

VICTORIAN INTERSEX OVERSIGHT PANEL PROPOSAL:

FINAL REPORT AND RECOMMENDATIONS TO THE VICTORIAN GOVERNMENT

September 2021

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CONTENTS

For	Foreword			
Pro	Proposal summary5			
1.	Т	he proposal snapshot	5	
2.	K	Xey changes from the draft proposal	11	
(a)	The role of the oversight body	11	
(b)	Composition and operation of the oversight body	12	
(c)	Strengthening the decision-making framework	13	
(d)	Other changes made since the draft proposal	15	
(e)	Consultation feedback not incorporated	16	
3.	۷	Vork leading to this proposal	18	
Scł	nedu	ule A: The final proposal	19	
Scł	Schedule B: The final proposal – Annotated with amendments and consultation feedback			
Scł	nedu	ule C: Consultation feedback and detailed response	.64	

ABOUT EQUALITY AUSTRALIA

Equality Australia is a national LGBTIQ+ organisation dedicated to achieving equality for LGBTIQ+ people.

Borne out of the successful campaign for marriage equality, and established with support from the Human Rights Law Centre, Equality Australia brings together legal, policy and communications expertise, along with thousands of supporters, to redress discrimination, disadvantage and distress experienced by LGBTIQ+ people.

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We acknowledge that our offices are on the land of the Kulin Nation and the land of the Eora Nation and we pay our respects to their traditional owners.

The views expressed in this report do not, and are not intended to, constitute legal advice.

FOREWORD

It is with great pleasure and privilege that we present the Victorian Government our final report and the proposal for a legal scheme to protect people with innate variations of sex characteristics from medical treatment that modifies their sex characteristics without their personal consent.

This proposal has been built with and by the people directly affected. It has been assembled at its heart with the inspiration, hopes, demands, advocacy, ideas and experiences of people with innate variations of sex characteristics. Thank you to the people with innate variations of sex characteristics who were part of our consultation, and to Intersex Human Rights Australia (IHRA), for working with us to refine this proposal so that we could do this legal policy work walking alongside you. We know and acknowledge that this work has only been possible because of the collective efforts of many intersex people and advocates over decades who set the groundwork for this reform.

We thank all the consultation participants, including the people with innate variations of sex characteristics, parents, partners and health professionals, whose generous feedback has significantly helped us improve the final proposal. We heard many different – and sometimes conflicting – views from and among people with innate variations of sex characteristics, their parents, their partners, health professionals and other stakeholders. All those views were considered and we have responded in detail to every item of feedback raised in our consultations. As a result, we have incorporated many amendments into the final proposal, based on the comments of both supporters and critics of the draft proposal.

Ultimately, this proposal is about protecting everyone's right to decide what happens to their own bodies. In the proposal, we have described this as the "significant and profoundly personal interest" of every individual to decide what happens to their own bodies. "Significant", because it cannot simply be ignored, understated, or just seen as part of a loose mix of factors that must be cited only to be put aside by someone else. And "profoundly personal", because it goes to deeply held views and values about our bodies, who we are and want to be, what makes us happy, how we exist in the world around us and what gives us lives of dignity, purpose and joy. These are profound questions, and they are also deeply personal – because each person can only truly answer them for themselves. That is why, this proposal puts the significant and profoundly personal interest of every person to decide what happens to their bodies at the centre of all decision-making. Or in other words, the oversight body we propose be established must always turn its mind to how its decision *today* preserves for this unique person the greatest range of options to decide what they want for themselves in the future.

When making decisions about whether medical treatment modifying a person's sex characteristics should be performed in circumstances where that person does not have capacity to make that decision for themselves, this proposal says that the law should require strong, objective, specific and compelling health-based reasons which give proper and full weight to every individual's significant and profoundly personal interest to decide what happens to their own body, whether now or in the future. It does not ignore other reasons, whether psychosocial or otherwise, but says that those reasons must come from the wants and needs that this person themselves has told or shown you – not what may be assumed for them based on general evidence that may not reflect what this unique person's wants and needs are or may be. When making decisions, this proposal centres the voice of that person, focuses everyone's best efforts to honouring that voice and giving it time to speak for itself wherever possible, but does not ignore that this person lives in a family and society that can also be supported to understand the benefits of letting people be, become and belong.

And when asking a person with innate variations of sex characteristics to decide for themselves whether they want medical treatment modifying their sex characteristics, the law should require that person to be given fair information, and the time and support they need, to come to their own decision without pressure or coercion.

We look forward to working with intersex people, the Victorian Government and other stakeholders on reforms that protect people with innate variations of sex characteristics from medical treatment that modifies their sex characteristics without their personal consent. We also acknowledge and support the demands for redress and greater education, acknowledging that for some people this reform will have come far too late.

We also hope that this proposal will be embraced by the Victorian community as a necessary step on a longer journey of making a world in which every person can live a full, dignified and satisfying life, no matter the sex characteristics innate to them.

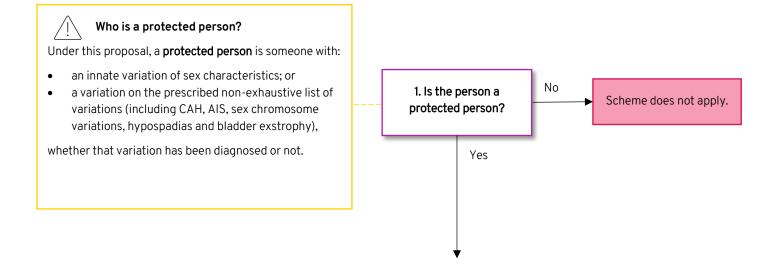
Thank you to the Victorian Government for commissioning us to do this legal policy work. We hope it will lead to world-leading reforms improving on the laws of Malta, Iceland, Germany, Portugal and the growing number of places that have taken steps to protect the next generation of people with innate variations of sex characteristics.

PROPOSAL SUMMARY

This summary sets out a snapshot of how our final recommended proposal works in practice, key changes we have made to the proposal since the consultation draft and feedback received from our consultation, as well as the steps we took to get to this point.

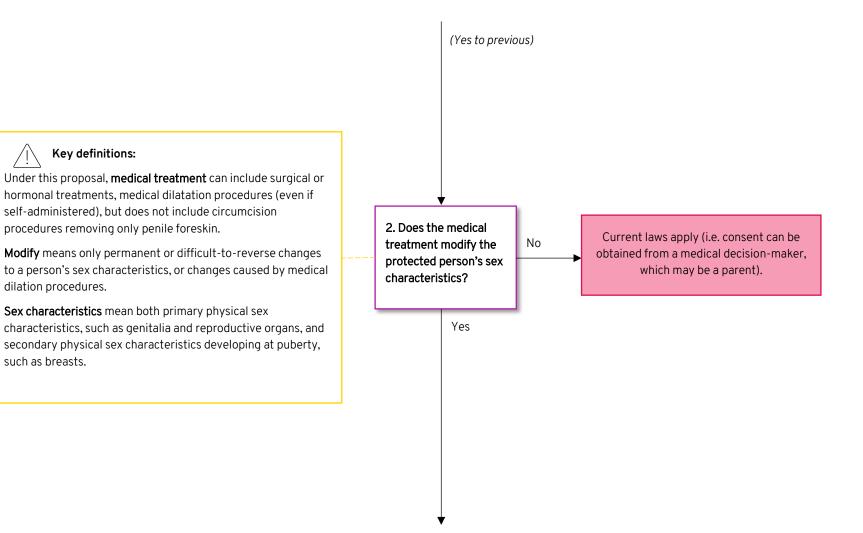
1. THE PROPOSAL SNAPSHOT

The final proposal is set out in **Schedule A** of this report. It is set out in a typical structure for a standard piece of legislation. This is a summary snapshot of how the proposal is intended to work if implemented into law as proposed. It shows how medical treatment modifying a protected person's sex characteristics may be allowed or prohibited by the proposed scheme. The yellow boxes contain summaries of key proposal details. However, the details of the oversight body and legal tests are further discussed in the following section 2, *Key changes from the draft proposal.* Further, many terms in the proposal have specific legal definitions, so it is important to check the full definitions in the proposal for the complete picture.



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Victorian Intersex Oversight Panel Proposal: Final report and recommendations



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Who has capacity to give consent?

Under this proposal, having the **capacity to give informed consent** means being able to understand, remember, use or weigh information, and being able to communicate a decision, relevant to the proposed medical treatment. This is consistent with existing Victorian laws.

But the proposal also says that capacity must be judged in light of **reasonable support** that the person could be given to allow them to understand, remember, use or weigh relevant information, or communicate. Reasonable support could include, for example, giving someone additional time, a translator, or an aid that helps them understand information or communicate. 3. Does the protected person have the capacity to give informed consent to the proposed treatment themselves?

No

(Yes to previous)



Yes

What is informed consent?

Under this proposal, **informed consent** requires the person to have been given adequate information and time to make an informed decision about their treatment without pressure or coercion. This is consistent with existing Victorian laws. However, the proposal also includes **additional safeguards** for obtaining informed consent from protected persons, including the need to give:

The protected person can give their own consent to

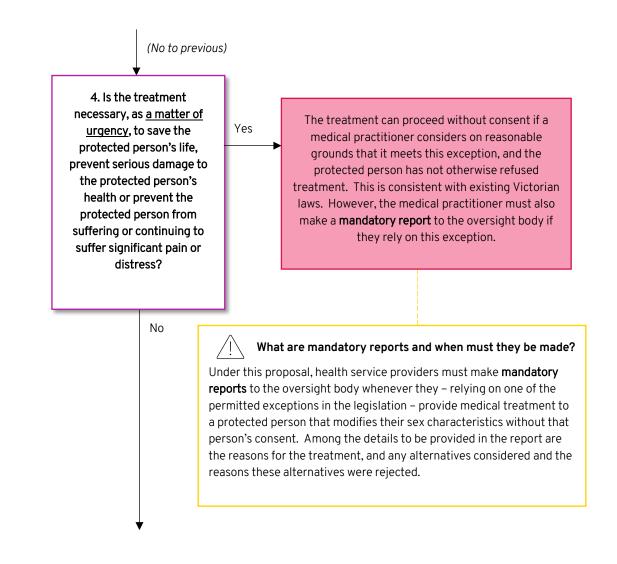
the treatment, if they wish, but medical

practitioners must ensure they have obtained

informed consent from the protected person.

- affirming, clearly understandable and factually objective information about their variation;
- a prescribed list of peer and psychological support contacts;
- information about the option of having no medical treatment at all or at the present time, and its consequences;
- a reasonable opportunity to discuss the treatment with someone else, including with or without the presence of someone else as they wish.

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What is a class exemption order?

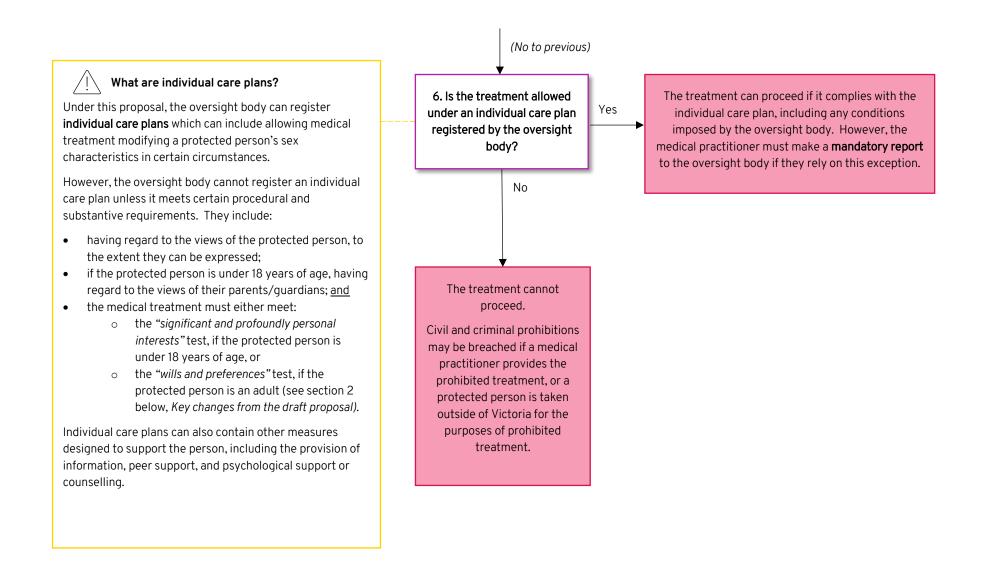
Under this proposal, the oversight body can make **class exemption orders** allowing a certain class of treatment that modifies a person's sex characteristics to be performed in certain circumstances. Where a class exemption order applies, and subject to any limitations or conditions imposed by the oversight body in the order itself, an ordinary medical decision-maker (which can be the person, a parent or someone else authorised to make medical decisions for the person) can consent to the treatment as appropriate.

However, the oversight body cannot make a class exemption order unless it meets certain procedural and substantive requirements. They include:

- a public consultation process;
- having regard to relevant human rights in the Victorian Charter of Human Rights and Responsibilities; <u>and</u>
- the medical treatment allowed by the order must meet the "significant and profoundly personal interests" test (see section 2 below, Key changes from the draft proposal).

(No to previous) 5. Is the treatment allowed under a class exemption order made by the oversight body? No No

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2. KEY CHANGES FROM THE DRAFT PROPOSAL

To accompany our consultation, we released a paper that included a draft proposal for a legal scheme to protect people from medical interventions on their sex characteristics without personal consent.¹

Schedule B shows the changes we made to the draft proposal in response to the feedback received through our consultations. **Schedule C** sets out our detailed response to all the consultation feedback received, including an explanation of the changes made to the draft proposal to arrive at the final proposal.

We made a significant number of substantive as well as minor changes between the draft proposal and the final proposal. The reasons for those changes are set out in full detail in the table in Schedule C.

Here is a summary of the key changes we made to the draft proposal.

(a) The role of the oversight body

Even among supporters of the proposed scheme, there were different views regarding the proper role of the oversight panel. Some consultation participants saw the panel having a role of last resort, making decisions only in cases where the person did not capacity to consent to their own medical treatment. Other consultation participants conceived of the oversight panel having an enlarged role that also tested the *quality* of consent obtained from an individual who had capacity to give consent. These participants saw the panel having a role in ensuring consent was fully informed and obtained without pressure or coercion.

We have built upon existing legal frameworks to provide additional safeguards for people who have capacity to give consent to medical treatment modifying their sex characteristics, while preserving the role of the oversight body as a decision-maker of last resort for people who do not have capacity to give consent to such treatment. This properly recognises a fundamental object of the scheme is to support people with innate variations of sex characteristics to make their own decisions about what happens to their own bodies, rather than having those decisions made for them.

Additional safeguards for obtaining and recording informed consent

Using the existing Victorian legal framework which defines who has 'capacity to give consent' and the meaning of 'informed consent', we have suggested additional safeguards for obtaining informed consent from people with innate variations of sex characteristics who are considering medical treatment modifying their sex characteristics.

When discussing medical treatment modifying the sex characteristics of a person with innate variations of sex characteristics, our suggested additional safeguards would require the health professional to give the person:

- affirming, clearly understandable and factually objective information about their variation;
- a prescribed list of peer support and psychological support contacts;
- information about the option of having no medical treatment at all or at the present time, and its risks and benefits;
- a reasonable opportunity to consider the options proposed, including a cooling off period appropriate to the nature of the treatment; and
- a reasonable opportunity to discuss the treatment with the treating health professional and a different health professional if they wish, including with or without the presence of someone else.

Our suggested proposal would also require a health professional to maintain written records of all the information provided to the protected person to comply with this section and to treat those records in accordance with existing Health Privacy Principles recognised under Victorian law. These principles include obligations on the proper

¹ Equality Australia (2021) <u>A Victorian Intersex Oversight Scheme: A consultation paper on a legal scheme to protected people from medical interventions</u> on their sex characteristics without personal consent, July 2021.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

storage of health information for a period of time based on the age of the person, and access by the person to their health information.

Breaches of these additional safeguards could:

- form part of a complaint to existing complaints mechanisms, such as to the Victorian Health Complaints Commissioner;
- lead to professional disciplinary action through existing regulatory systems, such as the Australian Health Practitioner Regulatory Agency; or
- support legal action through existing mechanisms, such as actions for medical negligence.

These additional safeguards recognise the concerns we heard from people with innate variations of sex characteristics about the need to redress information and power imbalances in the existing medical and cultural environment in which these decisions are made. These imbalances impair access to existing rights designed to ensure informed consent to medical treatment without pressure or coercion. These provisions would also give clarity to health professionals as to what is expected of them when obtaining informed consent from people with innate variations of sex characteristics concerning medical treatment modifying their sex characteristics.

Oversight body as decision-maker of last resort

For people with innate variations of sex characteristics who do not have capacity to consent to medical treatment modifying their sex characteristics, we have maintained the role of the oversight panel as a decision-maker of last resort. However, the panel must now make its decisions in accordance with a new legal test that recognises a person's significant and profoundly personal interest in deciding what happens to their own body (see section 2(c), *Strengthening the decision-making framework* below).

(b) Composition and operation of the oversight body

Size of oversight panel and selection of panel members

Our consultation heard that an oversight panel consisting of 9 members would be overwhelming for families and slow in making decisions. Some consultation participants said that a diversity of perspectives could still be achieved through other means than by simply enlarging the number of members on the oversight panel.

Considering this feedback, we have reduced the size of the full panel from 9 members to 5 members. The proposal for a sub panel of 3 members, to determine less contentious individual cases, remains in place.

However, we have strengthened the safeguards for ensuring a reasonable diversity of gender, clinical expertise and lived experience remains part of all decision-making by:

- Instating a pool of panel members, to be appointed by the Minister for Health after consultation
 with the Minister for Equality (if a different person), following an open selection process. When
 appointing members to the pool, the Minister for Health must have regard to ensuring a
 reasonable diversity of gender, clinical expertise and lived experience in the pool of members.
 Panel members must be allocated to at least one of these three categories: health professional,
 community representative, and/or specialists in human rights, children's rights or disability
 rights. From that pool, the Chair (or a deputy Chair) then has the task of assembling a full panel
 or sub panel, subject to further safeguards that ensure a reasonable diversity of gender, clinical
 expertise and lived experience in every panel. Clinical and lived experience must be part of
 every panel, and sub panel decisions must be made by consensus (or otherwise the matter must
 be heard by a full panel). The full panel must aim to make its decisions by consensus, but to
 avoid deadlocks, it can make its decisions by majority. Decisions of the panel can also be
 reviewed by courts exercising their powers of judicial review.
- We have also expanded the ability of the oversight body to obtain evidence, including from independent specialists, experts or people with lived experience, and evidence based on the experience learnt in past decisions.

Improvements to the operation of the oversight body

Many consultation participants were worried about the ability of panel members to work well together, fearing that panel members would come to their role with entrenched positions. Other consultation participants were worried about the panel process adding additional stress on families. To address these concerns, we have made several amendments to improve the operation of the oversight body.

We have suggested the law include a clear set of obligations requiring all panel members to act consistently with the duties expected of all persons exercising public functions. These include duties to:

- act with integrity, impartially, respectfully, fairly and accountability when performing their roles;
- maintain relevant professional registrations, accreditations or qualifications necessary for their role;
- attend such training and development as requested by the Chair from time to time;
- declare any actual or perceived conflicts of interests; and
- disqualify themselves from sitting as a panel member in respect of any matter in which there is any actual or apprehended bias.

In addition to strengthening the decision-making framework (see section 2(c) below), we have also placed several obligations on the oversight body when performing its functions. These include obligations to act fairly and according to the substantial merits of the case in all matters, and to comply with the rules of natural justice. To reduce the formality in which matters can be considered by the oversight panel, we have also specified that the oversight body:

- is not generally bound by the legal rules of evidence or court procedures;
- must conduct the hearing of any matter with as little formality and technicality, and as efficiently, as possible; and
- does not require parties to be represented by lawyers, and in fact requires the permission of the Chair for the appearance of lawyers on behalf of the parties.

We have also specified that the oversight body may:

- appoint an independent advocate to represent the interests of the protected person and provide their voice where they are not able to provide it themselves; and
- offer any affected person a referral to peer support or psychological support or counselling as part of its assessment processes.

To improve transparency, we have also specified that in addition to providing individual decisions to persons who appear before it, the oversight body can publish de-identified individual decisions and must publish annual reports on the operation of the scheme, including key aggregated data on the number and outcomes of matters.

(c) Strengthening the decision-making framework

As stated above, the oversight body will be a decision-maker of last resort. It will have a role in deciding whether to allow medical treatment modifying the sex characteristics of a protected person, in circumstances where that treatment is necessary (but not strictly an emergency), and the person does not have capacity to provide consent to the treatment themselves. The oversight body will be able to do so for an individual (by registering an individual care plan) or for a specific type of treatment (by making a class exemption order), and it will be able to impose any conditions or limitations it considers appropriate.

The key issue is how the oversight body should decide whether treatment is necessary or must be deferred. No international jurisdiction has approached the issue in the same way. And the draft proposal's suggestion to impose a principle deferring treatment unless it would likely cause harm to the health of the person was met with a range of views. Some consultation participants felt the principle was too loose (allowing too many treatments which ought to be deferred), while others thought it was too narrow (denying or delaying treatments which ought to be performed earlier).

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

Taking on the feedback received from consultation participants, we have reformulated the legal test based on several key principles and observations. These principles and observations are discussed in detail at item 6.3.3(a) of the table in Schedule C. Ultimately, we have suggested that the fundamental starting point for every oversight body decision should be that every individual has a significant and profoundly personal interest in deciding what happens to their own body. Accordingly, allowing medical treatment to modify a person's sex characteristics without the person's consent must only be done for the most compelling reasons.

We have therefore suggested that the oversight body must follow the following legal framework when making decisions.

No capacity to consent

First, the oversight body should only have power to make decisions in respect of persons with innate variations of sex characteristics who do not have capacity to provide their own consent. This means that the oversight body does not have the power to second-guess or override the decision of a person who has capacity to provide personal consent.

Procedural fairness

Second, the oversight body must follow the principles of natural justice and take into account the views of relevant persons. When considering *individual care plans*, this means considering the views of the protected person and, if the person is under 18 years of age, the views of their parents. When considering *class exemption orders*, this means following a public consultation process and consulting with the Minister for Health and Minister for Equality.

Risk assessment

Third, the oversight body "must have regard to the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing)".

This means considering the following factors:

- the significant and profoundly personal interest of a person in being able to decide what happens to their own body, and the extent to which that interest may be realised through:
 - the option of deferring medical treatment that modifies the protected person's sex characteristics to preserve any expected ability of the protected person to provide personal consent in future; or
 - the option of allowing medical treatment that preserves options for the protected person in the future;
- the likely benefits and risks of the proposed medical treatment to the protected person's health;
- any likely adverse consequences to the protected person's health of the proposed medical treatment not being provided; and
- any alternatives to the medical treatment being proposed, and the likely benefits and risks of those alternatives.

Social and psychosocial benefits

Fourth, the oversight body must not presume that a person with innate variations of sex characteristics would experience any social or psychosocial benefits from having their sex characteristics function or appear in a manner which conforms with norms for persons without that variation except where there is:

- specific evidence that has substantial probative value, or
- in individual cases, where the evidence comes directly from the protected person.

Human rights and lawfulness

Fifth, the oversight body must comply with the law, including having regard to relevant human rights contained in the Victorian Charter of Human Rights and Responsibilities and the objects and purposes of this scheme.

'Significant and profoundly personal interest' and 'will and preferences' tests

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

Sixth and ultimately, the oversight body must be satisfied that:

- in all individual decisions where the protected person is aged under 18: the protected person's "best interests are better served by the medical treatment proceeding without their personal consent over deferring the treatment to realise that person's significant and profoundly personal interest in deciding what happens to their own body"; or
- in all individual decisions where the protected person is aged 18 years or over: the medical
 treatment is "consistent with the protected person's will and preferences, or to the extent that
 those wills and preferences cannot be fully expressed, is consistent with the best ascertainment of
 what the protected person's will and preferences would likely be" subject to a proviso for
 decisions resulting in serious harm; or
- in all class exemption order decisions: "the best interests of any protected person who meets the conditions specified in the class exemption order would be better served by the medical treatment proceeding (with the consent of a medical-decision maker and on any conditions specified by the oversight body) over deferring the treatment to realise a person's significant and profoundly personal interest in deciding what happens to their own body."

(d) Other changes made since the draft proposal

We received further detailed feedback on specific aspects of the draft proposal. Some of the key changes made in response to that feedback includes:

- **Definition of 'protected person'.** We have removed polycystic ovary syndrome (**PCOS**) from the initial scope of the scheme. Given PCOS may be considered an intersex variation only when it involves androgen excess, we consider it better to leave it open to the oversight body to determine whether (and to what extent) it recommends PCOS to be prescribed under the scheme (see item 2.1.1(j) in Schedule C).
- Vaginal dilation. We have determined that dilation procedures that are recommended or advised by a health professional should come within the scope of treatments regulated by the scheme. This ensures for people who have the capacity to consent, the scheme's additional safeguards for obtaining personal consent are enlivened. For people who do not have the capacity to consent, the oversight body will be able to regulate these procedures through its class order exemption or individual care plan processes (see item 2.2.2 in Schedule C).
- **Individual care plans.** We have made several amendments to clarify the role and effect of individual care plans:
 - We have clarified that the provision of peer support, psychological support or counselling, and the provision of information to the protected person, can be among the matters contained in an individual care plan. We have also clarified that individual care plans can include provisions on when they will be reviewed by the oversight body (see item 4.1.2(b) in Schedule C).
 - We have suggested that an individual care plan and the panel's decision be treated as a
 personal health record, thereby requiring this information to be kept on a register in
 accordance with existing Health Privacy Principles (so that the protected person can
 access it when they are older) (see items 7.4.1 and 7.4.2 in Schedule C).
 - We have also clarified that an individual care plan has the legal effect of authorising the acts which are required or allowed by it, such as any medical treatment which has been approved by the oversight body (see items 7.5.1 and 7.5.2 in Schedule C).
- Interaction with other laws and schemes. We have suggested ancillary changes to current and historical health, guardianship and child protection legislation, so that any person currently authorised to consent to medical treatment on behalf of someone else must meet the requirements of the scheme.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

- **Future nationalisation.** Recognising that the scheme is now deeply embedded in existing Victorian laws, we have decided to remove the 'opt in' provisions allowing other states or territories to sign up to the Victorian scheme. We think a simpler way to achieve a degree of legal and operational consistency nationally may be to review the scheme after 5 years and consider further changes, such as the mutual recognition of decisions made by comparable panels in other states or territories. In the meantime, there is the option of appointing the same panel members to more than one state or territory oversight panel, such that expertise and professional development is operationally consolidated across jurisdictions.
- **Purposes and objects.** To reflect the above changes, we have updated the introductory provisions of the proposed legislation (including the purposes and objects of the scheme).

(e) Consultation feedback not incorporated

We received some consultation feedback which we did not incorporate into the final proposal for various reasons. In some cases, feedback was inconsistent among consultation participants, and we were persuaded by one view over another. In other cases, feedback did not accurately reflect the law, or could not be implemented for legal reasons. And in a few cases, we disagreed with the feedback on matters of policy, including because the feedback undermined fundamental objectives of the scheme. Our detailed response to each item of consultation feedback are set out in the table in Schedule C.

Here is a summary of the key feedback which was not incorporated into the final proposal

Use existing multidisciplinary panel processes

As set out in item 4.1.2(a) of Schedule C, we considered this option a less favourable pathway for several legal and policy reasons. This approach would not:

- change the legal framework to centre consent from the person receiving the medical treatment into decision-making;
- include people with lived experience fully and equally in decision-making;
- allow transparency in decision-making (because clinicians will remain subject to their confidentiality obligations); or
- give parents a 'seat at the table' or the right to be heard.

As set out in item 4.1.2(a) of Schedule C, there are distinct benefits in a legal scheme establishing an independent oversight body exercising public powers that cannot be replicated using the existing multidisciplinary panel forum.

Male circumcision

Some consultation participants wanted to see complete prohibitions on male circumcision as part of this scheme (see item 3.2.1 of Schedule C). Whatever the merits may be of prohibiting male circumcision, we have determined that this legislation would not be the correct vehicle to address these issues. This is because this scheme only applies to people with innate variations of sex characteristics and male circumcision practices affect a much broader population.

Narrowing the scope of 'protected persons'

Some consultation participants argued for the removal of congenital adrenal hyperplasia (**CAH**), hypospadias, cryptorchidism, bladder exstrophy, Kallmann Syndrome and/or Follicle-Stimulating Hormone Insensitivity (**FSH**) from the scope of the scheme (see items 2.1.1(d) to 2.1.1(i) in Schedule C).

For the reasons set out in the table, we were not persuaded by the rationales given for excluding these variations. The oversight body should be able to oversee medical treatment performed without personal consent that modifies the sex characteristics of a person with these variations.

Parents should have the ultimate say

Some parents in our consultation considered they should have the ultimate say over whether to consent on behalf of their child to medical treatment modifying their children's sex characteristics.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

This scheme ensures that parents can provide their views on any decision being made by the oversight panel in respect of their children and requires the oversight panel to take their views into account.

The scheme also includes a number of rights and protections for parents, including:

- ensuring family members can be appointed as community panel members, so that their voice is included within the oversight body;
- allowing the oversight body to refer parents to peer support and counselling if that is appropriate;
- ensuring parents are 'interested persons', which means they are entitled to bring their own
 applications for an individual care plan for their child to the oversight body, request written
 reasons for a panel's decision made in respect of their child, and appeal decisions of the
 oversight panel; and
- ensuring parents benefit from the scheme's confidentiality protections in the same way as their child.

Ultimately, we have determined that the weight given to the views of parents in an individual matter should depend on the circumstances of the case and the oversight panel should make its decisions by reference to what is in the best interests of the child. This is also consistent with existing limitations on parental authority; namely that, while people with parental responsibility can generally give consent to medical treatment on behalf of a child, there is an implicit constraint that parental authority must be exercised in the best interests of the child.² Courts can (and do) step in to override decisions of parents when they are not in the best interests of their child.³ So this scheme would mean that a specialist panel (rather than a court) could override the decision of a parent to authorise or withhold treatment which modifies the sex characteristics of their child if the decision were not in the child's best interests, but without the cost, expense or formality of a court proceeding.

Criminalisation

Some consultation participants wanted to see the removal of all criminal offences from the proposed legislation (see items 2.4.1, 2.4.4 and 2.4.6). However, doing so would be inconsistent with the approach taken to protecting the rights of people in vulnerable situations in other types of treatment settings, such as:

- offences for carrying out special medical procedures without the consent of the Victorian Civil and Administration Tribunal (VCAT);⁴
- offences relating to the use and storage of gametes and embryos in fertility treatments;⁵
- offences relating to female genital mutilation;⁶
- offences relating to breaches of the safeguards around voluntary assisted dying procedures;⁷
- offences relating to conversion practices;⁸ and
- offences relating to administering medical research procedures without consent or without approval.⁹

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

² <u>Marion's Case</u>, particularly at [26]-[27] per Mason CJ, Dawson, Toohey and Gaudron JJ.

³ See <u>Marion's Case</u>.

⁴ Guardianship and Administration Act 2019 (Vic), s 147.

⁵ Assisted Reproductive Treatment Act 2008 (Vic), ss 26-37.

⁶ Crimes Act 1958 (Vic), ss 32-34A.

⁷ Voluntary Assisted Dying Act 2017 (Vic), ss 83-91.

⁸ Change or Suppression (Conversion) Practices Prohibition Act 2021 (Vic), ss 10-14.

⁹ Medical Treatment Planning and Decisions Act 2016 (Vic), ss 84-85.

We have however clarified the elements of the criminal prohibitions to ensure that they are appropriately designed to capture conduct which evades the scheme or intentionally breaches it (see item 2.4.2 of Schedule C).

3. WORK LEADING TO THIS PROPOSAL

It is important to read this report in light of the work leading up to it, as documented in the following reports:

- Our <u>background paper</u> dated 31 May 2021 which contains a summary of the relevant Victorian and international human rights legal framework, the Victorian legal framework on consent to medical treatment, and examples of domestic and international oversight mechanisms (including overseas schemes regulating medical interventions on people with innate variations of sex characteristics). This background paper also drew from a paper prepared for a legal workshop that Equality Australia was commissioned to conduct by the ACT Government.
- Our <u>report</u> dated 31 April 2021 which contains the outcomes of a legal workshop commissioned by the ACT Government analysing legal issues arising from various models being explored in the ACT for implementing a prohibition on deferrable medical interventions on intersex people.
- Our <u>consultation paper</u> dated 12 July 2021 which set out the draft proposal for a legal scheme establishing a Victorian intersex oversight panel.
- Our <u>draft proposal summary</u> dated 16 July 2021 which set out a short summary of the draft proposal and ways that people could have their say through a series of online workshops, by private interview, in writing or through responding to an anonymous questionnaire.
- Our listening report dated August 2021 which set out the results of our consultation with 102 individuals and organisational representatives, and 97 survey respondents.

SCHEDULE A: THE FINAL PROPOSAL

1. INTRODUCTORY PROVISIONS

(a) Purposes and objects of the scheme

The main purposes of the legislation should be to:

- ensure that medical treatment modifying the sex characteristics of persons with innate variations of sex characteristics is performed only with the informed consent of the person receiving the treatment, except where limited exceptions apply;
- establish an oversight body to oversee care and support provided to persons with innate variations of sex characteristics, including medical treatments modifying their sex characteristics, where such persons do not have the capacity to provide personal consent to such medical treatment;
- place reporting obligations on health service providers when medical treatment modifying the sex characteristics of a person with innate variations of sex characteristics is performed without the informed consent of the person receiving the treatment;
- make consequential amendments to certain other legislation.

