>The adrenal glands fail to produce an enzyme that the body needs to make the hormones cortisol and aldosterone. Without these, the body produces more androgens (male sex hormones).</p> <p>Females with CAH can have a clitoris which begins growing atypically even before birth and can resemble a small penis, while the labia may be completely or partially fused together.</p> <p>The secretion of high levels of male hormones can lead to an early onset of puberty in both females and males.</p>
46, xy-dsd covers several types of variations, including Androgen Insensitivity Syndrome (AIS) and gonadal dysgenesis.	<p>People with AIS have xy chromosomes and are partially or completely insensitive to androgen. AIS occurs in different gradations, and a distinction is made between CAIS (complete) and PAIS (partial).</p> <p>Women diagnosed with CAIS do not have a uterus or ovaries.</p> <p>If the gonads are not typically developed, there may be another type of diagnosis, namely complete or partial gonadal dysgenesis.</p>
Hypospadias	<p>Hypospadias affect males and mean that the external opening of the urethra (urinary meatus) is not located at the tip of the penis. It may be located anywhere along the length of the penis or in the scrotum, and the foreskin is usually split.</p>
Mayer-Rokitansky-Küster-Hauser syndrome (MRKH)	<p>MRKH occurs only in females. They have xx chromosomes and ovaries, but are born without a (complete) vagina and/or uterus.</p>
Klinefelter syndrome	<p>This syndrome, also known as 47,xxy, only affects males. They have an extra X chromosome in addition to the usual 46 chromosomes. Males with this syndrome produce insufficient testosterone, leading to late onset of puberty. The penis and testes are relatively small prior to puberty.</p>
Turner syndrome	<p>Turner syndrome is also known as 45,X. There are mosaic forms of the syndrome where the person affected has 45,X in some cells and, for example, 46,xx or 46,xy in others. Only females are affected and in all cases they lack all or part of one X chromosome. That affects the</p>

² van Lisdonk, J. (2014) *Living with intersex/DSD: an exploratory study of the social situation of persons with intersex/DSD*. The Netherlands Institute for Social Research, p. 21-23.

³ This is not an exhaustive list.

	development of ovaries, the production of sex hormones, their height and physical sexual maturity.
--	--

[Source: van Lisdonk J (2014)]

How many people are there in the UK who have variations in sex characteristics?

14. There is no robust estimate of the number of people with variations in sex characteristics in the UK. There are several reasons for this. Firstly, as outlined above, for some, the variation may never be apparent. Secondly, some people may not disclose information when asked, for example via a survey. Thirdly, there is no consistent definition or approach to collecting data of people with variations in sex characteristics. Existing clinical research estimates that the 'birth prevalence of atypical genitalia may be as high as 1 in 300 births, but the birth prevalence of a condition that may lead to true genital ambiguity on expert examination may be as low as 1 in 5000 births.'⁴
15. Although the call for evidence will not provide us with a specific population estimate, it will provide the Government with insights into the types of variations people have in the UK and how this affects their experiences of everyday life.
16. The following chapters provide further information about what we currently know about people who have variations in sex characteristics in the UK.

⁴Cited from Ahmed SF, Achermann JC, Arlt W, Balen A, Conway G, Edwards Z, and Miles H (2016). Society for Endocrinology UK guidance on the initial evaluation of an infant or an adolescent with a suspected disorder of sex development (Revised 2015). *Clinical Endocrinology*. 2016;84(5):771-788. The basis of the estimates are i) Ahmed SF, Dobbie R, Finlayson AR, Youngson G, Chalmers J, Stone D (2004) Regional & temporal variation in the occurrence of genital anomalies amongst singleton births, 1988–1997 Scotland. *Archives of Disease Childhood*, 89, F149–F151.; and ii) Thyen U, Lanz K, Holterhus PM, Hiort O (2006). Epidemiology and initial management of ambiguous genitalia at birth in Germany. *Hormone Research*, 66, 195–203.

