



Government
Equalities Office

Variations in Sex Characteristics*

A Call for Evidence

January 2019

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



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About this Call for Evidence

Topic

This call for evidence seeks information on the experiences and needs of people in the UK who have variations in sex characteristics – which we define as physical sex development that is different to what is generally expected of males and females. The sex characteristics of focus here are naturally occurring genetic, chromosomal, gonadal, anatomical and hormonal variations. It includes diagnoses such as Congenital Adrenal Hyperplasia (or CAH), Hypospadias, Androgen Insensitivity Syndrome (AIS), Klinefelter syndrome and Turner syndrome, as well as many others. This is distinct from being transgender or non-binary, which are to do with a person's gender identity.

Variations in sex characteristics is the umbrella term we have chosen for this exercise, but we are also aware that there are other terms in use, such as intersex and differences of sex development.

The Government is aware from engaging with stakeholders and analysing the available evidence that people who have variations in sex characteristics face particular issues in their day-to-day lives.

We want to know more about these issues to determine whether Government intervention is necessary.

This call for evidence does not put forward any proposals for policy and/or legislative change, it is an evidence-gathering exercise. Once the call for evidence has closed, the Government will review and analyse the responses we receive. We will then publish a report of what we found and a statement detailing any next steps.

Duration

This call for evidence will run for 10 weeks.

Audience

This call for evidence is aimed at three respondent groups:

- A. those who have variations in sex characteristics.** We are interested in hearing the views of anyone who thinks they meet this definition.
- B. Those who look after people who have variations in sex characteristics in a personal capacity,** such as parents, legal guardians, carers.
- C. Those who work with or provide services to people who have variations in sex characteristics in a professional capacity.** This could include healthcare professionals, academics, teachers, employers, support services and service providers.

The questions in this call for evidence are divided into sections A, B and C and are designed for each of the three respondent groups listed above. You should only answer the set of questions most relevant to you.

We ask that respondents limit their answers to 500 words where possible.

Ways to respond

We would prefer responses to be submitted via the online response form.

Please tell us whether you are responding as an individual or whether you are representing the views of an organisation.

You can ask for hard copies of this call for evidence, by emailing VSC.EVIDENCE@geo.gov.uk.

If you have problems filling out the online response form, you can send your response via post to the address outlined below.

Geographical scope

This call for evidence is being issued by the UK Government and responses are welcomed from people living in all parts of the UK.

However, the issues covered include policy areas that are devolved to Scotland, Wales and Northern Ireland. In order to help us analyse responses, we ask that respondents specify the part of the country in which they live. The UK Government is working closely with the devolved administrations on this call for evidence. The evidence gathered will also support and inform the work of the devolved administrations in this area.

Impact assessment

The Government has not produced any impact assessment alongside this call for evidence because it is not making any policy proposals. Should we determine that a change in policy is necessary, a full impact assessment will be produced.

Enquiries

Please direct all enquiries about this call for evidence to: VSC.EVIDENCE@geo.gov.uk.

You can also write to the Government Equalities Office at:

Variations in Sex Characteristics

Government Equalities Office – 6th Floor Sanctuary Buildings

20 Great Smith Street

London, SW1P 3BT

Confidentiality of responses

We understand that having to provide details about your personal experiences when responding to the questions might be difficult. We take this very seriously and have included a list of resources at the end of this publication for people to obtain support.

Before you take part, you should also be aware of the following:

- Participation in this call for evidence is entirely voluntary, although we are keen to hear the views of as many people as possible.
- We want to reassure you that we will not seek to identify you through the responses you provide. To make sure of this, we ask you not to provide identifying information such as names, locations etc.
- All questions are optional. Feel free to complete as many as you wish.
- At the end of the survey, we will ask some questions about you, such as your age, your ethnicity and the part of the UK in which you live. These questions help us understand more about how people's experiences vary, again, these questions are also voluntary.

Privacy notice

The Government Equalities Office (GEO) wants all respondents to feel confident that any information they share with us through this call for evidence will be handled sensitively and in confidence.

The following is to explain your rights and give you the information you are entitled to under the Data Protection Act 2018 and the General Data Protection Regulation ("the Data Protection Legislation").

1. The identity of the data controller and contact details of our data protection officer.

The Department for International Development ('the department') is the data controller. The Government Equalities Office forms part of the department. The data protection officer can be contacted at: dataprotection@dfid.gov.uk. You can find out more here: <https://www.gov.uk/government/organisations/department-for-international-development/about/personal-information-charter>.

2. Why we are collecting your personal data

We are asking you for information as part of this call for evidence to inform the development of future Government policy. We will analyse the information that you provide in order to produce and publish a report that summarises the findings from the call for evidence and sets out the next steps. This report will not contain any information from which any individual respondent might be identified.

We may use anonymised quotations from your answers in any future research publication on this topic. We will only do so if you have explicitly given us your permission.

We do not want to collect any information that could identify you personally. We do not ask for respondents' names, e-mail addresses or postal addresses.

We ask a series of questions about your demographic details at the end, but you do not have to answer them if you do not want to. Collecting this demographic information will help us to understand whether different issues affect people with different characteristics, such as younger or older people, people from different parts of the country, and people from different religious or ethnic backgrounds.

Although we would prefer that you do not provide any personal data, we recognise that in their responses to questions, respondents may provide information from which they or others may be identifiable. This might be because of a combination of information provided, from which a person's identity could potentially be revealed, perhaps in combination with other data. Some of the information may also be what is known as 'special category data', such as sensitive information about health.

We will delete any obviously personal data, such as names or addresses, when we receive it.

3. Our legal basis for processing your personal data

The Data Protection Legislation states that, as a government department, the department may process personal data as necessary for the effective performance of a task carried out in the public interest, i.e. a call for evidence. The department may process 'special category data', such as information about an identifiable person's health, where necessary for reasons of substantial public interest.

4. Sharing your information with third parties

We may share the information you provide to this call for evidence with a third party processor (an organisation that we ask to analyse the responses for us). We will require any third party processor to demonstrate: a) its full compliance with legal data protection obligations; and b) that it is taking steps to ensure sensitive and responsible treatment of any data with which it is provided.

We are interested in hearing the views of people living in all parts of the UK. We are also asking about a wide range of topics, including healthcare and education. This means that we might want to share our findings with the devolved administrations in Scotland, Wales and Northern Ireland and/or with other Government Departments. We will not share your individual answers (except fully anonymised quotes where you have given us permission). We will only share our assessment of your answers in the aggregate. Beyond this, we will not share or disclose any information you provide unless required to do so by law.

Freedom of Information Act 2000

The GEO is subject to the Freedom of Information Act 2000. This means that we have to disclose information that we hold on request unless a statutory exemption applies. We are required to consider all requests for information individually and so cannot guarantee that your responses will not be disclosable. However, we want to reassure you that the available statutory exemptions usually allow us to refuse to disclose information which is personal or confidential.

Gender Recognition Act 2004

If you provide any information about an application for a Gender Recognition Certificate (GRC), or your (or someone's else) gender before obtaining a GRC, this information is protected by section 22 of the Gender Recognition Act 2004, which makes it a criminal offence to disclose the information unless certain exceptions apply. For example, it is not an offence to disclose the information if no individual can be identified. Where section 22 applies, the GEO will take necessary steps to ensure compliance.