The objects of the legislation should be to:

- end harmful practices performed on persons with innate variations of sex characteristics by prohibiting, except in limited circumstances, medical treatment modifying a protected person's sex characteristics without their personal consent;
- further promote and protect the right of persons with innate variations of sex characteristics to bodily integrity, physical autonomy and self-determination in respect of any medical treatment that would modify their sex characteristics;
- support the provision of information to persons with innate variations of sex characteristics to empower a protected person to make fully informed decisions about any medical treatment that would modify their sex characteristics;
- support other affected persons, such as the families of persons with innate variations of sex characteristics, by ensuring oversight body processes facilitate the provision of support and information as appropriate to them; and
- further promote and protect the human rights set out in the Charter.

The intention of the Parliament in enacting this legislation should be to:

- affirm that innate variations in sex characteristics are a natural part of human diversity and do not, in and of themselves, require fixing or correcting;
- recognise that individuals have a significant and profoundly personal interest in deciding what happens to their own bodies and that this interest must be protected and given full weight in all decisions concerning medical treatment that modifies their sex characteristics;
- affirm that all persons, without discrimination against persons with innate variations in sex characteristics, are entitled to access healthcare that promotes their health and wellbeing, and supports their bodily integrity, physical autonomy and self-determination over what medical treatments (if any) are performed on their bodies; and
- denounce medical treatments modifying a protected person's sex characteristics which are justified by rationales which discriminate against persons with innate variations of sex characteristics, including by reference to assumptions about how bodies should appear or function simply in order to accord with a particular gendered norm.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

(b) Human rights principles

The legislation should clarify that nothing in it is intended to abrogate or limit the rights or freedoms, or obligations placed on public authorities, under the *Charter of Human Rights and Responsibilities Act 2006* (Vic) (the **Charter**).

The legislation should clarify that the oversight body is an entity that has functions of a public nature (and is therefore a public authority under the Charter) and that, without limitation, the following decisions do not constitute acts or decisions of a private nature under s 38(3) of the Charter:

- a decision to register or not to register an individual care plan, including with or without any amendments;
- a decision to make, revoke or amend a class exemption order.

(c) Commencement of scheme

This scheme should commence on the earlier of:

- a day (or days) to be proclaimed for any particular part of the scheme; or
- 1 year after the legislation receives Royal Assent.

(d) Definitions

The legislation should include the following definitions. Wherever these terms are used in this proposal, they also have the following meanings.

Charter means the Charter of Human Rights and Responsibilities Act 2006 (Vic).

class exemption order means an order made by the oversight body [as set out in Part [x] of this Act – see section 6 below].

guardian means a person appointed as a guardian with medical decision-making responsibilities under a guardianship order made under the *Guardianship and Administration Act 2019* (Vic).

individual care plan means a plan registered with the oversight body [as set out in Part [x] of this Act – see section 5 below].

informed consent has the meaning set out in [Part [x] of this Act - see section 3 below].

interested person means any of the following:

- (a) a protected person, with or without of the support of their supportive guardian;
- (b) any person with parental responsibility for a protected person;
- (c) any person proposing to provide medical treatment that modifies the sex characteristics of a protected person;
- (d) any person concerned with the care, welfare or development of a protected person, including a guardian, supportive guardian, medical treatment decision-maker or support person, or other carer.

medical treatment means:

- (a) a surgical or medical procedure or treatment, including:
 - (i) the administration of any drugs whether by the protected person or any other person upon the advice or recommendation of a health practitioner;
 - (ii) a dilation procedure whether administered by the protected person or any other person upon the advice or recommendation of a health practitioner;
- (b) any part of a procedure or treatment listed in paragraph (a),

but does not include a procedure or treatment involving no more than the circumcision of a protected person's penis through the removal of a foreskin covering the glans.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

medical treatment decision-maker means a person (whether appointed or not) with responsibility for making medical decisions on behalf of a person, whether under the *Medical Treatment Planning and Decisions Act 2016* (Vic) or another law.

modify means:

- (a) permanent or irreversible changes to a protected person's sex characteristics; or
- (b) changes to a protected person's sex characteristics which are reversible only with invasive medical treatment; or
- (c) changes to a protected person's sex characteristics which are caused by dilation,

and includes such changes to sex characteristics referred to in paragraphs (a)-(c) above which are intended to or likely to result even if they have not yet occurred, but does not include:

- (d) changes to a protected person's sex characteristics which are reversible by ceasing medical treatment or with non-invasive medical treatment; or
- (e) the prevention of naturally occurring changes to a protected person's sex characteristics which is reversible by ceasing medical treatment or with non-invasive medical treatment.

personal consent means the protected person receiving the medical treatment has given informed consent to that medical treatment.

protected person means:

- (a) a natural person with innate variations of sex characteristics (whether diagnosed or not) that do not conform to medical norms for male or female bodies; or
- (b) without limitation to the definition in paragraph (a), a natural person with such innate variations of sex characteristics or such innate physical conditions affecting or in close proximity to sex characteristics (whether diagnosed or not) as may be declared by the Minister for Health upon the recommendation of the oversight body.

[Note: For the purposes of paragraph (b) of the definition of 'protected person' the following variations should be declared at the commencement of the scheme:¹⁰

For the purposes of paragraph (b) of the definition of 'protected person', a natural person with the following innate variations or physical conditions (whether diagnosed or not) is declared to be a 'protected person':

- (a) 5-alpha reductase deficiency (5-ARD)
- (b) 17-beta-hydroxysteroid dehydrogenase deficiency or 17β-Hydroxysteroid dehydrogenase III deficiency
- (c) androgen insensitivity syndromes including complete, partial and mild forms
- (d) aphallia
- (e) bladder exstrophy (also known as ectopia vesicae)
- (f) clitoromegaly (also known as large clitoris)
- (g) cloacal exstrophy
- (h) congenital adrenal hyperplasia (CAH)
- (i) cryptorchidism (also known as undescended testes)
- (j) de la Chapelle syndrome (also known as XX Male Syndrome)
- (k) epispadias
- (I) Follicle-Stimulating Hormone Insensitivity (FSH)
- (m) Fraser Syndrome
- (n) gonadal dysgenesis including partial and complete forms
- (o) hypospadias

¹⁰ If this non-exhaustive list of variations and physical conditions can be drafted and introduced as a regulation at the commencement of the scheme, we would have no objection to this list being included in regulation. However, it must be clear which variations and physical conditions will be captured within the scope of the scheme at its outset, and this list should include all the variations and physical conditions currently proposed.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

- (p) Jacobs Syndrome (also known as XYY Syndrome)
- (q) Kallmann Syndrome
- (r) Leydig cell gypoplasia
- (s) Mayer-Rokitansky-Küster-Hauser Syndrome (MRKH) (also known as vaginal agenesis, Müllerian agenesis, Müllerian (duct) aplasia or congenital absence of vagina)
- (t) micropenis
- (u) mosaicism involving sex chromosomes, including XY/XO and other variations
- (v) ovo-testes (formerly known as 'true hermaphroditism')
- (w) Persistent Mullerian Duct Syndrome (PMDS)
- (x) Progestin Induced Virilisation
- (y) sex chromosome variations including:
 - (i) 47XXY or Klinefelter Syndrome, and 48XXXY or 49XXXXY variations
 - (ii) 48XXXX/XXXX Syndrome (also known as Tetrasomy X or Quadruple X)
 - (iii) 49XXXXX, XXXXX Syndrome (also known as Pentasomy X)
 - (iv) Triple-X Syndrome (also known as XXX, triple-X, trisomy X, XXX syndrome or 47XXX aneuploidy)
 - (v) Turner Syndrome (also known as Ullrich-Turner Syndrome, Gonadal Dysgenesis, 45X0 or 45X)
- (z) Swyer Syndrome (also known as XY gonadal dysgenesis)

reasonable support includes (without limitation):

- (a) the conveying of the information by another person or in another manner;
- (b) the provision of additional time;
- (c) the provision of additional assistance or support, including by another person;
- (d) the provision of aids (including palliative or therapeutic devices) or other mechanisms,

in a manner which is reasonable, and which would enable the protected person to understand, remember and use or weigh relevant information, or communicate the relevant decision or information.

sex characteristics has the same meaning as in the Equal Opportunity Act 2010 (Vic).¹¹

supportive guardian means a person appointed to support medical decision-making making under a supportive guardianship order made under the *Guardianship and Administration Act 2019* (Vic).

support person means a person appointed as a support person under the *Medical Treatment Planning and Decisions Act 2016* (Vic).

2. PROHIBITIONS AND EXCEPTIONS

(a) General prohibition

The legislation should introduce a general prohibition against the provision of medical treatment which modifies the sex characteristics of a protected person unless:

- the protected person has provided personal consent to the medical treatment (see section 3 below); or
- a permitted exception applies.

The permitted exceptions should be:

• emergency medical treatment that:

¹¹ Under the *Equality Opportunity Act 2010* (Vic), '*sex characteristics*' means a person's physical features relating to sex, including– (a) genitalia and other sexual and reproductive parts of the person's anatomy; and (b) the person's chromosomes, genes, hormones, and secondary physical features that emerge as a result of puberty. This definition is yet to commence.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

- as a matter of urgency, is necessary to save the protected person's life, prevent serious damage to the protected person's health or prevent the protected person from suffering or continuing to suffer significant pain or distress; and
- the protected person has not otherwise refused treatment;
- the medical treatment complies with an individual care plan registered by the oversight body;
- the medical treatment complies with a class exemption order made by the oversight body.

Ensure that this law takes effect notwithstanding any other law (including any statutory or common law principle regarding consent to medical treatment).

The prohibition should commence once the oversight body has been established and has had time to register any individual care plans and make any necessary class exemption orders.

(b) Criminal prohibitions

The legislation should create two separate offences:

- Offence 1: An offence is committed by a person (<u>Person A</u>) if:
 - they are medical practitioner;
 - they provide medical treatment with the intention of modifying the sex characteristics of another person (<u>Person B</u>);
 - knowing that Person B has not or could not provide personal consent; and
 - knowing or being reckless to the fact that Person B is a protected person; and
 - knowing or being reckless to the fact that no exception applies (see above).
- Offence 2: An offence is committed by a person (<u>Person A</u>) if:
 - they remove or cause to be removed from Victoria another person (Person B); and
 - they do so with the intention of obtaining medical treatment to modify the sex characteristics of Person B without Person B's personal consent; and
 - they or another person provides medical treatment that modifies the sex characteristics of Person B without Person B's personal consent; and
 - they know or are reckless to the fact that Person B is a protected person; and
 - they know or are reckless to the fact that no exception applies (see above).

The offences should have the same extraterritorial application provisions as in the *Change or Suppression* (*Conversion*) *Practices Prohibition Act 2021* (Vic).

The offences should commence 12 months after the scheme has commenced to give people the opportunity to register any individual care plans with the oversight body and for the oversight body to make any necessary class exemption orders.

3. OBTAINING PERSONAL CONSENT

Given the prohibitions will allow medical treatment which modifies the sex characteristics of a protected person with their personal consent, the legislation should clearly define the requirements and pre-conditions necessary for obtaining personal consent.

As defined above, **personal consent** means the protected person receiving the medical treatment has given **informed consent** to that medical treatment.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

(a) Defining 'informed consent'

The legislation should define **informed consent** by adapting the definitions of **informed consent** and **capacity to give informed consent** in sections 68 and 69 of the *Mental Health Act 2014* (Vic) to the specific needs of this population, as follows.

Capacity to give informed consent

To be able to provide informed consent, the legislation must first require a protected person to have the capacity to give informed consent.

A protected person should have **capacity to give informed consent** to the medical treatment proposed if the person:

- 1. understands the information they are given that is relevant to the decision; and
- 2. is able to remember the information that is relevant to the decision; and
- 3. is able to use or weigh information that is relevant to the decision; and
- 4. is able to communicate the decision made by speech, gestures or any other means.

In determining whether a protected person has capacity to give informed consent, the legislation should require the determination to be made in light of whether the person would understand the relevant information, be able to remember the relevant information, be able to use or weigh relevant information, and be able to communicate the relevant decision with the provision of reasonable support.

The following principles are intended to provide guidance to any person who is required to determine whether or not a protected person has the capacity to give informed consent under this Act–

- 1. a protected person's capacity to give informed consent is specific to the decision that the person is to make;
- 2. a protected person's capacity to give informed consent may change over time;
- 3. it should not be assumed that a protected person does not have the capacity to give informed consent based only on their age, appearance, condition or an aspect of their behaviour;
- 4. a determination that a protected person does not have capacity to give informed consent should not be made only because the person makes a decision that could be considered to be unwise;
- 5. when assessing a protected person's capacity to give informed consent, reasonable steps should be taken to conduct the assessment at a time at, and in an environment in, which the person's capacity to give informed consent can be assessed most accurately.

Informed consent

For the purposes of determining whether a protected person has given personal consent to medical treatment which modifies their sex characteristics, the protected person receiving the medical treatment will have given **informed consent** to that medical treatment if the person–

- 1. has the capacity to give informed consent to the medical treatment proposed; and
- 2. has been given adequate information to enable the protected person to make an informed decision; and
- 3. has been given a reasonable opportunity to make the decision; and
- 4. has given consent freely without undue pressure or coercion by any other person; and
- 5. has not withdrawn consent or indicated any intention to withdraw consent.

For the purposes of principle 2 above, a protected person will have been given adequate information to make an informed decision if the person has been given—

- 1. affirming, clearly understandable and factually objective information about the nature of their innate variation of sex characteristics, including:
 - a. that it is a naturally occurring innate variation of sex characteristics;
 - b. if known, the approximate number of people who have that particular innate variation of sex characteristics;
 - c. how that innate variation of sex characteristics manifests physically, including over time; and

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

- 2. a prescribed list of peer support organisations and contacts for psychological support made by the Minister for Health after consultation with the Minister for Equality; and
- 3. the option of having no medical treatment at all or at the present time, and an explanation of the advantages and disadvantages of this option; and
- 4. an explanation of the proposed medical treatment including
 - a. the purpose of the medical treatment; and
 - b. the type, method and likely duration of the medical treatment; and
 - c. an explanation of the advantages and disadvantages of the medical treatment, including information about the associated discomfort, risks and common or expected side effects of the medical treatment; and
 - d. an explanation of any beneficial alternative treatments that are reasonably available, including any information about the advantages and disadvantages of these alternatives; and
 - e. answers to any relevant questions that the protected person has asked; and
 - f. any other relevant information that is likely to influence the decision of the protected person; and
 - g. in the case of proposed medical treatment, a statement of rights relevant to the protected person's situation.

For the purposes of principle 3 above, a protected person has been given a reasonable opportunity to make a decision if, in the circumstances, the person has been given—

- 1. a reasonable period of time in which to consider the matters involved in the decision, including a cooling off period appropriate to the proposed medical treatment; and
- 2. a reasonable opportunity to discuss those matters with the registered medical practitioner who is proposing the medical treatment, including the option to do so with or without the assistance or presence of another person; and
- a reasonable opportunity to discuss those matters with a different health professional to the one
 proposing the medical treatment, including the option to do so with or without the assistance or presence
 of another person; and
- 4. a reasonable amount of support to make the decision; and
- 5. a reasonable opportunity to obtain any other advice or assistance in relation to the decision.

(b) Recording of personal consent

A health professional who has obtained the personal consent of a protected person must maintain written records of all the information provided to the protected person in order to comply with this section and treat those records in accordance with the Health Privacy Principles set out in the *Health Records Act 2001* (Vic).

4. OVERSIGHT BODY

(a) Establishment of oversight body

The legislation should establish an oversight body exercising administrative (not judicial) powers.

The oversight body should have an oversight panel for making decisions (as set out below), as well as a secretariat supporting the work of the panel.

Appointment of pool of panel members

The Minister for Health, after consulting with the Minister for Equality, should have the power to appoint:

- a Chair and deputy Chair who are former judicial officers or senior lawyers of at least 10 years' standing;
- a pool of panel members that the Minister for Health is satisfied, after an open application process, have the knowledge, experience or skills relevant to their role.

The Minister for Health must appoint a minimum of 10 panel members to the pool, having regard to:

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

- the need to ensure a reasonable diversity of gender, clinical expertise and lived experience; and
- the proper functioning of the oversight body, including in the event that a full panel decision is remitted by a court on appeal for reconsideration by a differently constituted full panel.

The panel members should be appointed into one or more of the following categories:

- Health professional member, being health professionals with expertise in medicine, psychology, bioethics or other allied health areas relevant to the care of people with innate variations of sex characteristics;
- Community representative panel member, being persons with innate variations of sex characteristics and the family members of persons with innate variations of sex characteristics;
- Other specialist panel member, being experts in human rights, children's rights or the rights of people with disability.

The panel members should be appointed for a term of 3 years and can be reappointed for further terms of 3 years.

The panel members' tenure should be terminable by the Minister for Health or by resignation.

The panel members should be remunerated for work they perform as members of the oversight panel, including any professional development required of their role.

The panel members should be subject to a limitation on personal liability in connection with their functions.

The Chair

The Chair should have the power to conduct meetings of the panel.

The Chair should have powers to establish rules governing the process and procedures of the panel, subject to the requirements of the legislation.

The Chair should have day-to-day responsibility for the proper management of the oversight body, including ensuring policies, procedures, guidelines and a complaints system are in place.

The Chair should be able to receive and resolve complaints from members of the public regarding the failure of a panel member to comply with their obligations, subject to the Minister for Health having the final decision on termination. Any complaints regarding the Chair should be received and resolved by the Minister for Health.

The Chair should be able to delegate their role to the deputy Chair in the event that they are unable to perform their role, including because they have to disqualify themselves from sitting as a panel member in a particular matter. Wherever reference is made to the 'Chair' in this document, this should be taken to mean the deputy Chair where the Chair has delegated their role to the deputy Chair.

Panel members' obligations

The Chair, deputy Chair and panel members should be required to:

- act with integrity, impartially, respectfully, fairly and accountability when performing their roles;¹²
- maintain relevant professional registrations, accreditations or qualifications necessary for their role;
- attend such training and development as requested by the Chair from time to time;
- declare any actual or perceived conflicts of interests;
- disqualify themselves from sitting as a panel member in respect of any matter in which there is any actual or apprehended bias.

¹² In a manner similar to the public sector values in s 7 of the *Public Administration Act 2004* (Vic).

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

Full panel of the oversight body

The Chair must constitute a panel of 5 panel members (the **full panel**) drawn from the pool of eligible panel members to make a decision on behalf of the oversight body, including:

- a decision to register or not to register an individual care plan, including with or without any amendments;
- a decision to make, revoke or amend a class exemption order.

The full panel must always comprise either the Chair or deputy Chair, and one panel member belonging to each of the three categories of panel members.

In constituting a full panel, the Chair must have regard to ensuring a reasonable diversity of gender and relevant clinical expertise and lived experience on the full panel.

Decisions of the full panel should aim to reach consensus, but failing consensus, require the agreement of a majority of its members.

Three-member sub panel

The Chair should have the power to establish a sub panel to decide whether or not to register an individual care plan, including with or without amendment.

A sub-panel must be comprised of 3 members, being either the Chair or deputy Chair, and at least one health professional and one community member.

In constituting a sub panel, the Chair must have regard to ensuring a reasonable diversity of gender and relevant clinical expertise and lived experience on the sub panel.

All decisions of a sub-panel must be made by consensus. If the sub-panel fails to reach a consensus, the matter must be referred to a differently constituted full panel of the oversight body for a decision.

All decisions of a sub panel should also be open to internal review by a differently constituted full panel of the oversight body.

(b) Functions and powers of the oversight body

The oversight body should be given the following functions and powers:

- to register or amend individual care plans;
- to consider and make, where appropriate, class exemption orders;
- to receive and consider reports from health professionals when exemptions are relied upon;
- to receive reports of possible contraventions of the prohibitions and refer them to relevant bodies (e.g. state and territory law enforcement bodies, Victorian Health Complaints Commissioner, Victorian Ombudsman, Australian Health Practitioner Regulatory Agency, Victorian Equal Opportunity and Human Rights Commission);
- to promote compliance with the scheme by the provision of information to protected persons, their family members, guardians, support persons or carers, health professionals and members of the general public;
- to issue guidance on the interpretation and operation of the scheme, including the interpretation of the prohibitions;
- to conduct analysis of, and carry out research in relation to, the operation of the scheme;
- to provide advice to the Minister for Health, Minister for Equality or Secretary of the Department of Health or department responsible for Equality in relation to the operation of the scheme;
- to provide reports to the Minister for Health, Minister for Equality or Secretary of the Department of Health or department responsible for Equality in respect of any matter relevant to the functions of the oversight body as requested; and

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

• such powers that are necessary or convenient to perform its functions.

The oversight body should be required to publish an annual report on the operation of the Act every financial year, no more than 3 months from the end of each financial year.¹³ Without limitation to information which can be included in the report and subject to the confidentiality requirements, the report should be made public and include information on:

- the number of applications received by the oversight body for the registration or amendment of an individual care plan including by type of variation and the age range of protected persons at the time of application;
- trends in the outcomes of applications for the registration or amendment of an individual care plan including by:
 - type of variation;
 - the age range of protected persons at the time of application; and
 - the types of medical treatment sought and/or permitted (with non-identifying particulars on any procedures permitted by the oversight body in respect of particular classes of protected persons);
- the number and type of class exemption orders considered or made by the oversight body.

(c) How the oversight body must make decisions

In making decisions under this legislative scheme, the oversight body:

- must comply with the requirements set down by the legislation and in other laws, including the Charter, and having regard to the objects and purposes of this legislation;
- must act fairly and according to the substantial merits of the case in all matters;
- must comply with the rules of natural justice;
- is not bound by the rules of evidence or any practices or procedures applicable to courts of record, except to the extent the Chair adopts those rules, practices or procedures;
- may inform itself on any matter as it sees fit, including by reference to previous decisions or matters which have come before the panel;
- must conduct the hearing of any matter with as little formality and technicality as possible, and determine each matter with as much speed, as the requirement of this Act and a proper consideration of the matters before it permit.¹⁴

These principles apply (without limitation) to:

- a decision to register or not to register an individual care plan, including with or without any amendments; and
- a decision to make, revoke or amend a class exemption order.

5. INDIVIDUAL CARE PLANS

The legislation should make provision for the preparation, registration and amendment of individual care plans in respect of protected persons who do not have capacity to provide personal consent to medical treatment which would modify their sex characteristics. An individual care plan can allow medical treatment modifying a protected person's sex characteristics without personal consent if it complies with this section.

¹³ Modelled on s 107 of the Voluntary Assisted Dying Act 2017 (Vic).

¹⁴ Modelled on s 98 of the Victorian Civil and Administrative Tribunal Act 1998 (Vic).

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

(a) What is an individual care plan?

The legislation should clarify the matters which can be included in an individual care plan including:

- the name of the protected person, where they live, who they live with and who is responsible for making decisions regarding their care (including any medical decision-maker);
- referrals to peer support that will be provided or arranged for the protected person, and by whom and when;
- referrals to psychological support or counselling that will be provided or arranged for the protected person, and by whom and when;
- the information that will be provided to the protected person regarding their variation and any medical treatment associated with it, and by whom and when;
- any medical treatment which modifies that sex characteristics of the protected person that may be provided without personal consent, and any conditions on how and when it may be performed or provided including by whom;
- any medical treatment that is ancillary or incidental to the above, including any selfadministered treatment or care that follows any medical treatment;
- any medical treatment in connection with the protected person's variation for the purposes of diagnosis or monitoring;
- any records which must be retained in respect of any such medical treatment and how and when it will be provided or made available to the protected person;
- any reports which must be made to the oversight body regarding matters contained in the plan, and by whom and when;
- the term of the individual care plan and/or the time or circumstances in which the plan ceases to have effect or must be reviewed by the oversight body.

(b) Eligibility to apply

The legislation should allow an interested person to apply to the oversight body to register or amend an individual care plan in respect of a protected person if:

- medical treatment is proposed which would modify the sex characteristics of the protected person; and
- the protected person does not have capacity to provide informed consent.

(c) Preparing an application for an individual care plan

The application to register or amend an individual care plan should be made in a form prescribed by the regulations.

The regulations could require the application form to seek information on the following details:

- details regarding the protected person who is the subject of the application, including their age, particular variation, names and contact details of all persons with parental or other responsibility for their care and wellbeing and the names and contact details of the medical team overseeing their healthcare;
- details, to be completed by their health professional, of any proposed medical treatment that would modify the sex characteristics of the protected person, including:
 - full particulars of the treatment proposed;
 - who will be performing the treatment;
 - when the treatment is proposed to be performed;
 - reasons for why the treatment is proposed;

- any alternative treatments which have been considered and any reasons why they have been rejected;
- what information has been provided to the protected person, and/or persons with parental or other responsibility for the care and wellbeing of the protected person, regarding the risks and benefits of the proposed treatment and risks and benefits of any alternative treatment which has been considered by rejected; and
- any relevant medical history of the person, including past treatments whether undertaken in Victoria or elsewhere (to the extent known);
- details of what psychological and peer support before or after the treatment has been offered to the protected person;
- details of any existing individual care plan;
- details of any steps taken to ascertain whether the protected person the subject of the application is capable of providing personal consent (if relevant);
- details of any facts or circumstances which might suggest that the protected person the subject of the application does not or would not consent to the medical treatment (if relevant).

The legislation should require that the application form be completed by way of statutory declaration (such that there is a penalty for providing false or misleading information).

The legislation should require those completing the form or providing information to the panel (including any independent advocate) to provide full and frank disclosure of any matters regarding the application (including the protected person and proposed treatment) which might be relevant to the oversight body's consideration of the application. There should be a penalty for failures to comply with this duty.

The application process should be free.

An independent advocate should also have a duty to act:

- if the protected person is under 18 years of age: in the best interests of the protected person informed by the protected person's own views to the extent they can be expressed with reasonable support;
- if the protected person is 18 years or older: in the interests of the protected person and faithfully with their will and preferences, or the best ascertainment of their will and preferences, as can be expressed or ascertained with reasonable support.

(d) Processing an application to register or amend an individual care plan

Once an application has been made, the oversight body should have powers to:

- review the application and confirm its eligibility and, if eligible, must offer to the affected persons, including the protected person, such referrals to peer support and counselling as may be appropriate;
- appoint an independent advocate for the protected person whose role is to facilitate the
 expression of views from the protected person where they can be obtained directly (including
 with reasonable support), and provide assistance to the oversight panel in considering matters
 which cannot be or are not raised directly by the protected person;
- request further information from persons connected to the application if it may assist the oversight panel in considering the matter;
- if it may assist the oversight panel in considering the matter, arrange for independent consultants (such as a psychologist) with relevant expertise to do any or all of the following:
 - prepare a draft individual care plan or amendments to an existing individual care plan in consultation with the protected person, affected persons and any independent advocate;

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

- meet with the protected person who is the subject of the application and prepare a report containing, where relevant:
 - their views on the application and/or draft individual care plan;
 - the opinion of the expert as to the protected person's capacity to provide personal consent, including any support which could be provided to enable the person to provide personal consent;
- meet with persons with parental or similar responsibility for the care and wellbeing of the protected person and prepare a report containing, where relevant:
 - their views on the application and/or draft individual care plan;
 - the extent of information provided to them about the medical treatment proposed in the application, including the risks and benefits of the proposed treatment and any alternatives;
- meet with the health professionals responsible for the healthcare of the protected person and prepare a report containing their views on the application and/or draft individual care plan;
- prepare evidence on areas of medical or other research;
- prepare evidence derived from past decisions of the oversight panel;
- obtain the opinion of other specialists, experts or people with lived experience and ask them to provide any recommendations on the matters sought by the oversight panel;
- convene a meeting which must be held in private with the protected person, affected persons and any independent advocate to seek and obtain their views on the application and/or draft individual care plan.

The material before the panel should be made available to all relevant parties, including (as relevant) the protected person, their independent advocate, persons with parental or other responsibility for the person, and their health professionals.

(e) Consideration of the application by the oversight panel

The Chair must provide a reasonable opportunity for the protected person the subject of the application (or their independent advocate) and any affected persons to address the panel at any meeting or provide their views in writing, if they wish, prior to a decision of the oversight panel.

Parties may be legally represented in any matter before the oversight panel only with leave of the Chair (at their own cost).

The Chair may otherwise make such other rules and procedures regulating these meetings, which does not contradict these principles or the oversight panel's obligations, as they deem necessary.

(f) Making the decision

The oversight panel must make a decision as expeditiously as practicable to:

- register an individual care plan, with or without any amendments;
- refuse to register or amend an individual care plan.

The oversight panel (or sub-panel) must not make a decision to register or amend an individual care plan allowing medical treatment that modifies a protected person's sex characteristics without their personal consent unless it is satisfied that:

- the person is a protected person; and
- the protected person does not have capacity to provide personal consent to the proposed treatment that modifies their sex characteristics and which would be allowed by the individual

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

care plan; and

- to the extent that the protected person can express any views regarding the individual care plan, they have been given an opportunity, with reasonable support, to express those views and those views have been considered by the oversight panel; and
- if the person is aged under 18, to the extent that persons with parental responsibility wish to express any views regarding the proposed individual care plan, those persons have been given an opportunity, with reasonable support, to express their views and those views have been considered by the oversight panel; and
- either:
 - if the protected person is aged under 18: having regard to the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing), their best interests are better served by the medical treatment proceeding without their personal consent over deferring the treatment to realise their significant and profoundly personal interest in deciding what happens to their own body; and
 - if the protected person is aged 18 year or over: that it is consistent with their will and preferences, or to the extent that those will and preferences cannot be fully expressed, that is consistent with the best ascertainment of what the protected person's will and preferences would likely be, and which does not override the person's will and preferences unless it is necessary to do so to prevent serious harm.

In having regard to the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing), the following considerations must be taken into account by the oversight panel (or sub panel):

- the significant and profoundly personal interest of a person in being able to decide what happens to their own body, and the extent to which that interest may be realised through:
 - the option of deferring medical treatment that modifies a protected person's sex characteristics to preserve any expected ability of the protected person to provide personal consent in future; or
 - the option of allowing medical treatment that preserves options for the protected person in the future;
- the likely benefits and risks of the proposed medical treatment to the protected person's health;
- any likely adverse consequences to the protected person's health of the proposed medical treatment not being provided;
- any alternatives to the medical treatment being proposed, and the likely benefits and risks of those alternatives.

In having regard to the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing), the oversight panel (or sub-panel) must not presume that a person with innate variations of sex characteristics would experience any social or psychosocial benefits from having their sex characteristics function or appear in a manner which conforms with norms for persons without that variation unless:

- the protected person has themselves provided direct and compelling evidence to support the rebuttal of this presumption;
- if the protected person has not provided direct and compelling evidence, any other evidence relied upon;
 - is specific to the protected person and is not otherwise speculative or general in nature; and
 - has substantial probative value.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

(g) Provision of reasons

The panel must provide written reasons for its decision, which must be made available to the parties upon request. If the panel decides to register an individual care plan, the reasons for its decision must also be held on the register with the individual care plan.

The panel may publicly publish its reasons, or a summary of its reasons, provided that no information which may identify the protected person or any person connected to the protected person is included in the published reasons.

(h) Appeals

Decisions of a sub panel can be appealed on its merits to a differently constituted full panel of the oversight body. In which case, the process for considering the application above is repeated by the full panel, which may reconsider the matter and make a fresh decision considering any evidence before the sub panel and any additional evidence or submissions.

Decisions of the full panel of the oversight body can be appealed on judicial review (including for contraventions of the Charter).

(i) Maintenance and access to the register

Individual care plans that are registered by the oversight body should be held on a register maintained by the oversight body, along with the reasons for the oversight body's decision to register an individual care plan.

Information held about a protected person on the register (including the individual care plan and oversight body's decision and reasons) should be stored and made available for access in accordance with the Health Privacy Principles in the *Health Records Act 2001* (Vic).

(j) Legal effect of a registered individual care plan

An individual care plan which has been registered by the oversight body, and which has not otherwise expired or ceased to have effect, operates according to its terms as if it were an order of an administrative tribunal.

That is, to the extent that it compels or authorises such acts to be done, or compels or grants authority to another person (such as medical decision-maker or person with parental responsibility) to authorise such acts to be done:

- it requires such as actions as set out in its terms;
- it grants such authorisations as sets out in its terms (including the power to sign and do anything that is necessary to give effect to any power or duty vested in the person); and
- it constrains such power or authority according to its terms.

Acts done or consents given by a person in compliance with a registered individual care plan should have effect as if it were done or given by the protected person themselves, as if the protected person had the capacity to do those things or give such consents for themselves.¹⁵

6. CLASS EXEMPTION ORDERS

(a) Power to make class exemption orders

Subject to the requirements of the legislation, the oversight panel should have power to make orders exempting a class of medical treatment from the prohibitions (such that a person with parental responsibility or other medical decision-maker can consent to treatment in accordance with their powers, duties and responsibilities under law, and without further authorisation from the oversight body, when a person cannot provide personal consent).

¹⁵ Modelled on ss 38(3) and 142 of the *Guardianship and Administration Act 2019* (Vic).

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

The oversight body should only have the power to make class exemption orders where, having regard to the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing), the best interests of any protected person who meets the conditions specified in the class exemption order would be better served by the medical treatment proceeding (with the consent of a medical-decision maker and on any conditions specified by the oversight body) over deferring the treatment to realise a person's significant and profoundly personal interest in deciding what happens to their own body.

In having regard to the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing), the following considerations must be taken into account by the oversight panel:

- the significant and profoundly personal interest of a person in being able to decide what happens to their own body, and the extent to which that interest may be realised through:
 - the option of deferring medical treatment that modifies a protected person's sex characteristics to preserve any expected ability of the protected person to provide personal consent in future; or
 - the option of allowing medical treatment that preserves options for the protected person in the future;
- the likely benefits and risks of the proposed medical treatment to the protected person's health;
- any likely adverse consequences to the protected person's health of the proposed medical treatment not being provided;
- any alternatives to the medical treatment being proposed, and the likely benefits and risks of those alternatives.