Chapter 1: Terminology

Key findings

17. We are aware that there are diverse views about terminology in this area and that terms have evolved over time. For example, in 2006, at an international conference, medical practitioners collectively agreed the term 'Disorders of Sex Development' (DSD), as well as the names given to medically classified 'conditions' by publishing the Consensus Statement.⁵ Since then the term 'Disorders of Sex Development' became widely used amongst clinicians nationally and internationally.
18. Today, there are a wide range of terms in use, some of which include, 'intersex', 'differences of sex development', 'variations in sex characteristics', 'variations in sex development', 'divergence of sex development', 'intersex variations' or 'diverse sex development'.
19. Some organisations in the UK distance themselves with any medical language such as 'DSD' or 'conditions' and prefer to use the term 'intersex'. Such organisations do not agree with the acronym DSD, arguing that that the term 'disorder' is pathologising and stigmatising. On the other hand, other organisations tend to name their organisations with medical terms, such as Congenital Adrenal Hyperplasia or Klinefelter Syndrome. Some support groups have adapted the medicalised acronym to create *differences* in sex development (dsd).
20. The Australian study found that research participants changed the terms they used to describe their variation depending on who they were communicating with. For example, respondents preferred to use the terms 'intersex' or 'intersex variation' to describe themselves, but were more likely to use the terms 'disorders of sex development', 'my diagnosis', or 'my chromosomes' when communicating with medical professionals.⁶
21. The Government is conscious that there is an ongoing debate around the classification of hypospadias as a variation. This call for evidence invites people with hypospadias to respond to the call for evidence's questions.

Scope

22. After thorough consultation with stakeholders, the Government adopted the term 'variations in sex characteristics' for the purposes of this publication. This is by no means an attempt to limit terminology in this area and people should use whatever terms they feel comfortable with using.
23. The terminology section of call for evidence asks respondents about their views on our use of the term 'variations in sex characteristics' and what terms Government should use in the future.

⁵ Lee P, Houk C, Ahmed FS, and Hughes IA (2006). 'Consensus statement on management of intersex disorders'. *Pediatrics*, 118, 488–500, doi: 10.1542/peds.2006-0738.

⁶ Jones T, Hart B, Carpenter M, Ansara G, Leonard L and Lucke J (2016) *Intersex: Stories and Statistics from Australia*. Cambridge, UK: Open Book Publishers, 2016

Chapter 2: Health

Key Findings

24. People with variations in sex characteristics may have different experiences when interacting with the healthcare system depending on their variation. Some may require medical support throughout their life, whilst others may rarely need to have their health monitored by medical professionals.⁷ People who have variations in sex characteristics may access the healthcare system for a wide range of reasons, including psychological support, hormone therapy or surgical procedures. Through our stakeholder engagement, we learned of diverse experiences people have had when accessing the healthcare system and interacting with healthcare professionals; this largely centred around historical clinical practices, which are detailed in the points below.
25. Our understanding of current clinical practice is limited to what we learned from recently published medical guidance or standards developed by clinicians and patient representative groups and through our engagement with clinicians.⁸ We learned that some hospitals across the country have specialist multi-disciplinary teams who provide care to people with variations in sex characteristics - comprising a psychologist, endocrinologist, urologist, gynaecologist and a clinical nurse, which follow their own clinical standards of care. However, we know that this model of practice may not be found everywhere. We are aware that NHS England are in the early stages of scoping the feasibility of commissioning a clinical pathway for affected children and young adults.⁹
26. One of the prominent themes that emerged from our engagement with some stakeholders included reports of historical medical interventions or procedures which people had undergone. Although medical interventions can occur at any age, we heard of anecdotal evidence that some people underwent procedures before they were able to consent to medical treatment in their own right, e.g. during infancy. In addition, some stakeholders reported these interventions were not medically necessary but 'cosmetic' procedures. For example, some reported historical practices of 'feminising surgery', such as reducing the size of an enlarged clitoris, or gonadal removal surgery, such as removing undescended testes. We take 'cosmetic' to refer to surgeries performed for social, cultural, or religious reasons or any other reason where there is no immediate or long-term risk to the individual's health.
27. International evidence shows that some people who have historically undergone such medical interventions experienced a lifetime of poor physical and psychological health outcomes. These include infertility, osteoporosis, urinary tract infections, bodily scarring,

⁷ van Lisdonk J (2014).

⁸ Ahmed SF, Achermann JC, Arlt W, *et al.* (2016).

⁹ This is still subject to senior approval from NHS England.

loss of sexual sensation/functioning and psychological trauma.¹⁰ We also learned that in such cases people had to undergo multiple post-operative surgical procedures or were dependent on hormones to maintain their assigned sex.

28. Through our engagement with stakeholders, concerns were also raised around a lack of access for individuals or parents/carers to specialist clinical psychologists. It was argued that psychologists can provide a vital role in supporting parents or the individual in making decisions about any intervention by offering a breadth of balanced information, challenging assumptions and offering advice on alternative non-surgical pathways. However, the availability and accessibility of specialist psychologists was raised as an issue for affected individuals and families. Stakeholders argued that an absence of psychologists or related professionals can call into question whether parents were able to provide informed consent (to any treatment) on behalf of their child.