Organisational responses

We may publish responses received from organisations. We will only do so if the respondent organisation has given us their permission.

5. How long will we hold your information for?

As mentioned above, we will delete any obviously personal data as soon as we receive it. We will hold the other (anonymous) information you provide to us for as long as is necessary for our research and policy development purposes.

6. Your rights, e.g. access, rectification, erasure

If we do hold any of your personal data, you have the right:

- to see what data we have about you
- to ask us to stop using your data, but keep it on record
- to have all or some of your data deleted or corrected
- to lodge a complaint with the independent Information Commissioner (ICO) if you think we are not handling your data fairly or in accordance with the law.

You can contact the ICO at <https://ico.org.uk/>, by telephone 0303 123 1113, or by post to: ICO, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF.

7. Your personal data will not be sent overseas.

8. Your personal data will not be used for any automated decision making.

9. Your personal data will be stored in a secure government IT system.

Respond online

Next steps

Once the call for evidence has closed, the Government will review and analyse the responses we receive. We will then publish a report of what we found and a statement detailing any next steps.

Introduction

1. The Government Equalities Office is launching this 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 document contains a series of questions on issues that we want to learn more about. Alongside this document, we have also published a technical paper that sets out our current understanding of the evidence base and the relevant policy context. The technical paper can be found on gov.uk or via the following website: <https://www.gov.uk/government/organisations/government-equalities-office>.
2. This is an emerging and complicated area of policy, and one in which the Government is still developing its research and understanding. We are aware that increasing numbers of countries are engaging with the issues. We want to gather more evidence so we can determine if Government intervention is necessary in the UK.

What do we mean by ‘variations in sex characteristics?’

3. 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

4. This definition covers a wide range of variations. A variation could be identified during pregnancy, at birth, or it could become apparent later in life, such as when a girl finds she does not have periods. Some people may never find out that they have a variation. In some situations, the variations in sex characteristics can be associated with an underlying medical diagnosis. Generally, this will not be a diagnosis with long-term health consequences but in some cases, it can be and can require regular medical attention. Some diagnoses affect only males or only females, whereas other diagnoses may affect both sexes. Further detail can be found in the technical paper.
5. We adopted this broad definition after thorough consultation with stakeholder organisations (who support individuals who have variations in sex characteristics) and by studying academic literature. We recognise, however, that terminology in this area is evolving and there are many different views. Later on there is an opportunity for you to share your views on the term we have used.

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. 2014- 23. Available at: https://www.scp.nl/english/Publications/Publications_by_year/Publications_2014/Living_with_intersex_DSD

How many people in the UK have variations in sex characteristics?

6. 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. 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.'²

The Government's current position

7. 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 they thought 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.
8. To help us understand the issues faced by individuals and their families, 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.
9. 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.

²Cited 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.

10. 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. It allows us to ask questions about the issues that we know matter to people with variations in sex characteristics.

Scope

11. 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.

About You

Are you responding as an individual or an organisation?

Individual

Organisation

Please only select 'organisation' if you are explicitly responding on *behalf* of your organisation.

If you are responding as an **individual**, are you responding as (please specify all that apply):

Someone who has variations in sex characteristics

Someone who looks after people who have variations in sex characteristics in a personal capacity (e.g. a parent, carer, legal guardian)

Someone who works in the healthcare profession (e.g. a doctor, psychologist, nurse)

Someone who works in education (e.g. a teacher, school nurse, a head-teacher)

Someone who works with people who have variations in sex characteristics in a professional capacity outside of health or education services (e.g. social worker)

Someone who works in central or local government

An academic

Someone else: _____

If you are responding as an **organisation**, are you responding as:

An organisation that works specifically with, or advocates for, people who have variations in sex characteristics and/or their families.

Another kind of charity or advocacy organisation

A healthcare provider

- An educational institution
- A private company/service provider
- A governmental or official body
- A religious body
- Another organisation: _____

What is the name of your organisation?

In which part of the United Kingdom is your organisation based?

- England
- Scotland
- Wales
- Northern Ireland
- Outside the UK

For organisations only: The Government would like your permission to publish the responses from your organisation to the call for evidence. Please can you confirm how you would like your response to be treated:

- Publish my response, including the name of my organisation
- Publish my response in anonymised form only
- Do not publish my response

For individuals only:

The Government would like your permission to use anonymous quotes from the answers that you provide to this call for evidence. We might want to include these quotes in any report on our findings, but we will ensure that any respondent who is quoted is not identifiable.

Are you happy for us to publish quotes from your answers?

Yes

No

The call for evidence is aimed at three respondent groups. Please choose the set of questions that you feel is most relevant to you. You can only select **one** of the below options. If you think you fit into more than one respondent group and wish to answer more than one set of questions, you may complete this survey a second time, answering the questions from a different section.

Section A – These questions are designed for people who have variations in sex characteristics. We are interested in hearing the views of anyone who thinks they meet this definition.

Section B – Those who look after people who have variations in sex characteristics in a personal capacity, such as, parents, legal guardians, carers.

Section C – Those who work with or provide services to people who have variations in sex characteristics in a professional capacity, such as, healthcare professionals, academics, teachers, employers, support services and service providers.

Section A Questions

Questions in this section are designed for respondents who have variations in sex characteristics.

Chapter 1: Terminology

- We are aware that there are many views on the terminology used to describe the wide range of different variations in sex characteristics that exist. We are also aware that the terminology used has changed over time and differs between medical professionals, parental groups, individuals and others.
- Over the last year, we have learned that a wide range of terms are used, including ‘intersex’, ‘differences of sex development’, ‘variations in sex characteristics’, ‘variations in sex development’, ‘divergence of sex development’, ‘intersex variations’ or ‘diverse sex development’. We also learnt that some individuals prefer to use the specific diagnosis or description of the variation that they have, such as Klinefelter Syndrome, rather than an umbrella term. Further detail can be found in the accompanying technical paper.
- For the purposes of this publication, after consultation with stakeholders, we adopted the umbrella term ‘variations in sex characteristics’. We recognise that many individuals may use their own terms to describe their variations. The Government is approaching this with an open mind. In the questions below, we are seeking views on the umbrella term we have chosen and what term Government should use in the future.

Questions

Topic: Terminology

1. Do you agree or disagree with Government using the term ‘variations in sex characteristics’ as an umbrella term to describe people who have a body that is not typically male or female?
 - Agree
 - Disagree
 - Don’t know
 - Prefer not to say
2. Please list any other term(s) that you would prefer Government to use in the future when describing people who have a body that is not typically male or female.

Chapter 2: Health

- This section of the call for evidence invites respondents to share the variation(s) they have, describe how open they are with others about their variation, any medical interventions they have undergone and their perceptions and experiences of using healthcare services.
- We are asking about these topics because we have learnt from our stakeholder engagement and review of existing research that they are important to individuals with variations in sex characteristics. We are especially interested in what medical interventions people have undergone, how decisions were made about those interventions and what the impact of them has been. We are also interested in other experiences of the healthcare system, such as the availability of information and support and the ability to access medical records. Further detail can be found in the accompanying technical paper.
- The Government recognises that for many, sharing information about these topics can be difficult; we have therefore provided a list of organisations that can provide support. This page can be found after the final question of the call for evidence.

Questions

Your Variation

3. How would you describe your diagnosis and/or variation(s)?

Please select one or more of the listed options below.³

If your variation is not listed in the table, please use the 'other variation' category to describe the variation (*if you feel comfortable doing so*).

