‘A RIGHT TO BE, BELONG & BECOME’:

LISTENING REPORT FROM OUR CONSULTATIONS ON A PROPOSAL FOR A VICTORIAN INTERSEX OVERSIGHT PANEL

CONTENTS

ACKNOWLEDGEMENTS

Thank you to the people with variations of sex characteristics and their families, health professionals and other stakeholders who were involved in our consultation on a proposed Victorian intersex oversight scheme. We are grateful and sincerely appreciate the openness in which you engaged with us. We hope you find all your voices respectfully reflected in this listening report.

We, in particular, honour and thank the people with variations of sex characteristics who shared with us their ideas, vision and experience, including many of you who shared with us your personal stories. We heard your wisdom, expertise, hopes and concerns, as well the stories of discrimination, stigma, pathologisation, loss of agency and violation of human rights you entrusted to us. We hope this report has documented your views and experiences faithfully and with the respect and dignity that they deserve.

We acknowledge the decades of advocacy and work done by all people with variations of sex characteristics, including those involved in making the Darlington Statement. We acknowledge those who are named in this report and those who are not. Our work is indebted to the experience of leading organisations and individuals in the intersex movement in Australia and Aotearoa/New Zealand upon whose work and advocacy our legal policy work draws upon.

We thank Intersex Human Rights Australia (**IHRA**), which has been engaged by the Victorian Government to review existing resources and develop new resources for individuals, parents and families, and to provide policy advice in respect of a Victorian intersex oversight scheme, for their guidance and input on and into the consultation and draft proposal.

Finally, we thank all members of the Victorian Intersex Expert Advisory Group (**IEAG**) for their guidance and input into the consultation plan and earlier versions of the draft proposal.

ABOUT EQUALITY AUSTRALIA

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

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.

Sydney office: 414 Elizabeth Street Surry Hills NSW 2010
Melbourne office: Victorian Pride Centre, 79-81 Fitzroy Street St Kilda VIC 3182

Telephone: +61 03 9999 4527

Email: info@equalityaustralia.org.au

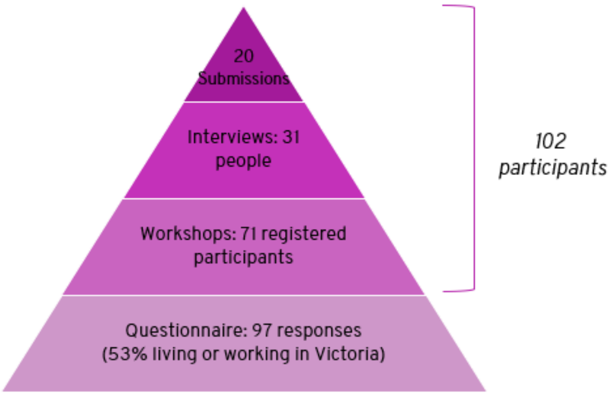
www.equalityaustralia.org.au

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.

EXECUTIVE SUMMARY

In July 2021, the Victorian Government announced its commitment to developing an intersex protection system to include an oversight panel to ensure compliance with a prohibition on deferrable medical interventions modifying a person's sex characteristics without personal consent. Equality Australia was commissioned by the Victorian Government to provide legal policy advice on a proposal to implement this commitment. It was in this context that Equality Australia conducted a public consultation based on the draft legal proposal contained in our consultation paper, *A Victorian Intersex Oversight Scheme: A consultation paper on a legal scheme to protect people from medical interventions on their sex characteristics without personal consent*.

CONSULTATION PARTICIPANTS



Our consultation heard from 102 individuals and organisational representatives through a series of online workshops, separate interviews and written submissions. 97 responses were also received through an online questionnaire which allowed feedback to be provided anonymously, with approximately half of these responses being from people who lived or worked in Victoria.

In total, at least 26 people with variations of sex characteristics, 21 parents and 2 partners of people with variations of sex characteristics, 49 clinicians and health professionals, and 13 individuals and representatives with legal, policy, human rights and other expertise were involved in the consultation through one or more of these channels.

Among the people with variations of sex characteristics were people with a range of variations. Among the parents of people with variations of sex characteristics were parents of children with ages ranging from infancy to adulthood.

Full details of our consultation process, recruitment and participants are set out in sections 2 and 3 of this report.

IN PRINCIPLE SUPPORT AND OPPOSITION

Consultation participants consisted of those that supported or opposed the general policy underlying the draft proposal for an oversight panel ensuring compliance with a prohibition on deferrable medical interventions modifying a person's sex characteristics without their personal consent.

Most people born with variations of sex characteristics, some parents, some health professionals, and legal and policy experts supported this policy in principle, while many clinicians, many of the parents and a few people born with variations of sex characteristics did not support this policy in principle. Some of the reasons given for that support and opposition are set out in section 4 of this report.

Clinicians (apart from mental health professionals) and many of the parents of children with congenital adrenal hyperplasia (**CAH**) featured strongly among the groups opposed to the general policy. Parents who regretted or felt pressured to make decisions about medical interventions on their children, as well as most people born with variations of sex characteristics featured strongly among the groups in support of the general policy. However, there were also exceptions in each group, and views on the detail of the draft proposal differed widely.

VIEWS ON THE DETAIL OF THE DRAFT PROPOSAL

The draft proposal in the consultation paper set out a detailed set of proposals, including in respect of:

- proposed prohibitions on certain medical treatments modifying a person's sex characteristics without their personal consent. These prohibitions included certain exceptions; and

- a proposed oversight body, including a panel comprised of 9 members, with several functions and powers, including the ability to allow certain medical treatments modifying a person's sex characteristics where a person did not have capacity to give consent.

Some opponents of the general policy did not provide further comment on the detail of the draft proposal, while most supporters of the general policy provided detailed feedback on particular aspects of the draft proposal.