In having regard to the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing), the oversight panel must not presume that a person with innate variations of sex characteristics would experience any social or psychosocial benefits from having their sex characteristics function or appear in a manner which conforms with norms for persons without that variation without evidence which has substantial probative value when weighed against the principle that a person has a significant and profoundly personal interest in deciding what happens to their own body.

A class exemption order can be made subject to any conditions or limitations that the oversight body thinks appropriate, including (without limitation):

- ensuring that, to the extent the views of the protected person receiving the treatment can be expressed with reasonable support, they do not object to the treatment; and
- placing an obligation on a person to report to the oversight body any reliance on the exemption, including the age of the protected person receiving the treatment, the type of treatment performed and reasons for the treatment.

Clarify that a class exemption order can be made in respect of any medical treatment that may have an ancillary or incidental effect on a protected person's sex characteristics. Example: a class exemption order regarding the closure of a bladder in the case of bladder exstrophy.

The legislation should ensure that class exemption orders are not legislative instruments.

(b) The process for making class exemption orders

Before making, amending or repealing a class exemption order, the legislation should require the oversight body to:

- consult with the Minister for Health and Minister for Equality;
- publish for public consultation any draft class exemption order or proposal to repeal an order, and its reasons for proposing the order or repeal, and take into account such feedback as may be provided to the oversight body; and
- publish any final class exemption order or repeal notice before it takes effect.

The oversight body should also have the power to obtain the opinion of other specialists or experts in forming its views on any draft class exemption order or repeal, and hold hearings to inform itself of any relevant matters as it thinks fit.

Each class exemption order should be subject to a 5-year sunset period, requiring a review by the oversight panel to repeal, amend or renew the order for further periods of 5 years. Reviews should follow the consultation process set out above.

(c) Challenging a class exemption order

A class exemption order or decision to repeal an order should be subject to judicial review (including for contraventions of the Charter).

7. MANDATORY REPORTING OBLIGATIONS

(a) Obligations to report

The legislation should require a health service provider to make a report to the oversight body, in a form prescribed by the oversight body, where it provides medical treatment without personal consent to a protected person that modifies their sex characteristics.¹⁶

The report should require the following details to be included:

- the age of the protected person;
- the type of variation;
- treatment provided;
- reasons for treatment;
- alternatives to treatment considered and reasons they were rejected;
- whether the treatment was provided in accordance with the:
 - statutory emergency exception;
 - a registered individual care plan; or
 - a class exemption order.

Failure to make a report should be an offence and also be subject to professional disciplinary consequences.

(b) Protection for complying with reporting obligation in good faith

A disclosure to the oversight body by any person in good faith under this obligation should not:

- constitute unprofessional conduct or a breach of professional ethics on the part of the discloser (such as a breach of confidentiality); or
- make the discloser subject to any liability in respect of the disclosure.¹⁷

8. CONFIDENTIALITY

(a) Confidentiality

The legislation should make it an offence for anyone, including the oversight body, to disclose (other than with the affected person's consent) any information that would identify a person connected to any medical treatment or proposed medical treatment, including:

¹⁶ This proposal is broadly modelled on s 184 of the *Children, Youth and Families Act 2005* (Vic).

¹⁷ This proposal is broadly modelled on s 189 of the *Children, Youth and Families Act 2005* (Vic).

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

- any protected person in respect of whom an application or report is made;
- any person related to the protected person (such as family members); and
- treating health professionals related to that treatment.

The legislation should provide an avenue for the oversight body to lawfully disclose information to relevant law enforcement bodies, courts or tribunals, as required by law or when necessary for its work. The Minister for Health should be allowed to prescribe law enforcement bodies in other states and territories.

The legislation should provide an avenue for the oversight body to lawfully disclose information when it is urgent and necessary to save life, prevent serious damage to the person's health, or prevent the person from suffering or continuing to suffer significant pain or distress, and it would not be appropriate or practicable to obtain consent from the person prior to the disclosure.

The legislation should allow the oversight body to publish its decisions, subject to such directions as the Chair determines are necessary to preserve personal privacy.

9. INTERACTION WITH OTHER LAWS AND SYSTEMS

The legislation should make consequential amendments to other Victorian legislation such that the oversight scheme's jurisdiction and process is prioritised for decisions involving medical treatment modifying a protected person's sex characteristics without their personal consent.

The laws which need to be amended include:

- *Medical Treatment Planning and Decisions Act 2016* (Vic) to ensure that a protected person's medical treatment decision maker (including any appointed medical treatment decision maker), any health professional or Public Advocate cannot consent to medical treatment modifying a protected person's sex characteristics other than in accordance with this scheme.
- *Guardianship and Administration Act 2019* (Vic) to ensure that a guardian cannot consent to medical treatment modifying a protected person's sex characteristics other than in accordance with this scheme.
- *Children, Youth and Families Act 2005* (Vic) to ensure a person granted parental responsibility for a child cannot consent to medical treatment modifying a protected person's sex characteristics other than in accordance with this scheme.
- Historical medical decision-making, guardianship and child protection legislation which preceded the above the legislation and which remains in effect, including a medical power of attorney under the *Medical Treatment Act 1988* (Vic), an enduring guardian under the *Guardianship and Administration Act 1986* (Vic) and an enduring attorney for personal matters with powers to make decisions about healthcare or medical treatment under the *Powers of Attorney Act 2014* (Vic) between 1 September 2015 and 11 March 2018.

The laws should keep in place the right of a protected person to make an advanced care directive and preserve for a person the right to recover the ability to provide consent within a reasonable time under s 59 of the *Medical Treatment Planning and Decisions Act 2016* (Vic).

The laws should also clarify the effect of the *Limitations of Actions Act 1958* (Vic) on the date of discoverability for actions for personal injury, by either excluding knowledge held by the parents from being imputed to their child, allowing a child to bring an action without any time limit in respect of medical treatment modifying their sex characteristics or allowing a reasonable time after a child becomes an adult and becomes aware that they received medical treatment modifying their sex characteristics.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

The legislation should also make consequential amendments to other Victorian legislation to ensure consistency with this scheme, including to the extent necessary with the:

- the *Health Complaints Act 2016* (Vic), to ensure the Health Complaints Commissioner can receive complaints referred to it from the oversight body, and consider complaints in respect of the breach of the civil prohibitions; and
- the *Health Records Act 2001* (Vic), *Privacy and Data Protection Act 2014* (Vic) and *Freedom of Information Act 1982* (Vic), to ensure the confidentiality settings in this scheme are reflected appropriately in legislation which protects personal privacy or allows the disclosure of information to the public.

A further audit of laws may be necessary to ensure that any public, complaints or law enforcement body receiving a referral from the oversight body has the power to deal with the issue in a manner which is consistent with the settings (including the confidentiality settings) set out in this legislation.

10. STATUTORY REVIEW

The legislation should require a review and report on the operation and effectiveness of the scheme 5 years after its operation.

Among the things to be considered should include:

- the scope of medical treatment regulated by the scheme;
- the operation and efficacy of the oversight body and its processes;
- the operation and effectiveness of the legal framework for regulating medical treatment modifying a protected person's sex characteristics;
- whether, and to what extent, it would be appropriate or desirable to recognise corresponding laws elsewhere in Australia or harmonise this scheme with corresponding laws elsewhere in Australia;
- whether, and to what extent, the legislation has achieved its objects and purposes.

SCHEDULE B: THE FINAL PROPOSAL -ANNOTATED WITH AMENDMENTS AND CONSULTATION FEEDBACK

This is an annotated version of the final proposal. It shows the key amendments made to the final proposal from the draft proposal published in the consultation paper, with annotations to consultation feedback contained in the items in Schedule C. Underlined text is new, while struck-through text has been deleted. Underlined text in green has been moved from elsewhere in the draft proposal but is not new in substance.

1. INTRODUCTORY PROVISIONS

(a) Purposes and objects of the scheme

The main purposes of the legislation should be to:

- <u>ensure that medical treatment modifying the sex characteristics of persons with innate</u> <u>variations of sex characteristics is performed only with the informed consent of the person</u> <u>receiving the treatment, except where limited exceptions apply;</u>
- establish an oversight body to oversee care and support provided to persons with innate variations of sex characteristics, including medical treatments modifying their sex characteristics, where such persons do not have the capacity to provide personal consent to such medical treatment;
- <u>place reporting obligations on health service providers when medical treatment modifying the</u> <u>sex characteristics of a person with innate variations of sex characteristics is performed without</u> <u>the informed consent of the person receiving the treatment;</u>
- end harmful practices on people with innate variations of sex characteristics through prohibitions on medical treatment modifying their sex characteristics without personal consent, except in limited circumstances;
- establish oversight and transparency mechanisms that will:
 - ensure that any medical treatment modifying a person's sex characteristics which is deferrable without causing or being likely to cause harm to the health of a person is deferred until the person receiving the treatment is able to make a decision for themselves as to any medical treatment they wish to personally consent to;
 - ensure that any medical treatments modifying a person's sex characteristics
 performed without personal consent are done so in accordance with individual care
 plans that protect the rights of individuals and support decision-making by the person
 and their parents or guardians to the extent possible; and
- make consequential amendments to certain other legislation.

The objects of the legislation should be to:

- end harmful practices performed on <u>people persons</u> with innate variations of sex characteristics by prohibiting, except in limited circumstances, medical <u>interventions treatment</u> modifying a <u>protected</u> person's sex characteristics without their personal consent;
- further promote and protect the right of persons with innate variations of sex characteristics to bodily integrity, physical autonomy and self-determination in respect of any medical treatment that would modify their sex characteristics;
- support the provision of information to people persons with innate variations of sex characteristics and their families to empower a protected person to make fully informed decisions about any medical treatment that would modify their sex characteristics;

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

- <u>support other affected persons, such as the families of persons with innate variations of sex</u> <u>characteristics, by ensuring oversight body processes facilitate the provision of support and</u> <u>information as appropriate to them</u>;¹⁸ and
- further promote and protect the <u>human</u> rights set out in the Charter of Human Rights and Responsibilities.

The intention of the Parliament in enacting this legislation should be to:

- affirm that innate variations in sex characteristics are a natural part of human diversity and do not, in and of themselves, require fixing or correcting;
- recognise that individuals have a significant and profoundly personal interest in deciding what happens to their own bodies and that this interest must be protected and given full weight in all decisions concerning medical treatment that modifies their sex characteristics.¹⁹
- affirm that all persons, without discrimination against persons with innate variations in sex characteristics, are entitled to access healthcare that promotes <u>their health and wellbeing</u>, and supports their bodily integrity, physical autonomy and self-determination over what medical treatments (if any) are performed on their bodies; and
- denounce medical treatments modifying a <u>protected</u> person's sex characteristics which are justified by rationales which discriminate against <u>people</u> <u>persons</u> with innate variations of sex characteristics, including by reference to assumptions about how bodies should appear or function simply in order to accord with a particular gendered norm.²⁰

(b) Human rights principles

The legislation should clarify that nothing in it is intended to abrogate or limit the rights or freedoms, or obligations placed on public authorities, under the *Charter of Human Rights and Responsibilities Act 2006* (Vic) (the **Charter**).

The legislation should clarify that the oversight body is an entity that has functions of a public nature (and is therefore a public authority under the Charter) and that, without limitation, the following decisions do not constitute acts or decisions of a private nature under s 38(3) of the Charter:

- a decision to register or not to register an individual care plan, including with or without any amendments;
- a decision to make, revoke or amend a class exemption order.

(c) Commencement of scheme

This scheme should commence on the earlier of:

- a day (or days) to be proclaimed for any particular part of the scheme; or
- 1 year after the legislation receives Royal Assent.

(d) Definitions

The legislation should include the following definitions. Wherever these terms are used in this proposal, they also have the following meanings.

Charter means the Charter of Human Rights and Responsibilities Act 2006 (Vic).

class exemption order means an order made by the oversight body [as set out in Part [x] of this Act – see section 6 below].

¹⁸ See items 4.1.1(a), 4.1.1(f), 4.1.1(g), 4.1.2(g) and 6.3.2(a).

¹⁹ See items 1.3 and 6.3.3(a).

²⁰ See item 1.1.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

guardian means a person appointed as a guardian with medical decision-making responsibilities under a guardianship order made under the *Guardianship and Administration Act 2019* (Vic).

individual care plan means a plan prepared and ²¹ registered with the oversight body [as set out in Part [x] of this Act – see section 5 below].

informed consent has the same meaning set out in [Part [x] of this Act – see section 3 below] as section 69(1) of the *Mental Health Act 2014* (Vic), but using gender inclusive language.

interested person means any of the following:

- (a) a protected person, with or without of the support of their supportive guardian;
- (b) any person with parental responsibility for a protected person;
- (c) any person proposing to provide medical treatment that modifies the sex characteristics of a protected person;
- (d) any person concerned with the care, welfare or development of a protected person, including a guardian, supportive guardian, medical treatment decision-maker or support person, or other carer.

medical treatment means:²²

- (a) any <u>a</u> surgical or medical procedure or treatment, including:
 - (i) the administration of any drugs whether by the protected person or any other person upon the advice or recommendation of a health practitioner;
 - (ii) a dilation procedure whether administered by the protected person or any other person upon the advice or recommendation of a health practitioner; 23
- (b) any part of a procedure or treatment <u>listed in paragraph (a), 24 </u>

but does not include a procedure or treatment involving no more than the circumcision of a protected person's penis through the removal of a foreskin covering the glans.²⁵

medical treatment decision-maker means a person (whether appointed or not) with responsibility for making medical decisions on behalf of a person, whether under the *Medical Treatment Planning and Decisions Act 2016* (Vic) or another law.²⁶

modify means:

- (a) permanent or irreversible changes to a protected person's sex characteristics; or
- (b) changes to a <u>protected</u> person's sex characteristics which are reversible only with invasive medical treatment; <u>or</u>
- (c) changes to a protected person's sex characteristics which are caused by dilation,²⁷

and includes such changes to sex characteristics referred to in paragraphs (a)-(c) above which are intended to or likely to result even if they have not yet occurred, but does not include:

- (d) changes to a <u>protected</u> person's sex characteristics which are reversible by ceasing medical treatment or with non-invasive medical treatment; or
- (e) the prevention of naturally occurring changes to a <u>protected</u> person's sex characteristics which is reversible by ceasing medical treatment or with non-invasive medical treatment.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

²¹ See items 7.2.1 and 7.2.2.

²² Cf see item 2.3.

²³ See item 2.2.2.

²⁴ See item 2.2.3.

²⁵ See items 3.2.1 and 3.2.2.

²⁶ See item 10.3.

²⁷ See item 2.2.2.

personal consent means the <u>protected</u> person receiving the medical treatment has given informed consent to that medical treatment.

protected person means:

- (a) a natural person with innate²⁸ variations of sex characteristics <u>(whether diagnosed or not)</u> that do not conform²⁹ to medical norms for male or female bodies; or
- (b) without limitation to the definition in paragraph (a), a natural person with <u>such other</u> innate variations of sex characteristics <u>or such innate physical conditions affecting or in close</u> <u>proximity to sex characteristics (whether diagnosed or not)</u> as may be declared by the Minister <u>for Health</u> upon the recommendation of the oversight body.³⁰

[Note: For the purposes of paragraph (b) of the definition of 'protected person' the following variations should be declared at the commencement of the scheme:³¹

For the purposes of paragraph (b) of the definition of 'protected person', a natural person with the following innate variations or physical conditions (whether diagnosed or not) is declared to be a 'protected person':³²

- (a) <u>5-alpha reductase deficiency (5-ARD)</u>
- (b) 17-beta-hydroxysteroid dehydrogenase deficiency or 17β-Hydroxysteroid dehydrogenase III deficiency
- (c) androgen insensitivity syndromes including complete, partial and mild forms³³
- (d) aphallia³⁴
- (e) bladder exstrophy (also known as ectopia vesicae)³⁵
- (f) clitoromegaly (also known as large clitoris)³⁶
- (g) cloacal exstrophy
- (h) congenital adrenal hyperplasia (CAH)³⁷
- (i) cryptorchidism (also known as undescended testes)³⁸
- (j) de la Chapelle syndrome (also known as XX Male Syndrome)
- (k) epispadias
- (I) Follicle-Stimulating Hormone Insensitivity (FSH)³⁹
- (m) Fraser Syndrome⁴⁰ (also known as Meyer Schwickerath's Syndrome, Fraser François Syndrome or Ullrich Feichtiger Syndrome)
- (n) gonadal dysgenesis including partial and complete forms
- (o) hypogonadism

³⁶ See item 2.1.3(d).

³⁸ See item 2.1.1(f).

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

²⁸ See item 2.1.1(b).

²⁹ See item 2.1.3(a).

³⁰ See items 2.1.1(c) and 2.1.1(g).

³¹ See item 2.1.1(c). If this non-exhaustive list of variations and physical conditions can be drafted and introduced as a regulation at the commencement of the scheme, we would have no objection to this list being included in regulation. However, it must be clear which variations and physical conditions will be captured within the scope of the scheme at its outset, and this list should include all the variations and physical conditions currently proposed.

³² See item 1.2.

³³ See item 2.1.3(b).

³⁴ See item 2.1.3(d).

³⁵ See item 2.1.1(g).

³⁷ See item 2.1.1(d).

³⁹ See item 2.1.1(i).

⁴⁰ See item 2.1.3(e).

- (p) hypospadias⁴¹
- (q) Jacobs Syndrome (also known as XYY Syndrome)
- (r) Kallmann Syndrome⁴²
- (s) Leydig cell gypoplasia
- (t) Mayer-Rokitansky-Küster-Hauser Syndrome (MRKH) (also known as vaginal agenesis, Müllerian agenesis, Müllerian (duct) aplasia <u>or congenital absence of vagina</u>)
- (u) micropenis
- (v) mosaicism involving sex chromosomes, including XY/XO and other variations⁴³
- (w) ovo-testes (formerly known as 'true hermaphroditism')
- (x) Persistent Mullerian Duct Syndrome (PMDS)
- (y) Poly cystic Ovary Syndrome (PCOS) (also known as hyperandrogenism)⁴⁴
- (z) Progestin Induced Virilisation
- (aa) <u>sex chromosome variations including:</u>
 - (i) <u>47XXY or Klinefelter Syndrome, and 48XXXY or 49XXXXY variations</u>
 - (ii) <u>48XXXX/XXXX Syndrome (also known as Tetrasomy X or Quadruple X)</u>
 - (iii) <u>49XXXXX, XXXXX Syndrome (also known as Pentasomy X)</u>
 - (iv) <u>Triple-X Syndrome (also known as XXX, triple-X, trisomy X, XXX syndrome or 47XXX</u> <u>aneuploidy)</u>
 - (v) <u>Turner Syndrome (also known as Ullrich-Turner Syndrome, Gonadal Dysgenesis, 45X0</u> or 45X)
- (bb) Swyer Syndrome (also known as XY gonadal dysgenesis)

reasonable support includes (without limitation):

- (a) the conveying of the information by another person or in another manner;
- (b) the provision of additional time;
- (c) the provision of additional assistance or support, including by another person;
- (d) the provision of aids (including palliative or therapeutic devices) or other mechanisms,

in a manner which is reasonable, and which would enable the protected person to understand, remember and use or weigh relevant information, or communicate the relevant decision or information.⁴⁵

sex characteristics has the same meaning as in the Equal Opportunity Act 2010 (Vic).⁴⁶

supportive guardian means a person appointed to support medical decision-making making under a supportive guardianship order made under the *Guardianship and Administration Act 2019* (Vic).

support person means a person appointed as a support person under the *Medical Treatment Planning and Decisions Act 2016* (Vic).

- ⁴² See item 2.1.1(h).
- ⁴³ See item 2.1.3(e).
- ⁴⁴ See item 2.1.1(j).
- ⁴⁵ See item 6.5.1.

⁴¹ See item 2.1.1(e).

⁴⁶ Under the *Equality Opportunity Act 2010* (Vic), 'sex characteristics' means a person's physical features relating to sex, including– (a) genitalia and other sexual and reproductive parts of the person's anatomy; and (b) the person's chromosomes, genes, hormones, and secondary physical features that emerge as a result of puberty. This definition is yet to commence.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

2. PROHIBITIONS AND EXCEPTIONS

(a) <u>General prohibition</u>⁴⁷

The legislation should introduce a general prohibition against the provision of medical treatment which modifies the sex characteristics of a protected person unless:

- the protected person has provided personal consent to the medical treatment (see section 3 below); or
- <u>a permitted exception applies.</u>48

The permitted exceptions should be:

- <u>emergency medical treatment that:</u>
 - as a matter of urgency, is necessary to save the protected person's life, prevent serious damage to the protected person's health or prevent the protected person from suffering or continuing to suffer significant pain or distress;⁴⁹ and
 - <u>the protected person has not otherwise refused treatment;⁵⁰</u>
- the medical treatment complies with an individual care plan registered by the oversight body;
- the medical treatment complies with a class exemption order made by the oversight body.

Ensure that this law takes effect notwithstanding any other law (including any statutory or common law principle regarding consent to medical treatment).⁵¹

The prohibition should commence once the oversight body has been established and has had time to register any individual care plans and make any necessary class exemption orders.

Introduce a provision to ensure parental consent is not a sufficient defence for treatment that modifies a protected person's sex characteristics (e.g. 'In any action involving medical treatment modifying a person's sex characteristics, the consent of a person or persons with parental responsibility will not be an sufficient defence if the person is a Protected Person').

(b) Criminal prohibitions

The legislation should create two separate offences:⁵²

- Offence 1: An offence is committed by a person (Person A) if:
 - they are medical practitioner;
 - they provide medical treatment to modify with the intention of modifying the sex characteristics of another person (<u>Person B</u>);
 - knowing that Person B's has not or could not provide personal consent; and
 - knowing or being reckless to the fact that Person B is a protected person; and
 - knowing or being reckless to the fact that no exception applies (see above).⁵³

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

⁴⁷ See items 4.2.1 and 4.2.2.

⁴⁸ Modelled on s 9 of the Change or Suppression (Conversion) Practices Prohibition Act 2021 (Vic).

⁴⁹ See items 3.1.1-3.1.4.

⁵⁰ Modelled on s 53 of the *Medical Treatment Planning and Decisions Act 2016* (Vic).

⁵¹ See item 10.2.

⁵² See items 2.4.1-2.4.6.

⁵³ See item 2.4.2.

- Offence 2: An offence is committed by a person (Person A) if:
 - they remove or cause to be removed from Victoria another person (Person B); and
 - they do so with the purpose intention of obtaining medical treatment to modify the sex characteristics of Person B without Person B's personal consent; and
 - <u>they or another person provides medical treatment that modifies the sex</u> <u>characteristics of Person B without Person B's personal consent; and</u>
 - they know or are reckless to the fact that Person B is a protected person; and
 - <u>they know or are reckless to the fact that</u> no exception applies (see above).⁵⁴

The offences should have <u>the same</u> extraterritorial application <u>provisions as in the Change or Suppression</u> (Conversion) Practices Prohibition Act 2021 (Vic).⁵⁵

The offences should commence 12 months after the scheme has commenced to give people the opportunity to register any individual care plans with the oversight body and for the oversight body to make any necessary class exemption orders.

Consider resting the onus on a defendant to prove, on the balance of probabilities, that one of the permitted exceptions applies (i.e. make the exceptions defences rather than part of the offence which must be proven by the prosecution beyond a reasonable doubt).

3. OBTAINING PERSONAL CONSENT⁵⁶

<u>Given the prohibitions will allow medical treatment which modifies the sex characteristics of a protected person</u> with their personal consent, the legislation should clearly define the requirements and pre-conditions necessary for obtaining personal consent.⁵⁷

<u>As defined above, **personal consent** means the protected person receiving the medical treatment has given informed consent to that medical treatment.</u>

(a) <u>Defining 'informed consent'</u>

The legislation should define **informed consent** by adapting the definitions of **informed consent** and **capacity to give informed consent** in sections 68 and 69 of the *Mental Health Act 2014* (Vic) to the specific needs of this population, as follows.⁵⁸

Capacity to give informed consent

To be able to provide informed consent, the legislation must first require a protected person to have the capacity to give informed consent.

<u>A protected person should have **capacity to give informed consent** to the medical treatment proposed if the person:</u>

- 1. <u>understands the information they are given that is relevant to the decision; and</u>
- 2. is able to remember the information that is relevant to the decision; and
- 3. is able to use or weigh information that is relevant to the decision; and
- 4. is able to communicate the decision made by speech, gestures or any other means.

⁵⁴ See items 2.4.2, 2.4.6, 4.1.2(t) and 11.1.

⁵⁵ See s 8 of the Change or Suppression (Conversion) Practices Prohibition Act 2021 (Vic). See item 11.1.

⁵⁶ See item 1.3.

⁵⁷ See item 6.2.2(h).

⁵⁸ See item 6.2.2(f).

In determining whether a protected person has capacity to give informed consent, the legislation should require the determination to be made in light of whether the person would understand the relevant information, be able to remember the relevant information, be able to use or weigh relevant information, and be able to communicate the relevant decision with the provision of reasonable support.

The following principles are intended to provide guidance to any person who is required to determine whether or not a protected person has the capacity to give informed consent under this Act–

- 1. <u>a protected person's capacity to give informed consent is specific to the decision that the person is to</u> <u>make;</u>
- 2. <u>a protected person's capacity to give informed consent may change over time;</u>
- 3. <u>it should not be assumed that a protected person does not have the capacity to give informed consent</u> based only on their age, appearance, condition or an aspect of their behaviour;
- 4. <u>a determination that a protected person does not have capacity to give informed consent should not be</u> <u>made only because the person makes a decision that could be considered to be unwise;</u>
- 5. <u>when assessing a protected person's capacity to give informed consent, reasonable steps should be taken</u> to conduct the assessment at a time at, and in an environment in, which the person's capacity to give informed consent can be assessed most accurately.

Informed consent

For the purposes of determining whether a protected person has given personal consent to medical treatment which modifies their sex characteristics, the protected person receiving the medical treatment will have given **informed consent** to that medical treatment if the person—

- 1. <u>has the capacity to give informed consent to the medical treatment proposed; and</u>
- 2. <u>has been given adequate information to enable the protected person to make an informed decision; and</u>
- 3. <u>has been given a reasonable opportunity to make the decision; and</u>
- 4. has given consent freely without undue pressure or coercion by any other person; and
- 5. <u>has not withdrawn consent or indicated any intention to withdraw consent.</u>

For the purposes of principle 2 above, a protected person will have been given adequate information to make an informed decision if the person has been given—⁵⁹

- 1. <u>affirming,⁶⁰ clearly understandable and factually objective information about the nature of their innate</u> <u>variation of sex characteristics, including:</u>
 - a. <u>that it is a naturally occurring innate variation of sex characteristics;</u>
 - b. <u>if known, the approximate number of people who have that particular innate variation of sex</u> <u>characteristics;</u>
 - c. how that innate variation of sex characteristics manifests physically, including over time;
- 2. <u>a prescribed list of peer support organisations and contacts for psychological support made by the</u> <u>Minister for Health after consultation with the Minister for Equality;⁶¹</u>
- 3. <u>the option of having no medical treatment at all or at the present time, and an explanation of the</u> <u>advantages and disadvantages of this option;</u>
- 4. <u>an explanation of the proposed medical treatment including</u>
 - a. <u>the purpose of the medical treatment; and</u>
 - b. the type, method and likely duration of the medical treatment; and
 - c. <u>an explanation of the advantages and disadvantages of the medical treatment, including</u> <u>information about the associated discomfort, risks and common or expected side effects of the</u> <u>medical treatment;⁶² and</u>

⁵⁹ See items 4.3.1(e) and 6.2.1(a).

⁶⁰ See item 6.2.1(c).

⁶¹ See item 6.2.1(d), 6.2.2(d), 6.2.2(e), 7.1.3 and 7.1.5.

⁶² See item 6.3.1(f).

- d. <u>an explanation of any beneficial alternative treatments that are reasonably available, including</u> <u>any information about the advantages and disadvantages of these alternatives; and</u>
- e. answers to any relevant questions that the protected person has asked; and
- f. <u>any other relevant information that is likely to influence the decision of the protected person;</u> <u>and</u>
- g. <u>in the case of proposed medical treatment, a statement of rights relevant to the protected</u> <u>person's situation.</u>

For the purposes of principle 3 above, a protected person has been given a reasonable opportunity to make a decision if, in the circumstances, the person has been given $-\frac{63}{2}$

- 1. <u>a reasonable period of time in which to consider the matters involved in the decision, including a cooling</u> off period appropriate to the proposed medical treatment; and
- 2. <u>a reasonable opportunity to discuss those matters with the registered medical practitioner who is</u> <u>proposing the medical treatment, including the option to do so with or without the assistance or presence</u> <u>of another person; and</u>
- a reasonable opportunity to discuss those matters with a different health professional to the one proposing the medical treatment, including the option to do so with or without the assistance or presence of another person; ⁶⁴ and
- 4. <u>a reasonable amount of support to make the decision; and</u>
- 5. <u>a reasonable opportunity to obtain any other advice or assistance in relation to the decision.</u>

(b) <u>Recording of personal consent</u>

<u>A health professional who has obtained the personal consent of a protected person must maintain written records</u> of all the information provided to the protected person in order to comply with this section and treat those records in accordance with the Health Privacy Principles set out in the *Health Records Act 2001* (Vic).⁶⁵

4. OVERSIGHT BODY

(a) Establishment of oversight body

The legislation should establish an oversight body exercising administrative (not judicial) powers.

The oversight body should have an oversight panel for making decisions (as set out below), as well as a secretariat supporting the work of the panel.

Appointment of pool of panel members

The oversight panel should be comprised of 9 permanent members comprised of:

- a Chair who is a former judicial officer or senior lawyer;
- <u>3 health professional members comprising:</u>

- The deletion is permitted, authorised or required by the regulations or any other law; or
- The deletion is not contrary to the regulations or any other law and occurs-

(i) in the case of health information collected while the individual was a child, after the individual attains the age of 25 years; or(ii) in any case, more than 7 years after the last occasion on which a health service was provided to the individual by the provider—whichever is the later.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

⁶³ See item 6.2.1(b)

⁶⁴ See item 6.2.1(d).

⁶⁵ See item 6.2.1(g). Under Principle 4 of the Health Privacy Principle, this means that health information relating to an individual must not be deleted unless:

an allied health professional (e.g. psychologist, social worker);

<u>3 community members comprising:</u>

<u>2 people with innate variations of sex characteristics;</u>

- 1 family member of a person with innate variations of sex characteristics;
- 2 other members comprising:
 - a bioethicist; and
 - a human rights or children's rights expert.

The Minister for Health should have the power to appoint a further pool of reserve panel members.

The Minister for Health, after consulting with the Minister for Equality,⁶⁶ should have the power to appoint:

- <u>a Chair and deputy Chair who are former judicial officers or senior lawyers of at least 10 years'</u> standing;⁶⁷
- <u>a pool of panel members that the Minister for Health is satisfied, after an open application</u> process,⁶⁸ the knowledge, experience or skills relevant to their role.⁶⁹

The Minister for Health must appoint a minimum of 10 panel members to the pool, having regard to:

- the need to ensure a reasonable diversity of gender, clinical expertise and lived experience;⁷⁰ and
- <u>the proper functioning of the oversight body</u>,⁷¹ including in the event that a full panel decision is remitted by a court on appeal for reconsideration by a differently constituted full panel.

The panel members should be appointed into one or more of the following categories:

- <u>Health professional member, being health professionals with expertise in medicine, psychology,</u> <u>bioethics or other allied health areas relevant to the care of people with innate variations of sex</u> <u>characteristics;⁷²</u>
- <u>Community representative panel member, being persons with innate variations of sex</u> <u>characteristics and the family members of persons with innate variations of sex</u> <u>characteristics;⁷³</u>
- <u>Other specialist panel member, being experts in human rights, children's rights or the rights of people with disability.</u>

The members and reserve panel members should be appointed for a term of 3 years and can be reappointed for further terms of 3 years.

The members' and reserve members' panel members' tenure should be terminable by the Minister for Health or by resignation.⁷⁴

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

⁶⁶ See item 4.3.2(b).

⁶⁷ See item 4.3.5(a).

⁶⁸ See items 4.3.2(a) and 4.3.2(c).

⁶⁹ See items 1.5, 4.2.4 and 4.3.3(c).

⁷⁰ See items 4.3.1(d), 4.3.3(a)-4.3.3(c), and 4.3.4(a)-4.3.4(c).

⁷¹ See item 1.5.

⁷² See item 4.3.4(d).

⁷³ See items 4.1.1(a) and 4.1.1(g).

⁷⁴ See item 4.4.2.

The <u>panel</u> members' should be remunerated for work they perform as members of the oversight panel<u>, including</u> any professional development required of their role.

The panel members should be subject to a limitation on personal liability in connection with their functions.⁷⁵

<u>The Chair</u>

The Chair should have the power to conduct meetings of the panel.

The Chair should have powers to establish rules governing the process and procedures of the panel, subject to the requirements of the legislation.⁷⁶

The Chair should have day-to-day responsibility for the proper management of the oversight body, including ensuring policies, procedures, guidelines and a complaints system are in place.⁷⁷

The Chair should be able to receive and resolve complaints from members of the public regarding the failure of a panel member to comply with their obligations, subject to the Minister for Health having the final decision on termination.⁷⁸ Any complaints regarding the Chair should be received and resolved by the Minister for Health.

The Chair should be able to delegate their role to the deputy Chair in the event that they are unable to perform their role, including because they have to disqualify themselves from sitting as a panel member in a particular matter. Wherever reference is made to the 'Chair' in this document, this should be taken to mean the deputy Chair where the Chair has delegated their role to the deputy Chair.