Variations (in alphabetical order)	Response
5-alpha reductase deficiency (5-ARD)	<input type="checkbox"/>
17alpha hydroxylase	<input type="checkbox"/>
17-beta-hydroxysteroid dehydrogenase deficiency	<input type="checkbox"/>
Androgen Insensitivity Syndrome – Complete (CAIS)	<input type="checkbox"/>
Androgen Insensitivity Syndrome - Partial (PAIS)	<input type="checkbox"/>
Aphallia / Penile agenesis	<input type="checkbox"/>
Bladder exstrophy	<input type="checkbox"/>
Clitoromegaly	<input type="checkbox"/>
Congenital Adrenal Hyperplasia – Classical CAH	<input type="checkbox"/>

³ This list of variations is derived in part from the 2016 study titled [Intersex: Stories and Statistics from Australia](#).

Congenital Adrenal Hyperplasia – Non-classical CAH	<input type="checkbox"/>
Cryptorchidism (undescended testicle/s)	<input type="checkbox"/>
Denys-Drash syndrome	<input type="checkbox"/>
Epispadias	<input type="checkbox"/>
Frasier Syndrome	<input type="checkbox"/>
45,X/46,XY Gonadal Dysgenesis (sometimes called Mixed Gonadal Dysgenesis or Mosaicism)	<input type="checkbox"/>
Gonadal dysgenesis – Partial	<input type="checkbox"/>
Hypospadias	<input type="checkbox"/>
Jacobs/XYY Syndrome	<input type="checkbox"/>
Kallmann Syndrome	<input type="checkbox"/>
Klinefelter Syndrome	<input type="checkbox"/>
Leydig Cell Hypoplasia	<input type="checkbox"/>
Micropenis	<input type="checkbox"/>
Mayer-Rokitansky-Küster-Hauser syndrome (MRKH)	<input type="checkbox"/>
Mullerian (Duct) Aplasia	<input type="checkbox"/>
Ovo-testicular (46 XX)	<input type="checkbox"/>
Persistent Mullerian Duct Syndrome	<input type="checkbox"/>
Progestin Induced Virilisation	<input type="checkbox"/>
Swyer Syndrome (sometimes known as Complete Gonadal Dysgenesis)	<input type="checkbox"/>
Testicular Regression Syndrome	<input type="checkbox"/>
Testicular DSD 46,XX (sometimes known as De la Chapelle syndrome)	<input type="checkbox"/>
Turner Syndrome	<input type="checkbox"/>
Triple-X Syndrome (XXX)	<input type="checkbox"/>
XXY/47	<input type="checkbox"/>
XY/XO Mosaics	<input type="checkbox"/>
Vaginal agenesis	<input type="checkbox"/>
Unknown	<input type="checkbox"/>
Other variation (please specify): _____	<input type="checkbox"/>

4. At what age were you diagnosed as having variations in sex characteristics?

- Please specify the age (in years): _____
- Don't know
- Not applicable (I have not received a diagnosis)
- Prefer not to say

5. At what age did you first find out about your diagnosis?

- Please specify the age (in years): _____
- Don't know
- Not applicable (I have not received a diagnosis)
- Prefer not to say

6. How did you first find out about your diagnosis? *Please select all that apply.*

- Discussion with clinicians
- Discussion with parents
- After accessing medical records
- At a support group
- By accident, during a routine GP appointment
- Not applicable (I have not received a diagnosis)
- Prefer not to say
- Other (please specify): _____

7. If you are able to, please could you describe how the process of finding out about your diagnosis was handled.

Openness

8. **Today**, how open are you with the following people about having variations in sex characteristics?

Please select from the listed options with Always /mostly / Sometimes/ Never/Prefer not to say

People	Options				
	A. Always	B. Mostly	C. Sometimes	D. Never	E. Prefer not to say
1. Friends	<input type="checkbox"/>				

2. Family members you live with (excluding partners)	<input type="checkbox"/>				
3. Family members you are not living with (excluding partners)	<input type="checkbox"/>				
4. Current Partner/s	<input type="checkbox"/>				
5. Colleagues	<input type="checkbox"/>				
6. Other people you have lived with (e.g. flatmates).	<input type="checkbox"/>				

9. Are you content with how open or private you are about having variations in sex characteristics with those you interact with in your everyday life?

- Yes
- No
- Don't know
- Prefer not to say

10. How has your level of openness affected your everyday life, if at all?

Medical interventions/procedures

We know that some people with variations in sex characteristics have undergone one or more medical interventions or procedures over the course of their lives. We would like to know more about this. We will ask you a series of questions about your experiences. Please only answer them if you feel comfortable doing so.

11. Are you willing to disclose information about the medical interventions or procedures you have undergone because of having variations in sex characteristics?

- Yes

- No
- Not applicable to me (I have never had any medical interventions/procedures)

**Respondents who answered with 'yes', will receive the following questions in this topic. Those that responded with 'no' or 'not applicable to me', will be directed to questions in the next topic: 'perceptions and experiences of healthcare services'.*

12. Have you ever undergone any medical interventions or procedures because of having variations in sex characteristics?

- Yes
- No
- Don't know
- Prefer not to say

**Respondents who answered with 'yes', will receive the following questions in this topic. Those that responded with 'no', 'don't know' or 'prefer not to say' will be directed to questions in the next topic: 'perceptions and experiences of healthcare services'.*

13. How old were you when you had your first medical intervention or procedure because of having variations in sex characteristics?

Please specify the age (in years): _____

- Don't know
- Prefer not to say

14. Have you undergone any further medical interventions or procedures from birth until now because of having variations in sex characteristics?

- Yes
- No
- Don't know
- Prefer not to say

15. If you are able to, please select one or more of the listed options below to identify which medical interventions or procedures you have undergone during your lifetime because of having variations in sex characteristics.

If you are unable to select one or more of the listed options, please use your own words to describe the type of medical interventions or procedures you have undergone in the 'other' box.

- Removal of gonads
- Vaginal/labial/clitoral reconstruction shaping or changes
- Penial/scrotal reconstruction shaping or changes

- Mastectomy (breast removal/ reduction)
- Chest Reconstruction/ shaping
- Hysterectomy
- Hormonal interventions (pills/ injections/creams)
- Dilatation
- Orchiopexy/orchidopexy (surgery to move undescended testicle/s into the scrotum)
- Other (please specify):_____
- I have had medical interventions but can't remember what they were

16. Have you had repeat medical interventions or procedures because of having variations in sex characteristics? By 'repeat', we are referring to medical interventions or procedures you underwent on more than one occasion for the same area of the body over the course of your life.

- Yes
- No
- Don't know
- Prefer not to say

**Those who have responded with 'yes', will be directed to question 17. If respondents answered with 'no', 'don't know' or 'prefer not to say', they will be directed to question 18.*

17. Please describe what repeat medical interventions or procedures you have undergone because of having variations in sex characteristics.

18. Overall, have you had a positive or negative experience of post-operative aftercare?

- Positive
- Neither positive nor negative
- Negative
- Don't know
- Prefer not to say

19. Have you had appropriate access to the following aftercare treatments after undergoing medical interventions or procedures related to having variations in sex characteristics?