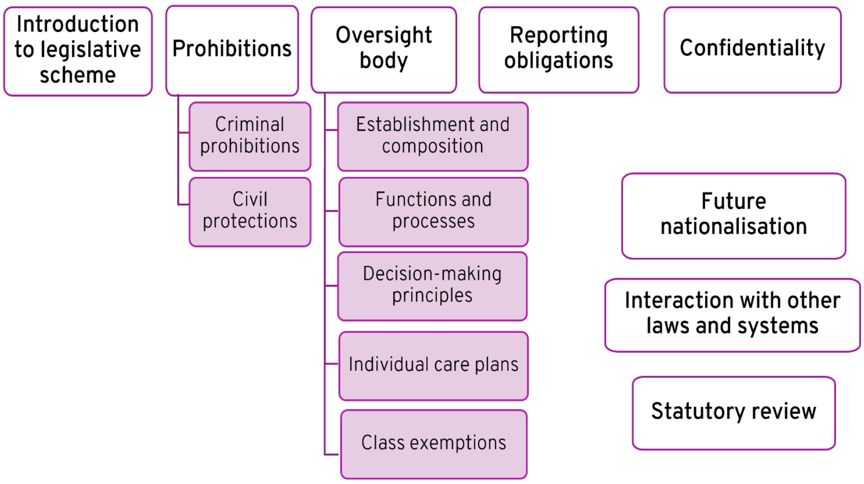


Figure 1: Overview of the draft proposal

PROHIBITIONS AND EXCEPTIONS

The draft proposal suggested criminal and civil prohibitions on certain medical treatment modifying the sex characteristics of people born with innate variations of sex characteristics except where:

- the person provided their personal consent to the treatment;
- in certain emergency situations; and
- in limited circumstances, as defined by an oversight panel.

The draft proposal suggested that these prohibitions apply to people born with innate variations of sex characteristics, including people with CAH, androgen insensitivity syndrome (**AIS**), hypospadias, undescended testes, Swyer syndrome, bladder exstrophy, mosaicism, Mayer-Rokitansky-Kuster-Hauser syndrome (**MRKH**) and sex chromosome variations such as Turner and Klinefelter syndromes. It was proposed that male circumcision would be outside the scope of the scheme.

Definition of 'protected person'

Among those who supported the general policy in principle, there was general support for a scheme that applied only to people born with innate variations of sex characteristics. However, there was some opposition to the inclusion of certain variations within the scope of the scheme (or a scheme at all), including among clinicians and some people and parents of people with CAH. See Definition of 'protected person' in section 5(b) for more information.

In scope treatments

Among those who supported the general policy in principle, there was general support for a scheme that covered both surgical and hormone treatments that modify a person's sex characteristics in ways which are permanent, or which are difficult to reverse without further invasive treatment. There was a divergence of views in respect of whether vaginal dilation should be included within the scope of the scheme. See In scope treatments in section 5(b) for more information.

Criminalisation

There were a range of views, among both in principle supporters and opponents regarding the proposal to introduce criminal prohibitions, including those with extraterritorial effect. While opponents of criminalisation were concerned with the potential adverse impacts of criminalisation and/or thought civil prohibitions would be sufficient, supporters of criminalisation felt criminalisation was necessary to effect change and that the offences were sufficiently clear. See Criminalisation in section 5(b) for more information.

Emergency treatment

There was general support for an exception allowing treatment in emergency situations. However, some were concerned that the terms used in the exception, namely *'urgent'* and *'distress'*, were potentially ambiguous and could be used to authorise treatments contrary to the intent of the scheme. See Emergency treatment in section 5(c) for more information.

Male circumcision

There were a range of views about the exception for male circumcision. In principle opponents of the scheme said that the exception highlighted double standards at play: namely, that parents would still be able to consent to medically unnecessary procedures while medically necessary procedures would be subject to the additional scrutiny of an oversight panel. In principle supporters of the scheme diverged in their views. Some thought male circumcision should be subject to the same requirement for personal consent unless the procedure was medically necessary. Others thought that a scheme applying only to people born with innate variations of sex characteristics would not be the correct vehicle by which to address the issue of male circumcision which also applied to the broader population, whatever views were held in respect of the procedure itself. See Male circumcision in section 5(c) for more information.

OVERSIGHT BODY – ESTABLISHMENT, COMPOSITION, FUNCTIONS AND POWERS

The draft proposal suggested the establishment of an oversight body with a 9-member panel, chaired by a senior lawyer or former judge, and comprised of a specific mix of health professionals, community members, a bioethicist and a human rights or children's rights expert.

The draft proposal suggested the chair should have powers to substitute members with alternative panel members drawn from a pool of reserve members, so that relevant expertise or lived experience could be represented on the panel in particular cases. The draft proposal also suggested certain rules on the number of panel members required for decisions of the panel to have effect; the possibility of 3-member sub-panels to hear individual cases; and a process for appealing panel decisions.

The draft proposal also suggested that the oversight body should have a range of functions apart from making decisions in particular cases, including educative, research and advisory functions.

Proposed oversight panel

- Chair (senior lawyer or former judge)
- 3x health professional representatives
- 3x community representatives
- Bioethicist
- Human rights or children's rights expert

General support for and opposition to a panel

Many of the parents and most clinical participants did not support the idea of an oversight panel in the form proposed or at all. However, most people with variations of sex characteristics, some parents and other consultation participants with community, policy, legal or human rights backgrounds supported the idea of an intersex oversight panel.

Among the parents who opposed the idea of a panel in principle, many felt that they were better placed than a panel of *'strangers'* to make decisions about the best interests of their children after consultation with the medical specialists they trusted. In contrast, the parents who supported the idea of a panel in principle said that the panel would give parents a voice, where existing medical ethics forums had excluded them. A panel would also give parents access to support and the benefit of collective experience in ensuring decisions were made in the best interests of children, even if those decisions were uncomfortable for the particular parents themselves.

While some clinicians liked certain aspects of the draft panel proposal (such as having a panel for *'serious or complex disorders'* and the inclusion of community representatives), most rejected the proposal. Among the reasons provided for their opposition included: that multidisciplinary forums already provided effective oversight; that the process would be *'bureaucratic'*, *'unworkable'* and would impose *'huge workloads'* on clinicians and the panel; that there would be negative effects from the process on the wellbeing of the child, including from delays in accessing treatment; and that parents would be frustrated and distressed by the panel process. See General support for and against a panel in section 5(d) for more information.

Size and composition of the panel

Among supporters of a panel, there were a range of views about its optimal size. For example, some felt 9 members would provide a good range of views, while others felt 9 would be intimidating to families and slow in reaching its decisions. Others felt a 3-member sub-panel was too small.

A common fear among all the participants was that the panel would be dominated by particular viewpoints – e.g. people who were either pro or anti medical intervention – and panel members would not work well together or approach their task impartially. All stakeholder groups were concerned about who would sit on the panel and were concerned both about people from within their own stakeholder group or from other groups that would come with pre-formed opinions, or without relevant expertise or lived experience. In respect of the position of chair, most recognised the significance of an appropriate appointment to the success of the panel. The person would need to engender the trust and confidence of all stakeholders and have a certain degree of gravitas.

