



**ACT**  
Government

# Proposed reforms to provide better care and support for people with variations in sex characteristics

Draft Legislation Consultation

2022

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## Draft Legislation Consultation

Under the First Capital of Equality Action Plan, the ACT government is continuing to develop regulation of medical interventions for people with variations in sex characteristics (also referred to as intersex people). You can find an overview of what the government has already done to consider this issue, and the reforms the government is proposing [here](#).

With careful consideration of the contributions of key stakeholders, we have prepared draft legislation to achieve the aims of the ACT government in improving the health and wellbeing of people with variations in sex characteristics and upholding their human rights in medical settings. This draft is titled the *Variations in Sex Characteristics (Restricted Medical Treatment) Bill 2022*, and referred to here as the draft Bill.

In this phase of the project, we are inviting you to review and comment on the draft Bill. This information has been prepared to assist you in reading and understanding the draft Bill. It is designed as a guide only, and is not intended as legal interpretation of this Bill or other laws. It is to assist you in thinking about the legislation and taking part in this consultation phase. In addition to this explanation, you may also wish to read the ACT Parliamentary Counsel's Office 'Reading Legislation' guide which may help in understanding the structure of ACT law and how ACT legislation is written.

You can download the draft Variations in Sex Characteristics (Restricted Medical Treatment) Bill 2022 [here](#).

## How to Contribute

This information about the draft Bill contains questions that we are seeking your feedback on. These questions are shown in blue text boxes. The questions have been framed around the parts of the Bill we believe need further careful consideration and where we think your input will be especially valuable. We also welcome your comments on any other aspect of the draft Bill.

We are inviting individuals to submit responses on the draft Bill online [here](#). We will not ask for your personal information, and your response will be anonymous.

If you are a professional body, organisation or group wanting to provide a formal response, please do so via email to [intersex@act.gov.au](mailto:intersex@act.gov.au).

You can also contact us via email to arrange a time to talk with us if you would prefer.

## How would the legislation work?

This legislation works by establishing a new process to be applied when medical treatment for people with variations in sex characteristics is being considered. It would permit these interventions only under conditions set out in the draft Bill.

This new approach requires that information, advice and psychological and peer support be provided to people with variations in sex characteristics and their families. It applies human rights already recognised in ACT law to important decisions. These include the rights not to receive medical treatment without consent, and the right of children to special protection, free of discrimination. The legislation would allow medical treatment where:

- The medical procedure is emergency treatment for health of the person; or
- The treatment is easily reversible; or
- The treatment does not affect their sex characteristics; or
- The person is seeking the medical procedure for themselves. The proposed law sets out conditions to be met for informed consent.

If a medical treatment proposed for a person with variations in sex characteristics is not permitted under any of those conditions, then it would be a restricted medical practice. This means it would not be permitted unless it is covered by a treatment plan that is approved by the expert panel set up under the legislation. It would be an offence to perform a restricted medical treatment on a person protected by the Bill without authorisation by a committee of the expert panel. It would also be an offence to remove a protected person from the ACT for the purpose of undergoing a restricted medical treatment.

There are two types of treatment plans:

### General Medical Treatment Plan

A general medical treatment plan (see sections 15-19 of the draft Bill) would be a plan approved by the expert panel that supports medical treatments of a particular type, or specific variation or set of circumstances that can apply to more than one person. Once a general treatment plan has been developed and approved by a committee of the expert panel, if a health professional proposes a medical treatment of a type, or in a circumstance, covered by a general treatment plan, it would be permitted. The development of a general treatment plan would include a period of consultation, including with health professions and community organisations.

### Individual Medical Treatment Plan

An individual medical treatment plan (see sections 20-23 of the draft Bill) would be a plan approved by a committee of the expert panel for an individual. A person (usually through their parents and/or their

treating doctor/s) would submit a proposed treatment plan to the expert panel committee. The proposal would need to set out a range of information and evidence that will be specified either in the legislation or by the expert panel. If the individual treatment plan is approved, then treatment can occur consistent with the plan.