29. We were also alerted to issues relating to people's broader experiences of the healthcare system through engaging with stakeholders who reported:

- That they found it hard to access their medical records containing diagnostic information.
- Historical experiences of live teaching surgeries and medical photography.
- Poor communication of diagnosis or treatment options to the individual and/or family by clinicians.
- Inability of clinicians to direct individuals to local support services.
- Unawareness amongst GPs and nurses of the individual's diagnosis.
- Specific language/translation barriers for BAME families when interacting with clinicians.
- Being 'forced' to choose a gender in order to receive medical treatment.
- Health professionals conflating transgender status and variations in sex characteristics.
- Lack of inclusive signage in single-sex healthcare spaces e.g. breast cancer screening waiting rooms.
- Lack of awareness of how to access free NHS prescriptions for people with diagnosed variations.

30. We want to learn more about these experiences in more detail through the call for evidence.

Scope

31. Despite gathering these insights, evidence gaps remain in relation to current clinical practice and people's historical experiences of healthcare services. The questions in the

¹⁰ Jones T, Hart B, Carpenter M, Ansara G, Leonard L and Lucke J (2016). *Intersex: Stories and Statistics from Australia*. Cambridge, UK: Open Book Publishers, 2016.

health chapter of the call for evidence invite respondents from section A (individuals who have variations in sex characteristics) to share the variation(s) they have, the age and the circumstances in which they first discovered their variation and how this affected them. In addition, questions are also designed to understand how open people are about their variation with others, whether they have undergone medical interventions/procedures. As well as the age at which they had their first medical intervention, their experiences of accessing healthcare services and whether it could be improved. There are also a set of tailored questions designed for respondents in section B (parents/legal guardians/carers) and respondents in section C (those who work with or provide services to people with variations in sex characteristics e.g. healthcare professionals, teachers) asking about medical interventions/procedures, the role of healthcare services and how they could be improved.

32. The Government is aware of calls from some UK stakeholders to end the practice of what they describe as 'medically unnecessary interventions'. However, before taking any steps, the Government must understand the nature and scale of the issue. The call for evidence is the first step to gathering this information. Once the Government has analysed the responses to the call for evidence, we may determine that further evidence is necessary before considering any policy or legislative proposals.

Chapter 3: Education

Key Findings

33. The Government recognises that there is little known about people who have variations in sex characteristics and their educational experiences in the UK. However, in developing this publication, we reviewed international evidence in this area from the Netherlands and Australia and consulted with various UK-based stakeholders.¹¹

34. The following themes emerged from our engagement with UK stakeholders around issues experienced within the education system. They reported that:

- Young people and their parents can face difficulties when being open with school staff and peers about their variation, if they do not have access to support groups or a psychologist. They claimed that this can result in young people feeling isolated, anxious or afraid of someone discovering their variation. When asked why some parents might feel uncomfortable with sharing this information, we learned that this may be due to a range of overlapping factors, some of which include social, cultural or religious reasons, taboo/stigma, language barriers or incomplete understanding of the child's diagnosis leading to difficulty in communicating this to others.
- Some individuals reflecting on their time at school shared their unwillingness to use school facilities e.g. toilets/changing rooms or participate in certain lessons, e.g. sport classes for fear of a negative reaction from peers or teachers if their variation was discovered.
- Teaching and other school staff lacked awareness of, or understanding about, variations in sex characteristics and how best to support them at school.
- Some young people experienced social exclusion or not being able to participate fully in school activities, such as attending residential trips. This was attributed to school staff not always being adequately trained on how to administer medication for pupils with certain diagnoses.

35. Some stakeholders reported lack of access to counselling/psychosocial support during their school life as an issue. When reflecting on their experiences in education, stakeholders argued that having access to a social worker or an educational psychologist at school would have helped them with making informed decisions about their medical treatment or coming to terms with their diagnosis. Stakeholders said that clinical psychologists can play a positive role in supporting parents to have conversations with their children about their body, which in turn could develop the child's knowledge, resilience and confidence.

36. We learned that some young people need regular time off from school to attend medical appointments. This was particularly the case for young people who had undergone

¹¹ van Lisdonk J (2014); Jones T *et al.* (2016).

medical interventions in childhood and required post-operative treatments or hormone therapy. To date, there is no study in the UK which explores what impact this has had on a person's academic performance or how they fare against pupils who do not have variations in sex characteristics. In Australia, although 62% of people with variations in sex characteristics who responded to a survey had a post-secondary qualification, 18% had only primary-level education.¹² This was reportedly due to pubertal medical interventions, bullying and poor mental health, as well as other psychosocial factors.