See Size of panel and Panel composition in section 5(d) for more information.

Professional development and conflicts of interest

Several consultation participants said that panel members would need induction and ongoing training, including about medical and non-medical pathways, as well as in the areas of administrative law and decision-making. Conflicts of interest would require careful management. The chair could also be expected to perform an important role in managing operational aspects of the panel. See Professional development and Conflicts of interest in section 5(d) for more information.

Situating the oversight body

Several participants with variations of sex characteristics wanted to see the oversight body sit in a neutral place, outside a health setting. See Situating the oversight body in section 5(d) for more information.

Educative, research and advisory functions

Several participants saw a greater educative, research and advisory role for the oversight body, including having clear periodic reporting requirements for its decisions. However, another participant cautioned that greater educative and guidance functions could leave the oversight body vulnerable to accusations of bias, hampering its administrative decision-making role. See Educative, research and advisory functions in section 5(e) for more information.

OVERSIGHT BODY – DECISION-MAKING PRINCIPLES

The draft proposal suggested that the panel should comply with 4 key legal principles when making any decision on whether to permit medical treatment modifying a person's sex characteristics in absence of the person's own capacity to consent. These 4 principles were that:

- **human rights framework principle:** the panel must make its decisions lawfully and in compliance with the Victorian Charter of Human Rights and Responsibilities;
- **principle of self-determination:** the panel only has power to make decisions if a person does not have the capacity to make those decisions themselves, and only after giving them reasonable support to express any views and taking those views into account;
- **principle of deferability**: the panel must ensure its decisions do not allow medical treatment modifying a person's sex characteristics unless that treatment cannot be deferred without causing or being likely to cause harm to the health of the person (the **'harm to health test'**);
- **principle of non-discrimination:** the panel must ensure its decisions do not presume without substantive evidence that a person with variations of sex characteristics would experience any

social or psychological benefits from having their sex characteristics function or appear in a matter which conforms with norms for persons without that variation.

Given the centrality of these propositions to the proposed scheme, many participants had views regarding these key principles.

Human rights framework principle

One legal participant noted that the human rights framework principle would mean that courts would still be able to exercise a degree of merits review in respect of panel decisions. See The human rights framework principle at section 5(f) for more information.

Principle of self-determination

Among supporters of the panel proposal, there were divergent views about the proper role of the panel. Consistent with the principle of self-determination, some saw the panel as a decision-maker of *'last resort'*, having a role only in cases where a person did not have capacity (after reasonable support was provided) to give personal consent. However, others suggested that the panel should have an enlarged supervisory role in testing the *quality* of consent obtained from a person who had capacity to give consent. This could include testing the neutrality and completeness of information provided to a person in order to obtain consent to ensure that consent was not pressured or coerced. See The principle of self-determination at section 5(f) for more information.

Principle of deferability

Most people with variations of sex characteristics, some parents, and a few health professionals supported the principle of deferability. However, a few people with variations of sex characteristics, many of the parents and most clinicians did not.

Among people with variations of sex characteristics, some saw this principle as a non-negotiable aspect of the reform and one person put it as follows: *'if the child can piss, poo, eat, drink and breathe, leave them the hell alone'*. Given it was the individual who had to live with the consequences of these decisions, it was important that decisions were left to them wherever possible. However, a few people with variations of sex characteristics, including two participants with CAH, were supportive of early interventions. One woman with CAH told us that to deny parents the right to consent to early surgery for girls with CAH, *'when it can be fixed'*, would be to deny *'a woman who is a woman the right to be a woman'*.

Among parents of people with variations of sex characteristics, some supported the principle of deferability while others opposed it. Those who supported the principle included some who still felt pressured to consent to early treatment or who regretted past decisions. However, not all parents agreed that they felt pressured to consent to early surgery and some (particularly parents of children with CAH) strongly favoured early treatment for a range of reasons. These reasons they gave included that: surgery would be required in future anyway; it was better to have the surgery when the child would not remember it; and that leaving surgery until later would present more issues, including the child discovering that *'they do not look what is considered normal'*.

Many clinical participants (but not all) objected to a universal principle of deferability, while mental health professionals tended to support the principle. Clinical objections to the principle of deferability included that the approach was untested, experimental and lacked a strong evidence base proving its benefits. Some clinicians said that the principle would cause harm given evidence suggested that most women with CAH preferred earlier surgery, and that deferring treatment for hypospadias had negative impacts on psychological health. However, other participants disputed that the evidence on the benefits of early interventions were so clear cut. Some clinicians also opposed the principle because the lack of evidence made it difficult to rebut the presumption or said that the principle should be framed neutrally. However, another participant said the principle was already common practice for certain conditions. See The principle of deferability at section 5(f) for more information.

Harm to health test and principle of non-discrimination

Several participants commented on the factors which the panel should and should not consider when deciding whether medical treatment is deferrable. While some participants said *'cosmetic'* considerations should never be justifications for treatment, others said that aesthetic considerations do matter when deciding on which procedure is preferable. Some participants were concerned that deferring procedures unless they were likely to cause harm to a person's health might prevent earlier interventions which preserve options for the future, such as procedures to preserve fertility. Other participants said that when considering the likelihood of harm to a person's health, it was essential that the panel be able to consider both the mental and physical health of the person. However, other parents also said that other considerations should be taken into account, including social factors such as the risk of stigma and discrimination. See The 'harm to health' test and principle of non-discrimination at section 5(f) for more information.

Supported decision-making principles

One human rights expert said that the scheme needed to accommodate the different human rights approach required for children and adults with disability. Referring to the principle of self-determination, disability rights experts said that this proposal had gone further towards incorporating the principles of supported decision-making for adults with disability than Australian guardianship systems to date. See Supported decision-making principles at section 5(f) for more information.

OVERSIGHT BODY – INDIVIDUAL CARE PLANS AND CLASS EXEMPTION ORDERS

Applying the decision-making principles set out above and certain procedural requirements, the draft proposal suggested that the oversight body should be able to allow certain medical treatment modifying a person's sex characteristics without their personal consent by either:

- registering an individual care plan in respect of a particular person; or
- making an order to exempt a class of treatment from the prohibitions (subject to any conditions that the oversight panel might consider appropriate).

The individual care plan proposal was designed to facilitate a process, overseen by the oversight panel and driven by employed support workers, where the person, their parents (or other guardians and carers), their clinicians and other experts are involved in exploring the pros and cons of proposed treatments and other alternatives, before the panel makes a decision to support or reject proposed treatment.