In approving either a general treatment plan or an individual treatment plan, committees of the expert panel must follow the general principles for restricted medical treatment set out in the draft Bill (section 10). These principles are grounded in human rights and are designed to ensure that when treatment decisions are being made, they are consistent with these principles.

1. In your opinion, will the general principles listed in section 10 of the draft Bill guide the committee to good decisions and care outcomes? Please outline why/why not.

## Who would the legislation apply to?

The draft Bill would apply to ‘protected people’. To understand who a protected person is, there are several parts of the draft Bill that need to be read together. This includes section 8 and 9, and the terms ‘sex characteristics’, and ‘variation in sex characteristics’ in the Bills’ dictionary. A protected person is someone who is *both* a person with a variation in sex characteristics *and* does not have decision-making capacity. While we expect that the majority of people to whom this applies would be infants and children, by making who is protected by the Bill a function of capacity this will also protect adults who either have a temporary or permanent impairment of their decision-making capacity.

### How are variations in sex characteristics defined?

‘Variations in sex characteristics’ refers to people who have biological features that constitute a variation in sex characteristics; it is not about how a person identifies. To define sex characteristics, we initially looked to how this has been described in human rights discussions, such as by United Nations committees and in the Yogyakarta Principles +10. We also received legal advice about suitable language to use in this legislation. The definition proposed in the draft bill reflects both existing definitions and our legal advice.

In order to clearly specify what a *variation* in sex characteristics is, we reached the view that this required reference to a list of variations rather than a principle-based definition. The advice we have received from both health and human rights advisors is that if we also try to apply a principle-based definition, there is a risk that the definition will not be sufficiently clear for individuals, families and health practitioners to know what is covered. This would not be consistent with human rights protections for those people.

In the Bill, variations in sex characteristics is currently described as “a variation in sex characteristics (whether diagnosed or not) prescribed by regulation.” This means that a list of what variations the legislation will cover is not part of the Bill itself but will sit in the accompanying regulation. Regulations are legally enforceable rules that address the details and practical application of an Act. For this consultation we have developed a list of variations in sex characteristics. This has been developed through review of medical literature that includes such lists, and in discussion with people who have variations in sex characteristics. This list follows on the next page.

Item	Variation in sex characteristics (including alternative names or acronyms)
1	17-beta-hydroxysteroid dehydrogenase deficiency (17 $\beta$ -Hydroxysteroid dehydrogenase III deficiency)
2	48XXXX/XXXX Syndrome (Tetrasomy X, Quadruple X)
3	49XXXXX, XXXXX Syndrome (Pentasomy X)
4	5-alpha reductase deficiency (5-ARD, Pseudovaginal perineoscrotal hypospadias, PPSH)
5	Androgen Insensitivity Syndrome (AIS, androgen resistance, testicular feminisation)
6	aphallia
7	bladder exstrophy (ectopia vesicae)
8	clitoromegaly (enlarged clitoris)
9	Complete Androgen Insensitivity Syndrome (CAIS)
10	Congenital Adrenal Hyperplasia (Adrenogenital Syndrome, CAH)
11	De la Chapelle Syndrome (XX Male Syndrome)
12	epispadias
13	Follicle-Stimulating Hormone Insensitivity (FSH)
14	Fraser Syndrome (Fraser-François Syndrome, Meyer-Schwickerath Syndrome, Ullrich-Feichtiger Syndrome)
15	gonadal dysgenesis (partial or complete)
16	hypogonadism
17	hypospadias
18	isolated 17,20-lyase deficiency (ILD)
19	Jacobs Syndrome (XYY Syndrome)
20	Kallmann Syndrome
21	Klinefelter Syndrome, including 47XXY, 48XXXY or 49XXXXY variations (XXY Syndrome)
22	Leydig cell hypoplasia
23	Mayer-Rokitansky-Küster-Hauser Syndrome (MRKH, Müllerian (duct) aplasia, Müllerian agenesis, vaginal agenesis)
24	micropenis
25	Mild Androgen Insensitivity Syndrome (MAIS)
26	mosaicism or chimerism involving sex chromosomes
27	Non-classical Congenital Adrenal Hyperplasia (NCAH)
28	ovo-testes (true hermaphroditism, ovotesticular disorder)
29	Partial Androgen Insensitivity Syndrome (PAIS)
30	Persistent Mullerian Duct Syndrome (PMDS)
31	progestin-induced virilisation
32	pseudohermaphroditism
33	Swyer Syndrome (XY gonadal dysgenesis)
34	Triple-X Syndrome (47XXX, triple-X, trisomy X, XXX, XXX syndrome)
35	Turner Syndrome (45X0 or 45X, gonadal dysgenesis, Ullrich-Turner Syndrome)
36	XO/XY Mosaics