37. When stakeholders reflected on their personal experiences in school they highlighted an absence of any content on diverse sex or bodily development in the school curriculum, including in PSHE, relationships and sex education or biology lessons.¹³ As a result, they argued that young people could feel isolated from their peers, experience body dissatisfaction and must access information about their sex development, puberty and sexual health from elsewhere.
38. The Government does not have robust evidence on whether young people who are have variations in sex characteristics experience peer-on-peer bullying but we are interested in investigating this issue through the call for evidence. International studies have explored this issue; the Australian study mentioned above showed that bullying was directed at a known variation or more frequently on the basis of having 'unusual traits' (e.g. tallness or shortness).¹⁴
39. Research in the Netherlands found that some people with chromosomal variations experience social and cognitive difficulties that can have an effect on their participation at school.¹⁵ Stakeholders based in the UK also provided anecdotal evidence of teachers struggling to understand why a young person with premature puberty may have behavioural issues and require specific support.

Scope

40. Although we learned about the issues detailed above, we have relatively little understanding of the scale and nature of specific education issues. We have designed questions in the education chapter of the call for evidence to fill these evidence gaps. Questions designed in section A (individuals who have variations in sex characteristics) ask respondents to share whether they or their parent/carer disclosed their variation to their educational institution, as well as their experiences in education and whether and how the education system could be improved. Questions are also included in section B (parents, legal guardians, carers) and section C (those who work with or provide services to people with variations in sex characteristics e.g. healthcare professionals, teachers) asking how the education system supports young people and whether and how it could be improved.

¹² Jones T, *et al.* (2016) [based on a survey of 272 respondents aged 16-87 years.

¹³ PSHE refers to personal, social, health and economic education.

¹⁴ Jones T *et al.*, (2016).

¹⁵ van Lisdonk J (2014).

Chapter 4: Support services/organisations

Key Findings

41. The availability and sustainability of support services for individuals with variations in sex characteristics and their families was a key theme that emerged from our engagement with stakeholders and from international research. By support services, we are referring to any organisation (outside of public health or education providers), that explicitly works with or for people who have variations in sex characteristics. This includes, but is not limited to the following: online forums, helplines, registered peer support charities, advocacy and voluntary organisations.
42. The UK has a range of organisations that operate in different ways to support their service users who have variations in sex characteristics. For example, there are 'condition'-specific support groups, advocacy/human rights-based organisations, a parent and family support organisation, as well as online community groups.
43. These organisations tend to provide the following types of services:
- Peer support – creating spaces for individuals and families to connect with each other, offering counselling, etc.
 - Training public sector professionals, e.g. teachers.
 - Building links with clinicians and healthcare providers.
 - Information sharing and developing educational resources.
 - Advocacy work, including media engagement, public speaking at international forums, contributing to international evidence-gathering exercises, lobbying Government/Parliament.
44. International research shows that support groups for people who have variations in sex characteristics can provide opportunities for people to connect with others and share common experiences, which in turn can help with their self-acceptance and wellbeing.¹⁶ This was supported by anecdotal evidence shared through our stakeholder engagement process, where people explained how they found a sense of belonging and were inspired to play an active role in supporting others like them. The Government is also aware of small, localised patient support groups developed in response to the needs of specific communities.
45. The Government is aware of concerns raised by some organisations around resourcing issues that are having an effect on their ability to continue providing support to affected individuals/families. We learned of organisations struggling to secure long-term funding, staff working voluntarily and the sustainability of organisations depending on the efforts of dedicated individuals.
46. This is supported by international research: a survey of 54 groups from across the globe

¹⁶ For example, van Lisdonk J (2014).

working on 'intersex' issues found that although funding had improved modestly in recent years the 'intersex' third sector was underfunded, understaffed and unregistered. In addition, these groups faced unique barriers to reaching donors and accessing funds (for example, it was often unclear whether funding was available for 'intersex groups').¹⁷ Similarly, a report by the University of Huddersfield found that there are 'only a small number of people who are public' about having variations in sex characteristics. The report goes on to say that this puts a high demand on those individuals to deliver; as a result, individuals can be overworked, particularly if they have a day job in addition to working voluntarily to run a support service.¹⁸

Scope

47. Although we have engaged with some organisations to learn about their experiences of providing support, we need further evidence on how everyday people interact with support organisations, if at all. Therefore, we have designed questions in the call for evidence to address these evidence gaps. There are questions for respondents in section A (individuals who have variations in sex characteristics) asking people what type of support services/organisations they access, how helpful they were and how they could be improved. In addition to understanding the needs of service users, the Government is equally interested in the views of respondents in section B (parents, legal guardians, carers) and section C (those who work with or provide services to individuals with variations in sex characteristics e.g. healthcare professionals). We want to know from these groups about the provision of support services and whether and how these could be improved.