Aftercare treatment	Options			
	A. Yes	B. No	C. Don't know	D. Prefer not to say
1. Aftercare information and advice from healthcare professionals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Psychosocial support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Medication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

20. If you feel able to, please describe how the medical interventions or procedures you have undergone related to having variations in sex characteristics have affected you, if at all.

This could include personal, physical and psychological effects, how it has affected personal relationships with your family members and partners, lifestyle, working life, as well as the effect on your wider social interactions.

Informed consent

For consent to be valid, it must be **voluntary** and **informed**, and the person consenting must have the **capacity** to make the decision.

In providing 'informed consent', the person must be given all of the information in terms of what the treatment involves, including the benefits and risks, whether there are reasonable alternative treatments, and what will happen if treatment doesn't go ahead.⁴

21. In general, have you felt able to provide informed consent to the medical interventions or procedures you have undergone because of having variations in sex characteristics?

- Yes
- No
- Don't know
- Prefer not to say

**If respondents answered with 'yes', they will be routed to question 22 and then 24 and onwards. If respondents answered with 'no', they will be routed to question 23 and onwards. If answered with 'don't know', they will be routed to*

⁴ <https://www.nhs.uk/conditions/Consent-to-treatment/>

question 24 and onwards. If answered with '**prefer not to say**', they will be routed to questions in the following topic: 'perceptions and experiences of healthcare services'.

22. Please specify the age at which you first started providing informed consent to the medical interventions or procedures you have undergone because of having variations in sex characteristics

- <10
- 10-12
- 13-15
- 16-17
- 18+

23. Why do you feel you were unable to provide informed consent to one or more of the medical interventions or procedures you have undergone because of having variations in sex characteristics?

24. In general, have you had appropriate information when making decisions about medical interventions or procedures undertaken because of having variations in sex characteristics?

- Yes
- No
- Don't know
- Prefer not to say

25. In general, have you had access to a clinical psychologist when making decisions about medical interventions or procedures undertaken because of having variations in sex characteristics?

- Yes
- No
- Don't know
- Prefer not to say

26. In general, were you given appropriate time when making decisions about medical interventions or procedures undertaken because of having variations in sex characteristics?

- Yes
- No
- Don't know
- Prefer not to say

27. How could the process of providing informed consent for medical interventions or procedures related to having variations in sex characteristics be improved, if at all?

Perceptions and experiences of healthcare services

We know that people with variations in sex characteristics have had unique experiences when using healthcare services. We know that issues such as specialist knowledge of healthcare professionals and accessing medical records matter to people with variations in sex characteristics. The following questions ask about perceptions and experiences of public and private healthcare services.

28. If you have used a healthcare service because of having variations in sex characteristics in the last three years, in general have you had a positive or negative experience?

Healthcare service Type	In general, my experience was...					
	Generally positive	Neither positive or negative	Generally negative	Don't Know	Prefer Not to Say	I did not use this service in the last 3 years
General Practitioner (GP) Service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hospital	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
NHS Specialist Clinic (paediatric care)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
NHS Specialist Clinic (adolescent and adult care)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mental health services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sexual health services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emergency services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gender Identity Clinics	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Private clinics (non-NHS)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Services outside the UK (overseas)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other healthcare services (please specify): _____	<input type="checkbox"/>					
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- b. Please describe the most positive experience you have had when using healthcare services related to having variations in sex characteristics in the last three years. Please clearly specify which service(s) you are referring to in your response.
- c. If you feel able to, please describe the most negative experience you have had when using healthcare services related to having variations in sex characteristics in the last three years. Please clearly specify which service(s) you are referring to in your response.

29. Have any of the following barriers prevented you from using healthcare services because of having variations in sex characteristics?

Barriers	Options			
	Yes	No	Don't know	Prefer not to say
Physical health issues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anxiety and fears of a negative reaction from healthcare professionals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Assumptions that healthcare professionals will not understand your variations in sex characteristics	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Problems accessing a healthcare service in your local area	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify): _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

30. How do you think healthcare services could be improved to better support the needs of people who have variations in sex characteristics, if at all? Please clearly specify which service(s) you are referring to in your response.

Chapter 3: Education

- This section of the call for evidence focuses on experiences in education. The Government is interested in understanding how someone who has variations in sex characteristics navigates through the education system, interacts with their peers or school staff and what effect their variation has had on their life in education. This includes experiences at all education levels from early years to higher education. Further information on what we are interested in and why can be found in the technical paper.

Questions

Education background

31. How recently were you last in education?

- I am still in education
- Up to two years ago
- Between two and ten years ago
- More than ten years ago
- Prefer not to say

32. What is the furthest level of education you have completed?

- Secondary Education (GCSE, O-Levels, or equivalent)
- Post-Secondary Education (College, A-Levels, NVQ3 or below, or equivalent)
- Vocational Qualification (Diploma, BTEC, NVQ4 and above, or equivalent)
- Undergraduate Degree (BA, BSc, etc. or equivalent)
- Post-graduate Degree (MA, MSc, etc. or equivalent)
- Doctorate (PhD, DPhil, etc. or equivalent)
- None of the above
- Prefer not to say

33. What type of educational institution did you attend during the majority of your schooling?

- Mainstream primary/secondary school
- Special school
- Alternative provision, including pupil referral units
- Hospital school
- Home education

- A combination of home and hospital teaching
- Other, please specify: _____

Disclosure to educational staff

34. Did you or your parent/carer/legal guardian discuss your variations in sex characteristics with any of the following? Select all that apply.

- Staff at your early years institution
- Staff at your primary school
- Staff at your secondary school
- Staff at your further education institution
- Staff at your higher education institution
- Staff at your alternative/special provision institution (please specify): _____
- It was never discussed
- Don't know
- Prefer not to say

Experiences in school

We know the following factors are important to people with variations in sex characteristics during their school life.

- Interactions with your peers, including making friendships, experiences of bullying;
- How having variations in sex characteristics affects experiences of school lessons and of using school spaces, such as sports lessons and changing rooms;
- Openness with school staff and the effect this can have;
- How having variations in sex characteristics affects experiences of interacting with the curriculum e.g. relationships and sex education;
- How school staff respond to specific needs e.g. administering medication.

35. Thinking about your experiences in school, did having variations in sex characteristics affect your school life?

- Yes
- No
- Don't know
- Prefer not to say

**Those who have responded with 'yes', will be routed to question 36. If respondents answered with 'no', 'don't know', or 'prefer not to say', they will be directed to question 37.*

36. Please describe the effect that having variations in sex characteristics has had on your experiences of participating in school life. *Please specify which education institution(s) you are referring to in your response.*

37. Reflecting on your experiences, how can primary and secondary school institutions be improved to better support the needs of young people who have variations in sex characteristics, if at all?

Secondary School Absence

38. During secondary school education, how often were you absent owing to having variations in sex characteristics?

- Very often
- Often
- Not often
- Never
- Don't know
- Prefer not to say

**Those who responded with 'prefer not to say' will be directed to questions in the following topic titled 'further and higher education'.*

39. In the year in which you had the most absences because of having variations in sex characteristics, what was the estimated total number of days you had off from secondary school?

Please provide an estimate (in days): _____

40. Which of the following reasons explains why were you absent from secondary school because of having variations in sex characteristics? Please select all that apply.