Panel members' obligations

The Chair, deputy Chair and panel members should be required to:79

- <u>act with integrity, impartially, respectfully, fairly and accountability when performing their</u> <u>roles;⁸⁰</u>
- <u>maintain relevant professional registrations, accreditations or qualifications necessary for their</u> role;⁸¹
- <u>attend such training and development as requested by the Chair from time to time;⁸²</u>
- <u>declare any actual or perceived conflicts of interests;⁸³</u>
- <u>disgualify themselves from sitting as a panel member in respect of any matter in which there is</u> <u>any actual or apprehended bias.⁸⁴</u>

Full panel of the oversight body

The Chair must constitute a panel of 5 panel members (the **full panel**)⁸⁵ drawn from the pool of eligible panel members to make a decision on behalf of the oversight body, including:

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

⁷⁵ See item 7.5.3.

⁷⁶ See item 4.3.5(b).

⁷⁷ See item 4.4.4.

⁷⁸ See item 4.4.5.

⁷⁹ See items 1.4, 1.5, 4.5.1, and 4.3.1(a)-4.3.1(b).

⁸⁰ In a manner similar to the public sector values in s 7 of the *Public Administration Act 2004* (Vic).

⁸¹ See item 4.4.3.

⁸² See item 4.4.1.

⁸³ See item 4.5.1.

⁸⁴ See item 4.5.1.

⁸⁵ See items 4.2.1-4.2.2.

- <u>a decision to register or not to register an individual care plan, including with or without any</u> <u>amendments;</u>
- <u>a decision to make, revoke or amend a class exemption order.</u>

The full panel must always comprise either the Chair or deputy Chair, and one panel member belonging to each of the three categories of panel members.

In constituting a full panel, the Chair must have regard to ensuring a ensuring a reasonable diversity of gender and relevant clinical expertise and lived experience on the full panel.⁸⁶

The full panel should comprise the 9 permanent members. The Chair should have the discretionary power to substitute permanent members of the panel with an alternative member drawn from the reserve pool of panel members if:

- a permanent member is unable to attend a meeting of the body, or
- the issue before the panel includes an area of clinical, bioethics or rights expertise, or lived experience, not currently represented on the body, and in the opinion of the Chair, the panel's deliberations would be assisted by having that expertise or experience represented on the panel.

However, the Chair must only substitute a permanent member with a reserve member of the same type, such that the composition of the full panel of members retains its allocation as between health professional, community and other members.

The Chair should have the power to conduct the meetings of the panel.

The Chair should have powers to establish rules governing the process and procedures of the panel, subject to the requirements of the legislation. 7 members of the panel should constitute a quorum, provided that at least one of the health professional, community and other members are present at meetings of the panel.

Decisions of the <u>full</u> panel should <u>aim to reach consensus</u>, <u>but failing consensus</u>, require the agreement of a majority of its members, including at least one health professional and one community member.⁸⁷

Three-member sub panel

The Chair should have the power to establish a sub panel comprised of three members to decide whether or not to register an individual care plan, including with or without amendment.⁸⁸

A sub-panel must be comprised of <u>three members, being either the Chair or deputy Chair, and</u> at least one health professional and one community member with knowledge, experience or skills relevant to the person or the medical treatment under consideration. The sub-panel can be drawn from either permanent or reserve members of the oversight panel.

In constituting a sub panel, the Chair must have regard to ensuring a reasonable diversity of gender and relevant clinical expertise and lived experience on the sub panel.⁸⁹

All decisions of a sub-panel must be made by consensus and be reported to the full panel of the oversight body.⁹⁰ If the sub-panel fails to reach a consensus, the matter must be referred to the <u>a differently-constituted</u> full panel of the oversight body for a decision.

⁸⁶ See items 4.3.1(d), 4.3.3(a)-4.3.3(c), 4.3.4(a)-4.3.4(c), and 4.3.5(d).

⁸⁷ See item 4.2.7.

⁸⁸ See items 4.1.2(d), 4.2.3, and 7.3.4(a).

⁸⁹ See items 4.3.1(d), 4.3.3(a)-4.3.3(c), 4.3.4(a)-4.3.4(c), and 4.3.5(d).

⁹⁰ See item 4.2.6.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

All decisions of a sub panel would should also be open to internal review by the <u>a differently constituted</u> full panel of the oversight body. In that case, no member who has participated in a decision made by a sub-panel should sit on the full panel while the full panel is reconsidering that sub-panel's decision.

(b) Functions and powers of the oversight body

The oversight body should be given the following functions and powers:

- to support persons in the preparation of an individual care plan;⁹⁴
- to consider and register register or amend individual care plans that contain any medical treatment modifying a protected person's sex characteristics for people who are unable to provide personal consent, including after reasonable support is provided;
- to consider and make, where appropriate, class exemption orders;
- to receive and consider reports from health professionals when exemptions are relied upon;
- to receive reports of possible contraventions of the prohibitions and refer them to relevant bodies (e.g. state and territory law enforcement bodies, Victorian Health Complaints Commissioner, Victorian Ombudsman, Australian Health Practitioner Regulatory Agency, Victorian Equal Opportunity and Human Rights Commission);⁹²
- to promote compliance with the scheme by the provision of information to <u>protected</u> persons who may benefit from the scheme, their family members, guardians, support persons or carers, health professionals and members of the general public;
- to issue guidance on the interpretation and operation of the scheme, including the interpretation of the prohibitions;⁹³
- to conduct analysis of, and carry out research in relation to, the operation of the scheme;
- to provide advice to the Minister for Health, <u>Minister for Equality</u> or Secretary of the Department of Health <u>or department responsible for Equality</u> in relation to the operation of the scheme;
- to provide reports to the Minister for Health, <u>Minister for Equality</u> or Secretary of the Department of Health <u>or department responsible for Equality</u> in respect of any matter relevant to the functions of the oversight body as requested; and
- such powers that are necessary or convenient to perform its functions.

The oversight body should be required to publish an annual report on the operation of the Act every financial year, no more than 3 months from the end of each financial year.⁹⁴ Without limitation to information which can be included in the report and subject to the confidentiality requirements, the report should be made public and include information on:

- <u>the number of applications received by the oversight body for the registration or amendment of</u> <u>an individual care plan including by type of variation and the age range of protected persons at</u> <u>the time of application;</u>
- <u>trends in the outcomes of applications for the registration or amendment of an individual care</u> <u>plan including by:</u>
 - type of variation;
 - the age range of protected persons at the time of application; and

⁹¹ See items 7.2.1 -7.2.2.

⁹² See item 8.2.1.

⁹³ See item 5.1 cf 5.2.

⁹⁴ Modelled on s 107 of the Voluntary Assisted Dying Act 2017 (Vic).

- the types of medical treatment sought and/or permitted (with non-identifying particulars on any procedures permitted by the oversight body in respect of particular classes of protected persons);
- the number and type of class exemption orders considered or made by the oversight body.⁹⁵

(c) How the oversight body must make decisions

In making decisions under this legislative scheme, the oversight body:

- must comply with the requirements set down by the legislation and in other laws, including the Charter, and having regard to the objects and purposes of this legislation;⁹⁶
- <u>must act fairly and according to the substantial merits of the case in all matters;⁹⁷</u>
- <u>must comply with the rules of natural justice</u>;⁹⁸
- <u>is not bound by the rules of evidence or any practices or procedures applicable to courts of</u> <u>record, except to the extent the Chair adopts those rules, practices or procedures;⁹⁹</u>
- <u>may inform itself on any matter as it sees fit, including by reference to previous decisions or</u> <u>matters which have come before the panel;¹⁰⁰</u>
- <u>must conduct the hearing of any matter with as little formality and technicality as possible,¹⁰¹</u> and determine each matter with as much speed, ¹⁰² as the requirement of this Act and a proper consideration of the matters before it permit.¹⁰³
- must be satisfied that any person who has capacity to provide personal consent, including with any reasonable support, will not be made subject to a decision which allows the provision of medical treatment contrary to that person's wishes;
- must be satisfied that any person who does not have capacity to provide personal consent, but who does have, with reasonable support, the ability to provide views on any proposed individual medical treatment affecting their body, is:
 - provided reasonable support to ensure those views can be expressed to the oversight body; and
 - the oversight body takes those views into account before it makes any decision in respect of that person;
- must be satisfied that any person who does not have capacity to provide personal consent is not
 provided medical treatment modifying their sex characteristics where that treatment can be
 deferred without causing or being likely to cause harm to the health of the person; and
- must not presume without substantive evidence that a person with innate variations of sex characteristics would experience any social or psychosocial benefits from having their sex characteristics function or appear in a manner which conforms with norms for persons without that variation.

⁹⁵ See items 5.3 and 9.2.

⁹⁶ See items 1.4 and 6.1.1.

⁹⁷ See items 4.1.2(c), 4.3.1(e), and 5.2.

⁹⁸ See items 4.3.1(e) and 5.2.

⁹⁹ See item 4.3.5(b).

¹⁰⁰ See item 4.1.1(i) and 4.2.5.

¹⁰¹ See item 4.3.5(b).

¹⁰² See item 4.1.2(d).

¹⁰³ Modelled on s 98 of the Victorian Civil and Administrative Tribunal Act 1998 (Vic).

These principles apply (without limitation) to:

- a decision to register or not to register an individual care plan, including with or without any amendments; and
- a decision to make, revoke or amend a class exemption order.

5. INDIVIDUAL CARE PLANS

The legislation should make provision for the preparation, registration and amendment of individual care plans in respect of protected persons who do not have capacity to provide personal consent to medical treatment which would modify their sex characteristics. An individual care plan can allow medical treatment modifying a protected person's sex characteristics without personal consent if it complies with this section.

(a) <u>What is an individual care plan?</u>

The legislation should clarify the matters which can be included in an individual care plan including:¹⁰⁴

- <u>the name of the protected person, where they live, who they live with and who is responsible for</u> making decisions regarding their care (including any medical decision-maker);
- <u>referrals to peer support that will be provided or arranged for the protected person, and by</u> <u>whom and when;¹⁰⁵</u>
- <u>referrals to psychological support or counselling that will be provided or arranged for the</u> protected person, and by whom and when;¹⁰⁶
- <u>the information that will be provided to the protected person regarding their variation and any</u> medical treatment associated with it, and by whom and when;
- any medical treatment which modifies that sex characteristics of the protected person that may be provided without personal consent, and any conditions on how and when it may be performed or provided including by whom;
- <u>any medical treatment that is ancillary or incidental to the above, including any self-</u> <u>administered treatment or care that follows any medical treatment;¹⁰⁷</u>
- <u>any medical treatment in connection with the protected person's variation for the purposes of diagnosis or monitoring;¹⁰⁸</u>
- <u>any records which must be retained in respect of any such medical treatment and how and when</u> <u>it will be provided or made available to the protected person;</u>
- <u>any reports which must be made to the oversight body regarding matters contained in the plan,</u> <u>and by whom and when;</u>
- the term of the individual care plan and/or the time or circumstances in which the plan ceases to have effect or must be reviewed by the oversight body.¹⁰⁹

(b) Eligibility to apply

The legislation should allow an interested person¹¹⁰ to apply to the oversight body to register or amend an

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

¹⁰⁴ See item 4.1.2(b).

¹⁰⁵ See items 6.3.3(k)-6.3.3(l), and 7.1.2.

¹⁰⁶ See items 6.3.3(k)-6.3.3(l), and 7.1.2.

¹⁰⁷ See item 6.3.1(f).

¹⁰⁸ See item 2.1.1.

¹⁰⁹ See items 6.3.3(b) and 7.1.4.

¹¹⁰ See item 4.1.1(a).

individual care plan in respect of a protected person if:

- medical treatment is proposed which would modify the sex characteristics of the protected person; and
- the protected person does not have capacity to provide informed consent.

(c) Preparing an application for an individual care plan

The application to register <u>or amend</u> an individual care plan should be made in a form prescribed by the regulations.

The regulations could require the application form to seek information on the following details:

- details regarding the protected person who is the subject of the application, including their age, particular variation, names and contact details of all persons with parental or other responsibility for their care and wellbeing and the names and contact details of the medical team overseeing their healthcare;
- details, to be completed by their health professional, of any proposed medical treatment that would modify the sex characteristics of the <u>protected</u> person, including:
 - full particulars of the treatment proposed;
 - who will be performing the treatment;
 - when the treatment is proposed to be performed;
 - reasons for why the treatment is proposed;
 - any alternative treatments which have been considered and any reasons why they have been rejected;
 - what information has been provided to the <u>protected</u> person, and/or persons with parental or other responsibility for the care and wellbeing of the <u>protected</u> person, regarding the risks and benefits of the proposed treatment and risks and benefits of any alternative treatment which has been considered by rejected;¹¹¹ and
 - any relevant medical history of the person, including past treatments whether undertaken in Victoria or elsewhere (to the extent known);
- <u>details of what psychological and peer support before or after the treatment has been offered to</u> <u>the protected person;</u>
- <u>details of any existing individual care plan;</u>
- details of any steps taken to ascertain whether the <u>protected</u> person the subject of the application is capable of providing personal consent (if relevant);
- details of any facts or circumstances which might suggest that the <u>protected</u> person the subject of the application does not or would not consent to the medical treatment (if relevant).

The legislation should allow the oversight body to assist in the preparation of an application. (As an operational matter, this role should be delegated to a support worker employed by the oversight body who is independent from any decision-making functions exercised by the panel).¹¹²

The legislation should require that the application form be completed by way of statutory declaration (such that there is a penalty for providing false or misleading information).

The legislation should require those completing the form or providing information to the panel <u>(including any</u> <u>independent advocate)</u> to provide full and frank disclosure of any matters regarding the application (including the

¹¹¹ See item 6.2.1(f).

¹¹² See items 7.2.1-7.2.2.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

<u>protected</u> person and proposed treatment) which might be relevant to the oversight body's consideration of the application. There should be a penalty for failures to comply with this duty.

The application process should be free.

An independent advocate should also have a duty to act:113

- if the protected person is under 18 years of age: in the best interests of the protected person informed by the protected person's own views to the extent they can be expressed with reasonable support;
- if the protected person is 18 years or older: in the interests of the protected person and faithfully with their will and preferences, or the best ascertainment of their will and preferences, as can be expressed or ascertained with reasonable support.

(d) Processing an application to register or amend an individual care plan

Once an application has been made, the oversight body (through a delegated support worker) should have powers¹¹⁴ to:

- review the application and confirm its eligibility <u>and, if eligible, must offer to the affected</u> persons, including the protected person, such referrals to peer support and counselling as may <u>be appropriate</u>;¹¹⁵
- <u>appoint an independent advocate for the protected person whose role is to facilitate the</u> <u>expression of views from the protected person where they can be obtained directly (including</u> <u>with reasonable support), and provide assistance to the oversight panel in considering matters</u> <u>which cannot be or are not raised directly by the protected person;¹¹⁶</u>
- request further information from persons connected to the application if it may assist the oversight panel in considering the matter;
- if it may assist the oversight panel in considering the matter, arrange for independent consultants (such as a psychologist) with relevant expertise to <u>do any or all of the following</u>:
 - prepare a draft individual care plan or amendments to an existing individual care plan in consultation with the protected person, affected persons and any independent advocate;
 - meet with the <u>protected</u> person who is the subject of the application and prepare a report containing, where relevant:
 - their views on the application <u>and/or draft individual care plan;</u>
 - the opinion of the expert as to the <u>protected</u> person's capacity to provide personal consent, including any support which could be provided to enable the person to provide personal consent;¹¹⁷
 - meet with persons with parental or similar responsibility for the care and wellbeing of the <u>protected</u> person and prepare a report containing, where relevant:¹¹⁸
 - their views on the application and/or draft individual care plan;
 - the extent of information provided to them about the medical treatment

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

¹¹³ See items 6.2.1(e) and 7.3.2(a).

¹¹⁴ See item 7.3.1(b).

¹¹⁵ See items 4.1.1(a), 4.1.1(g), 4.1.2(g), 6.2.2(d), 6.3.3(l), 7.1.2, 7.2.3, and 7.3.4(c).

¹¹⁶ See items 6.2.1(e), and 7.3.2(a).

¹¹⁷ See item 4.1.2(k).

¹¹⁸ See items 4.1.1(a), and 6.3.2(a)-6.3.2(d).

proposed in the application, including the risks and benefits of the proposed treatment and any alternatives;¹¹⁹

- <u>meet with the health professionals responsible for the healthcare of the protected</u> person and prepare a report containing their views on the application and/or draft individual care plan;¹²⁰
- prepare evidence on areas of medical or other research;
- prepare evidence derived from past decisions of the oversight panel;¹²¹
- obtain the opinion of other specialists, or experts or people with lived experience and ask them to provide in formulating any recommendations on the matters sought by to take to the oversight panel;¹²²
- convene a meeting which must be held in private with the protected person, affected persons and any independent advocate to seek and obtain their views on the application and/or draft individual care plan.¹²³
- prepare a brief for the oversight panel containing:
 - the application;

 - a recommendation whether or not to register an individual care plan in respect of the person, including with or without any conditions;
 - if a recommendation is being made to a register an individual care plan, a copy of the draft individual care plan which is proposed detailing the proposed medical treatment and any conditions; and
 - any relevant additional evidence or material (including medical or scientific research) supporting the support worker's recommendation.¹²⁴

The <u>brief material before the panel</u> should be made available to all relevant parties, including (as relevant) the <u>protected</u> person, <u>their independent advocate</u>, persons with parental or other responsibility for the person, and their health professionals.

(e) Consideration of the application by the oversight panel

Upon submission of the brief, the oversight panel (or sub-panel) must meet within 14 days to consider whether or not to register an individual care plan.

The meeting must be held in private with all affected people invited to attend the meeting.

The Chair must provide a <u>reasonable</u> opportunity for the <u>protected</u> person the subject of the application <u>(or their independent advocate)</u> and any affected persons to address the panel <u>at any meeting or provide their views in writing</u>, if they wish, <u>prior to a decision of the oversight panel</u>.

Attendees <u>Parties</u> may be legally represented at the meeting, if they wish in any matter before the oversight panel only with leave of the Chair (at their own cost).¹²⁵

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

¹¹⁹ See item 6.2.1(f).

¹²⁰ See item 4.1.2(I).

¹²¹ See item 4.1.1(i).

¹²² See items 4.1.2(I), 4.2.5, 6.3.3(h) and 7.3.1(a).

¹²³ See item 4.1.1(a).

¹²⁴ See items 7.2.1-7.2.2.

¹²⁵ See items 4.3.5(b) and 7.3.3(a).

The Chair may otherwise make such other rules and procedures regulating these meetings, which does not contradict these principles <u>or the oversight panel's obligations</u>, as they deem necessary.

(f) Making the decision

The oversight panel (or sub-panel) must make a decision within 14 days as expeditiously as practicable to:

- register an individual care plan, with or without any amendments;
- refuse to register or amend an individual care plan; or
- defer the matter for another 30 days to allow for the collection of such information or evidence as may be necessary for it to make a decision on the application, and provide directions for the oversight body to obtain such other evidence as necessary (in accordance with its powers above).

The oversight panel (or sub-panel) must not make a decision to register <u>or amend</u> an individual care plan allowing medical treatment that modifies a <u>protected</u> person's sex characteristics without their personal consent unless it is satisfied that:¹²⁶

- the person is a protected person; and
- the <u>protected</u> person does not have capacity to provide personal consent to the proposed treatment <u>that modifies their sex characteristics and which would be allowed by the individual care plan</u>, even after the provision of reasonable support;¹²⁷ and
- to the extent that the <u>protected</u> person can express any views regarding the proposed treatment <u>individual care plan</u>, they have been given an opportunity,¹²⁸ with reasonable support, to express those views and those views have been considered by the oversight panel;¹²⁹ and
- if the person is aged under 18, to the extent that persons with parental responsibility wish to
 express any views regarding the proposed treatment individual care plan, those persons have
 been given an opportunity,¹³⁰ with reasonable support, to express their views and those views
 have been considered by the oversight panel,¹³¹ and
- there is no evidence before the oversight body which would indicate that the person would object to the proposed treatment if they could; <u>and</u>
- the medical treatment cannot be deferred without causing or being likely to cause harm to the health of the person; and
- <u>either:</u>
 - if the protected person is aged under 18: having regard to the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing), their best interests are better served by the medical treatment proceeding without their personal consent over deferring the treatment to realise their significant and profoundly personal interest in deciding what happens to their own body;¹³² and
 - <u>if the protected person is aged 18 year or over: that it is consistent with their will and</u> preferences, or to the extent that those will and preferences cannot be fully expressed, that is consistent with the best ascertainment of what the protected person's will and

¹³² See items 4.1.1(h), 4.1.2(l) and 6.3.3(a).

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

¹²⁶ See items 4.1.1(c) and 6.3.3(a).

¹²⁷ See items 1.3, 6.2.2(a), 6.2.2(g)-6.2.2(h), and 6.3.2(a)-6.3.2(d).

¹²⁸ See item 7.3.1(c).

¹²⁹ See items 6.2.1(e), 6.2.2(b), 6.3.1(b), and 6.3.3(c).

¹³⁰ See item 7.3.1(c).

¹³¹ See items 4.1.1(a), 4.1.1(d), 4.1.1(f) and 4.1.1(g).

preferences would likely be, and which does not override the person's will and preferences unless it is necessary to do so to prevent serious harm.¹³³

In <u>having regard to the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing)</u> determining whether the medical treatment can be deferred without causing or being likely to cause harm to the health of a person, the following considerations must be taken into account by the oversight panel (or sub panel):¹³⁴

- <u>the significant and profoundly personal interest of a person in being able to decide what</u> <u>happens to their own body, and the extent to which that interest may be realised through:¹³⁵</u>
 - <u>the option of deferring medical treatment that modifies a protected person's sex</u> <u>characteristics to preserve any expected ability of the protected person to provide</u> <u>personal consent in future; or</u>
 - <u>the option of allowing medical treatment that preserves options for the protected</u> person in the future;¹³⁶
- the likely benefits and risks of the <u>proposed</u> medical treatment to the <u>protected</u> person's health;¹³⁷
- any likely adverse consequences to the <u>protected</u> person's health of the <u>proposed</u> medical treatment not being provided;
- any alternatives to the medical treatment being proposed that would preserve any expected ability of the person to provide personal consent in future, and the likely benefits and risks of those alternatives.¹³⁸

In having regard to the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing) In determining whether medical treatment can be deferred without causing or being likely to cause harm to the health of a person, the oversight panel (or sub-panel) must not presume without substantive evidence that a person with innate variations of sex characteristics would experience any social or psychosocial benefits from having their sex characteristics function or appear in a manner which conforms with norms for persons without that variation <u>unless</u>: ¹³⁹

- <u>the protected person has themselves provided direct and compelling evidence to support the</u> <u>rebuttal of this presumption;</u>¹⁴⁰
- <u>if the protected person has not provided direct and compelling evidence, any other evidence</u> <u>relied upon;</u>
 - is specific to the protected person and is not otherwise speculative or general in nature; and
 - has substantial probative value.

(g) Provision of reasons

The panel may <u>must</u> provide written reasons for its decision, <u>which must be made available to the parties upon</u> request. If the panel decides to register an individual care plan, the reasons for its decision must also be held on

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

¹³³ Modelled on s 9 of the *Guardianship and Administration Act 2019* (Vic). See items 6.2.2(g)-6.2.2(h) and 6.5.1-6.5.2.

¹³⁴ See items 4.1.2(c), 6.3.3(a), 6.3.3(e)-6.3.3(g) and 6.4.1-6.4.7.

¹³⁵ See item 6.3.3(i).

¹³⁶ See items 4.1.2(d) and 6.3.3(a).

¹³⁷ See item 4.1.2(p).

¹³⁸ See item 4.1.1(b).

¹³⁹ See items 4.1.2(c), 4.1.2(f), 6.3.3(a), 6.2.2(c), 6.3.1(b), 6.3.3(d), and 6.4.1-6.4.7.

¹⁴⁰ See items 6.3.1(c)-6.3.1(e) and 6.3.3(c).

the register with the individual care plan, and must do so, if requested by an interested person.

The panel may publicly publish its reasons, or a summary of its reasons, provided that no information which may identify <u>the protected person or any</u> person <u>connected to the protected person</u> is included in the published reasons.

(h) Appeals

Decisions of a sub-panel can be appealed on its merits to a differently constituted full panel of the oversight body. In which case, the process for considering the application above is repeated by the full panel, which may reconsider the matter and make a fresh decision considering any evidence before the sub panel and any additional evidence or submissions.

Decisions of the full panel of the oversight body can be appealed on judicial review (including for contraventions of the Charter).

(i) Maintenance and access to the register

Individual care plans that are registered by the oversight body should be held on a register maintained by the oversight body, along with the reasons for the oversight body's decision to register an individual care plan.

Information held about a protected person on the register (including the individual care plan and oversight body's decision and reasons) should be stored and made available for access in accordance with the Health Privacy Principles in the Health Records Act 2001 (Vic).¹⁴¹

(j) Legal effect of a registered individual care plan

An individual care plan which has been registered by the oversight body, and which has not otherwise expired or ceased to have effect, operates according to its terms as if it were an order of an administrative tribunal.

That is, to the extent that it compels or authorises such acts to be done, or compels or grants authority to another person (such as medical decision-maker or person with parental responsibility) to authorise such acts to be done:

- it requires such as actions as set out in its terms;
- <u>it grants such authorisations as sets out in its terms (including the power to sign and do</u> <u>anything that is necessary to give effect to any power or duty vested in the person); and</u>
- <u>it constrains such power or authority according to its terms.</u>

Acts done or consents given by a person in compliance with a registered individual care plan should have effect as if it were done or given by the protected person themselves, as if the protected person had the capacity to do those things or give such consents for themselves.¹⁴²

6. CLASS EXEMPTION ORDERS

(a) Power to make class exemption orders

Subject to the requirements of the legislation, the oversight panel should have power to make orders exempting a class of medical treatment from the <u>criminal</u> prohibitions (such that a person with parental responsibility <u>or other</u> <u>medical decision-maker</u> can consent to treatment in accordance with their powers, duties and responsibilities under law, and without further authorisation from the oversight body, when a person cannot provide personal consent).¹⁴³

¹⁴¹ See items 7.4.1-7.4.2.

¹⁴² Modelled on ss 38(3) and 142 of the Guardianship and Administration Act 2019 (Vic). See items 7.5.1-7.5.3.

¹⁴³ See items 4.1.2(d), 4.1.2(i), and 7.6.1-7.6.5.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

The oversight body should only have the power to make class exemption orders where, having regard to the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing), the best interests of any protected person who meets the conditions specified in the class exemption order would be better served by the medical treatment proceeding (with the consent of a medical-decision maker and on any conditions specified by the oversight body) over deferring the treatment to realise a person's significant and profoundly personal interest in deciding what happens to their own body.¹⁴⁴

In having regard to the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing), the following considerations must be taken into account by the oversight panel:¹⁴⁵

- the significant and profoundly personal interest of a person in being able to decide what happens to their own body, and the extent to which that interest may be realised through:¹⁴⁶
 - the option of deferring medical treatment that modifies a protected person's sex characteristics to preserve any expected ability of the protected person to provide personal consent in future; or
 - <u>the option of allowing medical treatment that preserves options for the protected</u> person in the future;¹⁴⁷
- <u>the likely benefits and risks of the proposed medical treatment to the protected person's</u> <u>health;¹⁴⁸</u>
- <u>any likely adverse consequences to the protected person's health of the proposed medical</u> <u>treatment not being provided;</u>
- any alternatives to the medical treatment being proposed, and the likely benefits and risks of those alternatives.¹⁴⁹

In having regard to the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing), the oversight panel must not presume that a person with innate variations of sex characteristics would experience any social or psychosocial benefits from having their sex characteristics function or appear in a manner which conforms with norms for persons without that variation without evidence which has substantial probative value when weighed against the principle that a person has a significant and profoundly personal interest in deciding what happens to their own body.¹⁵⁰

A class exemption order can be made subject to any conditions or limitations that the oversight body thinks appropriate, including (without limitation):

- ensuring that, to the extent the views of the <u>protected</u> person receiving the treatment can be expressed with reasonable support, they do not object to the treatment; and
- placing an obligation on a person to report to the oversight body any reliance on the exemption, including the age of the <u>protected</u> person receiving the treatment, the type of treatment performed and reasons for the treatment.

<u>Clarify that a class exemption order can be made in respect of any medical treatment that may have an ancillary or incidental effect on a protected person's sex characteristics. Example: a class exemption order regarding the closure of a bladder in the case of bladder exstrophy.</u>

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

¹⁴⁴ See item 6.3.3(a).

¹⁴⁵ See items 6.3.3(e)-6.3.3(g) and 6.4.1-6.4.7.

¹⁴⁶ See item 6.3.3(i).

¹⁴⁷ See item 6.3.3(a).

¹⁴⁸ See item 4.1.2(p).

¹⁴⁹ See item 4.1.1(b).

¹⁵⁰ See items 4.1.2(c), 4.1.2(f), 6.3.3(a), 6.3.3(d), and 6.4.1-6.4.7.

The legislation should ensure that class exemption orders are not legislative instruments.

(b) The process for making class exemption orders

Before making, amending or repealing a class exemption order, the legislation should require the oversight body to:

- consult with the Minister for Health and Minister for Equality;
- publish for public consultation any draft class exemption order or proposal to repeal an order, and its reasons for proposing the order or repeal, and take into account such feedback as may be provided to the oversight body; and
- publish any final class exemption order or repeal notice before it takes effect.

The oversight body should also have the power to obtain the opinion of other specialists or experts in forming its views on any draft class exemption order or repeal, and hold hearings to inform itself of any relevant matters as it thinks fit.

Each class exemption order should be subject to a 5-year sunset period, requiring a review by the oversight panel to repeal, amend or renew the order for further periods of 5 years. Reviews should follow the consultation process set out above.

(c) Challenging a class exemption order

A class exemption order or decision to repeal an order should be subject to judicial review (including for contraventions of the Charter).

7. MANDATORY REPORTING OBLIGATIONS

(a) Obligations to report

The legislation should require a health service provider to make a report to the oversight body, in a form prescribed by the oversight body, where it provides medical treatment without personal consent to a protected person that modifies their sex characteristics.¹⁵¹

The report should require the following details to be included:

- <u>the</u> age of <u>the protected</u> person;
- <u>the type of variation;</u>
- treatment provided;
- reasons for treatment;
- alternatives to treatment considered and reasons they were rejected;¹⁵²
- whether the treatment was provided in accordance with the:
 - statutory emergency exception;
 - a registered individual care plan; or
 - a class exemption order.

Failure to make a report should be an offence and also be subject to professional disciplinary consequences.

¹⁵² See item 8.1.3.

¹⁵¹ This proposal is broadly modelled on s 184 of the Children, Youth and Families Act 2005 (Vic).

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

(b) Protection for complying with reporting obligation in good faith

A disclosure to the oversight body by any person in good faith under this obligation should not:

- constitute unprofessional conduct or a breach of professional ethics on the part of the discloser (such as a breach of confidentiality); or
- make the discloser subject to any liability in respect of the disclosure.¹⁵³

8. CONFIDENTIALITY

(a) Confidentiality

The legislation should make it an offence for anyone, including the oversight body,¹⁵⁴ to disclose (other than with the <u>affected</u> person's consent) any information that would identify a person connected to any medical treatment or proposed medical treatment, including:

- any protected person in respect of whom an application or report is made;
- any person related to the <u>protected</u> person (such as family members);¹⁵⁵ and
- treating health professionals related to that treatment.

The legislation should provide an avenue for the oversight body to lawfully disclose information to relevant law enforcement bodies, courts or tribunals, as required by law or when necessary for its work. The Minister for Health should be allowed to prescribe law enforcement bodies in other states and territories.

The legislation should provide an avenue for the oversight body to lawfully disclose information when it is urgent and necessary to save life, prevent serious damage to the person's health, or prevent the person from suffering or continuing to suffer significant pain or distress, and it would not be appropriate or practicable to obtain consent from the person prior to the disclosure.¹⁵⁶

The legislation should allow the oversight body to publish its decisions, subject to such directions as the Chair determines are necessary to preserve personal privacy.¹⁵⁷

FUTURE NATIONALISATION

(a) 'Opt in' Provisions

To accommodate the potential for the oversight body being adopted nationally, the legislation should specify that:

- the Minister for Health can approve another state or territory of Australia 'opting in' to the scheme; and
- if another jurisdiction 'opts in' to the scheme, the Minister for Health must consult with their relevant counterparts in all participating jurisdictions prior to exercising their power to appoint members on the oversight panel; and
- the Minister for Health may make arrangements with participating jurisdictions regarding the sharing of costs involved in making the scheme accessible in jurisdictions outside Victoria.¹⁵⁸

¹⁵⁸ See item 11.1.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

¹⁵³ This proposal is broadly modelled on s 189 of the Children, Youth and Families Act 2005 (Vic).

¹⁵⁴ See item 4.1.2(s).

¹⁵⁵ See item 4.1.1(a).

¹⁵⁶ See item 9.1.

¹⁵⁷ See item 9.2.

9. INTERACTION WITH OTHER LAWS AND SYSTEMS

The legislation should make consequential amendments to other Victorian legislation such that the oversight scheme's jurisdiction and process is prioritised for decisions involving medical treatment modifying a protected person's sex characteristics without their personal consent.