The reform is intended to give people with variations in sex characteristics more control of decision-making about all aspects of their sex characteristics: it is not just about genitals, and is not related to current or future gender identity or sexual orientation. The scope of the legislation is intended to reflect these considerations. If you think the list captures items that are not appropriately considered as variations in sex characteristics, we encourage you to provide information and evidence around how the list could be amended. Removing items from the list would require careful consideration of how the integrity of the scheme would be maintained, and a strong understanding of the evidence that their removal would benefit individuals with those variation(s), as removal from the list would mean those individuals would lose the protections the scheme is intended to offer.

The definition of variations in sex characteristics is a crucial part of this reform, and we need your feedback about whether we have got this right.

2. In your view, are the definitions used for 'sex characteristics' and 'variation in sex characteristics' suitable? Does the list supplied (page 5 of this document) capture and correctly name all variations? If you wish to suggest anything should be added or removed, please provide evidence in support of your suggestions.

### **When does someone have decision-making capacity?**

Decision-making capacity is an important part of who the Bill applies to, and is explained in section 9 of the draft Bill. This lays out what is required for someone to be considered to have decision-making capacity for the purpose of this Bill. The intention of this section is to ensure that where a person does have decision-making capacity, which may include adolescents who are legally minors, they will make their own decisions and will not require treatment plans under the legislation. Where possible and desirable, we have sought to align this new law with existing laws that test decision-making capacity. In this case, these provisions have drawn on the *Mental Health Act 2015*, sections 7 and 8. It is important to note that decision-making capacity is specific to a particular medical decision and is not a blanket test for every kind of decision.

### **What medical treatments would the legislation restrict?**

What treatments are restricted is defined in section 7 of the draft Bill. Early in this project what treatments should be restricted was often described as 'deferrable medical treatment'. However, the term 'deferrable' was abandoned as it was not considered to be legally precise. It is important that this meaning is legally precise as it is essential that it both captures what is intended to be affected by this reform, and doesn't inadvertently prevent treatments which were not intended to be affected. A number of different approaches were considered, before choosing the one in this draft bill. It proposes a three-part meaning for restricted medical treatment:

- The first part is the descriptive definition in section 7(a)(i). This focusses on treatments that have a permanent effect on the person's sex characteristics.
- The second is a "prescribed surgical or medical procedure or treatment". Here, prescribed has a specific legal meaning that is different to how 'prescribed' is used in medical contexts. It means that this definition includes procedures that have been 'prescribed', or written, in the associated regulation. This clause allows the Minister responsible for the legislation to 'prescribe' in the

regulation treatments to which the Bill applies. This is important because it allows the Minister to name treatments that need to be in the scope of the Bill but which don't meet the first part of the meaning.

- An example of this that we are proposing to include in the regulation from its commencement is vaginal dilation. Vaginal dilation is generally considered reversible; however, we have heard from stakeholders that it is a medical treatment that the Bill should cover because of its high risk of human rights violations, and the trauma that some people have suffered as a result of its use.
- The third part of the meaning describes what will *not* be in scope and thus affected by the Bill, including urgent procedures or treatments. This will ensure that where treatment is urgently required it can proceed without the need for any prior consideration or approval from the expert panel. A definition of emergency medical procedure or treatment has been included, which adopts language used in *Victoria's Medical Treatment Planning and Decisions Act 2016 (VIC)*.
- Circumcision of the penis for people with variations in sex characteristics is also proposed to be excluded from the scope and thus would not be affected by the Bill. The effect of this exemption would be that rules for circumcision would be the same for people with variations in sex characteristics as for the rest of the population, we welcome your views about this topic.