- Attending medical appointments
- Feeling unwell
- Administering medication at home
- Recovering from medical interventions or procedures
- Other: please specify: _____

41. Please describe how your participation in secondary school life was affected because of these absences, if at all.

Further and higher education

This is your opportunity to share your views on how further and higher education institutions could be improved e.g. college and/or university.

42. Please describe how further and higher education institutions can be improved to better support people with variations in sex characteristics.

Chapter 4: Support services/organisations

- We are interested in the availability of support services for individuals/families and resourcing constraints for those who provide them.
- By support services/organisations, we are referring to any organisation (outside of a public health or education provider), that explicitly works with people who have variations in sex characteristics. This includes but is not limited to the following: online forums, helplines, registered peer support charities, advocacy organisations and voluntary organisations. Further detail can be found in the technical paper.
- This section of the call for evidence invites respondents to share which types of support services/organisations they have accessed or tried to access, how helpful/unhelpful they were and how they could be improved.

Questions

Support Services

43. Outside of your family, public health and education services, where do you seek support as a person who has variations in sex characteristics, if at all? *Examples of support services/organisations are listed in the points above.*

44. If applicable, how helpful or unhelpful was the support you received from the following services/ organisations?

Type of Support Service/organisations	Helpful	Neither helpful or unhelpful	Unhelpful	Prefer not to say	Don't know - I have not tried this service/organisation	Don't know - I have tried but cannot access it
Registered peer support charity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Volunteer-led groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Individualised support e.g. counselling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Overseas based organisations/networks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Faith leaders or groups	<input type="checkbox"/>					
Other (please specify): _____ _____	<input type="checkbox"/>					

45. How do you think support services/organisations could be improved, if at all?
Please specify which support service you are referring to in your response.

Chapter 5: Workplace, Benefits, Sport and Leisure Services

- 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 variations in sex characteristics affects experiences in the workplace, claiming benefits or using sport and leisure services. The Government is interested in gaining a better understanding of these issues. Further detail can be found in the accompanying technical paper.

Questions

Experiences in the workplace

46. Do you think having variations in sex characteristics has affected your experiences in the workplace?

- Yes
- No
- Don't know
- Prefer not to say
- I do not have any employment history

Those who responded with **'yes' to question 46 will be routed to question 47 and onwards. If respondents answered with **'no'**, **'don't know'**, or **'prefer not to say'**, they will be routed to question 48. Those who answered with **'I do not have any employment history'**, will be routed to questions in the following topic: 'experiences of claiming benefit payments'.*

47. Please describe how having variations in sex characteristics affected you in the workplace?

48. How can the workplace be improved for people who have variations in sex characteristics, if at all?

Experiences of claiming benefit payments

49. Do you think that having variations in sex characteristics has affected your experiences of claiming benefit payments?

- Yes
- No
- Don't know
- Prefer not to say
- I have not had any experience of claiming benefit payments

Those who responded with **'yes' to question 49 will be routed to question 50 and onwards. If respondents answered with **'no'**, **'don't know'**, or **'prefer not to say'**, they will be routed to question 51. Those who responded with **'I have not had any***

experience of claiming benefit payments' will be routed to questions in the following topic: 'experiences of using sport and leisure services'.

50. Please describe how having variations in sex characteristics affected your experience of claiming benefit payments?

51. How could the process of claiming benefit payments be improved for people who have variations in sex characteristics, if at all?

Experiences of using sport and leisure services

52. Do you think that having variations in sex characteristics has affected your experiences of using sport and leisure services?

- Yes
- No
- Don't know
- Prefer not to say
- I have never used a sport or leisure service

**Those who responded with 'yes' to question 52 will be routed to question 53 and onwards. If respondents answered with 'no', 'don't know', or 'prefer not to say', they will be routed to question 54. Those who responded with 'I have never used a sport or leisure service' will be directed to questions in the following chapter.*

53. Please describe how having variations in sex characteristics affected your experience of using sport and leisure services.

54. How could sport and leisure services be improved for people who have variations in sex characteristics, if at all?

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

- 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. The Government would like to better understand the scale and nature of these issues in this chapter of the call for evidence.
- There are processes in place to facilitate corrections to birth certificates where the sex was incorrectly registered at birth due to a medical error. These processes differ between England/Wales, Scotland and Northern Ireland. The questions in this chapter do not relate to the process of applying for a gender recognition certificate as set out in the Gender Recognition Act 2004.⁵ The accompanying technical paper provides more detail on the relevant legislation concerning the registration of births in England/Wales, Scotland and Northern Ireland, the way legal sex is determined and the evidence that the General Register Office for England and Wales, National Records of Scotland and the General Register Office for Northern Ireland require in order to amend a sex marker if it were incorrectly assigned at birth.⁶

Questions

Changing Birth certificates

55. Were you previously aware that people could change the sex marker on their birth certificate, if their sex was incorrectly assigned at birth as a result of a medical error?

- Yes
- No

56. Have you considered changing the sex marker on your birth certificate?

We are specifically asking about the processes practiced by the General Register Office for England and Wales, the National Records of Scotland and the General Register Office for Northern Ireland.

- Yes - I have considered changing the sex marker, but I have not done so
- No - I would not consider changing the sex marker

⁵ An Act of Parliament that allows transgender people to gain legal recognition of their acquired gender, so long as that gender is a man or woman. Applications for legal recognition made under the Act are determined by a Gender Recognition Panel which applies the evidential requirements set out in the Act.

⁶ The National Records of Scotland (NRS) is responsible for the arrangements for registering births, deaths, marriages, civil partnerships and other life events. NRS is headed by the Registrar General for Scotland.

- No - I did not know these services existed
- I have already changed the sex marker
- Don't know
- Prefer not to say
- Not applicable to me

57. How do you think process of changing the sex marker on a birth certificate could be improved, if at all?

We are specifically asking about the processes practiced by the General Register Office for England and Wales, the National Records of Scotland and the General Register Office for Northern Ireland. In your answer, please specify which of these processes you are referring to.

Chapter 7: Conclusion and Final Question

- The previous chapters of this call for evidence have covered the areas that the Government has identified as being of particular relevance in relation to the experiences and needs of people who have variations in sex characteristics.
- In order for the Government's consideration to be as well-informed as possible, we want to make sure that we hear a wide range of perspectives on all the issues that people consider to be of relevance. If you do not feel that your views are best expressed in answer to any of the previous questions in this call for evidence, or if you feel that we have not covered an issue that is important to you, please use the below box to provide us with any further views you might have.

Questions

Other issues

58. Is there anything else that you would like to share with us about being a person who has variations in sex characteristics in the UK?

Please use this opportunity to provide us with any information and evidence you think we should consider in any future policy development process.

Section B Questions

Questions in this section are designed for respondents who look after people who have variations in sex characteristics e.g. parents, carers and legal guardians.

Chapter 1: Terminology

- We are aware that there are many views on the terminology used to describe the wide range of different variations in sex characteristics that exist. We are also aware that the terminology used has changed over time and differs between medical professionals, parental groups, individuals and others.
- Over the last year, we have learned that a wide range of terms are used, including ‘intersex’, ‘differences of sex development’, ‘variations in sex characteristics’, ‘variations in sex development’, ‘divergence of sex development’, ‘intersex variations’ or ‘diverse sex development’. We also learnt that some individuals prefer to use the specific diagnosis or description of the variation that they have, such as Klinefelter Syndrome, rather than an umbrella term. Further detail can be found in the accompanying technical paper.
- For the purposes of this publication, after consultation with stakeholders, we adopted the umbrella term ‘variations in sex characteristics’. We recognise that many individuals may use their own terms to describe their variations. The Government is approaching this with an open mind. In the questions below, we are seeking views on the umbrella term we have chosen and what term Government should use in the future.