The laws which need to be amended include:

- Medical Treatment Planning and Decisions Act 2016 (Vic) to ensure that a protected person's medical treatment decision maker (including any appointed medical treatment decision maker), any health professional or Public Advocate cannot consent to medical treatment modifying a protected person's sex characteristics other than in accordance with this scheme.
- *Guardianship and Administration Act 2019* (Vic) to ensure that a guardian cannot consent to medical treatment modifying a protected person's sex characteristics other than in accordance with this scheme.¹⁵⁹
- <u>Children, Youth and Families Act 2005 (Vic) to ensure a person granted parental responsibility</u> for a child cannot consent to medical treatment modifying a protected person's sex characteristics other than in accordance with this scheme.
- Historical <u>medical decision-making, guardianship and child protection</u> legislation which
 preceded the above the legislation and which remains in effect, including a medical power of
 <u>attorney under the Medical Treatment Act 1988</u> (Vic), an enduring guardian under the
 <u>Guardianship and Administration Act 1986</u> (Vic) and an enduring attorney for personal matters
 with powers to make decisions about healthcare or medical treatment under the Powers of
 Attorney Act 2014 (Vic) between 1 September 2015 and 11 March 2018.¹⁶⁰
- Supreme Court Act 1986 (Vic) and Constitution Act 1975 (Vic) to ensure the Supreme Court cannot exercise its parens patriae jurisdiction in respect of medical treatment modifying a protected person's sex characteristics other than in accordance with this scheme.¹⁶¹

The laws should keep in place the right of a protected person to make an advanced care directive and preserve for a person the right to recover the ability to provide consent within a reasonable time under s 59 of the *Medical Treatment Planning and Decisions Act 2016* (Vic).

The laws should also clarify the effect of the *Limitations of Actions Act 1958* (Vic) on the date of discoverability for actions for personal injury, by either excluding knowledge held by the parents from being imputed to their child, allowing a child to bring an action without any time limit in respect of medical treatment modifying their sex characteristics or allowing a reasonable time after a child becomes an adult and becomes aware that they received medical treatment modifying their sex characteristics.¹⁶²

The legislation should also make consequential amendments to other Victorian legislation to ensure consistency with this scheme, including to the extent necessary with the:

- the *Health Complaints Act 2016* (Vic), to ensure the Health Complaints Commissioner can receive complaints referred to it from the oversight body, and consider complaints in respect of the breach of the civil prohibitions; and
- the *Health Records Act 2001* (Vic), *Privacy and Data Protection Act 2014* (Vic) and *Freedom of Information Act 1982* (Vic), to ensure the confidentiality settings in this scheme are reflected appropriately in legislation which protects personal privacy or allows the disclosure of information to the public.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

¹⁵⁹ See item 10.1.

¹⁶⁰ See item 10.3.

¹⁶¹ See item 10.1.

¹⁶² See item 10.4.

A further audit of laws may be necessary to ensure that any public, complaints or law enforcement body receiving a referral from the oversight body has the power to deal with the issue in a manner which is consistent with the settings (including the confidentiality settings) set out in this legislation.

10. STATUTORY REVIEW

The legislation should require a review and report on the operation and effectiveness of the scheme 5 years after its operation.

Among the things to be considered should include:

- <u>the scope of medical treatment regulated by the scheme;</u>
- the operation and efficacy of the oversight body and its processes;
- <u>the operation and effectiveness of the legal framework for regulating medical treatment</u> modifying a protected person's sex characteristics;
- whether, and to what extent, it would be appropriate or desirable to recognise corresponding laws elsewhere in Australia or harmonise this scheme with corresponding laws elsewhere in Australia:
- whether, and to what extent, the legislation has achieved its objects and purposes.

SCHEDULE C: CONSULTATION FEEDBACK AND DETAILED RESPONSE

This table includes a short summary of all feedback which raised concerns or provided suggestions for modifying the draft proposal. These concerns and suggestions were raised by people who both supported or opposed all or parts of the draft scheme.

The key to the colour coding

Items highlighted in **green** denote those matters where the proposal already incorporates the feedback or amendments have been made to incorporate the feedback in whole or in part. Items highlighted in **red** denote those matters where the proposal does not incorporate the feedback or no amendments have been made to incorporate the feedback. Items highlighted in **orange** denote those matters where the feedback has been considered but no amendments can be or should be made at this stage or by Equality Australia, including areas for future consideration.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
1	INTRODUCTION TO LEGISLATIVE SCHEME		
1.1	Legislation should affirm that people with innate variations of sex characteristics should not have to adapt their bodies to fit social norms, instead society should change its norms to affirm them.	15	Feedback incorporated. We have updated a number of statements affirming the intention of the Victorian Parliament in enacting the legislation including an affirmation denouncing medical treatments modifying a protected person's sex characteristics which are justified by rationales which discriminate against persons with innate variations of sex characteristics, including by reference to assumptions about how bodies should appear or function simply in order to accord with a particular gendered norm.
1.2	All parts of the scheme need to reflect the non-pathologising language used in the introductory provisions.	18	Feedback incorporated where possible. It is not entirely clear from this feedback which language was considered pathologising. However, to ensure that the scheme preserves the dignity and rights of the individual, we have reviewed the language used throughout in the proposal to ensure it is consistent with the underlying objects and purposes of the proposed scheme. As set out in item 6.3.3(a), we have also introduced a new concept to ground the scheme: the principle that <i>"individuals have a significant and profoundly personal interest in deciding what happens to their own bodies"</i> . This composite phrase embodies the principles of bodily integrity, self-determination and physical autonomy, and this

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			concept is invoked in all decisions which may be made by the oversight body concerning medical treatment that modifies the sex characteristics of a protected person. In some cases, it has been necessary to use language which may be considered pathologising for legal certainty (for example, the non-exhaustive list of variations uses medical terminology, but it is necessary to do so to ensure clinicians have clarity over which variations are covered by the scheme).
1.3	The scheme should be framed in terms of giving people options to make their own decisions when they have capability and capacity to do so.	18	Feedback incorporated. As set out in response to item 1.2 above and item 6.3.3(a) below, we have reviewed and amended the proposal to introduce the grounding principle that <i>"individuals have a significant and profoundly personal interest in deciding what happens to their own bodies"</i> . When decisions are made by the oversight body, they must consider this principle and consider the ways in which deferring or allowing medical treatment may maximise the opportunity for personal consent to medical treatment by the individual in the future or preserve options for the individual in the future.
1.4	Panel members should be required to comply with the objects and underlying values in the legislation.	18	Feedback incorporated. We have clarified that, when making decisions, the oversight body must comply with the legislation (including having regard to the objects and purposes of the scheme) and other laws, such as the Charter of Human Rights and Responsibilities. See also item 1.2 above.
1.5	Panel members should be selected by reference to the objects and underlying values in the legislation.	18	Feedback incorporated. As set out in item 4.2.1, we have suggested an open application process for the selection of panel members, with the appointment of panel members to be based on knowledge, experience and skills relevant to the role. Appointments must have regard to the need to ensure a reasonable diversity of gender, clinical expertise and lived experience.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			Once appointed, we have suggested that panel members be required to comply with certain obligations, including a duty to act with integrity, impartially, respectfully, fairly and accountably when performing their roles. The oversight panel must also be comprised of a specific mix of health professionals, community representatives and experts in human rights, children's rights or the rights of people with disability. Decisions of the oversight panel must also comply with the requirements of the legislation, which include having regard to its objects and purposes.
2	PROHIBITIONS		
2.1	DEFINITION OF 'PROTECTED PERSON'		
2.1.1	Use of the term 'intersex' and the list of variations		
2.1.1(a)	Do not use the term 'intersex' in the proposed scheme.	16, 19	 Feedback noted and was already incorporated. This feedback was provided by some parents of children with congenital andrenal hyperplasia (CAH) who were opposed to the inclusion of CAH in the scheme proposal. The definition of a 'protected person' under the scheme uses the phrase 'innate variations of sex characteristics' and provides a non-exhaustive list of the variations intended to be captured by the scheme. The scheme does not impose labels on protected persons.
2.1.1(b)	Definition of 'protected person' should not use the word ' <i>born</i> '.	20	Feedback noted and was already incorporated. The definition of 'protected person' refers to 'innate variations of sex characteristics', whether or not known at birth.
2.1.1(c)	The non-exhaustive list of variations should be contained in regulations, with the legislation allowing the Minister to prescribe variations on	21	Feedback incorporated. While the scheme allows the Minister for Health to prescribe further innate variations of sex characteristics on the recommendation of the oversight body, it is appropriate that the legislation be clear as to its scope from the

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
	recommendation of the oversight body.		 outset, particularly given contested definitions in this space. It would not be appropriate to leave a critical definition entirely outside the scope of parliamentary consideration. Accordingly, we have proposed: a general definition of 'protected person' that sits in the legislation itself. This defines a 'protected person' as 'a natural person with innate variations of sex characteristics that do not conform to medical norms for male or female bodies'; and without limitation to the above, a regulatory power for the Minister for Health, on the recommendation of the oversight body, to prescribe a non-exhaustive list of variations that are clearly within the scope of the legislation. This non-exhaustive list provides clarity for clinicians on which variations are definitely within the scope of the scheme, without limitation to the general definition. This should not be used to limit the scope of the scheme, and it is important that the draft regulation be made available with the draft legislation so it is clear which variations are captured by the scheme from the outset.
2.1.1(d)	Congenital adrenal hyperplasia (CAH) should be outside of scheme scope.	16, 19	 Feedback considered but not incorporated. Evidence from our consultations showed that: clitoral reductions and vaginoplasties are occurring for infants with CAH assigned female at birth who are born with visible variations of sex characteristics, such as ambiguous genitalia;¹⁶³ some parents report feeling pressured to consent to early interventions for their children with CAH;¹⁶⁴ some parents strongly speak to a desire to alter their children's bodies to conform with an assigned gender;¹⁶⁵

¹⁶³ Listening report, p. 42-3.

¹⁶⁴ Listening report, p. 39.

¹⁶⁵ Listening report, pp. 16, 19.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			 the absolute confidence in which some parents speak about their children's assigned gender is not borne out in medical evidence, which shows that up to 5% of people with CAH and 46,XX chromosomes may not go on to develop a female gender identity;¹⁶⁶ there is disagreement (including among clinicians, parents and people with CAH) regarding the optimal time for any genital surgery, with some supporting earlier interventions and others supporting later interventions;¹⁶⁷ and hormone treatments are critical life-saving treatments for people with salt wasting CAH, whether assigned female or male at birth.¹⁶⁸ Accordingly, it is not appropriate to remove a group of children who are at high risk of 'normalising' surgeries based on gender-based assumptions from the protective potential of this scheme. The oversight body will provide a forum for scrutinising the evidence and views regarding genital surgeries for children with CAH, while the scheme's emergency treatment exception ensures that life-saving treatments do not need prior approval from the oversight body and can be administered without delay.
2.1.1(e)	Hypospadias should be outside of scheme scope.	20	 Feedback considered but not incorporated. Evidence from our consultations suggested that: the incidence of hypospadias is high (around 1 in 300);¹⁶⁹ there may be evidence that early treatment for hypospadias has positive impacts on psychological health;¹⁷⁰ and

¹⁶⁹ Listening Report, p. 28.

¹⁷⁰ Listening Report, p. 41.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

¹⁶⁶ Listening report, p. 19 and Lee at al (2016) 'Global disorders of sex development update since 2006: Perceptions, approach and care', Hormone Research in Paediatrics, 2016:85-158-180 at 168.

¹⁶⁷ Listening report, pp. 37-40.

¹⁶⁸ Listening report, p. 25.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			 'standing to pee' is a reason which may be used to justify surgical interventions.¹⁷¹ The principal rationales given for excluding children with hypospadias from the scheme appear to be: (1) that hypospadias comes in different types; (2) the inclusion of hypospadias would impose a large workload on the oversight body due to its high incidence; and (3) that hypospadias is not considered an intersex variation by clinicians.¹⁷² However, hypospadias 'repair' involves surgery to reroute a urethral opening towards the tip of the penis, usually from a position near the tip ('distal') but occasionally from a position within or near the scrotum ('proximal'). One of the rationales for this surgery appears to be to allow boys to pee standing up. Repairing penile curvature ('chordee'), circumcision and orchiopexy (descending testes into the scrotum) may also be part of a procedure associated with hypospadias. Given treatment for hypospadias involves significant surgery on the penis (including in some cases its reconstruction) and some rationales for this surgery have psychosocial rather than medical justifications, it would not be appropriate to exclude hypospadias entirely from the protective potential of the scheme. A better way to deal with it is to ensure the oversight body has the power to make class exemption orders in respect of those procedures it considers justified,¹⁷³ once it has explored the evidence and views regarding this genital surgery. This will address any workload impact in a way which does not remove protection that it is otherwise warranted.
2.1.1(f)	Cryptorchidism (undescended testes) should be outside of scheme scope.	20	 Feedback considered but not incorporated. Evidence from our consultation heard that: clinicians do not always regard cryptorchidism as an intersex variation;¹⁷⁴ and

¹⁷¹ Listening Report, pp. 39-40.

¹⁷² Listening Report, p. 20.

¹⁷³ Listening report, p. 47.

¹⁷⁴ Listening report, p. 20.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			• there may be health reasons to justify earlier procedures in connection with cryptorchidism. ¹⁷⁵ While there may be good reason to exclude treatment for cryptorchidism from the requirement for individual panel oversight, a better way to do this is through a class exemption order process which allows the oversight panel to consider the evidence and views regarding this genital surgery. The oversight body will be able to permit surgery associated with cryptorchidism based on its merits.
2.1.1(g)	Bladder exstrophy should be outside of scheme scope.	20	 Feedback considered but not incorporated. Evidence from our consultation heard that: there may be strong health reasons to justify urgent procedures in connection with bladder exstrophy;¹⁷⁶ procedures recommended to people with bladder exstrophy can include assumptions made about their gender and sexuality due to their physical characteristics;¹⁷⁷ aesthetic considerations may be relevant in informing which procedure is recommended;¹⁷⁸ and clinicians do not always regard bladder exstrophy as an intersex variation.¹⁷⁹ While there may be good reason to exclude some treatment for bladder exstrophy from the requirement for individual panel oversight, a better way to do this is through the emergency treatment exception (for urgent treatments) and the class exemption order process, which allows the oversight panel to consider all the evidence and views regarding any surgery modifying sex characteristics, and stipulate the conditions for when the exemption can be relied on without further pre-approval from the oversight panel.

¹⁷⁵ Listening report, p. 28.

¹⁷⁶ Listening report, p. 25.

¹⁷⁷ Listening report, p. 20.

¹⁷⁸ Listening report, p. 42.

¹⁷⁹ Listening report, p. 20.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			Given the bladder is not a sex characteristic but bladder and cloacal exstrophy may have closely associated impacts on sex characteristics, we have suggested that for clarity the Minister for Health should be able to prescribe (on the recommendation of the oversight body) physical conditions affecting or in close proximity with sex characteristics to avoid any doubt as to the scope of the scheme.
2.1.1(h)	Kallmann Syndrome should be outside of scheme scope.	20	Feedback considered but not incorporated. The principal reason given for excluding Kallmann Syndrome from scope was that it emerges after birth – at puberty. ¹⁸⁰ However, there is no requirement for an innate variation of sex characteristics to be known at birth (see item 2.1.1(b)). Kallmann Syndrome is listed as an intersex variation in the Victorian Government's <i>Health and wellbeing of people with intersex variations</i> information and resource paper.
2.1.1(i)	Follicle-Stimulating Hormone Insensitivity (FSH) should be outside of scheme scope.	20	Feedback considered but not incorporated. FSH is listed as an intersex variation in the Victorian Government's <i>Health and wellbeing of people with intersex variations</i> information and resource paper.
2.1.1(j)	Polycystic ovary syndrome (PCOS) should be outside of scheme scope.	20	Feedback considered and incorporated in principle. It is only when PCOS involves androgen excess that it may be considered an intersex variation. ¹⁸¹ Given the oversight body will have the ability to recommend to the Minister for Health the declaration of further variations, there will be an opportunity for the oversight body to later recommend the inclusion of variations it considers appropriate.

¹⁸⁰ Listening report, p. 20.

¹⁸¹ Victorian Department of Health and Human Services (2018) *Health and wellbeing of people with intersex variations: information and resource paper.* Initially prepared by T. Jones and W. Leonard; revised and edited J. Rostant on behalf of Department of Health and Human Services 2016–2018 Intersex Expert Advisory Group. Department of Health and Human Services: Melbourne, p. 42.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE	
2.1.2	Universalist versus specific approach			
2.1.2(a)	Ensure endosex trans and gender diverse young people are not captured by the scope of the scheme.	20	Feedback noted and was already incorporated. Only trans and gender diverse people with innate variations of sex characteristics, or innate physical conditions affecting or in close proximity with sex characteristics, are included in the definition of a 'protected person'.	
2.1.3	Technical improvements			
2.1.3(a)	Replace 'ascribe to' with 'conform with' in definition of 'protected person'.	fn14	Feedback incorporated.	
2.1.3(b)	Group together all androgen insensitivity syndromes (CAIS, PAIS and MAIS) in the list of variations.	fn14	Feedback incorporated. The non-exhaustive list of variations has been updated.	
2.1.3(c)	Include the general descriptor 'differences or disorders of sex development' in the list of variations.	fn14	Feedback considered but not incorporated. The purpose of the non-exhaustive list of variations is to give legal clarity by specifying examples of variations which are included in the scheme, without limiting the general definition of 'protected person'. 'Differences or disorders of sex development' is a general descriptor that does not provide legal clarity. Additionally, the language is unnecessarily pathologising and thereby inconsistent with the feedback received in item 1.2.	
2.1.3(d)	Remove 'aphallia' and 'clitoromegaly (also known as enlarged clitoris)' from the list of variations.	fn14	Feedback considered but not incorporated.	

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			Evidence from our consultation heard that these terms were anatomical descriptions rather than diagnoses. ¹⁸² However, they each describe an innate variation of sex characteristics which may be the subject of surgical interventions.
2.1.3(e)	Remove from the list of variations language not commonly used such as 'Meye-Schwickerath's Syndrome, Fraser-Francois Syndrome, Ullrich- Feichtiger Syndrome and XY/XO Mosaics'.	fn14	Feedback considered and incorporated in part. The purpose of the non-exhaustive list of variations is to give legal clarity by specifying examples of variations which are included in the scheme, without limiting the general definition of 'protected person'. The non-exhaustive list of variations has been updated were appropriate.
2.1.3(f)	Ensure the list of variations clarifies that these traits may be <i>'known or</i> <i>formerly known as</i> ' the listed variations.	fn14	Feedback considered but not incorporated. This is not necessary given the oversight body can recommend that the Minister for Health update the non- exhaustive list of variations if terminology changes.
2.2	IN SCOPE TREATMENTS		·
2.2.1	Consider whether invasive genital examinations should be included within scope.	22	Feedback considered and incorporated in part. We acknowledge that genital examinations (whether invasive or not) can cause long lasting trauma for people. Our consultation heard from at least one person who reported genital examinations that were conducted on them as a child without consent and which appear to have been gratuitous. ¹⁸³ The oversight panel will be able to consider the potential for trauma from medical approaches that involve invasive genital examinations when making decisions about medical treatment that would modify a protected

¹⁸² Listening report, p. 21.

¹⁸³ Listening report, p. 49.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			 person's sex characteristics. We have also suggested that individual care plans can include matters about medical treatment performed for the purposes of diagnosis or monitoring. However, the scheme remains focused on medical or surgical procedures or treatments that modify a protected person's sex characteristics in ways which are permanent, only reversible with further invasive medical treatment or, as set out in item 2.2.2, when caused by dilation. A broader prohibition on genital examinations could introduce barriers to accessing diagnostic tests, and so we have not expanded the class of medical treatments prohibited by the scheme. However, we have included a requirement that the statutory review to be conducted after 5 years should consider the scope of medical treatment regulated by the scheme.
2.2.2	Consider whether vaginal dilation should be included within scope.	22	 Feedback considered and amendments made. Evidence from our consultation heard that: people with innate variations of sex characterises could feel pressure or coerced to dilate;¹⁸⁴ vaginal dilation could be recommended by health professionals based on assumptions that the person would wish to engage in penetrative sex;¹⁸⁵ dilation could have significant psychological consequences for a person who undergoes it;¹⁸⁶ and some people with innate variations of sex characteristics were not told that they would need to dilate vaginally until after their surgery had been performed, suggesting that the information provided to them before their surgery was not adequate.¹⁸⁷

¹⁸⁴ Listening report, p. 22.

¹⁸⁵ Listening report, pp. 22, 36.

¹⁸⁶ Listening report, p. 22.

¹⁸⁷ Listening report, p. 36.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			However, there were mixed views among consultation participants about whether changes caused to a protected person's sex characteristics through dilation procedures should be covered by the scheme. ¹⁸⁸ Among the concerns of opponents to the inclusion of dilation procedures were that:
			 dilation could be wholly self-administered, making it different to other types of medical or surgical procedures; and including it within the scheme could discourage people from seeking medical support if they felt they would need to get panel approval.¹⁸⁹
			We agree that there may be some differences in the way that dilation procedures are administered that requires a nuanced approach. However, when dilation is recommended or advised by health professionals for the purposes of changing a person's sex characteristics, it forms part of a medical procedure or treatment. The context in which that medical advice or recommendation is given is the same as for other medical or surgical procedures, and this justifies applying the safeguards for ensuring informed personal consent to dilation procedures.
			By including changes of sex characteristics caused by dilation on the advice or recommendation of a health professional within the scope of 'medical treatment' covered by the scheme, this means that:
			 dilation is still allowed with personal consent – but the scheme can clarify the meaning of 'informed consent' so that people are provided with all the information they need to make an informed decision without pressure or coercion;
			 the oversight body can monitor the use of dilation for changing a protected person's sex characteristics if the person is not able to provide personal consent (for example, because they are too young); and the oversight body can still make a class exemption order excluding dilation in certain circumstances from the scope of the scheme, where it has considered all the relevant evidence and views regarding this procedure and the circumstances in which it may be provided.

¹⁸⁸ Listening report, p. 22.

¹⁸⁹ Listening report, p. 22.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			Accordingly, we have amended the definition of 'medical treatment' and 'modifies' to ensure modifications of sex characteristics caused by dilation are within the scope of the scheme, meaning the same safeguards ensuring personal informed consent are in place.
2.2.3	Ensure each part of a treatment can be considered separately by the panel.	23	Feedback noted and already incorporated. This is already incorporated in the definition of 'medical treatment', which can include part of a surgical or medical treatment or procedure.
2.2.4	Consider whether the panel should have a role in regulating pre-natal treatment.	23	 Feedback considered and further review needed. This scheme is currently premised on there being a person with innate variations of sex characteristics who has individual legal rights and protections, including a significant and profoundly personal interest in deciding what happens to their own body. That means that this scheme operates from birth, when an individual's right to make decisions about their own medical treatment can be separated from the rights of another person who may be making decisions about their own medical treatment during pregnancy or pre-conception. Pre-natal treatment is currently partially regulated under the <i>Assisted Reproductive Treatment Act 2008</i> (Vic), with the Patient Review Panel established under that Act having a role in approving certain procedures for the purposes of sex selection.¹⁹⁰ However, there are questions about the efficacy of that legal scheme due to the interpretation which might be given to the exception in s 28(2)(a) of the Act. Namely, it is important to clarify whether that exception may allow sex selection procedures to occur for certain intersex variations that are considered transmissible 'genetic abnormalities' or 'genetic diseases'. Accordingly, we recommend reviewing s 28 of the <i>Assisted Reproductive Treatment Act 2008</i> (Vic), clarifying the interpretation of s 28(2)(a), and regulating the issue of pre-natal treatment through the existing mechanisms.

¹⁹⁰ Assisted Reproductive Treatment Act 2008 (Vic), s 28.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE		
2.3	Consider whether definition of 'medical treatment' should be the same as <i>Medical Treatment and Planning</i> <i>Decisions Act 2016</i> (Vic).	23	Feedback considered but not incorporated. The definition of 'medical treatment' in the <i>Medical Treatment and Planning Decisions Act 2016</i> (Vic) is too broad and captures medical treatments which are not relevant for this scheme (such as dental treatment). Consistent with what we heard during the consultation, it is important that the definition of 'medical treatment' captures medical (including surgical or hormonal) treatments that modify sex characteristics, as well as discrete <i>parts</i> of a treatment, so that the oversight body has the power to consider whether certain parts of a treatment should be allowed or not.		
2.4	CRIMINALISATION				
2.4.1	Remove criminal offences (leaving only civil prohibitions).	24	Feedback considered but not incorporated. There were mixed views in our consultation regarding criminalisation as a mechanism for achieving reform. Proponents of criminalisation said it was necessary to effect change, would convey the seriousness of the prohibition and was justified given the offences could be clearly defined. Opponents of criminalisation were concerned about unintended adverse effects, including its potential to discourage access to treatment which may be needed and the effectiveness of criminal enforcement mechanisms. ¹⁹¹ We agree that governments should not criminalise conduct without good reason. However, given what is envisaged is a scheme which allows people to rely on certain exceptions and oversight processes, the seriousness of potential impacts for people (particularly children) from 'normalising' surgeries being performed without personal consent or appropriate justification deserves admonishment through appropriately drafted offences.		

¹⁹¹ Listening report, pp. 24, 36, 38.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			 These offences would be similar to many other offences already in place to protect the rights of people in vulnerable situations, such as: offences for carrying out special medical procedures without the consent of the Victorian Civil and Administration Tribunal (VCAT);¹⁹² offences relating to the use and storage of gametes and embryos in fertility treatments;¹⁹³ offences relating to female genital mutilation;¹⁹⁴ offences relating to breaches of the safeguards around voluntary assisted dying procedures;¹⁹⁵ offences relating to conversion practices;¹⁹⁶ and offences relating to administering medical research procedures without consent or without approval.¹⁹⁷ To address any potential unintended adverse effects of criminalisation, we have proposed some amendments that reflect the approach taken in the <i>Change or Suppression (Conversion) Practices Act 2021</i> (Vic), namely, a general prohibition followed by specific targeted criminal prohibitions dealing with intentional misconduct.
2.4.2	Alternatively, limit criminal offences to wilful conduct (not recklessness) and do not reverse the burden of proof for defences.	24	Feedback incorporated. We generally agree that people should not be criminalised if they have done all they can do to comply with the scheme. For example, they may have believed that a 16-year-old could provide informed personal consent to a medical procedure, only to have a court later declare that they did not have legal capacity.

¹⁹² Guardianship and Administration Act 2019 (Vic), s 147.

- ¹⁹⁴ Crimes Act 1958 (Vic), ss 32-34A.
- ¹⁹⁵ Voluntary Assisted Dying Act 2017 (Vic), ss 83-91.

¹⁹⁶ Change or Suppression (Conversion) Practices Prohibition Act 2021 (Vic), ss 10-14.

¹⁹⁷ Medical Treatment Planning and Decisions Act 2016 (Vic), ss 84-85.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

¹⁹³ Assisted Reproductive Treatment Act 2008 (Vic), ss 26-37.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			However, generally speaking, the onus must be on the person who is providing medical treatment to ensure they have the proper consent or authorisation to proceed with medical treatment. Accordingly, there are elements of a criminal offence where it is appropriate to place a requirement to undertake proper inquiries, and for which recklessness may be the more appropriate legal standard. We have amended the criminal prohibitions to make clearer when intention, knowledge or recklessness (as appropriate) is required in respect of each particular element of the offence. This would ensure that the criminal offences capture conduct which is designed to evade the scheme or intentionally breach it.
2.4.3	Further or alternatively, protect clinicians from any misconduct for providing treatment they consider to be in the best interests of a patient at the time.	24	 Feedback considered but not incorporated. The emergency medical treatment exception found in section 53 of the Medical Treatment Planning and Decisions Act 2016 (Vic) allows medical practitioners to make split-second decisions in cases of strict emergencies where it is not possible to obtain consent and action must be taken to avoid catastrophic consequences to the person. This emergency exception will be preserved, and protects a medical practitioner's professional judgement when based on reasonable grounds and made in cases of real urgency. The criminal prohibitions have also been clarified to ensure that they capture conduct which is designed to evade the scheme or intentionally breach it. Otherwise, it would be inappropriate to enable clinicians to simply evade the scheme simply because they believe they are acting in their patient's best interests. Informed consent is a pillar of good medical practice, and no law currently allows medical practitioners to simply administer treatment to someone simply because they believe it to be in their best interests without informed consent (other than in strict emergencies as set out above).
2.4.4	Replace criminal option with resources for informed consent, standardised pathways, and psychological and peer support, with follow ups around satisfaction with surgery for 15 years.	24	Feedback considered but not incorporated. While the scheme puts in place the framework for ensuring either personal consent to medical treatment or a pathway through the oversight body, as well as the option of psychological and peer support, it is clear that existing standards and laws on their own have not prevented some parents from feeling pressured to consent to

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			medical treatment on behalf of their children, or regretting decisions they have made. ¹⁹⁸ There is a need to respond to the environment in which these decisions are currently made by parents to redress an imbalance of power and knowledge (including knowledge gained through lived experience). That is what the oversight body framework allows to occur.
2.4.5	Make criminal offences clearer in prohibiting masculinising or feminising surgeries.	24	Feedback considered but not incorporated. The problem with any prohibition is how to define it (and its exceptions) to ensure that it is sufficiently certain, considers the individual circumstances of each person (including circumstances which are difficult to predict or know in advance), and does not delay or deny treatment to a person which is necessary or wanted by the person. While we considered a general prohibition on masculinising or feminising surgeries, it became very difficult to define in practice – particularly when treatments (such as hormonal treatments) have an incidental or ancillary masculinising or feminising effect, or a mixture of effects which are not easily categorised in male/female binaries. We think the better approach is to put in place a series of broader principles, a good process that allows the scrutiny and testing of evidence and claims, and a legal test which allows decision-makers to consider each case on its merits so decisions can be tailored to the needs of the particular person. For that reason, we think the amended decision-making approach (discussed in item 6.3.3(a)) below achieves this objective in a legally defensible way that protects the rights of the individual but minimises the risk of unintended consequences. One of the principles incorporated into the decision-making test is to ensure that the panel does not presume <i>without evidence</i> that a person with innate variations of sex characteristics would experience any social or psychosocial benefits from having their sex characteristics function or appear in a manner which conforms with norms for persons without that variation. Evidence of social and psychosocial benefits can only be considered if it comes directly from the protected person, or is specific to the protected person, not otherwise speculative or general in nature, and has substantial probative value. This limits purely cosmetic rationales in decision-making.

¹⁹⁸ Listening report, pp. 39-40.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE	
2.4.6	Remove extraterritorial offences.	24	Feedback considered but not incorporated. There are strong precedents for extraterritorial offences where there is the risk of a person evading the protection offered to another person under a local legal regime by going outside the jurisdiction. ¹⁹⁹ Additionally, many offences have extraterritorial elements provided there is some connection to the local jurisdiction (as there would be with a Victorian resident taking a Victorian child outside its territory for acts that could not be performed in Victoria). ²⁰⁰ Extraterritorial offences, when drafted appropriately, protect the integrity of the local law against evasion. That risk will be heightened given Victoria will be the first state to prohibit practices that our consultation revealed have occurred or continue to occur in other places in Australia and overseas. ²⁰¹	
3	EXCEPTIONS			
3.1	EMERGENCY TREATMENT			
3.1.1	Consider or clarify the meaning of 'distress' in the proposed exemption.	25	Feedback considered and already incorporated. We've clarified that that the emergency medical treatment exception should be modelled on (although not necessarily identical to) section 53 of the <i>Medical Treatment Planning and Decisions Act 2016</i> (Vic). It is important that urgent medical treatment is not denied or delayed, including because of confusion about inconsistent standards.	

²⁰¹ Listening report, p. 24.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

¹⁹⁹ See, for example, *Crimes Act 1958* (Vic), s 33 (offence to take a person from the State with the intention of having prohibited female genital mutilation performed); *Change or Suppression (Conversion) Practices Prohibition Act 2021* (Vic), s 12 (offence of taking a person from Victoria for a change or suppression practice); *Criminal Code Act 1995* (Cth), Schedule, s 271.4(2) (offence of trafficking in children), s 271.7B(2) (offence of organ trafficking); Division 272 (child sex offences outside Australia).

²⁰⁰ See, for example, *Crimes Act 1958* (Vic), s 80A (fraud and blackmail offences); *Criminal Code Act 1995* (Cth), Schedule, ss 15.1-15.4; ss 115.1-115.4 (murder, manslaughter or causing serious harm to an Australian citizen or a resident of Australia).