Scope of individual care plans

Supporters of the proposal in principle generally wanted to see the scope of individual care plans enlarged to include provisions on support, such as psychological counselling before and after any medical treatment. However, one participant was concerned that people who had a registered individual care plan would have greater access to support than those that did not. See The scope of individual care plans at section 5(g) for more information.

Support workers

Participants wanted clarification regarding the proposed role of employed support workers. One participant said that employed support workers could not express policy positions if they were to sit within the oversight body, given the requirement for procedural fairness. See Support workers at section 5(g) for more information.

Consideration by the panel

Participants raised a range of suggestions regarding the procedure which should be followed by the panel when considering whether to register an individual care plan, including:

- the panel should have its own independent evidence gathering powers;
- children should have an independent advocate representing their voice during panel deliberations;
- legal representatives should only be allowed to appear with leave of the panel to avoid overly legalistic formalities;
- the panel would need to make some decisions quickly, while in other cases a general timeframe of 14 days may be optimistic.

See Consideration by the panel at section 5(g) for more information.

Registration and implementation

Some participants sought clarification on operational and technical issues regarding the individual care plan proposal, such as how the register of individual care plans would be maintained and accessed, and who would have responsibility for the implementation of individual care plans. See Registration and Matters for clarification at section 5(g) for more information.

Class exemption orders

Some participants agreed that class exemption orders could have a beneficial role in allowing some lower risk procedures to occur without needing individual applications to the panel. Among the procedures that could be dealt with through carefully drafted class orders might be: orchiopexy and chordee repair, certain fertility preservation treatments, and gonadectomies for evidenced high risk of cancer. However, participants were also concerned about the potential for class orders to reduce accountability to individuals. See Class exemption orders at section 5(g) for more information.

MANDATORY REPORTING OBLIGATIONS, CONFIDENTIALITY AND OTHER ISSUES

The draft proposal included several other provisions dealing with mandatory reporting obligations for health service providers, confidentiality, the interaction of the proposed scheme with other laws and systems, and the potential for the scheme to be nationalised in future.

Among the feedback received from participants were:

- differing views on whether mandatory reporting obligations should arise when diagnoses are made rather than when medical interventions are provided or performed;
- the need for exceptions to confidentiality obligations to enable mental health crisis support;
- opposition to excluding the *parens patriae* jurisdiction of the Victorian Supreme Court;
- the need to consider the interaction of the proposed scheme with historical medical consent legislation still in operation.

OTHER MATTERS

Outside of responses to the draft proposal, participants raised several other issues:

- **the need for redress**, including an apology or acknowledgement of past wrongs, the need for answers, the need for peer support, the need for financial support for psychological care or further medical treatment, and clear avenues for compensation;
- **the need for education**, including for health professionals and the general public, and to ensure parents were supported when a child with variations of sex characteristics was born;
- **the impact on relationships,** recognising that the impacts of past decisions weigh heavily not only on people with variations with sex characteristics but also the people who love them.

AS ONE CONSULTATION PARTICIPANT TOLD US...

"Being told to keep things a secret is difficult. It damages your quality of life. Having parents that understand it from a peer perspective would be very good. So many people out there have wonderful lives and haven't had to be traumatised. The education system needs to address the issue. It doesn't teach anything about variants, or even anything to do with intersex. So, a lot of the issues that parents have are: "my child is different", "how will they fit in?", "I should do something now so they can exist [in the world]". But how about we educate people that we exist. That we may be different but we're still human beings. We exist, breathe, love, add value to community, just like anyone else. … It wasn't 'til I got to about 5 and people pointed out that I was different. I didn't know it at the time. If you educate people, you won't have half of these problems or a push to have people being 'modified' in first place. They would be able to exist in own form, without complications for the rest of their lives. Maybe we need to educate the educators."

CONSULTATION SUMMARY

1. BACKGROUND

In its *(i) Am Equal: Future directions for Victoria's intersex community* paper released on 12 July 2021, the Victorian Government committed to developing an intersex protection system inclusive of:

- a mechanism to prohibit deferrable medical interventions modifying a person's sex characteristics without personal consent;
- an oversight panel to ensure compliance with the prohibition;
- provisions which ensure the collection of data and transparency over what treatments are being performed, including a requirement to report to the Department of Health when medical treatment modifying sex characteristics is provided to people with intersex variations without personal consent.

The Victorian Government commissioned Equality Australia to provide legal policy advice on a proposal implementing this commitment, working in consultation with Intersex Human Rights Australia (**IHRA**), people with variations of sex characteristics and their families, and other key stakeholders including health professionals.

The Victorian Government's commitment and our legal policy work builds on decades of work and advocacy by people with variations of sex characteristics, including through demands for a prohibition, better oversight mechanisms, transparency and human rights-based lifetime standards of care which were crystallised in the Darlington Statement. Made in March 2017, the Darlington Statement is a joint consensus statement by Australian and Aotearoa/New Zealand intersex community organisations and independent advocates, including the Androgen Insensitivity Syndrome Support Group Australia (**AISSGA**), Intersex Trust Aotearoa New Zealand (**ITANZ**), Organisation Intersex International Australia (**OIIAU**) (now IHRA), Eve Black, Kylie Bond (AISSGA), Tony Briffa (OIIAU/AISSGA), Morgan Carpenter (OIIAU/Intersex Day Project), Candice Cody (OIIAU), Alex David (OIIAU), Betsy Driver (Bodies Like Ours), Carolyn Hannaford (AISSGA), Eileen Harlow, Bonnie Hart (AISSGA), Phoebe Hart (AISSGA), Delia Leckey (ITANZ), Steph Lum (OIIAU), Mani Bruce Mitchell (ITANZ), Elise Nyhuis (AISSGA), Bronwyn O'Callaghan, Sandra Perrin (AISSGA), Cody Smith (Tranz Australia), Trace Williams (AISSGA), Imogen Yang (Bladder Exstrophy Epispadias Cloacal Exstrophy Hypospadias Australian Community (**BEECHAC**)) and Georgie Yovanovic. We thank each individual and organisation involved in the Darlington Statement for their vision and leadership, and we acknowledge the work done by many people with variations of sex characteristics to date, and since, in getting us to a stage where a proposed legislative model could be prepared for public consultation. Further information about some of the previous work advancing reforms in this area are discussed in our background paper, *Bodily Integrity, Physical Autonomy and Self-Determination: A background paper on protecting intersex people from medical interventions without personal consent*.