Questions

Terminology

1. Do you agree or disagree with Government using the term ‘variations in sex characteristics’ as an umbrella term to describe people who have a body that is not typically male or female?
 - Agree
 - Disagree
 - Don’t know
 - Prefer not to say

Please list any other term(s) that you would prefer Government to use in the future, when describing people who have a body that is not typically male or female.

Chapter 2: Health

- This section of the call for evidence invites respondents to give their views on how people with variations in sex characteristics are catered for by the healthcare system. We are interested in medical interventions or procedures, as well as, wider experiences of the healthcare system. Further background information can be found in the accompanying technical paper.

Questions

Diagnosis

2. If you are able to, please select one of the following options which best describes the diagnosis your child/person you look after has.⁷ If the diagnosis is not listed, please use the 'other' field.

Variations (in alphabetical order)	Response
5-alpha reductase deficiency (5-ARD)	<input type="checkbox"/>
17alpha hydroxylase	<input type="checkbox"/>
17-beta-hydroxysteroid dehydrogenase deficiency	<input type="checkbox"/>
Androgen Insensitivity Syndrome – Complete (CAIS)	<input type="checkbox"/>
Androgen Insensitivity Syndrome - Partial (PAIS)	<input type="checkbox"/>
Aphallia / Penile agenesis	<input type="checkbox"/>
Bladder exstrophy	<input type="checkbox"/>
Clitoromegaly	<input type="checkbox"/>
Congenital Adrenal Hyperplasia – Classic CAH	<input type="checkbox"/>
Congenital Adrenal Hyperplasia – Non-classical CAH	<input type="checkbox"/>
Cryptorchidism (undescended testicle/s)	<input type="checkbox"/>
Denys-Drash syndrome	<input type="checkbox"/>
Epispadias	<input type="checkbox"/>
Frasier Syndrome	<input type="checkbox"/>
45,X/46,XY Gonadal Dysgenesis (sometimes called Mixed Gonadal Dysgenesis or Mosaicism)	<input type="checkbox"/>
Gonadal dysgenesis – Partial	<input type="checkbox"/>
Hypospadias	<input type="checkbox"/>
Jacobs/XYY Syndrome	<input type="checkbox"/>

⁷ This list of variations is in part derived from the 2016 study titled [Intersex: Stories and Statistics from Australia](#).

Kallmann Syndrome	<input type="checkbox"/>
Klinefelter Syndrome	<input type="checkbox"/>
Leydig Cell Hypoplasia	<input type="checkbox"/>
Micropenis	<input type="checkbox"/>
Mayer-Rokitansky-Küster-Hauser syndrome (MRKH)	<input type="checkbox"/>
Mullerian (Duct) Aplasia	<input type="checkbox"/>
Ovo-testicular (46 XX)	<input type="checkbox"/>
Persistent Mullerian Duct Syndrome	<input type="checkbox"/>
Progestin Induced Virilisation	<input type="checkbox"/>
Swyer Syndrome (sometimes known as Complete Gonadal Dysgenesis)	<input type="checkbox"/>
Testicular Regression Syndrome	<input type="checkbox"/>
Testicular DSD 46,XX (sometimes known as De la Chapelle syndrome)	<input type="checkbox"/>
Turner Syndrome	<input type="checkbox"/>
Triple-X Syndrome (XXX)	<input type="checkbox"/>
XXY/47	<input type="checkbox"/>
XY/XO Mosaics	<input type="checkbox"/>
Vaginal agenesis	<input type="checkbox"/>
Unknown	<input type="checkbox"/>
Other variation (please specify): _____	<input type="checkbox"/>

3. At what age did your child/person you look after have their variation diagnosed?

- Specify age (in years): _____
- Don't know
- Not applicable (they have not received a diagnosis)
- Prefer not to say

4. To what extent were you satisfied with the advice you received from healthcare professionals upon diagnosis?

- Very satisfied
- Satisfied
- Not very satisfied

- Unsatisfied
- Don't know
- Prefer not to say

Medical Interventions or procedures

We know that some people with variations in sex characteristics have undergone one or more medical interventions or procedures over the course of their lives. We would like to know more about this. We will ask you a series of questions about your experiences as a parent/carer/legal guardian. Please only answer them if you feel comfortable doing so.

5. Are you willing to disclose information about medical interventions or procedures your child/person you look after has undergone because of having variations in sex characteristics?

- Yes
- No

**If respondents answered 'yes', you will be directed to questions 6 and onwards. If respondents answered with 'no', 'don't know', 'prefer not to say', they will be directed to questions in the following topic titled: 'healthcare services for people with variations in sex characteristics'.*

6. At what age did your child/person you look after have their first medical intervention or procedure?

- Specify age (in years): _____
- Don't know

7. If you are able to, please specify what medical interventions your child/the person you look after has undergone from birth until now?

Informed consent

We know that when providing informed consent to medical interventions or procedures, the following factors matter to people who look after those with variations in sex characteristics.

- The availability of information to individuals and families about any clinical decisions;
- Access to an expert clinical psychologist;
- Support provided to parents when discussing the clinical decision with their child;
- Information on deferring medical interventions or non-surgical treatment options;
- The role of any external influences/pressures when making decisions, e.g. the legally mandated time-period to register a child's birth;

- Role of support organisations.

8. If your child/person you look after underwent medical intervention/procedures(s), was your informed consent sought?⁸

- Yes
- No
- Don't know
- Prefer not to say

**Those who responded with 'prefer not to say' will be directed to questions in the following topic titled, 'healthcare services for people with variations in sex characteristics'.*

9. In general, did you have **appropriate information** when making decisions about the medical intervention/procedure(s) your child/person you look after has undergone because of having variations in sex characteristics?

- Yes
- No
- Don't know
- Prefer not to say

10. In general, did you have **appropriate time** when making decisions about the medical intervention/procedure(s) your child/person you look after has undergone because of having variations in sex characteristics?

- Yes
- No
- Don't know
- Prefer not to say

11. In general, did you have access to a **clinical psychologist** when making decisions about the medical intervention/procedure(s) your child/person you look after has undergone because of having variations in sex characteristics?

- Yes
- No
- Don't know
- Prefer not to say

⁸ The NHS [consent to treatment webpage](#) states that for consent to be valid, *it must be voluntary and informed, and the person consenting must have the capacity to make the decision. In providing 'informed consent', the person must be given all of the information in terms of what the treatment involves, including the benefits and risks, whether there are reasonable alternative treatments, and what will happen if treatment doesn't go ahead.*⁸

12. When providing informed consent to medical interventions/procedures on behalf of your child/person you look after, how can the process of making this decision be improved, if at all?

Healthcare Services for people who have variations in sex characteristics

We know that parents/carers/legal guardians of people with variations in sex characteristics are interested in the following healthcare service related issues.

- Access to psychosocial support for parents and families in order to understand the diagnosis or treatment options;
- Access to a child's medical records;
- The training and awareness of healthcare staff;
- Referral pathways to specialist services;
- Clinical staff's knowledge of external support services e.g. peer support organisations.