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			Among other requirements, the emergency medical treatment exception currently requires a medical practitioner to believe on reasonable grounds that the treatment is necessary, as a matter of urgency, to save the person's life, prevent <i>serious</i> damage to the person's health, or prevent the person from suffering or continuing to suffer <i>significant</i> pain or distress. The exception therefore clarifies that the use of the exception must be exercised reasonably, in cases of urgency and where the consequences (including any pain or distress) are significant not slight. Our proposal is that the oversight body also can monitor any use of this exception through mandatory reporting obligations.
3.1.2	Consider or clarify the meaning of 'urgent' in the proposed exemption.	25	Feedback incorporated. We've clarified that that the emergency medical treatment exception should be modelled on (although not necessarily identical to) section 53 of the <i>Medical Treatment Planning and Decisions Act 2016</i> (Vic). Among other requirements, the emergency medical treatment exception requires a medical practitioner to believe on reasonable grounds that the treatment is <i>necessary</i> , as a matter of <i>urgency</i> , to save the person's life, prevent serious damage to the person's health, or prevent the person from suffering or continuing to suffer significant pain or distress.
3.1.3	Consider potential for the exemption to be used for psychosocial rationales.	25	Feedback noted. As explained in item 3.1.1 and 3.1.2 above, the emergency treatment exception has a limited purpose and has a number of safeguards against misuse, including that the procedure must be both urgent <i>and</i> necessary to avoid certain significant consequences for the individual, such threats to their life, <i>serious</i> damage to their health, or <i>significant</i> pain or distress. Given the narrow scope of the exception and the need to ensure consistency with existing law, we do not propose to make further changes.
3.1.4	Ensure emergency treatment exception can be used to enable the	25	Feedback incorporated.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
	closure of a bladder for a person born with bladder exstrophy and cortisol to address salt wasting CAH.		The bladder is not a 'sex characteristic' (as defined by this scheme), therefore there is no prohibition to medical treatments that involve its modification (including its initial closure). If the surgery to close the bladder also involved a permanent or difficult-to-reverse modification to a sex characteristic (such as genitalia), there are three ways in which this surgery may be permitted by the scheme:
			 under emergency treatment exception (this would depend on the extent of the treatment and whether it was both urgent and necessary to save the person's life, prevent serious damage to the person's health, or prevent the person from suffering or continuing to suffer significant pain or distress); under an individual care plan; or under a class exemption order.
			To provide further clarity, we have clarified that the oversight body can make (subject to the recommend safeguards) class exemption orders in respect of any medical treatment that may have associated affects or impacts on sex characteristics.
			It is our understanding that the absence of cortisol for people with CAH could lead to adrenal crisis which is life- threatening. Based on that understanding, even if cortisol treatment had a permanent or difficult-to-reverse effect on a person's sex characteristics, it would be permitted by the emergency treatment exception we have already proposed.
3.2	MALE CIRCUMCISION		
3.2.1	Remove exception (i.e. prohibit male circumcision for non-medical reasons).	25	Feedback considered but not incorporated. Consultation participants had mixed views on the issue of male circumcision. ²⁰² Whatever those views, we agree with the observation made by some participants that a scheme applying only to people with innate variations of sex characteristics would not be the correct vehicle through which to respond to a procedure or ritual performed

²⁰² Listening report, p. 25.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE		
			on a much broader part of the population, whether for medical or non-medical purposes. ²⁰³ A debate on circumcision broadly would require a consultation among, and with, the broader population.		
3.2.2	Ensure male circumcision exception cannot be used to authorise treatment for hypospadias.	25	Feedback incorporated. We have ensured the circumcision exception covers medical treatment that involves ' <u>no more</u> than the circumcision of a protected person's penis through the removal of a foreskin covering the glans'.		
4	OVERSIGHT BODY - ESTABLISHMENT AND COMPOSITION				
4.1	GENERAL VIEWS ON THE PANEL				
4.1.1	View of parents				
4.1.1(a)	Consider concerns regarding additional stress and distress placed on parents when going through panel process.	27	 Feedback incorporated. We have made several amendments to the scheme to mitigate any stress or distress which some parents may feel in going through a panel process including: reducing the number of panel members – from 9 to 5 members for a full panel, and 3 members for a sub-panel; ensuring family members of persons with innate variations of sex characteristics can be represented as panel members on the panel; ensuring the oversight body: must act fairly and comply with the rules of natural justice (which include hearing from all affected parties such as the parents); 		

²⁰³ Listening report, pp. 25-26.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			 conduct the hearing of any matter with as little formality and technicality as possible, and determine matters as expeditiously as possible; is not bound by formal rules of evidence or practices or procedures applicable to courts; providing the oversight body with a mechanism to refer parents to peer support and counselling if that is appropriate; ensuring that parents are invited to any meetings of the oversight panel and can provide their views on any decisions being made by the oversight panel in respect of their child, and requiring that the oversight panel take these views into account; ensuring that lawyers are not involved in proceedings without leave of the Chair of the oversight panel; ensuring parents are 'interested persons' entitled to bring their own applications for an individual care plan for their child to the oversight body, request written reasons for a panel's decision made in respect of their child, and appeal decisions of the oversight panel; ensuring parents benefit from the confidentiality protections of the scheme in the same way as their child; and placing duties on panel members to act with integrity, impartially, respectfully, fairly and accountability when performing their roles and allowing the Chair to receive and resolve complaints regarding the failure of a panel member to comply with their obligations. However, we also heard from some parents in our consultation who said that they felt unsupported or pressured when making decisions for their child (including some decisions they now regret or feel guilty about) under existing arrangements without such a scheme.²⁰⁴ One parent told us that existing medical ethical processes excluded them, and they wanted parents to have a seat at the table.²⁰⁵ For those parents, this scheme may give them the support and assurance they need to take comfort that their child's best interests are central to decision-making.

²⁰⁴ Listening report, pp. 27-28.

²⁰⁵ Listening report, p. 27.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
4.1.1(b)	Consider concerns regarding invasiveness of ongoing monitoring procedures.	27	Feedback incorporated. When making decisions, the oversight panel must consider the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing).
4.1.1(c)	Ensure no blanket prohibition on surgeries.	27	Feedback considered and incorporated in part. As set out in item 6.3.3(a), we have strengthened the decision-making framework which must be followed by the oversight panel. When making decisions, the panel must consider the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing). Ultimately, this scheme is about ensuring that people with innate variations of sex characteristics have the right to decide what happens to their bodies to the maximum extent possible. Where a person does not have capacity to consent to treatment, the scheme's purpose is not to prohibit medical treatment modifying a protected person's sex characteristics which is justified but to ensure claims can be properly scrutinised and weighed up against every important consideration, including the risks of any procedure. What the panel cannot do is presume <i>without evidence</i> that a person with innate variations of sex characteristics would experience any social or psychosocial benefits from having their sex characteristics function or appear in a manner which conforms with norms for persons without that variation. Evidence of social and psychosocial benefits can be considered if it comes directly from the protected person, or is specific to the protected person, not otherwise speculative or general in nature, and has substantial probative value. This is to ensure that claims or assumptions made on behalf of a protected person whose voice cannot be heard are properly scrutinised.
4.1.1(d)	Parents should have ultimate say in deciding on treatments for their children.	16,27	Feedback considered but not incorporated. The scheme ensures that parents can provide their views on any decision being made by the oversight panel in respect of their children and requires the oversight panel to take their views into account. The scheme also includes a number of rights and protections for parents, as set out in item 4.1.1(a). However, this feedback mistakenly assumes that parents currently have the ultimate say in deciding on treatments for their children. While people with parental responsibility can generally give consent to medical

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			treatment on behalf of a child, there is an implicit constraint that parental authority must be exercised in the best interests of the child. ²⁰⁶ Courts can (and do) step in to override decisions of parents when they are not in the best interests of their child. ²⁰⁷ This scheme would mean that a specialist panel (rather than a court) could override the decision of a parent to authorise or withhold treatment which modifies the sex characteristics of their child if the decision were not in the child's best interests, but without the cost, expense or formality of a court proceeding.
4.1.1(e)	Consider the extent to which parents' views should be determinative or persuasive in panel deliberations.	27	Feedback considered and some amendments made. The scheme ensures that parents can provide their views on any decision being made by the oversight panel in respect of their children and requires the oversight panel to take their views into account. The scheme also includes a number of rights and protections for parents, as set out in item 4.1.1(a). Ultimately, the weight given to the views of parents in an individual matter will depend on the circumstances of the case and the oversight panel must make its decisions by reference to what is in the best interests of the child.
4.1.1(f)	Ensure parents have a 'seat at the table'.	16,27	Feedback incorporated. The scheme provides a number of rights and protections for parents, as set out in item 4.1.1(a). These include the right to be heard in any decision made in respect of their children.
4.1.1(g)	Ensure scheme is not intimidating or overwhelming for parents.	27	Feedback incorporated. As set out in item 4.1.1(a), the scheme provides a number of rights and protections for parents to ensure it is not intimidating or overwhelming for parents.

²⁰⁷ See <u>Marion's Case</u>.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

²⁰⁶ <u>Marion's Case</u>, particularly at [26]-[27] per Mason CJ, Dawson, Toohey and Gaudron JJ.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
4.1.1(h)	Ensure the panel can make decisions in the best interests of the child.	27	Feedback incorporated. As set out in item 6.3.3(a), the test by which the oversight panel has to make decisions about medical treatment modifying the sex characteristics of children is now framed by reference to the best interests of that child, as defined below.
4.1.1(i)	Ensure the panel can consider evidence from past matters.	28	Feedback incorporated. We have amended the proposal to allow the oversight panel to take into account evidence derived from its past decisions.
4.1.2	Clinical views		
4.1.2(a)	Consider utilising the existing multidisciplinary forum in lieu of the panel.	28	 Feedback considered but not incorporated. This suggestion is not consistent with the Victorian government policy in (i) am Equal and does not meet many of the demands and expectations we heard in our consultation from many consultation participants, including for: protections for people with innate variations of sex characteristics that respect their right to make decisions about their own bodies – only a legal scheme that centres personal consent in medical decision-making can achieve this; the full and equal inclusion of people with lived experience in decision-making, including in a neutral if not affirming environment for people with innate variations of sex characteristics; transparency in decision-making – only a legal scheme that removes liability from clinicians that provide personal data subject to confidentiality obligations and imposes new confidentiality protections can achieve this; and a process that gives parents a 'seat at the table' and a right to be heard. In our consultation, we observed a strong division between those who felt supported by and satisfied with existing processes and those who did not. In that context, it is difficult to see how you could build trust and confidence

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			among many people with variations of sex characteristics and some parents by using an existing framework which many approach with strong feelings of distrust, disappointment and even anger.
			Some clinicians in our consultation believed strongly in the robustness of the existing multidisciplinary processes. Equality Australia's Legal Director was invited to observe one meeting of a clinical multidisciplinary meeting at RCH subject to a confidentiality undertaking. To honour that confidentiality undertaking, the details of matters observed cannot be disclosed here without permission from the RCH. However, the confidential nature in which that forum operates and the inability to talk about what takes place in it without specific consent of every party involved means it is impossible for others to test how well it protects the rights of children.
			Overall, based on our consultation and what was observed about the process and discussion at the multidisciplinary team meeting, it is our opinion that the oversight panel provides a better forum for ensuring:
			 there is a dynamic exchange between people with different experiences and expertise directed to the ultimate question of protecting the interests of the protected person; all decisions are guided by a structured decision-making framework that ensures appropriate considerations are taken into account (and given due weight) and inappropriate considerations are not; the protected person (whether directly or through an independent advocate) and parents have a voice in the process which is heard directly; there can be transparency (while maintaining confidentiality) over what is discussed and what decisions are made on behalf of a protected person; and there is clear accountability and independence in decision-making, including protections to ensure procedural fairness, the management of potential conflicts of interests, a right to know the reasons for decisions and an ability to appeal decisions which may be wrong.
4.1.2(b)	Concern that individualised care plans will become <i>pro forma</i> and not patient- centred and individualised.	28	 Feedback incorporated. We have included a broad list of matters which can be included in an individual care plan to ensure care plans can be patient-centred and individualised. Apart from the details of any medical treatment (including medical treatment modifying a protected person's sex characteristics), among the matters that they can now include are: referrals to peer support, psychological support and counselling, including by whom and when;

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			 information that will be made available to the protected person, including by whom and when; records which must be retained and how and when they will be provided to the protected person.
4.1.2(c)	Concern that panel will not consider unique circumstances of each case, including unique medical needs and familial circumstances.	28	Feedback noted and already incorporated. As set out in item 6.3.3(a), the oversight body will be able to (and, in fact, must) consider the unique circumstances of each case, including unique medical needs and familial circumstances. It is required to hear the views of the protected person (whenever they can be expressed) and their parents (if the protected person is under 18) and take those views into account. When making decisions, the panel must consider the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing). What the panel cannot do is presume <i>without evidence</i> that a person with innate variations of sex characteristics would experience any social or psychosocial benefits from having their sex characteristics function or appear in a manner which conforms with norms for persons without that variation. Evidence of social and psychosocial benefits can be considered if it comes directly from the protected person, or is specific to the protected person, not otherwise speculative or general in nature, and has substantial probative value. This is to ensure that claims or assumptions made on behalf of a protected person whose voice cannot be heard are properly scrutinised.
4.1.2(d)	Concern that delaying treatment for undescended testes would lead to poorer fertility outcomes and cancer risk.	28	 Feedback considered and further amendments incorporated. As set out in item 6.3.3(a), we have strengthened the decision-making framework which must be followed by the oversight panel. The oversight panel will be able to take into account the option of allowing medical treatment that preserves options for the protected person in the future (such as their fertility), as well as any likely adverse consequences to the protected person's health of the proposed medical treatment not being provided. To ensure there are no delays that would affect a person's health, the scheme includes a number of safeguards, including: the oversight body must make its decisions as expeditiously as the matter allows; the oversight body can be constituted as a 3-member sub panel to enable it to make faster decisions in less contentious cases; and

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			 if there is a class of medical treatment which is always preferrable, the oversight body can make a class exemption order allowing it to occur without an individual application. The scheme's purpose is not to prohibit medical treatment modifying a protected person's sex characteristics which is justified but to ensure claims, such as opinions as to the risk of cancer, can be properly scrutinised and weighed up against every important consideration, including the risks of any procedure.
4.1.2(e)	Concern that the proposal would delay treatment because it is easier to defer treatment than go through exemption process.	28	 Feedback considered and further amendments incorporated. A health professional who deferred necessary treatment simply to avoid going through a regulatory process would risk liability for medical negligence and professional misconduct. As set out in 4.1.2(d) above, the scheme includes a number of safeguards to protect against delays that would affect a person's health.
4.1.2(f)	Studies on people with feminising genioplasties report that the vast majority of people with CAH preferred surgery done in infancy rather than later.	28	Feedback considered and further amendments incorporated. As set out in item 6.3.3(a), we have made strengthened the decision-making framework which must be followed by the oversight panel. When making decisions, the panel must consider the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing). The scheme's purpose is not to prohibit medical treatment modifying a protected person's sex characteristics which is justified but to ensure claims, such as general evidence as to preferences for earlier surgery, can be properly scrutinised and weighed up against every important consideration particular to that person, including the risks of any procedure and the principle that every individual has a significant and profoundly personal interest in deciding what happens to their own body. What the panel cannot do is presume <i>without evidence</i> that a person with innate variations of sex characteristics would experience any social or psychosocial benefits from having their sex characteristics function or appear in a manner which conforms with norms for persons without that variation. Evidence of social and psychosocial benefits can be considered if it comes directly from the protected person, or is specific to the protected person,

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			not otherwise speculative or general in nature, and has substantial probative value. This is to ensure that claims or assumptions made on behalf of a protected person whose voice cannot be heard are properly scrutinised.
4.1.2(g)	Concern that parents would be frustrated and distressed by a panel process and this would exacerbate impacts on clinicians who already try to tell them to wait.	28	 Feedback considered and further amendments made. As set out in item 4.1.1(a), the scheme provides a number of rights and protections for parents to ensure they are not frustrated or distressed by the panel process. Clinicians who currently feel pressure from parents advocating for earlier interventions will be able to point to the law to help manage the expectations of parents. If parents do not agree with the assessment of a clinician and believe that their child's best interests would be better served by medical treatment modifying their sex characteristics before the child is able to provide personal consent, they will be able to apply to the oversight body and make their views known.
4.1.2(h)	Parents are already subject to legal limits on their ability to consent for their children.	28	Feedback noted. As set out in item 4.1.1(d), this is a correct statement of law. However, given the Family Court's decision in <i>Re Carla</i> , it is clear that the Family Court regards at least some treatment as therapeutic and within the scope of parental authority, ²⁰⁸ thereby oversight is often not required in these cases. This scheme would ensure the protected person's significant and profoundly personal interest in deciding what happens to their body is given sufficient weight in a manner in which the current legal framework does not allow.
4.1.2(i)	The approach is arbitrary or exceptional.	28	Feedback noted. This is an incorrect statement of the law. A number of medical procedures are regulated through an oversight panel or tribunal process including:

²⁰⁸ *Re Carla (Medical Procedure)* [2016] FamCA 7 at [52].

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			 special medical procedures under the <i>Guardianship and Administration Act 2019</i> (Vic), which require consent from VCAT.²⁰⁹ They include procedures that are reasonably likely to have the effect of rendering permanently infertile the person on whom it is carried out; the termination of a pregnancy; and the removal of tissue for the purposes of transplantation to another person;²¹⁰ certain assisted reproductive treatments under the <i>Assisted Reproductive Treatment Act 2008</i> (Vic), which require the approval of the Patient Review Panel. They include surrogacy arrangements; the use of gametes or embryos for sex selection; and the treatment of a patient who does not meet the criteria under the Act;²¹¹ electroconvulsive treatment on a young person or without consent, or neurosurgery for mental illness, under the <i>Mental Health Act 2014</i> (Vic), which requires Mental Health Tribunal approval;²¹² voluntary assisted dying under the <i>Voluntary Assisted Dying Act 2017</i> (Vic), which requires a number of disclosures to be made to the Voluntary Assisted Dying Review Board for the purposes of it reviewing the exercise of any function or power under the Act.²¹³
4.1.2(j)	The proposal would impose a huge workload on the panel and clinicians (e.g. up to 5% of boys are born with undescended testes; 1 in 300 children are born with hypospadias).	28	Feedback considered and incorporated in part. We agree that funding will be necessary to ensure the panel and the people who interact with it are appropriately supported to facilitate their involvement in the panel process. Through mandatory reporting obligations, the oversight scheme will provide data on the actual number of procedures which are performed without personal consent to modify the sex characteristics of children with undescended testes or hypospadias. This will provide a robust evidence base that will allow the oversight body to

²⁰⁹ Guardianship and Administration Act 2019 (Vic), Part 6 (it is an offence under s 147 to carry out a special medical procedure without the consent of VCAT).

²¹⁰ Guardianship and Administration Act 2019 (Vic), s 140 (definition of 'special medical procedure').

²¹¹ See e.g. Assisted Reproductive Treatment Act 2008 (Vic), ss 10(1)(b)(ii), 28(2)(b), 39, 47 and 85.

²¹² Mental Health Act 2014 (Vic), ss 92, 100.

²¹³ See e.g. Voluntary Assisted Dying Act 2017 (Vic), ss 90 and 93.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			use the tools at its disposal (such as class exemption orders and the possibility of a 3-member sub panel) to deal efficiently with justified medical treatments, if they are indeed not contentious and should be permitted without further individual consideration.
			However, this feedback assumes that every child with undescended testes or hypospadias is likely to receive medical treatment that modifies their sex characteristics in permanent or difficult-to-reverse ways. If that is correct, then this reinforces the need for oversight to ensure these procedures are necessary.
			For more information on the approach to hypospadias and undescended testes, see items 2.1.1(e) and 2.1.1(f).
			For more information on measures to mitigate the risk of delay, see item 4.1.2(d).
4.1.2(k)	It will take enormous resources and time for the panel to determine whether a person had capacity to consent.	29	 Feedback considered and incorporated in part. We agree that funding will be necessary to ensure the panel is appropriately supported to be able to obtain evidence regarding a person's capacity to consent. But the task facing the panel is no different to that which is currently undertaken by clinicians under the <i>Medical Treatment Planning and Decisions Act 2016</i> (Vic) and by several panels, tribunals and courts, including VCAT, the Mental Health Tribunal and Voluntary Assisted Dying Review Board. We have suggested the same legal test for capacity to consent which is currently used across Victorian laws, ²¹⁴ and have suggested that the oversight panel be able to seek the opinion of an expert as to the protected person's capacity to provide personal consent.
4.1.2(1)	Burden of proof placed on clinicians to prove the harm of delaying a procedure is unreasonable and difficult to meet.	29	Feedback considered and amendments made. As set out in item 6.3.3(a), we have strengthened the decision-making framework which must be followed by the oversight panel. We have also refocused the test away from a universal presumption of deferability to one which

²¹⁴ Medical Treatment Planning and Decisions Act 2016 (Vic), s 4; Guardianship and Administration Act 2019 (Vic), s 5; Mental Health Act 2014 (Vic), s 68; and Voluntary Assisted Dying Act 2017 (Vic), s 4.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			balances all relevant considerations against an individual's significant and profoundly personal interest in deciding what happens to their own body.
			As set out in item 7.3.1(a), we have strengthened the ability of the oversight panel to seek evidence, including through the appointment of an independent expert to provide recommendations on matters sought by the oversight panel. Clinicians will be able to provide their own views to the oversight panel, but there is no burden of proof placed on them. The burden rests with the oversight panel to be satisfied of the matters necessary for it approve certain medical treatment, and the oversight panel is given powers to request information and obtain evidence (including expert opinion) in order to do so.
4.1.2(m)	Clinicians will become disengaged from work in this area, find the burdens professionally unrewarding or risks too great, leading to skills shortages.	29	Feedback noted. We agree that the potential for skills shortages is a relevant consideration in determining the best approach to regulation. However, clinical disengagement is not a sound basis for allowing procedures to be performed, particularly on children, if they are not justified. Clinicians will still be able to perform procedures which are justified, following an oversight process that is similar to the process followed by a number of other panels and tribunals in other medical contexts (see items 2.4.1 and 4.1.2(i)). We have also suggested a 5-year statutory review period so that the scheme's effectiveness and operation can be reviewed.
4.1.2(n)	Clinicians will lose skills while there is a moratorium on surgeries until children can consent.	29	Feedback noted. The loss of clinical skill is not a sound basis for allowing procedures to be performed, particularly on children, if they are not justified. Clinicians will still be able to perform procedures which are justified, following an oversight process that is similar to the process followed by a number of other panels and tribunals in other medical contexts (see items 2.4.1 and 4.1.2(i)). We have also suggested a 5-year statutory review period so that the scheme's effectiveness and operation can be reviewed.
4.1.2(o)	Clinicians would need additional funding to address additional workload.	29	Feedback noted. We agree that funding will be necessary to ensure the panel and the people who interact with it are appropriately supported to facilitate their involvement in the panel process.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
4.1.2(p)	The proposal does not reflect the quiet majority of past patients who were happy with the results of their medical treatment.	29	 Feedback considered and further amendments made. Our consultation heard from people who were satisfied with medical procedures performed on their sex characteristics as children,²¹⁵ as well as parents who felt supported by their children's medical teams.²¹⁶ However, our consultation also heard from: people who were satisfied with medical procedures performed on their bodies but who objected to those decisions being made for them in the way they had been;²¹⁷ people who were not satisfied with medical procedures performed on their sex characteristics;²¹⁸ people who were unhappy with the way in which these procedures were explained to them (including the information provided to them about their variations and the proposed procedure);²¹⁹ and parents who felt pressured to make decisions about procedures to be performed on their children.²²⁰ All of these views were taken into account, particularly the testimonies of people with innate variations of sex characteristics who shared with us positive experiences they had of their medical treatments. All personal testimonies were critical in our thinking to: as set out in item 6.2.1(a), strengthen the provisions around informed consent, to ensure that people who have the capacity to provide personal consent are given the opportunity to do so in a fully informed way;

²¹⁵ Listening report, pp. 38-39.

²¹⁶ Listening report, pp. 36, 40.

²¹⁷ Listening report, pp. 36, 38-39.

²¹⁸ Listening report, p. 38.

²¹⁹ Listening report, p. 49.

²²⁰ Listening report, pp. 39-40.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			 as set out in item 6.3.3(a), strengthen the decision-making framework which must be followed by the oversight panel. In so doing, we have refocused the test away from a universal presumption of deferability to one which balances all relevant considerations against an individual's significant and profoundly personal interest in deciding what happens to their own body; and as set out in item 7.3.1(a), strengthen the ability of the oversight panel to seek reliable evidence, including from people with lived experience themselves and including on any benefits of procedures being performed earlier.
			The scheme's purpose is not to prohibit medical treatment modifying a protected person's sex characteristics which is justified but to ensure claims, such as general evidence as to preferences for earlier surgery, can be properly scrutinised and weighed up against every important consideration particular to that person, including the risks of any procedure and the principle that every individual has a significant and profoundly personal interest in deciding what happens to their own body.
4.1.2(q)	Lawyers and community representatives are not in a better position than clinicians to judge the nuances of clinical situations.	29	 Feedback noted. Clinicians, and clinical evidence, are a fundamental part of this scheme. This can be seen through: the mandatory seats allocated to health professionals on the panel; the ability of the oversight panel to obtain information and other evidence from the health professionals involved in the care of the protected person, as well as evidence on areas of medical research and from independent specialists and experts; and the requirement for the oversight panel to have regard to the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing), which necessarily requires the consideration of clinical evidence. So while clinicians may be in a unique position to provide a clinical view informed by their experience, so too will others on the panel who will bring different and equally important perspectives. As set out in item 4.1.2(p), people with variations of sex characteristics and their parents do not always report positive experiences of their interactions in medical settings.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			 This scheme follows other examples which recognise that a diversity of experience and perspectives makes for better decision-making, including: the Mental Health Tribunal, which includes legal, psychiatric, registered medical practitioner and
			 community members;²²¹ and VCAT, which includes lawyers and members with subject matter expertise.²²²
4.1.2(r)	The panel would be able to override medical evidence.	29	 Feedback noted. The oversight body, like any public authority decision-maker, must consider and weigh up all relevant evidence in order to make a decision in accordance with the law. If relevant medical evidence is before the panel, the panel must consider it properly – it cannot ignore evidence. Among the implied public law duties that an oversight body must follow when making decisions are: a duty to afford procedural fairness; a duty to make decisions lawfully, including applying the decision-making framework correctly and following the procedures set down by the law; a duty to take into account relevant considerations and ignore irrelevant considerations; and a duty to make decisions which are legally reasonable.²²³
			 We have also suggested that the scheme include a number of explicit obligations, including: that the oversight body must act fairly and according to the substantial merits of the case when making decisions; that the oversight body must take into account certain mandatory considerations when making decisions regarding medical treatment, including:

²²¹ Mental Health Act 2014 (Vic), s 159.

²²² Victorian Civil and Administrative Tribunal Act 1998 (Vic), ss 13-14.

²²³ See, for example, *Minister for Immigration and Citizenship v Li* [2013] HCA 18.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			 the likely benefits and risks of the proposed medical treatment to the protected person's health; any likely adverse consequences to the protected person's health of the proposed medical treatment not being provided; any alternatives to the medical treatment being proposed, and the likely benefits and risks of those alternatives; that panel members must act with integrity, impartially, respectfully, fairly and accountability when performing their roles; that panel members must maintain relevant professional registrations, accreditations or qualifications necessary for their role; and that panel members must attend such training and development as requested by the Chair from time to time. This feedback assumes that medical evidence is incontrovertible when there may be disputes among medical experts. The panel will be required to assess all the evidence before it according to law.
4.1.2(s)	Personal medical records of people with variations of sex characteristics will be shared with members of the community who sit on the panel, without their consent.	29	Feedback considered and amendments made. Personal privacy is a fundamentally important concern. That is why the scheme proposes a criminal offence if any information is disclosed which would identify a person whose matter is being considered by the oversight panel, as well as the identities of their family members and treating health professionals. Hearings of the oversight body must also be held in private and decisions cannot be published with any identifying details. The mandatory reporting obligations do not require the identification of the patient, so long as relevant particulars are provided (such as their age, the type of variation, the type of treatment performed, reasons for treatment, alternatives to treatment considered and reasons they were rejected). Conversely, the scheme recognises that people have a right to their medical records, requiring health professionals to maintain written records of information which has been provided to a protected person in order to obtain informed consent, and store and provide access to those records in accordance with the Health Privacy Principles set out in the <i>Health Records Act 2001</i> (Vic). We have also strengthened obligations on panel members by ensuring that they must:

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			 act with integrity, impartially, respectfully, fairly and accountability when performing their roles; declare any actual or perceived conflicts of interests; and disqualify themselves from sitting as a panel member in respect of any matter in which there is any actual or apprehended bias. Accordingly, while certain identifying details will become known to the panel members when matters are before the oversight body, there are significant safeguards in place to protect personal privacy.
4.1.2(t)	The proposal will lead to a blackmarket of illicit procedures.	29	 Feedback considered and already incorporated. The 5-year statutory review will allow a review into the effectiveness and operation of the scheme to ensure this does not occur. The scheme also utilises a number of features to discourage evasion from occurring including: It offers clear benefits to people with variations of sex characteristics and their families, given the panel process unlocks the potential for support and expertise to facilitate better decision-making concerning medical treatment modifying a person's sex characteristics. The panel process has been designed to ensure it is accessible and responsive to the needs of people with variations of sex characteristics and their families, giving them a voice and access to information and support. The obligations for complying with the prohibitions largely fall on the health professional providing the treatment. This will ensure that people with variations of sex characteristics without personal consent in permanent or difficult-to-reverse ways. Given the regulated procedures are mostly surgical procedures and treatments prescribed by clinicians, it would be difficult for a person who is not appropriately qualified to offer to perform them on the 'blackmarket'. The proposal includes a prohibition on taking a person outside the jurisdiction to perform a medical treatment which would otherwise be prohibited in Victoria. This provides an additional deterrent to a parent seeking to evade the scheme.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
4.2	SIZE OF PANEL		
4.2.1	A 9-member panel is intimidating to a family appearing before it.	30	 Feedback incorporated. We have amended the proposal to reduce the overall number of panel members needed to make a decision, while adding safeguards to ensure good quality decision-making that includes a diversity of perspectives. A full panel consisting of 5 members (drawn from a pool of members) will now be able to hear all matters, including those dealing with class order exemptions, individual applications and matters on appeal from sub panel decisions. A sub panel consisting of 3 members drawn from a pool of members will be able to hear individual cases which are not contentious. Safeguards have been added to ensure good quality decision-making that includes a diversity of perspectives and relevant experience. These include: After an open application process, the Minister for Health, in consultation with the Minister for Equality, must appoint a pool of members who have the knowledge, experience and skills relevant to their role, and who represent a reasonable diversity of gender, clinical expertise and lived experience. The panel members must be appointed as Chair (with an optional deputy Chair). When constituting a panel of members to hear a particular matter, the Chair (or deputy Chair) of the panel must also ensure a reasonable diversity of gender and relevant clinical expertise and lived experience on that specific panel. The Chair must ensure that a full panel always has at least the Chair (or deputy Chair), and one panel member belonging to each of the three categories of panel members. The Chair must ensure that a sub panel has the Chair (or deputy Chair), and one panel member belonging to each of the three categories of panel members. The Chair must ensure that a sub panel has the Chair (or deputy Chair), and one panel member belonging to each of the three categories of panel members. The Chair must ensure that a sub panel has the Chair (or deputy Chair), and at least one health professional and one community member.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			 by a differently constituted full panel). All decisions of a sub panel can be reviewed on appeal by the full panel. Decisions of a full panel can be reviewed by a court in a judicial review application. Whenever making decisions, the oversight body: must act fairly and according to the substantial merits of the case; must comply with the rules of natural justice (including hearing from the protected person and affected persons, such as the family of the protected person); is generally not bound by formal rules of evidence; and must conduct the hearing of any matter with as little formality and technicality, and as efficiently, as possible. The oversight panel has been given the power to obtain relevant evidence, including from specialists, experts or people with lived experience, and from past decisions. For the panel's duties to consider all relevant evidence according to law, see also 4.1.2(r). For other ways in which we have mitigated the stress or distress which some parents may feel in going through a panel process, see item 4.1.1(a).
4.2.2	A 9-member panel would be slow to make decisions.	30	Feedback incorporated. We have reduced the size of the panel, see item 4.2.1.
4.2.3	The Chair should have flexibility to constitute panels of various sizes, depending on the matter.	30	Feedback incorporated. We have introduced a new model that facilitates the appointment of a pool of members from which panels of either 5 or 3 members can be constituted by the Chair, as set out in item 4.2.1. However, we have retained some important safeguards on the size and composition of the panel, to ensure a diversity of voices and prevent a situation of deadlock.
4.2.4	There should be a pool of potential panel members to constitute a panel from, with smaller panels for individual	30	Feedback incorporated. We have adopted this proposed general approach, with some additional detail, as set out in item 4.2.1.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
	decisions and larger for class exemption orders.		
4.2.5	Consider other ways for different views to be taken into account, rather than the size of the panel.	30	Feedback incorporated. We have reduced the size of the panel but enlarged the ways in which the panel can inform itself when making decisions, as set out in item 4.2.1.
4.2.6	Concern that a smaller panel of 3 or 4 members may circumvent proper purpose.	31	Feedback considered and further amendments made. We have ensured that decisions made by a sub panel must be made by consensus, as set out in item 4.2.1. Panels of any size will be required to make decisions properly, as set out in item 4.1.1(a).
4.2.7	Decisions should be made by consensus as much as possible, rather than by majority.	31	Feedback considered and incorporated in part. As set out in item 4.2.1, we have suggested that decisions made by a sub panel must be made by consensus and decisions made by a full panel must attempt to reach consensus. However, it is important that the scheme allows deadlocks to be resolved – otherwise a decision (and any associated medical treatment) may be unreasonably delayed. Accordingly, if a sub panel cannot reach consensus, the matter must be referred to a full panel. If a full panel cannot reach a consensus, then a majority decision is required. Decisions of a full panel can also be appealed to a court through a judicial review application.
4.3	PANEL COMPOSITION		
4.3.1	Panel dynamics		
4.3.1(a)	Concern about certain perspectives dominating the panel.	31	Feedback considered and further amendments made. As set out in items 4.1.1(a) and 4.2.1, the oversight body will be required to comply with certain obligations when making decisions and must include a diversity of types of members in its composition, including health professionals, community representatives and rights specialists.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
4.3.1(b)	Concern that panel would be stacked with people in favour of treatment.	31	Feedback considered and further amendments made. As set out in items 4.1.1(a) and 4.2.1, the oversight body will be required to comply with certain obligations when making decisions and a panel must include a diversity of types of members in its composition, including health professionals, community representatives and rights specialists. Like all decisions made by a public body, no panel member can make a decision based on a pre-determined personal view (as this would breach the principles of procedural fairness). Further, as set out in item 6.3.3(a), the oversight body will have to make its decisions in accordance with the specific legal test proposed by the scheme, and follow the decision-making process set out by the scheme.
4.3.1(c)	Objection to healthcare being determined by people without medical training.	31	Feedback noted. Health decisions are made by people without medical training all the time. This is because <i>patients</i> – who rarely have medical training – rely on information being provided to them in order to make an informed decision about their own healthcare. The oversight body will be no different. It will inform itself and consider evidence put before it to make a decision in accordance with the requirements of the scheme.
4.3.1(d)	Objection to healthcare being determined by people with a different variation than that of the protected person.	31	Feedback considered and incorporated in part. As set out in item 4.2.1, we have suggested the scheme adopts a pool of panel members that includes people with a variety of variations, and that the Chair be required to have regard to that diversity when constituting a specific panel to hear a matter.
4.3.1(e)	Ensure people are told 'both sides of the story'.	31	Feedback incorporated. As set out in item 6.3.3(a), we have strengthened the decision-making framework which must be followed by the oversight panel. When making decisions, the panel must consider the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing). For the panel's duties to consider all relevant evidence according to law, see also item 4.1.2(r).