¹⁷ Howe E, Frazer S, Dumont M, and Zomorodi G (2017). *The State of Intersex Organizing (2nd Edition): Understanding the Needs and Priorities of a Growing but Under-Resourced Movement*. New York: American Jewish World Service, Astraea Lesbian Foundation for Justice and Global Action for Trans Equality. The term 'intersex' is used because this is the terminology used in the cited report.

¹⁸ Monro S, Crocetti D, Yeadon-Lee T, Garland F and Travis M (2017) *Intersex, Variations of Sex Characteristics and DSD: The Need for Change*, University of Huddersfield.

Chapter 5: Workplace, Benefits, Sport and Leisure Services

Key findings

48. The Government recognises that there is limited evidence on the experiences of those in the UK who have variations in sex characteristics as they navigate through their adult lives. For example, we do not know whether having a variation affects people's experiences in the workplace, or in claiming benefits or using sport and leisure services. Our knowledge of people's experiences in the workplace and of accessing sport and leisure services is largely drawn from international research.
49. A Dutch study found a few historical cases where individuals had experienced difficulties in remaining in full time employment.¹⁹ This included not having their contract renewed after they told their employer about their variation or being declared 'unfit to work'. This was due to a range of factors, including physical health limitations, what was perceived to be the discriminatory attitudes of their employer and experiencing unpleasant reactions from colleagues when they were open about their diagnosis. Similar findings were found in the Australian study, where 48% of respondents surveyed said their 'intersex variation' affected their experiences in employment.²⁰ This study explored both negative and positive examples of how people's variations in sex characteristics affected their experience of the workplace or employment.
50. Through our engagement with stakeholders in the UK, we found that some people who have variations in sex characteristics can face difficulties in the workplace as a result of the health problems associated with their diagnosis or due to surgeries or other medical interventions they have undergone. For example, we learned that long-hour contracts, limited breaks and no access to workplace support can make the workplace a negative experience for some adults with variations in sex characteristics.
51. Furthermore, stakeholders reported that some people who have variations in sex characteristics could benefit from reasonable adjustments in the workplace but required support when explaining their needs to their employers. The Government also heard of reports about some employers and employees who were unaware of the Equality Act 2010 and the protections against discrimination afforded to employees with a disability.²¹
52. Issues with seeking disability benefits was also an issue that was raised by some stakeholders. For example, some reported the difficulties they faced when completing application forms for Personal Independence Payments. The Government is interested in learning more about this issue, given the existing evidence on people who have variations in sex characteristics reporting having a disability. The findings from the Government's National LGBT Survey found that 'intersex' respondents were

¹⁹ van Lisdonk J (2014).

²⁰ Jones T *et al.*, (2016).

²¹ The Equality Act 2010 defines the term 'disability' as a physical or mental impairment, where the impairment has a substantial and long-term adverse effect on the person's ability to carry out normal day-to-day activities.

considerably more likely to report that they had a disability (31%) than non-intersex respondents (17%).²² Similarly, the Australian study found that 27% of respondents identified as having one or more disabilities, this was higher than the broader Australian population who have disabilities (18.5%, based on data from 2012).²³

Scope

53. As outlined above, the Government is aware of some anecdotal evidence of people's experiences of the workplace and seeking disability benefits. However, we are interested in supporting this evidence with a thorough understanding of the full breadth of issues faced in these two areas, as well as whether having variations in sex characteristics affects people's experiences of using sport and leisure services. This is why we have designed questions in the call for evidence asking respondents in section A (people who have variations in sex characteristics) to describe whether having a variation affects their experiences of the workplace, claiming benefits and accessing leisure services and what improvements are needed. We have also asked questions of respondents in section B (parents, legal guardians, carers) and section C (work with or provide services to people with variations in sex characteristics e.g. healthcare professionals, teachers) to understand their views and experiences to strengthen our evidence base.

²² Government Equalities Office (2018). The National LGBT Survey Research Report.

²³ Jones *et al.* (2016).