2. THE CONSULTATION PROCESS

(a) Preparing the draft proposal and consultation plan

In May 2021, we presented to the Victorian Intersex Expert Advisory Group (**IEAG**) a proposed consultation plan on a draft intersex oversight model. Members of the IEAG were provided with an outline of the draft legislative model which would form the basis of public consultation. Feedback was received from the IEAG on the draft model and the consultation strategy. That feedback informed a revised draft proposal and public consultation plan, which commenced with the release of the *(i) Am Equal* paper on 12 July 2021.

In the formulation of the draft proposal, Equality Australia also engaged directly with a range of community and subject matter experts, including people with variations of sex characteristics, clinicians, lawyers and human rights experts. Equality Australia also: reviewed a range of laws and policy literature, including submissions made to the

ACT Government's recent discussion paper[1]; undertook reviews of international and domestic oversight mechanisms (including overseas intersex protection schemes); and hosted a legal workshop commissioned by the ACT Government.[2]

(b) Public consultation

To launch the public consultation process on the draft proposal, Equality Australia released a consultation paper with a draft proposal, along with its background paper outlining the key legal and policy issues informing the draft proposal. We also released a two-page summary of the draft proposal.

The public consultation was designed to encourage people and organisations to share their views in the way which felt most comfortable for them. The public consultation included:

- **workshops:** six 1.5 hour online workshops intended for:
    - people with variations of sex characteristics (including a specific one for people with congenital adrenal hyperplasia (**CAH**));
    - parents, guardians, carers and family members of people with variations of sex characteristics (including a specific one for families of people with CAH);
    - clinicians and health professionals; and
    - interested stakeholders;
- **interviews:** the opportunity to book a time to speak directly with us;
- **anonymous feedback:** the opportunity to give feedback anonymously through an online questionnaire; and
- **submissions:** the opportunity to provide feedback or submissions in writing.

All workshops were conducted under the Chatham House Rule,[3] interviews and submissions were taken in confidence, and all participants were given a commitment that only non-identifying information would be disclosed. This was to ensure people felt they could contribute openly and in a way which felt safe for them.

The public consultation period was open between 12 and 31 July 2021, with extensions granted to those who asked for additional time to provide a response or speak with us. The questionnaire was left open until 10 August 2021.

The consultation was advertised via our website, email, social media and through direct invitations sent to intersex organisations, specific peer support groups for particular variations, LGBTQ+ organisations, health professional organisations, legal professional organisations, civil society and human rights organisations, public agencies, individual legal, clinical and human rights experts, and other stakeholders. Organisations and individuals were also invited to pass on information to their members and other interested people. We also received further recommendations for organisations to invite, who were then directly invited.

All consultation participants were provided with information on accessing free and confidential one-on-one counselling support, including through a dedicated arrangement with Thorne Harbour Health. People with lived experience were also offered a gift card as a token of our appreciation for their time in sharing their views and stories with us by way of an interview or in workshops.

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[1] ACT Government (2020) *Key issues in the prohibition of deferrable medical interventions on intersex people: Discussion paper*, December.

[2] Equality Australia (2021) *Towards a prohibition on deferrable medical interventions on intersex people: Report on the outcomes of the legal workshop on how a prohibition could operate in the Australian Capital Territory*, 30 April.

[3] The Chatham House Rule allows disclosure of the content of what was discussed but not information which would identify the participant who made the contribution.

3. WHO DID WE SPEAK TO?

In total, 102 people (including representatives on behalf of organisations) engaged with us through online workshops, separate interviews or by providing written submissions. 97 people provided responses through our anonymous questionnaire. Some people took the opportunity to provide feedback through more than one channel.

We heard from at least 26 people born with variations of sex characteristics, 21 parents of people with variations of sex characteristics, 49 clinicians and health professionals, along with several other legal, policy and human rights experts or organisations.

Among our consultation channels:

- 71 people engaged with us through our online workshops (including at least 20 people with variations of sex characteristics, 21 parents and 2 partners of people with variations of sex characteristics; and 14 clinicians or health professionals);
- 31 people took up the opportunity for an interview (17 people with variations of sex characteristics; 6 parents of people with variations of sex characteristics; and 8 people with other clinical, legal or policy expertise);
- 20 people or organisations took up the opportunity to provide us feedback in writing.

Of the 97 questionnaire responses received:

- 26 responses were from people born with innate variations of sex characteristics; 13 responses were from parents, guardians or carers of a person born with innate variations of sex characteristics; 49 responses were from clinicians or health professionals; 9 responses were from persons interested in reform in this area; and 1 person used another descriptor (multiple descriptors were allowed).
- 51 of the questionnaire respondents lived or worked in Victoria; 43 lived or worked outside Victoria, and the remainder preferred not to say where they worked or lived. Of the 51 respondents who lived or worked in Victoria, 16 responses were from people born with innate variations of sex characteristics; 5 responses were from parents, guardians or carers of a person born with innate variations of sex characteristics; 23 responses were from clinicians or health professionals; 7 responses were from people interested in reform in this area; and 1 person used another descriptor (multiple descriptors were allowed).

The people with variations of sex characteristics, parents and family members also had a range of professional, clinical, legal and policy expertise which they drew upon in providing us submissions and feedback.

Among the consultation participants who disclosed to us their particular variation these included people with CAH, androgen insensitivity syndrome (**AIS**), hypospadias, undescended testes, Swyer syndrome, bladder exstrophy, mosaicism, Mayer-Rokitansky-Kuster-Hauser syndrome (**MRKH**) and sex chromosome variations such as Turner and Klinefelter syndromes. We acknowledge that some consultation participants felt this language to be pathologising and preferred to describe themselves as people who were intersex, while other consultation participants rejected some variations being described as intersex. This is discussed further below.

Among the parents who were involved in our consultation, their children ranged in age, including parents who had very young children, school-aged children (including adolescents), and adult children. Several parents discussed with us decisions they had made regarding treatments for their children, particularly decisions about whether to consent to or defer surgeries. Some parents told us they were currently in the process of making those decisions; some parents had the made these decisions at some point over the last 10 years; while others told us that these decisions had been made more than 10 years ago.

To protect the privacy and confidentiality of consultation participants, we have taken several steps to minimise the risk of identification for consultation participants referred to in this report. To avoid the risk of inadvertent disclosure, we have minimised the degree of personal information included when referring to what participants told us. For example, we have generally anonymised or removed personal details such as specific titles, roles, areas of expertise, or personal markers such as gender or age. We have used singular or plural descriptors to give a sense of whether a particular view was unique to a participant or common among participants.