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			As set out in item 6.2.1(a), we have also strengthened the provisions around informed consent, to ensure that people who have the capacity to provide personal consent are offered the opportunity to do so in a fully informed way.
4.3.2	Appointment of panel members		
4.3.2(a)	Appointments should be made transparently.	31	Feedback incorporated. We have suggested that panel member appointments be made by the Minister for Health after consultation with the Minister for Equality (if a different person) after an open application process.
4.3.2(b)	Appointments should be made by the Minister for Equality with community input and oversight from the panel.	31	Feedback considered and incorporated in part. We have added a requirement for the Minister for Health to consult with the Minister for Equality on panel appointments. However, we have opted for an open application process to keep the process robust and fair.
4.3.2(c)	To avoid appointments being politicised, there should be an open selection process.	31	Feedback incorporated. See item 4.3.2(a).
4.3.3	Representing lived experience on the	panel	
4.3.3(a)	Concern that people with more common variations may dominate.	32	Feedback incorporated. When appointing panel members to the pool of members or selecting them to sit on specific panels, we have suggested that the Minister for Health and Chair each have an obligation to have regard to ensuring a reasonable diversity of gender, clinical experience and lived experience are represented on the panel.
4.3.3(b)	Ensure a balance of voices (including diversity in variations and gender).	32	Feedback incorporated. See item 4.3.3(a).

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
4.3.3(c)	The panel should be convened from a pool so that a person with a similar variation can sit on the panel when considering a person's individual care plan.	32	Feedback incorporated. See item 4.3.3(a).
4.3.4	Representing clinical expertise on the	panel	
4.3.4(a)	Include mental health professionals on the panel where appropriate.	32	Feedback considered and amendments made.When appointing panel members to the pool of members or selecting them to sit on specific panels, we have suggested that the Minister for Health and Chair each have an obligation to have regard to ensuring a reasonable diversity of gender, clinical experience and lived experience are represented on the panel. We have also enlarged the ways in which the panel can inform itself when making decisions so that other views which are not represented on the panel can be obtained through evidence, as set out in item 4.2.1.For more information on the how the panel will be constituted, see item 4.2.1.
4.3.4(b)	Include sexual health professionals on the panel where appropriate.	32	Feedback considered and amendments made. See item 4.3.1(a).
4.3.4(c)	Include fertility specialists on the panel where appropriate.	32	Feedback considered and amendments made. See item 4.3.1(a).
4.3.4(d)	Bioethicists should be treated as allied health professionals on the panel (leaving room for two human rights or child's rights specialists).	32	Feedback considered and incorporated in part. As set out in item 4.2.1, we have amended the proposal to reduce the overall number of panel members needed to make a decision, while adding safeguards to ensure good quality decision-making that includes a diversity of

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			perspectives. We have also enlarged the ways in which the panel can inform itself when making decisions so that other views which are not represented on the panel can be obtained through evidence.
4.3.4(e)	An ethicist should always be part of the panel.	32	Feedback noted. When appointing panel members to the pool of members or selecting them to sit on specific panels, we have suggested that the Minister for Health and Chair each have an obligation to have regard to ensuring a reasonable diversity of gender, clinical experience and lived experience are represented on the panel. We have also enlarged the ways in which the panel can inform itself when making decisions so that other views which are not represented on the panel can be obtained through evidence, as set out in item 4.2.1. For more information on the how the panel will be constituted, see item 4.2.1.
4.3.5	The Chair		
4.3.5(a)	The Chair must have sufficient gravitas to manage the panel and establish trust and confidence in the panel's processes.	32	Feedback considered and amendments made. Recognising the importance of the appointment, we have suggested that the Chair (and any deputy Chair) be appointed by the Minister for Health after consultation with the Minister for Equality (if a different person). We have suggested that the Chair (and any deputy Chair) be a former judicial officer or senior lawyer of at least 10 years' standing. While the appointment of the Chair (and any deputy Chair) is no doubt important in establishing trust and confidence in the panel process, we have included a number of provisions that make clear that whoever is appointed must comply with obligations applicable to all panel members, including the obligation to act with integrity, impartially, respectfully, fairly and accountably when performing their roles.
4.3.5(b)	The Chair must establish culture and process with as little legalism and formality as possible.	32	 Feedback incorporated. We have suggested adopting key provisions found in the Victorian Civil and Administrative Tribunal Act 1998 (Vic), namely that: unless and to the extent adopted by the Chair, the oversight body is not bound by the rules of evidence or any practices or procedures applicable to the courts; and

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			 the oversight body must conduct the hearing of any matter with as little formality and technicality, and as efficiently, as possible. We have also specified that parties may only be legally represented with leave of the Chair.
4.3.5(c)	The Chair should be a human rights lawyer.	32	Feedback noted. While it may be ideal for the Chair to have human rights expertise, all judicial officers and senior lawyers in Victoria would be expected to have experience, given the Charter of Human Rights and Responsibilities. Rather than limit the criteria for the Chair, a more appropriate way to ensuring human rights are embedded in decision- making is to ensure the oversight body must make decisions that comply with the Charter, which is a requirement that was already part of the proposal.
4.3.5(d)	The Chair should have respect for lived experience.	32	Feedback considered and amendments made. As set out in item 4.2.1, the Chair must ensure that any panel (whether a full or sub panel) must include a community representative panel member (being a person with innate variations of sex characteristics or a family member of a person with innate variations of sex characteristics). The Chair must also comply with the legislation (including having regard to its objects and purposes) and with the obligations placed on all panel members, which include an obligation to act with integrity, impartially, respectfully, fairly and accountably when performing their roles.
4.3.5(e)	The Chair should be a judge with experience deciding cases involving children with disabilities.	32	Feedback noted. While it may be ideal for the Chair to have expertise with cases involved children with disabilities, such an eligibility criterion is too restrictive. A more appropriate way to ensure the scheme operates as intended is to establish a decision-making framework that ensures due regard is given to human rights, which has been already been incorporated in the proposal.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
4.3.5(f)	The Chair should not be a former judge because they would preside over the panel as though it were a court.	32	Feedback considered and amendments made. As set out in item 4.3.5(b), we have suggested a number of provisions that guard against the oversight body becoming court-like. Rather than limit the pool of potential Chairs, this is a more appropriate way to address this concern.
4.3.5(g)	The Chair should not be a former Family Court judge, given criticisms of the Family Court in decisions approving interventions.	32	Feedback considered but not incorporated. Rather than limit the pool of potential Chairs, a more appropriate way to address this concern is to ensure the decision-making framework of the oversight body is fit for purpose. See item 6.3.3(a), for more information on how the oversight body must make decisions.
4.4	PROFESSIONAL DEVELOPMENT		
4.4.1	Panel members should have an induction and ongoing training about evaluating evidence; questioning people in non-confrontational ways; administrative law and decision- making.	32	Feedback incorporated. The proposal has been amended to enable the Chair to require panel members to attend training and development from time to time.
4.4.2	There should be provisions for termination of panel members.	33	Feedback already incorporated. The proposal already allows panel members to be terminated by the Minister for Health.
4.4.3	Clinical and legal panel members should be required to maintain professional registration or accreditation.	33	Feedback incorporated. The proposal has been amended to include a new provision regarding the obligations of panel members.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE	
4.4.4	The chair should ensure policies, procedures, guidelines and a complaints system are in place.	33	Feedback incorporated. The proposal has been amended to enable the Chair to manage the day-to-day operation of the oversight body.	
4.4.5	The Chair should have a disciplinary role should there be complaints about a panel member.	33	Feedback incorporated. The proposal has been amended to enable the Chair to receive and resolve complaints from members of the public regarding the failure of a panel member to comply with their obligations.	
4.5	CONFLICTS OF INTEREST			
4.5.1	Actual and perceived conflicts of interest should be carefully managed and considered.	33	Feedback incorporated. The proposal has been amended to include a new obligation on panel members regarding the declaration and management of conflicts of interest.	
4.6	SITUATING THE OVERSIGHT BODY			
4.6.1	The panel should be independent and sit within a human rights body, to ensure it is removed from a medical setting.	33	Feedback considered and incorporated in part. This proposal would establish the oversight body as a separate entity (but not part of the Equal Opportunity and Human Rights Commission).	
5	OVERSIGHT BODY - FUNCTIONS AND POWERS			
5.1	More should be made of the panel's educative powers.	34	Feedback considered and incorporated in part. The proposal includes giving the oversight body powers to provide information to people who may benefit from the scheme and issue guidance on the interpretation and operation of the scheme. The oversight body can also conduct analysis and carry out research on the operation of the scheme, and provide advice and reports to the	

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE	
			relevant government representatives. Within those boundaries, the oversight body will have an educative function. However, given the concern raised in item 5.2, we think that is an appropriate balance that ensures the oversight body can maintain its impartial decision-making role.	
5.2	Concern that the panel could be accused of bias the more it engages in educative functions and policy positions.	34	Feedback incorporated. We have added a requirement that the oversight panel must comply with the rules of natural justice, which will necessarily require the oversight panel to adhere to the legal rules against bias.	
5.3	Importance of clear periodic reporting requirements.	34	Feedback incorporated. A new periodic reporting obligation has been included in the proposal.	
6	OVERSIGHT BODY - DECISION-	MAKIN	G PRINCIPLES	
6.1	THE HUMAN RIGHTS FRAMEWORK PR	INCIPLE		
6.1.1	Consider that decisions of the oversight body should not be immune from courts considering the merits of a decision.	35	Feedback noted. It is appropriate that courts have oversight of decisions made by public authorities in the usual way.	
6.2	THE PRINCIPLE OF SELF-DETERMINA	ΓΙΟΝ		
6.2.1	The quality of consent			
6.2.1(a)	Concern that people with capacity to consent may not have access to full or unbiased information.	35	Feedback incorporated. Our consultation heard from many participants who were concerned about the way in which information could be conveyed to a person with innate variations of sex characteristics who is considering medical treatment modifying	

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			their sex characteristics and the impact that this could have on the quality of consent obtained from that person, including whether consent is fully informed and freely given without any coercion or pressure. ²²⁴
			There were divergent views, however, as to the proper role of the oversight panel in overseeing medical consent generally, given that there are existing obligations placed on clinicians regarding medical consent. ²²⁵ There are also existing avenues for patients to make complaints about health professionals who do not met their obligations regarding the need to obtain fully informed consent prior to performing medical procedures, such as through the Victorian Health Complaints Commissioner and Australian Health Practitioner Regulation Agency. ²²⁶
			There was also a view among some participants emphasising supported decision-making, meaning that the proper role of the oversight body is not to substitute its views for the views of a person who could otherwise provide their own fully informed consent with reasonable support. ²²⁷ This view also emphasised that people should be left to make properly informed and non-coerced decisions as they wish, and the oversight panel should not have a role in second-guessing properly informed and non-coerced decisions no matter if others would have made a different decision. ²²⁸
			To address these differing visions for the oversight panel we have made several amendments to clarify the proper role of the oversight body depending on whether a person has capacity to provide consent to the proposed medical treatment or not. We have suggested a proposal that also uses existing Victorian legal frameworks and does not duplicate existing complaints bodies, such as the Health Complaints Commissioner.
			People who have capacity to give personal consent

²²⁷ Listening report, pp. 37, 43.

²²⁸ Listening report, pp. 37, 43.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

²²⁴ Listening report, pp. 35-37.

²²⁵ Listening report, p. 37.

²²⁶ Health Complaints Act 2016 (Vic), s 5; Health Practitioner Regulation National Law, ss 144-145 (as in force because of s 4 of the Health Practitioner Regulation National Law (Victoria) Act 2009 (Vic)).

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			For people with innate variations of sex characteristics who <i>do</i> have capacity to consent to proposed medical treatment modifying their sex characteristics, we have suggested using the existing meaning of 'informed consent' in the <i>Mental Health Act 2014</i> (Vic) ²²⁹ and clarifying its application in this context, so that safeguards are in place to ensure consent is freely given and fully informed when people with innate variations of sex characteristics are considering medical treatment to modify their sex characteristics.
			We have suggested that the existing legal definition of 'informed consent' in the <i>Mental Health Act 2014</i> (Vic) be adapted to include some important additional safeguards (<i>italicised below</i>) in addition to the existing requirements. They include:
			 Ensuring that the person has been given adequate information to enable them to make an informed decision by the provision of: affirming, clearly understandable and factually objective information about the nature of their innate variation of sex characteristics (including its incidence, if known, and how it manifests physically over time); a list of peer support organisations and contacts for psychological support, being a list prescribed by the Minister for Health after consultation with the Minister for Equality; information on the option of having no medical treatment whether now or later, including the advantages and disadvantages of this option; and a full explanation of the proposed medical treatment (including its advantages and disadvantages, expected side effects, and any beneficial alternatives). Ensuring a person has been given a reasonable opportunity to make a decision by the provision of: a reasonable period of time in which to consider the matters involved in the decision, including a cooling off period appropriate to the proposed medical treatment; a reasonable opportunity to discuss the matter with the registered medical practitioner who is proposing the medical treatment, including the option to do so with or without the assistance or presence of another person; and

²²⁹ See Mental Health Act 2014 (Vic), s 69.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			 a reasonable opportunity to discuss the matter with a different health professional to the one proposing the medical treatment, including the option to do so with or without the assistance or presence of another person. Ensuring that consent has been given freely without undue pressure or coercion by any other person. Ensuring that the person has not withdrawn consent or indicated any intention to withdraw consent. We have also included a clear obligation to keep records documenting all the information provided to the person in order to obtain their consent and to treat those records in accordance with the with the Health Privacy Principles set out in the <i>Health Records Act 2001</i> (Vic). For people who have capacity to provide their own fully informed consent, the oversight panel would not have a role to play in making decisions on their behalf or overseeing their decisions. Rather, these people would be able to directly raise complaints with the Victorian Health Complaints Commissioner or Australian Health Practitioner Regulation Agency in respect of conduct that fell below these standards (in addition to ordinary legal remedies through the courts). This ensures that people with innate variations of sex characteristics who have capacity to make their own decisions are given the same rights and protections (including the right to privacy, self-determination, physical autonomy and bodily integrity) as anyone else accessing healthcare. People who do not have capacity to give personal consent As set out in item 6.3.3(a), the oversight body would have a role in overseeing medical treatment modifying the sex characteristics of a protected person who <i>does not</i> have the capacity to provide informed consent to the proposed treatment. Further, in working out whether a person has capacity to give personal consent, we have suggested applying existing Victorian laws that recognise a person has capacity to g

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			they can understand, remember, use and weigh relevant information to make a decision, and can communicate their decision through any means. ²³⁰
			As set out in item 6.5.1, we have also clarified that capacity to give informed consent must be assessed in light of whether the person would be able to understand, remember, use and weigh the relevant information, or communicate their decision, with reasonable support. This is to ensure that people with disabilities are given reasonable support in order to exercise fully their capacity to make decisions for themselves.
6.2.1(b)	Concern about people being pressured to consent.	36	Feedback incorporated. As set out in item 6.2.1(a), we have suggested incorporating an existing legal definition of 'informed consent' into this scheme with additional safeguards to mitigate against the risk of pressure to consent. One safeguard will be the ability of a person to speak with their own doctor or another health professional, with or without the presence or assistance of someone else.
6.2.1(c)	Concern that people are provided negative or stigmatising information about a variation.	36	Feedback incorporated. As set out in item 6.2.1(a), we have suggested incorporating an existing legal definition of 'informed consent' into this scheme with additional safeguards to mitigate against the risk of negative or stigmatising information. Safeguards will include the requirement to provide affirming, clearly understandable and factually objective information about the nature of a person's innate variation of sex characteristics and a prescribed list of peer support organisations and contacts for psychological support when obtaining consent to medical treatment proposed to modify a person's sex characteristics.
6.2.1(d)	Concern that medical advice might be based on assumptions about sexuality.	36	Feedback incorporated. As set out in item 6.2.1(a), we have suggested incorporating an existing legal definition of 'informed consent' into this scheme with additional safeguards to mitigate against the risk of doctors making any assumptions about

²³⁰ Medical Treatment Planning and Decisions Act 2016 (Vic), s 4; Guardianship and Administration Act 2019 (Vic), s 5; Mental Health Act 2014 (Vic), s 68; and Voluntary Assisted Dying Act 2017 (Vic), s 4.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			their patients' sexuality. Safeguards will include the requirement to provide a prescribed list of peer support organisations and contacts for psychological support and providing a reasonable opportunity for consulting with another health professional when obtaining consent to medical treatment proposed to modify a person's sex characteristics.
6.2.1(e)	Consider importance of explaining concepts to children, supporting them, and increasingly involving them in decisions.	36	 Feedback incorporated. We have included a number of protections to ensure children are involved in decisions being made about them, even if they do not yet have capacity to provide their own consent to treatment. They include: To the extent that a child can express any views regarding their individual care plan, the oversight panel must give them an opportunity, with reasonable support, to express those views and those views must be considered by the oversight panel. The oversight panel can also appoint an independent advocate for the child. Their role is to facilitate the expression of views from the child where they can be obtained directly (including with reasonable support), and provide assistance to the oversight panel in considering matters which cannot be raised directly by the child.
6.2.1(f)	Oversight body should have power to commission standard documentation required to be provided to parents.	36	Feedback considered and incorporated where appropriate. For people who have capacity to consent to their own medical treatment, the information provided to their parents will be subject to the ordinary rules governing patient confidentiality. As set out in item 6.2.1(a), we have suggested incorporating an existing legal definition of 'informed consent' into this scheme with additional safeguards. For people who do not have capacity to consent to their own medical treatment, the oversight body will have a role in overseeing medical treatment that proposes to modify a person's sex characteristics where that person cannot provide personal consent. The oversight body will be able to register an individual care plan allowing certain medical treatment. The application process for an individual care plan requires the treating health

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			professional to provide information as to what information has been provided to the parents. See also item 4.1.1(e).
6.2.1(g)	Health professionals should have an obligation to provide the reasons and consent forms given to patients and parents.	36	 Feedback considered and incorporated where appropriate. For people who have capacity to consent to their own medical treatment, as set out in item 6.2.1(a), we have suggested incorporating an existing legal definition of 'informed consent' into this scheme with additional safeguards, including a requirement to keep records of the information provided to obtain consent. For people who do not have capacity to consent to their own medical treatment, the oversight body will have a role in overseeing medical treatment that proposes to modify a person's sex characteristics where that person cannot provide personal consent. The oversight body will be able to register an individual care plan allowing certain medical treatment. The application process for an individual care plan requires the treating health professional to provide information as to what information has been provided to the parents, as well as the option of providing their views as to any proposed treatment. See also item 4.1.1(e).
6.2.1(h)	Some parents already feel supported by medical experts and existing ethics panels.	36	Feedback noted. While we acknowledge that some parents have had positive experiences, our consultation revealed that this was not a universal experience among all parents. ²³¹ Ultimately, this scheme is about ensuring their children have the right to decide what happens to their bodies to the maximum extent possible.
6.2.1(i)	Some parents feel they had access to information, including about risks associated with surgery.	36- 37	Feedback noted. See item 6.2.1(h).

²³¹ Listening report, pp. 39-40, 50.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
6.2.2	Testing the quality of consent – a role f	or the pa	inel?
6.2.2(a)	The oversight panel should have a role in testing the correctness and neutrality of information provided to persons who otherwise have capacity to consent to medical treatment.	37	Feedback considered but not incorporated. As set out in item 6.2.1(a), we have suggested adapting an existing legal definition of 'informed consent' with additional safeguards, and using existing mechanisms – such as the Victorian Health Complaints Commissioner – to allow complaints regarding the correctness and neutrality of information provided to persons who can consent. The oversight body will also be able to refer to existing regulatory and enforcement bodies matters that raise questions as to compliance with the law, as well as issue guidance on the operation of the scheme. This approach will ensure that people with innate variations of sex characteristics who have capacity to make their own decisions are given the same rights and protections (including the right to privacy, self-determination, physical autonomy and bodily integrity) as anyone else accessing healthcare.
6.2.2(b)	A person close to the protected person should ask them questions about the proposed treatment.	37	Feedback considered and incorporated where appropriate. As set out in item 6.2.1(e), we have included a number of protections to ensure children are involved in decisions being made about them, even if they do not yet have capacity to provide their own consent to treatment. We have suggested that the child be given reasonable support to be able to have their views expressed, and that can include assistance from someone they know if that is appropriate in a particular case.
6.2.2(c)	Concern that the panel may be influenced by parents' distress.	37	Feedback considered and amendments made. As set out in item 6.3.3(a), we have strengthened the decision-making framework which must be followed by the oversight panel. When making decisions, the panel must consider the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing). As set out in item 4.1.1(a), the views of parents must also be considered by the panel. But ultimately, the weight given to the views of parents in an individual matter will depend on the circumstances of the case, and the oversight panel must consider the outcome by reference to what is in the best interests of the child.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
6.2.2(d)	Ensure access to independent peer support for young people.	37	Feedback incorporated. As set out in item 6.2.1(a), we have suggested adapting an existing legal definition of 'informed consent' with additional safeguards. One safeguard will be to ensure a prescribed list of peer support organisations and psychological support is given to people with innate variations of sex characteristics who are being asked to consent to medical treatment modifying their sex characteristics. We have also suggested that the oversight panel be able to provide a referral to peer support and counselling to any affected person, whenever it is reviewing an application for registering an individual care plan.
6.2.2(e)	Concern that some peer support groups may bully others or otherwise be homophobic or transphobic.	37	Feedback incorporated. To ensure that peer support organisations are safe and inclusive, we have suggested that the Minister for Health prescribe a list of such organisations after consulting with the Minister for Equality (if that person is different). The Minister for Health and Equality can then seek recommendations or feedback from affected persons and the broader community as to organisations that should be placed on the list of prescribed peer support organisations.
6.2.2(f)	Medical professionals already have a duty to ensure they have received informed consent, so quality could be improved through training for medical professionals and peer support (rather than a role for the oversight panel).	37	Feedback considered and incorporated in part. As set out in item 6.2.1(a), we have suggested adapting an existing legal definition of 'informed consent' with additional safeguards. This will ensure medical professionals are familiar with the concepts they are being asked to follow, while providing clarity as to the minimum safeguards required to ensure informed consent has been properly obtained. However, as set out in 4.1.2(a), we do not agree with the view that existing multidisciplinary forums are adequate.
6.2.2(g)	The panel should only be a decision- maker of last resort and embrace supported decision-making.	37	Feedback incorporated. As set out in items 6.2.1(a), 6.3.3(a) and 6.5.1-6.5.2, the panel will only have a role in making decisions for those people who do not have capacity to consent. Otherwise, the scheme proposes to improve the framework for informed consent, to ensure people who have capacity to give consent have the information, time and support needed to come to their own decisions.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
6.2.2(h)	People should be able to make choices for themselves even if they are bad choices. The legislative scheme should focus on ensuring decision-making environments are not coercive.	37	Feedback incorporated. As set out in items 6.2.1(a), 6.3.3(a) and 6.5.1-6.5.2, the panel will only have a role in making decisions for those people who do not have capacity to consent. Otherwise, the scheme proposes to improve the framework for informed consent, to ensure people who have capacity to give consent have the information, time and support needed to come to their own decisions.
6.3	THE PRINCIPLE OF DEFERABILITY		
6.3.1	Views among people with variations of	sex char	acteristics
6.3.1(a)	Decisions should be informed by three principles: right to be, right to belong, and right to become.	38	Feedback incorporated. As set out in item 6.3.3(a), we have strengthened the decision-making framework which must be followed by the oversight panel. The framework now uses the grounding principle that <i>"individuals have a significant and profoundly personal interest in deciding what happens to their own bodies"</i> . This composite phrase embodies the principles of bodily integrity, self-determination and physical autonomy. As set out in item 6.2.1(a), we have also strengthened the provisions around informed consent, to ensure that people who have the capacity to provide personal consent are offered the opportunity to do so in a fully informed way. These changes help ensure a person has the right to be, belong and become.
6.3.1(b)	Some participants with CAH opposed deferability and liked not having to have made the decision themselves or grown up different to classmates.	38	Feedback considered and incorporated in part. We acknowledge that for some people with innate variations of sex characteristics they may ultimately agree with the decisions made for them as infants and would make decisions today based on social or psychosocial benefits they regard as important for themselves. However, our consultation revealed that this was not the universal experience for all people with innate variations of sex characteristics. As set out in item 6.3.3(a), we have strengthened the decision-making framework which must be followed by the oversight panel to centre the voice of the person who is receiving the treatment. The framework allows the oversight panel to consider the views of the person receiving the treatment, even if they do not have legal

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			capacity to make the decision for themselves. That means a child may be able to provide their own views as their capacity evolves. This may persuade the oversight panel to consider earlier treatment for some children than it would for others. Further, while we have also placed limitations on the ability of the oversight panel to rely on speculative or general evidence of psychosocial and social benefits, we have recognised that one of the exceptions to this rule should be where that evidence of those benefits comes directly from the protected person themselves.
6.3.1(c)	Early surgery on people with CAH allows surgery to grow with the body.	38	Feedback considered and incorporated in part.We acknowledge that some people with innate variations of sex characteristics may ultimately prefer earlier surgery on their bodies and would make decisions today based on benefits they regard as important for themselves. However, our consultation revealed that this was not the universal experience for all people with innate variations of sex characteristics.For information on how we have struck the balance between divergent views among people with innate variations of sex characteristics, see items 6.3.1(b) and 6.3.3(a).
6.3.1(d)	Early surgery can avoid stigmatising experiences with doctors.	38	Feedback considered and incorporated in part.We acknowledge that some people with innate variations of sex characteristics may ultimately prefer earlier surgery on their bodies and would make decisions today based on benefits they regard as important for themselves. However, our consultation revealed that this was not the universal experience for all people with innate variations of sex characteristics.For information on how we have struck the balance between divergent views among people with innate variations of sex characteristics, see items 6.3.1(b) and 6.3.3(a). The oversight body will be able to consider the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing). However, evidence of psychosocial benefits will need to meet certain requirements to be taken into account.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
6.3.1(e)	Some people who required multiple surgeries wish they could have all been performed at one time.	38	Feedback considered and incorporated in part. We acknowledge that some people with innate variations of sex characteristics may ultimately prefer earlier surgery on their bodies and would make decisions today based on benefits they regard as important for themselves. However, our consultation revealed that this was not the universal experience for all people with innate variations of sex characteristics. For information on how we have struck the balance between divergent views among people with innate variations of sex characteristics, see items 6.3.1(b) and 6.3.3(a). The oversight body will be able to consider the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing).
6.3.1(f)	When a person undertakes surgery, ensure that person is fully informed about the procedure and has suitable post-treatment support.	39	Feedback incorporated. As set out in item 4.1.2(b), we have included a broad list of matters which can be included in an individual care plan to ensure care plans can include provisions on post-treatment support and the provision of information to the protected person.
6.3.1(g)	Consider that consequences of treatment such as infertility may be weighted differently by different people.	39	Feedback incorporated. As set out in item 6.3.3(a), we have strengthened the decision-making framework which must be followed by the oversight panel. The framework now uses the grounding principle that <i>"individuals have a significant and profoundly personal interest in deciding what happens to their own bodies"</i> . This composite phrase embodies the principles of bodily integrity, self-determination and physical autonomy, and recognises that the interest of an individual is <i>"profoundly personal"</i> . This centres the individual in every decision, including when they do not yet have capacity to make their own decisions.
6.3.2	Views among parents		
6.3.2(a)	Some parents who have opted for deferring treatment often second	39	Feedback incorporated.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
	guess their decision or are subject to pressure from medical professionals.		This scheme will require the oversight body to oversee any medical treatment modifying the sex characteristics of a protected person in circumstances where they cannot provide personal consent. This means that parents can take comfort in a specialist panel whose role will be to consider what is in the best interests of their child.
			The scheme also ensures that parents can provide their views on any decision being considered by the oversight panel in respect of their children and requires the oversight panel to take their views into account. The scheme also includes several other rights and protections for parents, as set out in item 4.1.1(a).
6.3.2(b)	Some parents feel they would not make the same decisions had they had access to information.	40	Feedback incorporated. This scheme will require the oversight body to oversee any medical treatment modifying the sex characteristics of a protected person in circumstances where they cannot provide personal consent. This means that parents can take comfort in a specialist panel whose role will be to consider what is in the best interests of their child. The scheme also ensures that parents can provide their views on any decision being considered by the oversight panel in respect of their children and requires the oversight panel to take their views into account. The scheme also includes several other rights and protections for parents, as set out in item 4.1.1(a).
6.3.2(c)	Some parents are comfortable with surgeries they have consented to on behalf of their child.	40	Feedback noted. We acknowledge that some parents are comfortable with the surgeries they have consented to on behalf of their children, and similarly some people with innate variations of sex characteristics are also comfortable with the decisions made for them by their parents. ²³² Unfortunately, that was not the universal experience of all our consultation participants. ²³³ This scheme will require the oversight body to oversee any medical treatment modifying the sex characteristics of a protected person in circumstances where they cannot provide personal consent. However, the scheme also ensures that parents can provide their views on any decision being considered by the oversight panel in respect of

²³² Listening report, pp. 38-40.

²³³ Listening report, pp. 35-40, 49-50.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			their children and requires the oversight panel to take their views into account. The scheme includes several other rights and protections for parents, as set out in item 4.1.1(a).
			Ultimately, the weight given to the views of parents in an individual matter will depend on the circumstances of the case, and the oversight panel must consider the outcome by reference to what is in the best interests of the child.
6.3.2(d)	Some parents oppose deferability because young children are less likely	40	Feedback noted.
	to remember surgeries or realise their body is 'different'.		We acknowledge that some people with innate variations of sex characteristics may ultimately prefer earlier surgery on their bodies and would make decisions today based on benefits they regard as important for themselves. However, our consultation revealed that this was not the universal experience for all people with innate variations of sex characteristics.
			As set out in item 6.3.3(a), the oversight body will be able to consider the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing). However, evidence of psychosocial benefits will need to meet certain requirements to be taken into account. Those requirements are that the evidence either comes directly from the protected person themselves, or has substantial probative value.
6.3.3	Views among clinicians and health pro	fessional	5
6.3.3(a)	Concerns about the 'assumption of universal deferability'.	40	 Feedback incorporated. The oversight panel will be responsible for determining if medical treatment which modifies a protected person's sex characteristics will be allowed in circumstances where: the emergency medical treatment exception does not apply (for example, because the procedure may be desirable but is not urgent); and the protected person does not have capacity to consent to the treatment themselves (for example, because they are too young to do so). The oversight panel will be allowed to make decisions authorising such treatment either by:

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			 registering an individual care plan which includes the treatment (and which may include any conditions or limitations on the scope of that treatment); or making class exemption orders for particular types of treatment (and which may include any conditions or limitations on the scope of that exemption).
			A class exemption order means that, subject to any conditions or limitations imposed in the order, the treatment does not require individual approval from the oversight body and the ordinary medical decision-maker (usually the parent) can provide informed consent to the treatment within the boundaries of what is permitted by the class exemption order.
			The fundamental question is how the oversight body should decide whether or not to permit medical treatment modifying the sex characteristics of a protected person, in circumstances where that treatment is necessary, but the person does not have capacity to provide consent to the treatment themselves. Our consultation participants differed in their views as to what factors should be considered in determining whether treatment is necessary, or should be deferred until a person could decide for themselves later. ²³⁴
			No international jurisdiction which has considered this issue has approached the test in the same way:
			• Iceland places a prohibition on undertaking permanent medical changes to the sex characteristics of a child under 16 years with atypical sex characteristics unless the child is able to express their own will or the treatment is for 'health reasons' (following a detailed assessment of the need for and consequences of such treatment). Social, psychosocial and appearance-related reasons are expressly excluded from the scope of a 'health reason'. ²³⁵
			• Malta prohibits surgical interventions on a person under 16 unless they can provide personal informed consent or in 'exceptional circumstances' (where an interdisciplinary panel and the parents/guardians can consent to the treatment). However, this decision cannot be driven by 'social factors'. ²³⁶

²³⁴ Listening report, pp. 37-43.

²³⁵ Act on Gender Autonomy No 80/2019 as amended by Act No 159/2019, No 152/2020 and No 154/2020, art 11a. See Appendix C of our Background Paper.

²³⁶ Gender Identity, Gender Expression and Sex Characteristics Act 2015, art 14. See Appendix C of our Background Paper.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			 Germany prohibits interventions aimed at altering an intersex child's physical appearance with the intention of making them appear more 'male' or 'female' unless the interventions are 'vital and not deferrable', or are approved by a family court and are not <i>solely</i> aimed at aligning the child's physical appearance to male or female sex characteristics.²³⁷ Portugal prohibits surgical and pharmacological procedures that 'imply' changes in the body and characteristics of a minor intersex person until the moment their 'gender identity is manifested' or if there is a proven risk to health.²³⁸
			The draft proposal's principle of deferability and 'harm to health' test were broadly inspired by these international approaches, but none of the international approaches are legally sound in the Australian context. This is because: (1) we have a federalist system which requires considering the powers existing at both the Commonwealth and state level, (2) our legal system generally provides public authorities with more clarity over how they must exercise their powers (including listing mandatory or relevant considerations they must or must not consider), (3) our separation of powers tradition means the relationship between an administrative decision-maker and a court has to be more clearly delineated and certain functions are customarily exercised by either an administrative decision-maker or court within our constitutional framework, and (4) the international prohibitions above are broader in some respects and narrower in others, meaning that any Victorian prohibition and its exceptions must be carefully read together to ensure all necessary treatment is not denied or delayed to a protected person.
			 For this reason, we have suggested a unique legal test that amalgamates key principles raised in our consultation and translates them into a proposal that is legally sound in the Victorian legal context. Those principles include: That modifying a person's sex characteristics without their personal consent is an affront to the bodily integrity, physical autonomy and self-determination of the person. Accordingly, the significant and profoundly personal interest that an individual has in deciding what happens to their own body is – and

²³⁷ Law No. 19/24686, see summary prepared by OII Europe: https://oiieurope.org/wp-content/uploads/2021/03/press-release_German-Ban_igm_30-03-2021.pdf. See Appendix C of our Background Paper.