13. How do you think healthcare services could be improved to better support the needs of people who have variations in sex characteristics, if at all? Please clearly specify which healthcare service you are referring to in your response.

Chapter 3: Education

- This section of the call for evidence focuses on experiences in education. The Government is interested in understanding how someone who has variations in sex characteristics navigates through the education system, interacts with their peers or school staff and what effect their variation has had on their life in education. This includes experiences at all education levels from early years to higher education. Further detail outlining our understanding can be found in the technical paper.

Questions

Education system for people who have variations in sex characteristics

14. What type of education institution does/did your child/person you care for attend during the majority of their schooling?

- Mainstream primary/secondary school
- Special school
- Alternative provision, including pupil referral units
- Hospital school
- Home education
- A combination of home and hospital teaching
- Other, please specify: _____

15. In general, do you agree or disagree that the educational institutions attended by your child/person you care for provided appropriate support for pupils with variations in sex characteristics?

- Agree
- Disagree
- Don't know
- Prefer not to say

16. How could educational institutions be improved to better support the needs of pupils with variations in sex characteristics, if at all?

Chapter 4: Support services/organisations

- We are interested in the availability of support services for individuals/families and resourcing constraints faced by those who provide them.
- By support services, we are referring to any organisation (outside of public health or education providers), who explicitly work 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 organisations and voluntary organisations. Further detail can be found in the technical paper.
- This section of the call for evidence invites respondents to share which types of support services/organisations they have accessed or tried to access, how helpful/unhelpful they were and how they could be improved.

Questions

Support services/organisations

17. Have you used a support service or organisation (as described above) for people with variations in sex characteristics and those who look after them in the last 3 years?

- Yes
- No
- Don't know
- Prefer not to say

**If respondents answered with 'yes', they will be directed to question 18 and onwards. If respondents answered with 'no', 'don't know', 'prefer not to say', they will be directed to question 20.*

18. Please select which of the following support services/organisations you have used in the last 3 years.

- Registered peer support charity
- Volunteer-led groups
- Individualised support e.g. counselling
- Overseas based organisations/networks
- Faith leaders or groups
- Other (please specify): _____

19. How useful have you found support services or organisations for people who have variations in sex characteristics and those who look after them?

- Very useful

- Quite useful
- Not very useful
- Not at all useful
- Don't know
- Prefer not to say

20. Please describe how support services/organisations could be improved for people who have variations in sex characteristics and those who look after them, if at all?

Chapter 5: Workplace, Benefits, Sport and Leisure Services

- 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 variations in sex characteristics affects experiences in the workplace, claiming benefits or using sport and leisure services. The Government is interested in gaining a better understanding of these issues. Further detail can be found in the accompanying technical paper.
- This section of the call for evidence invites parents/carers/legal guardians who look after people with variations in sex characteristics to share their experiences of the workplace, claiming benefits and using sport and leisure services.

Questions

Experiences in the workplace

- 21.** What challenges, if any, have you experienced in the workplace as someone who looks after a person with variations in sex characteristics?
- 22.** How could the workplace be improved for those who look after people with variations in sex characteristics, if at all?

Claiming benefits

- 23.** What challenges, if any, have you experienced when claiming benefits because the person you look after has variations in sex characteristics?
- 24.** How could the process of claiming benefits by those who look after people with variations in sex characteristics be improved, if at all?

Sport and leisure services

- 25.** What challenges, if any, have you experienced when using sport and leisure services as someone who looks after a person with variations in sex characteristics?
- 26.** How could sport and leisure services be improved for people who have variations in sex characteristics and those who look after them if at all?

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

- 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. The Government would like to better understand the scale and nature of these issues in this chapter of the call for evidence.
- There are processes in place to facilitate corrections to birth certificates where the sex was incorrectly registered at birth due to a medical error. These processes differ between England/Wales, Scotland and Northern Ireland. The questions in this chapter do not relate to the process of applying for a gender recognition certificate as set out in the Gender Recognition Act 2004.⁹ The accompanying technical paper provides more detail on the relevant legislation concerning the registration of births in England/Wales, Scotland and Northern Ireland, the way legal sex is determined and the evidence that the General Register Office for England and Wales, National Records of Scotland and the General Register Office for Northern Ireland require in order to amend a sex marker if it were incorrectly assigned at birth.¹⁰

Questions

Birth certificates

27. Please tell us whether you had a positive or negative experience when registering your child's sex at birth.

- Positive
- Negative
- Neither positive or negative
- Don't know
- Prefer not to say
- Not applicable, I did not register my child's birth in the UK

We know that the following things matter when it comes to registering a child's birth if they variations in sex characteristics.

- Interactions with clinicians and registrars

⁹ An Act of Parliament that allows transgender people to gain legal recognition of their acquired gender, so long as that gender is a man or woman. Applications for legal recognition made under the Act are determined by a Gender Recognition Panel which applies the evidential requirements set out in the Act.

¹⁰ The National Records of Scotland (NRS) is responsible for the arrangements for registering births, deaths, marriages, civil partnerships and other life events. NRS is headed by the Registrar General for Scotland.

- Access to support services
- Timeframe to register the birth (e.g. 42 or 21 days).

28. If applicable, what challenges, if any, did you experience in registering your child's birth because of their variations in sex characteristics?

29. How do you think the process of registering the birth of a child with variations in sex characteristics could be improved, if at all?

Changing birth certificates

30. If applicable, have you changed your child's sex marker on their birth certificate because their sex was incorrectly assigned at birth due to a medical error? We are specifically asking about the processes practiced by the General Register Office for England and Wales, the National Records of Scotland and the General Register Office for Northern Ireland.

- Yes
- No
- Don't know
- Prefer not to say

31. How could the process of changing the sex marker on a birth certificate be improved for someone who has variations in sex characteristics, if at all?

We are specifically asking about the processes practiced by the General Register Office for England and Wales, the National Records of Scotland and the General Register Office for Northern Ireland. In your answer, please specify which of these processes you are referring to.

Chapter 7: Conclusion and Final Question

- The previous chapters of this call for evidence have covered the areas that the Government has identified as being of particular relevance in relation to the experiences and needs of people who have variations in sex characteristics.
- In order for the Government's consideration to be as well-informed as possible, we want to make sure that we hear a wide range of perspectives on all the issues that people consider to be of relevance. If you do not feel that your views are best expressed in your answers to any of the previous questions in this call for evidence, or if you feel that we have not covered an issue that is important to you, please use the below box to provide us with any further views you might have.

Questions

Other issues

32. Is there anything else that you would like to share with us about being a parent/carer/legal guardian of someone who has variations in sex characteristics in the UK?

Please use this opportunity to provide us with any information and evidence you think we should consider in any future policy development process.

Section C Questions

Questions in this section are designed for respondents who work with or provide services to people who have variations in sex characteristics e.g. clinicians, teachers, academics, support services, service providers or employers.