We thank all the participants who took part in our consultations for sharing their views with us. To the people with variations of sex characteristics and their families, who shared with us deeply personal and sometimes traumatic experiences from their lives, we are especially grateful to you.

4. SUPPORT AND OPPOSITION

There was a strong distinction between those who supported and opposed in principle the key policy planks of the draft proposal. Many of the participants' positions reflected their own experiences or underlying values and beliefs, some of which were expressed while others were implied in what they said.

There was a strong distinction among participants who spoke to a worldview that approached innate variations of sex characteristics as predominantly an issue to be managed through specialist medical care and those who spoke to a worldview that saw social attitudes towards people with variations of sex characteristics and their bodily difference as the critical issue, with that stigma reinforced by medical responses. Most participants were cognisant of both worldviews: some held views that recognised and reflected both worldviews, while others preferred one view to the other.

(a) Supporters in principle

Most people born with variations of sex characteristics, some parents, some health professionals, and legal and policy experts who were part of our consultation supported in principle the idea of an independent, carefully-selected oversight panel and a prohibition on medical treatment modifying a person's sex characteristics unless this occurs with personal consent or is otherwise justified for certain health-related reasons.

'In principle' supporters had a variety of views on the details of the draft proposal but generally approved of its grounding principle of delaying deferrable treatment to maximise the opportunity for a person to make their own decision about treatment affecting their sex characteristics.

Some of the typical views and underlying values in the feedback provided to us by supporters in principle included:

- people should be able to decide what happens to their own bodies, particularly as these decisions have potential life-long consequences that the person receiving the treatment has to live with;
- people with variations of sex characteristics should not have to adapt their bodies to fit social norms, instead society should change its norms to affirm them;
- people with variations of sex characteristics and their parents are not given neutral information about their variations from doctors to be able to make an informed decision about proposed medical treatment. This proposal would provide an avenue for families to access information and tap into support (including peer support) that might give them more time to understand and respond to their child's variation in a way which is affirming;
- while there are already clinical panels conducting such reviews, parents are not invited into those processes while decisions are being made about our children – this proposal gives parents a seat at the table;
- the medical evidence of the benefits of treatment, particularly surgery and early treatment, is contested, not compelling and/or still developing.

The first three bullet points were particularly resonant among people with variations of sex characteristics who were 'in principle' supporters; some of whom were distrustful of or concerned about the dominance of medical voices in this space. Parents who were 'in principle' supporters including several who felt pressured to make decisions, or regretted decisions they had made, for their children and saw the value of a panel process in which they were included. Clinicians and health professionals who were 'in principle' supporters tended to see the evidence of the benefits of treatment as contested or less clear cut, that treatments were not always necessary, and that mental health support for families and children was better than 'normalising' procedures.

(b) Opponents in principle

Many clinicians and health professionals, many of the parents and a few people born with variations of sex characteristics who were part of our consultation did not support the principle of deferring medical treatment that modifies a person's sex characteristics in either such a strict way or at all, or in giving an oversight panel (independent of the clinicians and parents of the particular child in question) the final say over whether treatment is provided to a particular child.

Some of the typical views and underlying values in the feedback provided to us by opponents in principle included:

- parents and specialist clinicians are better placed to make decisions in the best interests of their children than a *'bunch of strangers'* on a panel;
- certain variations, such as CAH, should not be described as 'intersex' and should be excluded from scope. Some of these variations are medical conditions, and it is unfair to deny a child treatment that would return their body to the way *'it was meant to be'*;
- the perceived problem being addressed by the scheme does not exist, as modern approaches to treatment of children with intersex variations involve evidence-based care, multidisciplinary discussion and ethics involvement that include discussing with parents the various options, risks and benefits, including the option of doing nothing;
- this approach is experimental, harmful, exceptional, unworkable and would introduce greater bureaucracy into medical decision-making, making it more stressful for parents in moments of crisis, and would impose great additional burdens on clinicians;
- the medical evidence on the benefits of deferring treatment is absent and/or current medical evidence supports early treatment.

People with variations of sex characteristics who were 'in principle' opponents tended to trust in the decisions made by their parents and clinicians and were happy to have had earlier treatment (or would have preferred it earlier). Parents who were 'in principle' opponents, most of whom had children with CAH, tended to trust in their child's clinical teams and did not want to see more barriers to accessing healthcare for their children. Many did not believe that stigma and discrimination would simply go away; reacted negatively to 'intersex' labels for their children; and thought that early interventions were in their children's best interests. Clinicians also featured strongly among the 'in principle' opponents, although there were degrees of opposition among clinicians. Some acknowledged that existing oversight mechanisms could be slightly improved, while many reacted strongly against the proposal. Given the extensiveness of the feedback received from clinicians, their views are more fully set out in General support for and against a panel at section 5(d) below.

5. SPECIFIC COMMENTS REGARDING THE DRAFT PROPOSAL

In this section, we set out the specific feedback we received on the draft proposal contained in our consultation paper. As set out in the figure below, the draft proposal had several proposed legislative components.

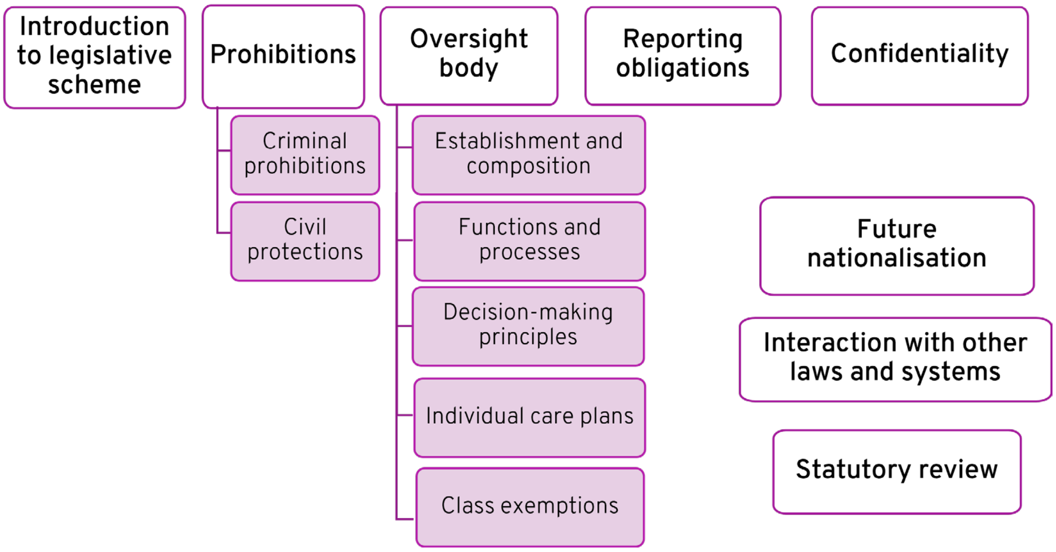

Figure 2: Overview of the draft proposal

Those proposed legislative components included:

- **introduction**: provisions setting out the objects and purposes that the legislation was seeking to achieve, as well as the scope of the scheme;
- **prohibitions:** provisions that set out when medical treatment modifying a person's sex characteristics can be performed and in what circumstances, and that provide the framework for the oversight body's work;
- **oversight body:** the establishment of an oversight body and provisions detailing its functions and processes, including a 9-member panel and 3-member sub-panel comprised of clinical, community, legal and human rights representatives;
- **transparency and confidentiality:** provisions that mandate reporting if certain treatments are provided without personal consent, while personal privacy is protected through confidentiality protections;
- **future nationalisation:** provisions that could allow the scheme to be adopted nationally in future, and which provide a mechanism for this to be achieved;
- **interaction with other laws and systems:** provisions that make consequential amendments to other laws so the scheme works harmoniously with existing systems;
- **statutory review:** provisions that mandate a review period so that the effectiveness and operation of the scheme can be reviewed.

We received detailed feedback about each of these potential aspects of the draft proposal, which are set out in detail below. This feedback came from people who supported and opposed the proposal in principle.

(a) Introductory provisions of the proposed scheme

SUMMARY OF THE DRAFT PROPOSAL

Section 2(a) of the draft proposal set out some potential introductory provisions for the proposed legislative scheme, including proposed legislative objects and purposes.[4] These proposed legislative objects and purposes included the intention to end harmful practices on people born with variations of sex characteristics through certain prohibitions on medical treatment; establishing oversight and transparency mechanisms; further promoting human rights; supporting the provision of information to people with variations of sex characteristics and their families to better inform decision-making; and to deferring certain medical treatment modifying a person's sex characteristics so that a person could make their own decision about whether they wish to receive that treatment.[5] The draft proposal also included several proposed legislative affirmations recognising that people with variations of sex characteristics were a natural part of human diversity, entitled to non-discriminatory healthcare that promotes and supports their bodily integrity, physical autonomy and self-determination; and denouncing medical treatment justified by discriminatory rationales about how bodies should appear or function in order to accord with particular gendered norms.[6]

OBJECTS AND PURPOSES

Most participants did not provide specific comments about the introductory aspects of the draft proposal, instead addressing the proposed details of the scheme. Accordingly, some participants supported, and some participants objected to, the proposed purposes and objects. These are addressed in detail below.

However, a few participants provided specific comments about these proposed introductory provisions. One participant with a variation of sex characteristics said that they supported the proposed introductory provisions but felt the draft scheme then failed to live up to their promise, and that all parts of the scheme needed to reflect the non-pathologising language used in these provisions.

Some participants said that the scheme had to be framed so that it did not stop people getting what they wanted in terms of treatment. The scheme should be framed in terms of giving people options so they can make their own decisions when they have the capability and capacity to do so.

One participant with experience in administrative decision-making bodies also emphasised the importance of the objects of the legislation setting the values by which panel members had to abide by. More could be done to set out these values, given the objects of the legislation would help with the selection of panel members and ensure that all panel members paid attention to the values that the legislation was designed to uphold.

(b) Prohibitions

SUMMARY OF THE DRAFT PROPOSAL

Sections 3(a), 4(a) and 5(a) of the draft proposal set out the criminal and civil prohibitions underpinning the proposed scheme.[7] These proposed provisions were designed to prohibit certain medical treatment that modified the sex characteristics of a person born with innate variations of sex characteristics without their personal consent. However, the prohibitions also included exceptions allowing treatment in emergencies or when certain processes, overseen by the oversight body, were followed.[8] The prohibitions also included an exception for male

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[4] Consultation paper, pp. 9-10.

[5] Id, p. 9.

[6] Id, p. 10.

[7] Id, pp. 12-13, 14-16, and 20.

[8] Id, p. 15.

circumcision.[9] There were several technical legal definitions included in these sections which addressed the extent of the protections and prohibitions offered by the scheme.[10]

DEFINITION OF 'PROTECTED PERSON'

Several participants commented on the proposed definition of a 'protected person' which limited the overall scope of the scheme to people born with innate variations of sex characteristics. Section 3(a) of the draft proposal defined a 'protected person' as *'a natural person born with variations of sex characteristics that do not ascribe to medical norms for male or female bodies'*.[11] The definition then provided a non-exhaustive list of variations that fit that description, allowing the Minister to expand the list of variations fitting that description upon the recommendation of the oversight body.[12]

Use of the term 'intersex' and the list of variations

Several participants, including several parents, clinicians and some participants with variations of sex characteristics, raised concerns regarding the use of the term 'intersex' and the non-exhaustive list of variations captured by the proposed scheme.

Several participants, including a few with variations of sex characteristics, said that terminology was important, and that they did not use the term 'intersex' to refer to either themselves or their children. Some parents went further in saying they did not want their children associated with the term 'intersex' at all. Meanwhile, other participants – both among those who supported or opposed the proposed scheme in principle – were concerned that a list of variations had a pathologising effect on people with variations of sex characteristics.