Chapter 6: Sex Assignment, Birth registration and Correcting Birth Certificates

Key Findings

54. Through the Government's stakeholder engagement process, we are aware of concerns from adult representative organisations about the processes for sex assignment, birth registration and correcting birth certificates. Concerns tend to focus on the time limits for registering births, as well as the perceived barriers to applying to change the sex marker on a birth certificate, where the sex was incorrectly assigned at birth. We have met people who have said they are unable to change the incorrect sex marker on their birth certificate. The Government would like to better understand the scale and nature of these issues in this chapter of the call for evidence.
55. The Births and Deaths Registration Act 1953 and the Births and Deaths Registration (Northern Ireland) Order 1976 require that the birth of every child born in England, Wales and Northern Ireland be registered within a period of 42 days. Regulations set out the particulars to be registered.²⁴ In Scotland, however, it is a legal requirement to register the child's birth and the sex within a period of 21 days.²⁵ The Births and Deaths Registration Act 1953 and the Registration of Births, Deaths and Marriages (Scotland) Act 1965 do not prescribe how sex is to be determined or assigned. There is no provision for registering the birth of a child with unspecified, or indeterminate sex; children are registered as either male or female in accordance with the information provided by the informant. The General Register Office for England and Wales (GRO) report that there are circumstances where the registration can be delayed if the registrar is informed prior to, or at the point of registration that there is some ambiguity in the child's sex. This provides parents with the opportunity to obtain further medical advice to determine the child's sex.
56. Some stakeholders argued that the time restrictions of 42/21 days for assigning the child's sex and registering the birth can result in parents making decisions to consent (on behalf of their child) to medical interventions.
57. The Government is also aware of some cases where individuals have discovered that their sex was wrongly assigned at birth by medical professionals and consequently their sex was recorded incorrectly on their birth certificate. Where it is determined that the legal sex – as registered on the birth certificate in infancy – is incorrect, there are processes in place to facilitate this correction. However, as set out in the following points, this process differs between England/Wales, Scotland and Northern Ireland.
58. In England and Wales, when requesting a change to the recorded sex in the

²⁴ The Registration of Births and Deaths Regulations 1987, regulation 7(1) and form 1, Schedule 1.

²⁵ Registration of Births, Deaths and Marriages (Scotland) Act 1965, part II, Section 14

original registration if it were incorrectly assigned/registered at birth, the GRO relies on medical evidence to make this correction and will consider all applications on a case by case basis, taking into account the particular circumstances.

59. As a starting point, the GRO would ask for medical evidence that shows at the time of registration the wrong sex was declared/assigned. The medical evidence can be based on results of chromosomal or gonadal tests carried out in childhood or current tests that confirm gonads, genitalia and chromosomes are congruent with the requested birth registration correction.

60. The GRO would ask for evidence that the following biological factors are congruent and the opposite of what is shown in the birth registration:

- gonads – the organ that creates the initial cells that fuse at conception. These are the ovaries for females and the testes for males;
- genitalia – the primary sex organs – broadly the penis, scrotum and testicles for a male and the labia, clitoris and vagina for a female;
- chromosomes – humans have 46 chromosomes which encode an individual's genetic information. Usually each person has two sex chromosomes (one from each parent) which together determine that person's sex. Female sex chromosomes are denoted by XX, male chromosomes XY.

61. In Scotland, the National Records of Scotland (NRS) is responsible for the arrangements for registering births, deaths, marriages, civil partnerships and other life events. The NRS is headed by the Registrar General for Scotland. Under the provisions of the Registration of Birth, Deaths and Marriages (Scotland) Act 1965, the Registrar General for Scotland has the power to authorise corrections to the Register of Births in certain circumstances. The NRS report that evidence must be produced to confirm that an error was made when the sex of the child was recorded at birth. If the reason for the error was that the subject had a variation of sex characteristics, the Registrar General would authorise correction provided written evidence from a suitably qualified health professional is produced, confirming such an error had been made. The Registrar General for Scotland does not seek to obtain or interpret evidence about the individual's sex characteristics.

62. In Northern Ireland, the Deputy Registrar General for Northern Ireland reports that Northern Ireland legislation allows for the sex marker to be amended on a birth certificate for individuals with variations in sex characteristics; assuming that the individual provides appropriate evidence to support the change. Through Articles 18 or 36 of the Births and Deaths Registration (Northern Ireland) Order

1976, the Registrar General would make a decision on which particular Article to use dependent on the individual request.

63. The Government heard from stakeholders who shared their concerns with the current process of correcting a sex marker on a birth certificate. This included concerns that the current requirement to submit highly detailed and sensitive medical records as evidence is intrusive. Another stakeholder outlined there were additional costs of obtaining medical information by having to undergo scans privately. Some expressed that this process fails to take into account instances where people do not have access to their medical records, so are unable to provide the required evidence. Some stakeholders outlined the lack of publicly available information about the process, which has meant people being unaware that this process was an option for them. We also heard that the criteria of gonads, genitalia and chromosomes has not kept pace with medical advancements, as it doesn't recognise evidence of variations in hormone receptors that could prove that the sex assignment was wrong at birth.
64. It is important to note that this section of the call for evidence focuses on the process of changing the sex marker on a birth certificate outside of the Gender Recognition Certificate application process. Separately, the Government invited people with variations in their sex characteristics to share their views about what changes are necessary to the legal gender recognition process in the recent consultation on reforming the Gender Recognition Act. The responses to this consultation will be analysed and published later this year.