²³⁸ Law No. 38/2018. See Appendix C of our Background Paper.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			 must be - the fundamental starting point.²³⁹ We have suggested adopting this concept of a "person's significant and profoundly personal interest in deciding what happens to their own body" throughout the scheme, as a grounding concept for all decisions. That deferring medical treatment is not an end in and of itself.²⁴⁰ It is done for a purpose: to maximise the opportunity for a person to realise their own capacity to decide what happens to their own body in the future. That means that, in some cases, allowing treatments which preserve options for the future (such as preserving fertility) can facilitate a person's future capacity to make decisions for themselves, and thereby promote their right to bodily integrity, physical autonomy and self-determination over the life course. The legal test needs to allow that balancing of considerations to occur, and so, we agree that a 'universal assumption of deferability' alone is not the correct approach. That allowing medical treatment to modify a person's sex characteristics without their personal consent must only be done for the most compelling of reasons, particularly where there is doubt or where the treatment can wait until the person can decide for themselves. It was here that consultation participants particularly diverged, with a wide range of reasons (including psychosocial and even economic reasons) sometimes being provided to justify earlier treatment.²⁴¹ However, most consultation participants with variations of sex characteristics, and some parents, were adamant that the reasons for justifying earlier treatment can be too loosely put or considered, you risk swallowing up the fundamental objective of the scheme, which is to promote the right of an individual to decide what happens to their own body. That different people with innate variations of sex characteristics will have different views on how to balance competing considerations. Accordingly, the test must always centre the voice of the person receiving the trea

 $^{^{\}scriptscriptstyle 239}$ See for example the views expressed in the Listening report, pp. 37-39, 42.

²⁴⁰ See for example the views expressed in the Listening report, pp. 41, 42.

²⁴¹ See for example the views expressed in the Listening report, pp. 42-43.

²⁴² See for example the views expressed in the Listening report, pp. 37-40, 42.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			 that affirms what the person wants even if the person does not have legal capacity to make that decision themselves. That because these decisions are profoundly personal and different people with innate variations of sex characteristics will have different views, we must guard against a test that allows mere speculation or assumptions to be made as to what the person might eventually want if it is possible to wait until they can express their own views. That international human rights law, and particularly the principles of supported decision-making, requires a different approach between children, and adults with disability.²⁴³ The test should conform to the requirements of the Convention on the Rights of the Child and Convention on the Rights of Persons with Disabilities. For children, that means the best interests of the child as the paramount consideration, although acknowledging that past determinations of best interests has been heavily criticised.²⁴⁴ For adults, that means listening to the will and preferences of the person, or ascertaining what their will and preferences would be if they could fully express them, and only overriding their wishes if it is necessary to prevent serious harm.²⁴⁵ Taking those principles into account, we have suggested the following decision-making framework should apply:
			 That the oversight body only have power to make decisions in respect of protected persons that do not have capacity to provide personal consent to the proposed medical treatment modifying their sex characteristics. This means that the oversight body does not have the power to second-guess or override the decision of a person who has capacity to provide personal consent. That, when making decisions, the oversight body must follow the principles of natural justice and take into account the views of relevant persons as follows:

²⁴³ Listening report, p. 43.

²⁴⁴ Listening report, pp. 27-28, 32, 43.

²⁴⁵ Listening report, p. 43. See also s 9 of the *Guardianship and Administration Act 2019* (Vic).

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			 when considering individual care plans: the oversight body must take into account the views of the protected person, and if the protected person is under 18 years of age, also their parents; and when considering class exemption orders: the oversight body must follow a public consultation process and consult also with the Minister for Health and Minister for Equality. That, when making decisions, the oversight body "must have regard to the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing)". This means taking into account the following factors: the significant and profoundly personal interest of a person in being able to decide what happens to their own body, and the extent to which that interest may be realised through: the option of deferring medical treatment that modifies the protected person's sex characteristics to preserve any expected ability of the protected person to provide personal consent in future; or the option of allowing medical treatment that preserves options for the protected person's health; any likely adverse consequences to the protected person's health; any likely adverse consequences to the protected person's health; any alternatives. That, when making decisions, the oversight body must not presume that a person with innate variations of sex characteristics would experience any social or psychosocial benefits from having their sex characteristics (1) specific evidence that has substantial probative value, or (2) in individual cases, the evidence comes directly from the protected person. That, when making decisions, the oversight body must not presume that a person without that variation except where there is: (1) specific evidence that has substantial probative value, or (2) in individual cas

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			 if the protected person is aged under 18: the oversight body must be satisfied that the protected person's "best interests are better served by the medical treatment proceeding without their personal consent over deferring the treatment to realise that person's significant and profoundly personal interest in deciding what happens to their own body"; or if the protected person is aged 18 year or over: that the oversight body must be satisfied that the medical treatment modifying a protected person's sex characteristics is "consistent with their will and preferences, or to the extent that those will and preferences cannot be fully expressed, is consistent with the best ascertainment of what the protected person's will and preferences would likely be." (However, consistent with section 9 of the Guardianship and Administration Act this may include a proviso protecting against serious harm.) That ultimately, when making decisions regarding class exemption orders, that "the best interests of any protected person who meets the conditions specified in the class exemption order would be better served by the medical treatment proceeding (with the consent of a medical-decision maker and on any conditions specified by the oversight body) over deferring the treatment to realise a person's significant and profoundly personal interest in deciding what happens to their own body."
6.3.3(b)	Concern that there is a high potential for similar or higher rates of dissatisfaction with the 'experimental' deferral approach.	40	Feedback considered and incorporated in part. As set out in item 4.1.2(b), we have included a broad list of matters which can be included in an individual care plan to ensure that the individual care plan may be periodically reviewed. This ensures reviews and amendments of the individual care plan can occur where a revised assessment of risks and benefits weighs against the further deferral of treatment.
6.3.3(c)	Consider later regret, anger or distress stemming from surgeries not being provided earlier in life.	41	 Feedback considered and incorporated in part. This feedback wrongly assumes that a child will be silent throughout the entire process of the registering and reviewing their individual care plan. As set out in item 6.3.3(a), we have strengthened the decision-making framework which must be followed by the oversight panel to centre the voice of the person who is receiving the treatment. The framework allows the oversight panel to consider the views of the person receiving the treatment, even if they do not have legal

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			capacity to make the decision for themselves. That means a child may be able to provide their own views as their capacity evolves. This may persuade the oversight panel to consider earlier treatment for some children than it would for others.
			Further, while we have also placed limitations on the ability of the oversight panel to rely on speculative or general evidence of psychosocial and social benefits, we have recognised that one of the exceptions to this rule should be where that evidence of those benefits comes directly from the protected person themselves.
6.3.3(d)	Evidence suggests adults are pleased	41	Feedback considered and incorporated in part.
	with procedures done in infancy.		As set out in item 6.3.3(a), we have strengthened the decision-making framework which must be followed by the oversight panel. The oversight body will be able to consider the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing). However, evidence of psychosocial benefits will need to meet certain requirements to be taken into account. Those requirements are that the evidence either comes directly from the protected person themselves, or has substantial probative value specific to the protected person. The panel will therefore be able to scrutinise any specific evidence of substantial probative value that suggests adults in the position of the protected person are pleased with procedures done in infancy.
6.3.3(e)	Deferability would cause harm for women with CAH.	41	Feedback considered and incorporated in part. As set out in item 6.3.3(a), we have strengthened the decision-making framework which must be followed by the oversight panel. The oversight body will be able to consider the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing). However, evidence of psychosocial benefits will need to meet certain requirements to be taken into account. Those requirements are that the evidence either comes directly from the protected person themselves, or has substantial probative value specific to the protected person. The panel will therefore be able to scrutinise any specific evidence of substantial probative value that deferability would cause harm for women with CAH if it is evidence of a psychosocial benefit.
6.3.3(f)	Deferability would cause harm for people with hypospadias.	41	Feedback considered and incorporated in part.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			As set out in item 6.3.3(a), we have strengthened the decision-making framework which must be followed by the oversight panel. The oversight body will be able to consider the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing). However, evidence of psychosocial benefits will need to meet certain requirements to be taken into account. Those requirements are that the evidence either comes directly from the protected person themselves, or has substantial probative value specific to the protected person. The panel will therefore be able to scrutinise any specific evidence of a psychosocial benefit.
6.3.3(g)	Early surgery can improve fertility in those with undescended testes.	41	Feedback considered and incorporated in part. As set out in item 6.3.3(a), we have strengthened the decision-making framework which must be followed by the oversight panel. The oversight body will be able to consider the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing). This includes the option of allowing medical treatment that preserves options for the protected person in the future.
6.3.3(h)	Lack of evidence means the presumption of deferability would be hard to rebut, potentially leaving people without treatment that would be in their best interests.	41	 Feedback considered and incorporated in part. We have provided the oversight body with its own powers to obtain evidence or opinions from specialists to help reduce any evidentiary gaps. The oversight body can also include provisions in an individual care plan allowing the plan to be reviewed when circumstances change or after a period of time. As set out in item 6.3.3(a), we have also strengthened the decision-making framework which must be followed by the oversight panel. The oversight body will be able to consider the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing). This includes: the option of deferring medical treatment that modifies a protected person's sex characteristics to preserve any expected ability of the protected person to provide personal consent in future; or the option of allowing medical treatment that preserves options for the protected person in the future. Ultimately, if there is no evidence to show the benefits of treatment, then there is no justification for medical treatment modifying a person's sex characteristics without their personal consent.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
6.3.3(i)	Express the principle more neutrally, for example by factoring in the benefits of deferability (rather than presuming).	41	 Feedback considered and incorporated in part. As set out in item 6.3.3(a), we have strengthened the decision-making framework which must be followed by the oversight panel. The oversight body will be able to consider the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing). This includes: the option of deferring medical treatment that modifies a protected person's sex characteristics to preserve any expected ability of the protected person to provide personal consent in future; or the option of allowing medical treatment that preserves options for the protected person in the future.
6.3.3(j)	Deferral is already common practice for several conditions including androgen insensitivity, 5-alpha reductase deficiency and 17 beta HSD.	41	Feedback noted. If that is the case, then there is no requirement to apply to the panel. The proposal only requires applications to the panel when proposed medical treatment modifies a protected person's sex characteristics in ways which are permanent or difficult-to-reverse, and they do not have capacity to provide personal consent.
6.3.3(k)	Consider potential harm to mental health during deferral period.	41	Feedback incorporated. As set out in item 4.1.2(b), we have included a broad list of matters which can be included in an individual care plan to ensure care plans can include provisions for peer support and psychological support.
6.3.3(I)	Provide psychological support to families during the deferral period.	42	Feedback incorporated. As set out in item 4.1.2(b), we have included a broad list of matters which can be included in an individual care plan to ensure care plans can include provisions for peer support and psychological support. The oversight body can also make referrals to peer support and counselling for any affected person that comes before it.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
6.4	THE 'HARM TO HEALTH' TEST AND PF	RINCIPLE	OF NON-DISCRIMINATION
6.4.1	Consider an approach strictly ruling out some procedures, for example cosmetic treatments.	42	 Feedback considered and incorporated in part. As set out in item 2.4.5, there are difficulties in defining a prohibition (and its exceptions) to ensure it is sufficiently certain, considers the individual circumstances of each person (including circumstances which are difficult to predict or know in advance), and does not delay or deny treatment to a person which is necessary or wanted by the person. There is also a distinction between treatment carried out for a purely cosmetic purpose, and treatment which is not cosmetic but may have some relevant cosmetic considerations. An example we were provided in the consultation was in relation to treatment connected to bladder exstrophy, which is undertaken for health reasons (to achieve continence and maintain kidney function) but may require some aesthetic considerations to be taken into account in deciding on the preferred approach to treatment.²⁴⁶ We think the better approach is to put in place a series of broader principles, a good process that allows the scrutiny and testing of evidence and claims, and a legal test which allows decision-makers to consider each case on its merits so decisions can be tailored to the needs of the particular person. For that reason, we think the amended decision-making approach (discussed in item 6.3.3(a)) achieves this objective in a legally defensible way that protects the rights of the individual but minimises the risk of unintended consequences. It includes a restriction on the oversight panel relying on cosmetic rationales for treatment, but allows evidence of social or psychosocial benefits if the protected person provides that evidence themselves or the evidence has substantial probative value is specific to the protected person.
6.4.2	Concern that the 'harm to health' test may be too broad and allow social and	42	Feedback considered and incorporated in part. As set out in item 6.3.3(a), we have strengthened the decision-making framework which must be followed by the oversight panel. The oversight body will be able to consider the risks and benefits of the medical treatment and

²⁴⁶ Listening report, p. 42.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
	psychological considerations under mental health.		any alternatives (including the option of doing nothing). However, evidence of social and psychosocial benefits will need to meet certain requirements to be taken into account. Those requirements are that the evidence either comes directly from the protected person themselves, or has substantial probative value specific to the protected person.
6.4.3	Concern that the 'harm to health' test may be too narrow, and future considerations (such as future fertility) should be taken into account.	42	 Feedback incorporated. As set out in item 6.3.3(a), we also strengthened the decision-making framework which must be followed by the oversight panel. The oversight body will be able to consider the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing). This includes: the option of deferring medical treatment that modifies a protected person's sex characteristics to preserve any expected ability of the protected person to provide personal consent in future; or the option of allowing medical treatment that preserves options for the protected person in the future.
6.4.4	Cosmetic factors should not be entirely excluded given aesthetic considerations may be linked to other procedures.	42	Feedback incorporated. See item 6.4.1.
6.4.5	The notion of health should involve both physical and psychological health.	42	Feedback considered and incorporated in part. As set out in item 6.3.3(a), we have strengthened the decision-making framework which must be followed by the oversight panel. The oversight body will be able to consider the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing). This includes all aspects of health. However, evidence of social and psychosocial benefits will need to meet certain requirements to be taken into account. Those requirements are that the evidence either comes directly from the protected person themselves, or has substantial probative value specific to the protected person.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
6.4.6	Stigma and discrimination should be considered by the panel in determining whether treatment should proceed.	16	Feedback considered and incorporated in part. As set out in item 6.3.3(a), we have strengthened the decision-making framework which must be followed by the oversight panel. The oversight body will be able to consider the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing). This includes all aspects of health. However, evidence of social and psychosocial benefits will need to meet certain requirements to be taken into account. Those requirements are that the evidence either comes directly from the protected person themselves, or has substantial probative value specific to the protected person. This recognises that stigma and discrimination cannot be used as a reason to justify modifying a person's body, particularly when other support may address that unfair burden that will continue to be carried by individuals until society collectively takes responsibility and addresses attitudes which impose these burdens on people. If a person themselves wants changes made to their body for a social or psychosocial reason, the oversight body will have the ability to listen to the specific needs and wants of the person, consider with them the alternatives available, and provide them with the option of information, support or additional time as part of their individual care plan. Through the panel process, that person will have the opportunity to explore medical and non-medical alternatives that may address the underlying burden they are experiencing as a result of stigma and discrimination.
6.4.7	Some parents were comfortable with 'cosmetic' procedures such as clitoral reduction and vaginoplasty for their children, emphasising intermingling of physical, psychosocial and socioeconomic rationales.	43	 Feedback noted. This scheme will require the oversight body to oversee any medical treatment modifying the sex characteristics of a protected person in circumstances where they cannot provide personal consent. As set out in item 6.3.3(a), we have strengthened the decision-making framework which must be followed by the oversight panel. The oversight body will be able to consider the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing). Evidence of social and psychosocial benefits will need to meet certain requirements to be taken into account. Those requirements are that the evidence either comes directly from the protected person themselves, or has

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			substantial probative value. Ultimately, the oversight body must give proper weight to the principle that every individual has a significant and profoundly personal interest in deciding what happens to their own body.
6.5	SUPPORTED DECISION-MAKING PRIN	ICIPLES	
6.5.1	The scheme should be framed in accordance with supported decision- making principles.	43	 Feedback incorporated. Supported decision-making means assisting, or supporting, someone to make a decision for themselves. We have incorporated supported decision-making principles by: Ensuring that the oversight body does not make decisions for people who otherwise have the capacity to make their own decision and clarified that the capacity to provide informed consent must be assessed in light of whether the person would be able to understand, remember, use and weigh the relevant information, or communicate a decision, with <i>reasonable support</i>. We have defined 'reasonable support' to include (a) the conveying of the information by another person or in another manner; (b) the provision of additional time; (c) the provision of additional assistance or support, including by another person; or (d) the provision of aids (including palliative or therapeutic devices) or other mechanisms, and in a manner which is reasonable, and which would enable the protected person to understand, remember and use or weigh relevant information, or communicate the relevant decision or information. Ensuring that the oversight body applies the '<i>wills and preferences</i>' test when it makes decisions for adults who do not have capacity to give informed consent. Rather than considering what it thinks is best for the person, this test requires the oversight body to consider what the person would want for themselves, or the best ascertainment of what the person would want for themselves, or the best ascertainment of what the person would want for themselves, their views, unless overriding those wishes is necessary to prevent serious harm to the person.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
6.5.2	Consider international human rights law differences in approach to consent between children and adults with a disability.	43	Feedback incorporated. As set out in item 6.3.3(a), we have amended the decision-making framework to conform with the different approach in international human rights law applicable to children under the Convention on Rights of the Child and adults with disability under the Convention on the Rights of Persons with Disabilities. For children, that means the best interests of the child as the paramount consideration, although acknowledging that past determinations of best interests has been heavily criticised, ²⁴⁷ and ensuring children are given a say in decisions affecting them as their capacity develops. ²⁴⁸ For adults, that includes listening to the will and preferences of the person, or ascertaining what their will and preferences would be if they could fully express them. ²⁴⁹
7	OVERSIGHT BODY - INDIVIDUA	L CAR	E PLANS AND CLASS EXEMPTION ORDERS
7.1	SCOPE OF INDIVIDUAL CARE PLANS		
7.1.1	Require individual care plans from birth.	44	Feedback considered but not incorporated. While it will be possible for an interested person to seek an individual care plan from the birth of a child, there is no requirement to do so. In most cases, we expect an individual care plan will be sought where medical treatment is proposed which would modify the sex characteristics of a protected person without their personal consent. As set out in item 6.2.1(a), the role of the oversight body is not to regulate every instance of care given to people with innate variations of sex characteristics.

²⁴⁷ Listening report, pp. 27-28, 32, 43.

²⁴⁸ Convention on Rights of the Child, arts 3(1) and 12.

²⁴⁹ Convention on the Rights of Persons with Disabilities, art 12(2)-(4). See also Australian Law Reform Commission (2014) Equality, Capacity and Disability in Commonwealth Laws, recommendation 3.3.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE		
7.1.2	Ensure individual care plans include support before and after any treatment.	44	Feedback incorporated. As set out in item 4.1.2(b), we have included a broad list of matters which can be included in an individual care plan to ensure care plans can be patient-centred and individualised. However, we have not been prescriptive so that an individual care plan can be tailored to the needs of the individual.		
7.1.3	Ensure appropriate counselling or psychological support is built into decision-making.	44	Feedback incorporated. We have suggested that the oversight panel be able to provide a referral to peer support and counselling to any affected person, whenever it is reviewing an application for registering an individual care plan.		
7.1.4	Ensure longevity and regular review of individual care plans.	44	Feedback incorporated. Among the matters which can be included in an individual care plan, we have specified "the term of the individual care plan and/or the time or circumstances in which the plan ceases to have effect or must be reviewed by the oversight body."		
7.1.5	Concern that the inclusion of mental health supports in individual care plans would result in unequal access to mental health support for those who do not have to go through the panel process (ie, those with capacity to consent).	44	Feedback considered and amendments made where appropriate. We have included a greater emphasis on peer support and psychological support through the scheme, whether a protected person's medical treatment is overseen by the oversight body or the person has the capacity to make their own decisions.		
7.2	SUPPORT WORKERS				
7.2.1	Ensure support worker helps people through the process but does not advocate their own views.	45	Feedback incorporated. We have opted to replace the concept of a support worker employed by the oversight body with granting a power to the oversight body to appoint an independent advocate on behalf of the protected person. This allows the		

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			independent advocate to put forward views in support of the protected person without those views being seen to have come from the same oversight body that will ultimately decide the matter; thus protecting the impartiality of the oversight body and guarding against the risk of apprehended or actual bias. The oversight body will still be able to employ a secretariat to provide neutral assistance to people interacting with the oversight body without risking the oversight body being seen as lacking in impartiality.
7.2.2	Employ support workers through a different public body.	45	Feedback incorporated. As set out in item 7.2.2, we have opted to replace support workers employed by the oversight body with independent advocates appointed by the oversight body. This allows the oversight body to act (and be seen to be acting) impartially.
7.2.3	Ensure there is a counselling model before and after the process.	45	Feedback incorporated. We have suggested that the oversight panel be able to provide a referral to peer support and counselling to any affected person, whenever it is reviewing an application for registering an individual care plan.
7.3	CONSIDERATION BY THE PANEL	4	
7.3.1	Evidence gathering powers		
7.3.1(a)	Ensure panel has power to appoint someone (e.g. a psychologist) to provide independent evidence.	45	Feedback incorporated. We have strengthened the ability of the oversight panel to seek evidence, including through the appointment of an independent expert to provide recommendations on matters sought by the oversight panel. This can include clinical experts or people with lived experience.
7.3.1(b)	Ensure flexibility so that decisions can be made on the papers where appropriate.	45	Feedback incorporated.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE	
			We have suggested that the oversight body be given a power to convene a private meeting with all affected parties to seek and obtain their views on the application and draft individual care plan. However, subject to the requirement to comply with the rules of natural justice, there is no requirement for a private hearing to be held.	
7.3.1(c)	Ensure people are not forced to speak by the panel.	45	Feedback considered and already incorporated. The oversight panel must afford affected persons the opportunity to express their views but there is no obligation on them to take up that opportunity.	
7.3.2	Independent advocate			
7.3.2(a)	Consider including provision for an independent advocate for the child.	45	Feedback incorporated. We have amended the proposal to include the ability for the oversight body to appoint an independent advocate.	
7.3.3	Legal representatives			
7.3.3(a)	Only permit lawyers to appear with leave of the panel.	45	Feedback incorporated. We have amended the proposal to include this suggestion.	
7.3.4	Time for making decisions			
7.3.4(a)	Ensure panel can be convened quickly.	46	Feedback incorporated. We have included the option for a sub panel to be convened comprised of 3 members, and included an obligation on the oversight body to make decisions as efficiently as possible.	

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE	
7.3.4(b)	Concern about workload of the panel	46	Feedback incorporated.	
	and backlog of cases.		As set out in item 4.1.2(d), we have adopted a number of safeguards to minimise the potential for delays. These include the ability of the oversight panel to make class exemption orders where appropriate, reducing the need for individual applications and thereby the workload.	
7.3.4(c)	Concern for psychological impacts of	46	Feedback incorporated.	
	delays.		As set out in item 4.1.2(d), we have adopted a number of safeguards to minimise the potential for delays. We have also suggested that the oversight panel be able to provide a referral to peer support and counselling to any affected person, whenever it is reviewing an application for registering an individual care plan.	
7.4	REGISTRATION			
7.4.1	Ensure more clarity around the	46	Feedback incorporated.	
	registration of care plans and access to the register.		We have suggested that individual care plans be held on a register maintained by the oversight body and available for access in accordance with the Health Privacy Principles in the <i>Health Records Act 2001</i> (Vic).	
7.4.2	Ensure panel's notes are retained and	46	Feedback incorporated.	
	made available to individual upon request.		The panel must provide written reasons for its decisions, and these must be held on the register with any registered individual care plan.	
7.5	MATTERS FOR CLARIFICATION			
7.5.1	Consider the effect of the panel	46	Feedback incorporated.	
	refusing to register an individual care plan.		We have suggested amendments to clarify that a current individual care plan which has been registered by the oversight body operates according to its terms as if it were an order of an administrative tribunal. That means it	

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			compels or authorises such as acts to be done, or compels or grant authority to another person to authorise such as acts to be done, as set out in its terms.
7.5.2	Consider who is responsible for implementing an individual care plan.	46	Feedback considered and amendments made. The individual care plan can function like an order of a tribunal. We have allowed the oversight body to determine – by specifying in the individual care plan itself – whether the individual care plan authorises an act directly, or whether it authorises another person to perform an act.
7.5.3	Consider liability for wrong decisions.	46	Feedback considered. In the same way as a court or tribunal exercising medical decision-making powers, it is intended that the oversight body be responsible for making its decisions according to law, and its decisions can be appealed. Individual panel members are relieved from personal liability in the same way as tribunal members.
7.6	CLASS EXEMPTION ORDERS		
7.6.1	Fistula repair should be subject to a class exemption order.	47	Feedback considered and incorporated as appropriate. This is ultimately a matter for the oversight body to determine. For more information on the decision-making framework which must be followed by the oversight panel in order to make a class exemption order, see item 6.3.3(a). The oversight body will be able to consider whether it should make a class exemption order in respect of fistula repair, given it can consider the risks and benefits of a proposed medical treatment and any alternatives (including the option of doing nothing).
7.6.2	Orchiopexy and chordee repair should be subject to a class exemption order.	47	Feedback considered and incorporated as appropriate. This is ultimately a matter for the oversight body to determine. For more information on the decision-making framework which must be followed by the oversight panel in order to make a class exemption order, see item 6.3.3(a). The oversight body will be able to consider whether it should make a class exemption order in respect of

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			orchiopexy and chordee repair, given it can consider the risks and benefits of a proposed medical treatment and any alternatives (including the option of doing nothing).
7.6.3	Certain fertility preservation treatments should be subject to a class exemption order.	47	Feedback considered and incorporated as appropriate. This is ultimately a matter for the oversight body to determine. For more information on the decision-making framework which must be followed by the oversight panel in order to make a class exemption order, see item 6.3.3(a). The oversight body will be able to take into account the risks and benefits of certain fertility preservation treatments, given it can consider options of allowing medical treatment that preserves options for the protected person in the future.
7.6.4	Gonadectomies for evidenced high risk of cancer should be subject to a class exemption order.	47	Feedback considered and incorporated as appropriate. This is ultimately a matter for the oversight body to determine. For more information on the decision-making framework which must be followed by the oversight panel in order to make a class exemption order, see item 6.3.3(a). The oversight body will be able to take into account evidenced high cancer risk, given it can consider the risks and benefits of the medical treatment and any alternatives (including the option of doing nothing).
7.6.5	Treatment for evidenced repeated urinary tract infection over a long term should be subject to a class exemption order.	47	Feedback considered and incorporated as appropriate. This is ultimately a matter for the oversight body to determine. For more information on the decision-making framework which must be followed by the oversight panel in order to make a class exemption order, see item 6.3.3(a). The oversight body will be able to take into account evidenced repeated urinary tract infection, given it can consider the risks and benefits of a medical treatment and any alternatives (including the option of doing nothing).

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
8	MANDATORY REPORTING OBLIGATIONS		
8.1	OBLIGATION TO REPORT		
8.1.1	The panel should be notified of any diagnosis of a person with a variation of sex characteristics.	47	 Feedback considered but not incorporated. This suggestion was not universally supported by all people with variations of sex characteristics. We are persuaded by the consultation participants who argued that: reporting should be directed to the areas of greatest risk (which is the provision of treatments without personal consent); reporting of diagnoses is prone to error due to the risk of misdiagnosis; and reporting obligations on diagnosis may have the unintended effect of discouraging diagnosis.²⁵⁰ Given reporting obligations involve the collection and disclosure of personal health information, the information collected should be limited to that information which is strictly necessary for the oversight body to perform its functions.
8.1.2	Reporting obligations should extend to past medical procedures, including the last 10–15 years.	47	Feedback considered but not incorporated. The intention behind this suggestion was to give the oversight body a baseline set of data about medical procedures performed historically, so it could monitor the effectiveness of the scheme going forward. ²⁵¹ Given the scheme imposes new obligations (including on the consistent recording and reporting of appropriate data going forward), we do not think that imposing retrospective reporting obligations is practical, or would provide complete and consistent data that would be meaningful.

²⁵⁰ Listening report, p. 47.

²⁵¹ Listening report, p. 47.

Victorian Intersex Oversight Panel Proposal: Final report and recommendations

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
			Further, given reporting obligations involve the collection and disclosure of personal health information, the reportable information should be limited to that information which is strictly necessary for the oversight body to perform its functions.
8.1.3	Reporting should include information on alternative treatments considered.	47	Feedback incorporated. The proposal has been amended to include this requirement.
8.2	MANAGING PERCEPTIONS OF BIAS		
8.2.1	Ensure the oversight body remains a decision-making body rather than a regulatory body.	47	Feedback incorporated. As set out in item 7.2.1, we have opted to replace support workers employed by the oversight body with independent advocates appointed by the oversight body. This allows the oversight body to act (and be seen to be acting) impartially. We have also ensured that the oversight body does not have its own powers to consider contraventions of the prohibitions – but instead can refer them to relevant regulatory and law enforcement bodies. We have maintained an ability for the oversight body to issue guidance on the interpretation and operation of the scheme, including the interpretation of the prohibitions. This function will need to be exercised cognisant of its duties to comply with the rules of natural justice and act fairly and according to the substantial merits of the case in all matters.
9	CONFIDENTIALITY		
9.1	Confidentiality requirements should allow the panel to contact a mental health crisis team where appropriate.	48	Feedback incorporated. We have amended the confidentiality protections to ensure that the oversight body can lawfully disclose information when it is urgent and necessary to save life, prevent serious damage to the person's health, or prevent the person from suffering or continuing to suffer significant pain or distress, and it would not be appropriate or practicable to obtain consent from the person prior to the disclosure.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
9.2	Reporting should be aggregated (rather than publishing individual decisions) to protect privacy.	48	Feedback considered and incorporated in part. A new periodic reporting obligation has been included in the proposal in addition to an option for the oversight body to publish individual decisions without any identifying information.
10	INTERACTION WITH OTHER LAWS AND SYSTEMS		
10.1	The <i>parens patrie</i> jurisdiction of the Victorian Supreme Court should not be removed.	48	Feedback incorporated. The proposal has been amended to remove this aspect of the draft proposal.
10.2	Consider interaction of the civil protection proposal with persons appointed as medical decision-makers under the <i>Medical Treatment Planning</i> <i>and Decisions Act.</i>	48	Feedback incorporated. We have suggested that the law (including any prohibitions) should take effect notwithstanding any other law (including any statutory or common law principle regarding consent to medical treatment).
10.3	Consider interaction with powers given to foster carers and other appointments under historical legislation.	48	Feedback incorporated. We have suggested that the law (including any prohibitions) should take effect notwithstanding any other law (including any statutory or common law principle regarding consent to medical treatment), including historical legislation that remains in effect.
10.4	Amend statute of limitations legislation to provide clearer avenues for redress.	49	Feedback incorporated. We have suggested clarifying the effect of the <i>Limitations of Actions Act 1958</i> (Vic) on the date of discoverability for actions for personal injury, by either excluding knowledge held by the parents from being imputed to their child, allowing a child to bring an action without any time limit in respect of medical treatment modifying their sex characteristics or allowing a reasonable time after a child becomes an adult and becomes aware that they received medical treatment modifying their sex characteristics.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
11	FUTURE NATIONALISATION		
11.1	Concern that there might be 'border- hopping' without nationally consistent laws.	49	 Feedback considered and incorporated as appropriate. As set out in item 2.4.6, we have suggested the inclusion of extraterritorial offences to discourage forum shopping intended to evade the protections of the scheme. While we would support a nationally consistent approach that protects people with innate variations of sex characteristics wherever they live in Australia, we have reconsidered the ability of a Victorian law to set that foundation. Initially we suggested provisions allowing other jurisdictions to 'opt in' to the Victorian oversight body model. On further reflection however, and given that this scheme will now incorporate many references to existing Victorian laws on medical consent, we cannot see that another jurisdiction would be able to simply adopt this law as its own, without making significant amendments to ensure harmony with its own laws in many other areas. Accordingly, we suggest an easier way to ensure some national consistency is to: encourage each state and territory to adopt laws similar to this proposal; and allow each state and territory to adopt laws similar to this proposal; and allow each state and territory to mappoint to their oversight panels people who may also be appointed to the oversight panels of other jurisdictions. As more states and territories adopt their own laws, it may be possible to explore other efficiencies and synergies across various laws, such as: amendments to recognise individual care plans adopted in another jurisdiction; operational measures that allow for the appointment and training of panel members across jurisdictions; information sharing between the oversight bodies of different jurisdictions. For this reason, we have suggested that the future harmonisation of laws with other jurisdictions be considered as part of the 5-year statutory review.

NO.	CONSULTATION CONCERNS OR SUGGESTIONS	PAGE	RESPONSE
12	REDRESS		
12.1	Include redress for historical practices (suggestions included an apology, access to health information, peer support or compensation)	49	Feedback noted. While this feedback deals with matters which are outside the scope for our engagement, we would support such redress measures and encourage the Victorian Government to consult with people with innate variations of sex characteristics in this regard.
13	NEED FOR EDUCATION		
13.1	Ensure greater education in health professionals, GPs and the general public.	50	Feedback noted. While this feedback deals with matters which are outside the scope for our engagement, we would support such education, and encourage the Victorian Government to consult with people with innate variations of sex characteristics in this regard.
13.2	Ensure resources and information are in accessible language.	50	Feedback noted. While this feedback deals with matters which are outside the scope for our engagement, we would support such resources and information, and encourage the Victorian Government to consult with people with innate variations of sex characteristics in this regard.