Chapter 1: Terminology

- We are aware that there are many views on the terminology used to describe the wide range of different variations in sex characteristics that exist. We are also aware that the terminology used has changed over time and differs between medical professionals, parental groups, individuals and others.
- Over the last year, we have learned that a wide range of terms are used, including ‘intersex’, ‘differences of sex development’, ‘variations in sex characteristics’, ‘variations in sex development’, ‘divergence of sex development’, ‘intersex variations’ or ‘diverse sex development’. We also learnt that some individuals prefer to use the specific diagnosis or description of the variation that they have, such as Klinefelter Syndrome, rather than an umbrella term. Further detail can be found in the accompanying technical paper.
- For the purposes of this publication, after consultation with stakeholders, we adopted the umbrella term ‘variations in sex characteristics’. We recognise that many individuals may use their own terms to describe their variations. The Government is approaching this with an open mind. In the questions below, we are seeking views on the umbrella term we have chosen and what term Government should use in the future.

Questions

Terminology

- 33.** Do you agree or disagree with Government using the term ‘variations in sex characteristics’ as an umbrella term to describe people who have a body that is not typically male or female?
- Agree
 - Disagree
 - Don’t know
 - Prefer not to say
- 34.** Please list any other term(s) that you would prefer Government to use in the future when describing people who have a body that is not typically male or female.

Chapter 2: Health

- This section of the call for evidence invites respondents to give their views on how people who have variations in sex characteristics are catered for by the healthcare system. We are interested in medical interventions or procedures, as well as wider experiences of the healthcare system. Further background information can be found in the accompanying technical paper.

Questions

Medical Interventions or procedures

In relation to medical interventions/procedures, we know the following issues matter to those who work with or provide healthcare services to people who have variations in sex characteristics:

- Clinical standards and guidance;
- How decisions are made about medical interventions/procedures;
- Composition of specialist clinical teams;
- The availability of information to individuals and families about any clinical decisions;
- The level of aftercare that is offered.

35. With regard to medical interventions/procedures, how could the care, support and information provided to people who have variations in sex characteristics be improved, if at all?

Healthcare Services for people who have variations in sex characteristics

In relation to broader healthcare services, we know the following issues matter to those who work with or provide services to people who have variations in sex characteristics:

- The training and awareness of healthcare staff;
- Referral pathways to specialist services;
- Clinical standards and guidance;
- Clinical staff's knowledge of external support services e.g. peer support organisations.

36. How do you think healthcare services could be improved to better support the needs of people who have variations in sex characteristics, if at all? Please clearly specify which healthcare service you are referring to in your response.

Chapter 3: Education

- This section of the call for evidence focuses on experiences in education. The Government is interested in understanding how someone who has variations in sex characteristics navigates through the education system, interacts with their peers or school staff and what effect their variation has had on their life in education. This includes experiences at all education levels from early years to higher education. Further detail outlining our understanding can be found in the technical paper.

Questions

Education system for people who have variations in sex characteristics

37. How could educational institutions be improved for pupils with variations in sex characteristics and their families, if at all?

Please specify which educational institution(s) you are referring to in your response.

Chapter 4: Support services/organisations

- We are interested in the availability of support services for individuals/families and resourcing constraints faced by those who provide them.
- By support services, we are referring to any organisation (outside of public health or education providers), who explicitly work 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 organisations and voluntary organisations. Further detail can be found in the technical paper.
- This section of the call for evidence invites respondents to share which types of support services/organisations they have accessed or tried to access, how helpful/unhelpful they were and how they could be improved.

Questions

Support Services/Organisations

We know the following issues matter to support services/organisations designed for people with variations in sex characteristics:

- The type of support that exists;
- How it is funded;
- Experiences of frontline staff.

38. How could support services/organisations be improved for people who have variations in sex characteristics and those who look after them, if at all?

Chapter 5: Workplace, Benefits, Sport and Leisure Services

- 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 variations in sex characteristics affects experiences in the workplace, claiming benefits or using sport and leisure services. The Government is interested in gaining a better understanding of these issues. Further detail can be found in the accompanying technical paper.

Questions

Experiences in the workplace

- 39.** How could the workplace be improved for people who have variations in sex characteristics and those who look after them, if at all?

Claiming benefits

- 40.** How could the process of claiming benefits for people who have variations in sex characteristics and those who look after them be improved, if at all?

Sport and leisure services

- 41.** How could sport and leisure services be improved for people who have variations in sex characteristics and those who look after them, if at all?

Chapter 7: Conclusion and Final Question

- The previous chapters of this call for evidence have covered the areas that the Government has identified as being of particular relevance in relation to the experiences and needs of people who have variations in sex characteristics.
- In order for the Government's consideration to be as well-informed as possible, we want to make sure that we hear a wide range of perspectives on all the issues that people consider to be of relevance. If you do not feel that your views are best expressed in your answers to any of the previous questions in this call for evidence, or if you feel that we have not covered an issue that is important to you, please use the below box to provide us with any further views you might have.

Questions

Other issues

42. Is there anything else that you would like to share with us about working with or providing services to people who have variations in sex characteristics in the UK?

Please use this opportunity to provide us with any information and evidence you think we should consider in any future policy development process.

Demographic Questions

Asking the following questions will help us to better analyse and understand your response to the call for evidence. The information you provide will only be used for analytical purposes. You don't have to answer them if you don't want to.

1. How old are you?

- 16-17
- 18-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65+

2. Which area of the United Kingdom do you live in?

- North East
- North West
- Yorkshire and the Humber
- East Midlands
- West Midlands
- East of England
- London
- South East
- South West
- Wales
- Scotland
- Northern Ireland
- Outside of the UK, please specify: _____
- Prefer not to say

3. What is your ethnic group?

Choose one option that best describes your ethnic group or background.

- White
- Mixed/multiple ethnic groups
- Asian/Asian British
- Black/African/Caribbean/Black British
- Other ethnic group, please specify: _____
- Prefer not to say

4. Do you consider yourself to have a disability?

- Yes
- No
- Prefer not to say

5. If you answered yes, to question 4, is your disability related to having variations in sex characteristics?

- Yes
- No
- Prefer not to say
- Not applicable to me

6. What is your religion?

- Christian
- Buddhist
- Hindu
- Jewish
- Muslim
- Sikh
- No religion
- Any other religion, please specify: _____

7. What is your sexual orientation?

- Bisexual
- Gay/lesbian

- Heterosexual/straight
- Don't know
- Prefer not to say
- Other, please specify:_____

8. What was your sex assigned at birth?

- Female
- Male
- Don't know
- Prefer not to say

9. What is your gender identity?

- Man
- Woman
- Don't know
- Prefer not to say
- I identify in another way, please specify:_____

Support and Advocacy Groups

We understand that having to provide details about your personal experiences when responding to the questions in this call for evidence might be difficult. Here are some web-links to a few of the various UK based support and advocacy groups, from where you can obtain further resources and advice:

- Androgen Insensitivity Syndrome Support Group (AISSG): <http://www.aissg.org/>
- dsdfamilies: <https://www.dsdfamilies.org>
- dsdteens: <http://www.dsdteens.org/>
- Hypospadias UK Charitable Trust: <http://www.hypospadiasuk.co.uk/>
- Intersex UK: @intersexuk
- Intersex Community Support Group: <https://www.facebook.com/groups/1802512236484671/>
- Klinefelter's Syndrome Association UK: <http://www.ksa-uk.net/>
- CAH Support Group: <http://www.livingwithcah.com/>
- Living MRKH: <http://livingmrkh.org.uk/>
- MRKH National Centre: <http://www.mrkh.org.uk/>
- OII-UK: <http://oiiuk.org/>
- Turner syndrome society: <https://tss.org.uk/>
- UK Intersex Association: <http://www.ukia.co.uk/>

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