Scope

65. Through the call for evidence, the Government would like to hear from individuals who have changed or considered changing their sex marker on their birth certificate and is equally interested in hearing about parent/carer/legal guardian's experiences. This is why we have designed questions seeking views about the process for correcting birth certificates and the process of registering a child's birth and how these could be improved in sections A and B.

Chapter 7: Conclusion

66. This paper is intended to provide information on Government's current understanding of the key issues pertinent to people who have variations in sex characteristics and the rationale behind the scope and design of the call for evidence questions.
67. We acknowledge that although we have some understanding of the key issues, the existing evidence has a number of gaps. We are therefore hoping to address some of these through the call for evidence. In order for the Government to make informed decisions about potential policy interventions to meet the needs of people who have variations in sex characteristics, we are acutely aware of the need to strengthen the evidence base. This is why we want to make sure that we hear a wide range of perspectives on all the issues that people consider to be of relevance.
68. If you would like to respond to the call for evidence, search for 'Variations in Sex Characteristics: A Call for Evidence' on gov.uk or through the following website: <https://www.gov.uk/government/organisations/government-equalities-office>. The call for evidence will be open for 10 weeks.

References

Ahmed SF, Dobbie R, Finlayson AR, Youngson G, Chalmers J, Stone D (2004). Regional & temporal variation in the occurrence of genital anomalies amongst singleton births, 1988–1997 Scotland. *Archives of Disease Childhood*, 89, F149–F151.

Ahmed SF, Achermann JC, Arlt W, Balen A, Conway G, Edwards Z, and Miles H (2016). Society for Endocrinology UK guidance on the initial evaluation of an infant or an adolescent with a suspected disorder of sex development (Revised 2015). *Clinical Endocrinology*. 84(5), 771-788. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4855619/>.

Government Equalities Office (2018) The National LGBT Survey Research Report. Available at: <https://www.gov.uk/government/publications/national-lgbt-survey-summary-report>.

Howe E, Frazer S, Dumont M, and Zomorodi G (2017). *The State of Intersex Organizing (2nd Edition): Understanding the Needs and Priorities of a Growing but Under-Resourced Movement*. New York: American Jewish World Service, Astraea Lesbian Foundation for Justice and Global Action for Trans Equality.

Jones T, Hart B, Morgan Carpenter M, Ansara G, Leonard W, and Lucke J (2016). *Intersex: Stories and Statistics from Australia*. Cambridge, UK: Open Book Publishers, 2016.

Lee P, Houk C, Ahmed FS, and Hughes IA (2006). 'Consensus statement on management of intersex disorders'. *Pediatrics*, 118, 488–500, doi: 10.1542/peds.2006-0738. Available at: https://www.pedsendo.org/education_training/healthcare_providers/consensus_statements/assets/DSDconsensusPediatrics2006.pdf

van Lisdonk J (2014). *Living with intersex/DSD: an exploratory study of the social situation of persons with intersex/DSD*. The Netherlands Institute for Social Research. 2014- 23. Available at: https://www.scp.nl/english/Publications/Publications_by_year/Publications_2014/Living_wit_h_intersex_DSD

Monro S, Crocetti D, Yeadon-Lee T, Garland F, and Travis M (2017). *Intersex, Variations of Sex Characteristics, and DSD: The Need for Change*. Research Report. University of Huddersfield. Available at: <http://eprints.hud.ac.uk/id/eprint/33535/>.

Thyen U, Lanz K, Holterhus PM, Hiort O (2006). Epidemiology and initial management of ambiguous genitalia at birth in Germany. *Hormone Research*, 66, 195–203.

Annex A: International Approaches and Wider Evidence

1. In this Annex we briefly set out the approach that other countries take to addressing the needs of people with variations in sex characteristics, and we summarise the main relevant findings from the National LGBT survey 2017.