The meaning of restricted medical treatment is an area of the Bill where we are specifically seeking input on to ensure that we have this right. We welcome your views on how this is best described.

3. Are there medical or other treatments that might inadvertently be captured as a restricted medical treatment that we would not want to affect with this Bill? If there are, what are they and why do you think they would they be captured? Will the definition fail to capture any treatments that should be addressed?

## What are the expert panel and committees?

For a restricted treatment on a protected person to occur, it must be approved by a committee of the expert panel. The committee is not making medical decisions: it is a multidisciplinary body tasked with considering whether a proposed course of treatment meets the requirements in this sensitive area of health care.

The panel and its committees are laid out in sections 24-31 in the draft Bill. The panel can be thought of as a pool of people from which smaller committees are appointed to consider a specific treatment plan. In this way, committees can be made up of those on the panel who have the most relevant expertise to the matter at hand. The responsible Minister will appointment members to the panel, on the basis of their skills and experience. Each committee is proposed to comprise five people, one person from each of the following categories of member:

- medicine;
- ethics;

- human rights;
- variations in sex characteristics;
- provision of psychosocial support.

The president of the panel would appoint committees but would not be a member of them themselves. This will allow them to potentially be the person who conducts merit reviews of committee decisions (see the information on challenges to decisions below). There is no requirement that a person appointed to the panel be from the ACT, and our advice is that the Minister should appoint the best expertise available, wherever it is located, given this is a specialised field. The intention is that the category of member called ‘variation in sex characteristics’ can include people with different kinds of lived experience of variations in sex characteristics. For example, this could include a parent with experience in health decision-making. However, a clause has been included to ensure that at least one member of the panel in this category has to be a person with a variation.

It is important to remember that where a treatment plan has been approved by a committee, this does not mean that it *must* occur, just an authorisation that it is legal for it occur. Where the protected person is a child, those with parental responsibility would still need to provide their consent for the treatment to proceed, as they would for any other medical treatment.

4. What kinds of experience, skills and expertise do you think a committee needs, and are these the appropriate categories of member to achieve this? Why/why not?

## What are treatment plans?

Treatment plans are the process by which a restricted medical treatment proposed for a person with variations in sex characteristics can be authorised. The bill refers to two different types of medical treatment plans: individual (sections 20-23) and general (sections 15-19). An individual plan is for one person whereas a general plan applies to a type of treatment, variation or set of circumstances that can apply to more than one person. Where a general treatment plan applies, an individual treatment plan would not be needed. However, every treatment under a general plan must be notified to the panel and reported on in the annual report, to maintain line of sight to what treatments are occurring. The content required to be in an Annual Report is explained in section 31.

### General medical treatment plan

General treatment plans will need to be developed by the panel, with a committee appointed to draft a general treatment plan and decide whether to approve it. The Bill sets out how they should prepare a draft, principles (section 10) that a plan must meet, requirements for public consultation and how to finalise a general treatment plan. The public consultation process would allow the panel, for example, to write to medical specialist bodies and groups representing people with particular variations in sex characteristics, making sure they knew a plan was being proposed and giving them an opportunity to participate in its development.

5. In your view, will the process for creating a general treatment plan, outlined in sections 15-19, support appropriate information gathering, consultation, and decisions for establishing a general treatment plan?

## Individual medical treatment plan

The legislation sets out what an individual application needs to include, a process for how committees should consider them, principles (section 10) that a plan must meet in order to be approved, and a description of what an approved plan must contain. As individual plans will refer to a specific person and contain private health information, they will be subject to existing privacy protections (see below for information about interactions with other legislation).

6. What kind of information should be required and who should be consulted to ensure that a committee can make a well-informed decision for an individual treatment plan?

## Can treatment plan decisions by a committee be challenged?

Good practice in administrative law includes providing a pathway for what is called merits review of decisions, and this should be easily accessible to the person affected by the decision, such as a parent. In the draft Bill, it is proposed that in the first instance the president of the panel be empowered to review decisions of a committee (sections 34-38). The president should be able to consider whether all the required processes were followed, particularly whether the principles in section 10 were followed, and to consider whether, given all the available information, an individual treatment plan should be approved. The president would be able to confirm/uphold the committee's decision, or approve an individual medical treatment plan, or if the president believes the proper process has not been followed, be able to send the application back to the committee and ask them to follow the procedure. If an affected person is still unhappy with the outcome, the ACT Civil and Administrative Tribunal (ACAT) can conduct a limited review of the president's decision (sections 39-40). This would focus on whether a decision has been properly made, following correct processes of the legislation, but ACAT would not reconsider the facts of the application.

While these are the two forms of review in the draft Bill, they are not the only pathways that a person could challenge a decision made by a committee. Some of these other pathways are addressed below. In addition, it would be possible to seek an alternate treatment decision through either the Family Court or through the *parens patriae* jurisdiction of the Supreme Court.

## The legislation wouldn't operate in isolation

It is important to understand that this law would not operate in legal isolation, so everything it achieves cannot be found just within this Bill. Some things that are important to its overall effect are:

- This law is designed to apply human rights in the field of intersex healthcare. The *ACT's Human Rights Act 2004* continues to apply, which means all the rights in that Act remain rights that apply to people with variations in sex characteristics. In particular:

- Under the *Human Rights Commission Act 2005*, a person can complain about their health care if they believe it does not comply with any law (including this new one), and they are also able to complain about any health care that doesn't meet health provision principles regarding standards of care. This is already the case, and this new law, together with proposed new psychosocial care, would set the bar against which the Health Services Commissioner can assess complaints.
- The expert panel in this legislation would be a public authority within the meaning of the *Human Rights Act 2004*, making it unlawful for its committees, in making a decision, to fail to give proper consideration to a relevant human right.
- Under national laws regulating registered health practitioners, one of the things that a health practitioner must do is comply with laws. Therefore, failure to comply with the new ACT law could result in a breach of their professional standards.
- The *Health Records (Privacy and Access) Act 1997* would apply to any health record created as a result of this new legislation, and will act to protect privacy in the same way as it does to other existing health records and information. The one exception we are considering (see section 33 of the draft Bill) is whether these records should be kept for a longer period than other health records, because there is sometimes a long time between when someone might be treated as a child, and when they might want to access their records later in life, such as when they are considering having children themselves.
- If someone is dissatisfied with how a decision was made under the new legislation, they will have access to judicial review under the *Administrative Decisions (Judicial Review) Act 1989*.

In addition, we are considering other changes to make alongside the law, including better psychosocial care for individuals with variations in the sex characteristics and their families, and peer support. You can see more information about these proposals [here](#).

## What about people who not protected persons under the Bill?

Where an individual has decision-making capacity, they are not a 'protected person' in the Bill. However, the Bill contains general obligations for restricted medical treatment for all people with variations in sex characteristics (see section 11), even if they have decision-making capacity. This includes ensuring that where an individual has decision-making capacity, they have given their informed consent to the treatment.

Informed consent has not previously been defined in detail elsewhere in ACT law. The draft Bill provisions draw on the *Victorian Mental Health Act 2015*. In the draft Bill, section 12 sets out the requirements for informed consent, including what required information that must be given for consent to be fully informed. This provision is needed because of the importance and sensitivity of the content and detail of information provided to people with variations in sex characteristics and their families, when considering the choices they may need to make. We expect further discussion about the wording of this provision and we welcome input.

7. In your opinion, does section 12 adequately describe informed consent and what is required for it, in the context of a person with variations in sex characteristics consenting to a restricted medical treatment? Please outline why/why not.

## How to Contribute

You are welcome to make responses to the questions here, or to make comments about any other aspect of the draft Bill.

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