Medical

2. With respect to health care provision, there is not a wealth of information about what clinical models are in place to support people with variations in sex characteristics in different countries. However, the media have reported on those countries that have either introduced legislation to end medical interventions or those countries that have officially recognised the practice of medical interventions on the sex characteristics of minors as having harmful effects, for example, South Africa and Chile. Chile allows surgeons to lawfully refuse a parent's request for early genital or gonadal surgery to be performed on their child, if it is deemed 'medically unnecessary'.
3. In 2015, Malta became the first country to pass legislation making it unlawful for medical practitioners or other professionals to conduct any sex assignment treatment and/or surgical intervention on the sex characteristics of a minor, when the intervention can be deferred until the person can provide informed consent. In 2018, Portugal announced its intention to ban 'unnecessary medical interventions'. In 2018, California became the first US State to pass a resolution stating that medically unnecessary procedures on children which carry a risk of harm should be deferred, and calling on medical professional associations to develop standards of care for people who have variations in sex characteristics.²⁶

Support Services/organisations

4. Internationally, there are a range of organisations in this field, including, a campaigns and advocacy organisation called Organisation Intersex International (OII) established in 20 countries. In 2015, The Astrea Lesbian Foundation for Justice introduced the Intersex Human Rights Fund to provide global financial support to organisations. The US based organisation InterAct provides a platform for young people.

Anti-discrimination law

5. A number of countries have introduced 'intersex' or 'sex characteristics' as a protected characteristic within their anti-discrimination laws. This includes, South Africa, Finland, Greece, Bosnia-Herzegovina, Australia and Malta. Scotland extends hate crime legislation to cover 'intersex people' under Section 2 Offences (Aggravation by Prejudice) (Scotland) Act 2009.

Birth registration and correcting birth certificates

6. Denmark, France and the Netherlands have processes in place to facilitate corrections for the sex marker on a birth certificate. However, other countries have introduced

²⁶ https://leginfo.ca.gov/faces/billTextClient.xhtml?bill_id=201720180SCR110

different measures, for example:

- a) **Malta and Germany** have provisions for the entry of a sex marker to be postponed. Furthermore, Malta's 'Gender Identity, Gender Expression and Sex Characteristics Act' 2015 allows that in cases where the sex of the child is unclear, this does not need to be listed until the person is 18yrs old.
- b) **Australia and New Zealand** allow 'intersex' people to have an 'x' marker assigned to their birth certificate to record the sex as indeterminate. In December 2018, the **German Parliament** approved an option to be made available for 'intersex' people to mark themselves as 'divers' (*translates as other*) on identity documents.

The LGBT Survey

7. The Government Equalities Office launched a national LGBT survey in July 2017 in order to develop a better understanding of the lived experiences of lesbian, gay, bisexual and transgender people, and people who identify as having any other minority sexual orientation or gender identity, or as 'intersex'. The survey covered a range of issues relating to the everyday lives of LGBT people, including personal safety, education, the workplace and healthcare.
8. The Government recognises that 'being intersex' is not a minority gender identity or a minority sexual orientation in and of itself; however, of course, people with variations in sex characteristics can also be LGBT.
9. Almost 2,000 people responded to the survey identifying as 'intersex'. We analysed the responses provided by 'intersex' respondents to the health questions in the LGBT survey and have summarised these below. The full analysis can be found in the LGBT Survey Research Report 2018 here:
<https://www.gov.uk/government/publications/national-lgbt-survey-summary-report>.
10. Through the LGBT survey, 'intersex' respondents reported the following experiences of accessing healthcare services:
 - a) 75% of 'intersex' respondents had accessed, or tried to access public healthcare services.
 - b) The negative experiences most frequently included: having their specific needs ignored or not taken into account (12%), avoiding treatment or accessing services for fear of discrimination or intolerant reactions (10%), and inappropriate curiosity (10%).
 - c) 'Intersex' respondents were more likely than non-intersex respondents to have found accessing mental health services difficult. 37% stated that accessing mental health services had not been at all easy, compared to 28% of non-intersex respondents. 48% had to wait too long to access the service and 26% had been worried, anxious or embarrassed about going.
 - d) When accessing mental health services, 'intersex' respondents were more likely to report that their GP had not been supportive (19%) than non-intersex respondents

(16%), and also more likely to say that their GP had not known where to refer them (13%) than non-intersex respondents (11%).

- e) 'Intersex' respondents were more likely than non-intersex respondents to have found accessing sexual health services difficult. Of those who had accessed sexual health services, or had tried but were unsuccessful, 11% stated that accessing sexual health services had not been at all easy, compared to 5% of non-intersex respondents.



Government
Equalities Office

OGL

© Crown copyright 2018

This publication is licensed under the terms of the Open Government Licence v3.0 except where otherwise stated. To view this licence, visit nationalarchives.gov.uk/doc/open-government-licence/version/3

Where we have identified any third party copyright information you will need to obtain permission from the copyright holders concerned.

This publication is available at www.gov.uk/government/publications

Any enquiries regarding this publication should be sent to us at Variations in Sex Characteristics Call for Evidence, Government Equalities Office, Sanctuary Buildings, Great Smith Street, London, SW1P 3BT

ISBN 978-1-78655-738-4

01/19