Two people with CAH and a group of parents of children with CAH advocated for the removal of CAH from the scheme altogether. Several parents said their children with CAH were either male or female, and they did not consider them to be *'truly intersex'*. One parent said that CAH was a *'hormone-based complication, not a sex-based complication'*, and several parents objected to the terminology of 'intersex' being used to refer to people with CAH. Some parents reflected on genital surgery being mostly an issue for girls with CAH, and one parent said they wanted their girls to have access to surgeries that *'returned them to what they should have been'* and would give their daughters *'the sex characteristics they deserve to have'*. For parents of boys with CAH, they were concerned about their boys being labelled as 'intersex' or being bullied by people who assumed that all people with CAH had ambiguous genitalia. One parent said that they felt the proposal was being driven by a group of adults who have had *'botched surgeries'* in the past and who did not want that to happen to more kids, but that surgery had improved over the years with better outcomes. However, not all participants, including those with CAH, supported these views. For example, one participant said what while it was true that people with CAH usually had a gender identity consistent with their sex chromosomes, it was not always the case. Another participant provided us with a copy of an article published in the International Journal of Endocrinology and Metabolism which identified 3 out of 52 people with CAH whose gender identity and sex assignment had been mismatched.[13]

While most opposed and a few supported the proposed scheme in principle, several clinical participants also said that certain variations should not be within the scope of the scheme for several reasons. Hypospadias, cryptorchidism, hypogonadism, bladder exstrophy, Kallmann Syndrome, Follicle-Stimulating Hormone Insensitivity (**FSH**) and Polycystic Ovary Syndrome (**PCOS**) were among those variations which clinicians told us should be removed from the list altogether, or at least narrowed to some instances. Among the reasons included that hypospadias affected a large number of children and had different types; that hypospadias, cryptorchidism (also known as undescended testes) and bladder exstrophy were not generally understood as intersex variations by any *'reasonable clinician or parent'* and that including them would stigmatise these populations; and that some

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[9] Ibid.

[10] Id, pp. 12-13 and 15-16.

[11] Id, p. 12.

[12] Id, pp. 12-13.

[13] Razzaghy-Azar et al (2017) 'Gender identity in patients with congenital adrenal hyperplasia', *International Journal of Endocrinology and Metabolism*, 30 July, 15(3):e12537.

variations, such as PCOS and Kallmann syndrome, did not fit the definition of a person *born* with variations of sex characteristics because they could develop later in life.

On the other hand, a person with bladder exstrophy said they recalled objecting to a clinician who had told them they did not have an intersex variation. They said when that, when you look at the experience they and others with bladder exstrophy have had, including the assumptions made about their gender and sexuality due to their physical characteristics, it was an experience that was common to people born with other variations.

One submission suggested removing the word '*born'* from the definition of 'protected persons', so that the definition applied to variations of sex characteristics that could develop after birth. It supported, in a modified form, the non-exhaustive list of variations in the draft proposal with the omission of 'hypogonadism'.

Universalist versus specific approach

Several participants supported limiting the scope of the scheme only to people born with variations of sex characteristics, as opposed to a prohibition on medical treatment modifying sex characteristics applying to the general population.

Among those who supported an intersex-specific approach were human rights and disability rights experts that considered issues of non-consensual treatment facing other populations, such as the sterilisation of women with disability, required further thinking and a different approach. However, they said that there may be an opportunity to start first with a narrower scheme like the one proposed and see whether its scope might be broadened later following a review of its operation. Participants also said that this more focused approach avoided having to consider the impact of the scheme on a wider group of people whose treatment may incidentally impact on their sex characteristics but whose treatment did not raise the same issues.

Some participants with experience in transgender and gender diverse healthcare also supported the definition of 'protected person', recognising that the scheme would apply to transgender and gender diverse people if they were also born with innate variations of sex characteristics. One participant thought that this was a good thing, given it recognised the different experiences of transgender and gender diverse people who were intersex and those who were not in respect of hormone treatment which may be prescribed to them by doctors. By applying the scheme to transgender and gender diverse people born with innate variations of sex characteristics, this participant thought that the scheme would guard against the risk of gender incongruent hormones being prescribed to people born with innate variations of sex characteristics based on their assumed gender at birth. However, for endosex transgender and gender diverse people this was less of a risk. Several transgender and gender diverse health and community advocates said they did not want to see a new oversight mechanism that made it harder for transgender and gender diverse young people to access gender affirming healthcare, given the advances already made to remove unnecessary court oversight from *consensual* decision-making about gender affirming healthcare.

Technical improvements

A few participants, including some with legal or clinical experience, suggested technical improvements to the definition of 'protected person'.[14]

One participant suggested that the non-exhaustive list of variations might be better contained in regulation rather than legislation. Their concern was about the creation of hierarchies between variations by including some variations in legislation, which could not be revised later, while others could be prescribed by the Minister on the recommendation of the oversight body. However, to avoid the ability of the legislation being limited in scope by

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[14] This included participants who suggested that:

- the phrase *'ascribe to'* in the definition of 'protected person' be replaced with phrase *'conform with'*;
- androgen insensitivity syndromes are not separately listed as CAIS, PAIS and MAIS;
- the inclusion of the general descriptor 'differences or disorders of sex development';
- the removal of 'aphallia' and 'clitoromegaly (also known as large clitoris)', as these were anatomical descriptions rather than diagnoses;
- the removal of language that was not commonly used such as Meyer-Schwickerath's Syndrome, Fraser-François Syndrome, Ullrich-Feichtiger Syndrome and XY/XO Mosaics.

political pressure, this participant suggested that the regulation-making power be narrowed (for example, to only allow the Minister to prescribe or remove variations on the recommendation of the oversight body).

Another submission noted that diagnoses were increasingly being based on genetics, so it may be appropriate to refer to traits in the non-exhaustive list of variations as '*known or formerly known as*'.

IN SCOPE TREATMENTS

Section 4(a) of the draft proposal limited the scope of the prohibitions to certain types of medical treatment provided without personal consent or as otherwise permitted under the exceptions. In scope treatments were:

- surgical or medical procedures or treatments (including the administration of drugs), including any part of a procedure or treatment, performed on protected persons; and
- which permanently change the sex characteristics of a person, or which effect changes that are only reversible with further invasive medical treatment (the **'permanence or invasiveness requirement'**).[15]

The sex characteristics of a person were defined to include primary and secondary sex characteristics, including genitalia, sexual and reproductive parts of a person's anatomy, and secondary physical features that emerge as a result of puberty.[16]

The scheme would otherwise not apply to any other type of treatment, including medical treatments that change (or prevented changes to) a person's sex characteristics in a way which is reversible or which can be reversed with further non-invasive medical treatment.[17] In such cases, the scheme would leave the existing rules for medical consent in place. This means that, in most cases, persons with parental responsibility would retain the ability to consent on behalf of their children to any 'out of scope' treatments subject to any existing legal limitations.

The consultation paper also set out some examples of treatments that were expected to be in and out of scope.[18] Illustrating the permanence or invasiveness requirement, we suggested that puberty suppressants may therefore be outside the scope of the prohibition, while surgeries and hormone treatments may be within scope.

The permanence or invasiveness requirement

Several 'in principle' supporters of a proposed oversight scheme, including people with variations of sex characteristics, nonetheless highlighted potential concerns with the requirement that treatments have permanent or difficult-to-reverse effects on a person's sex characteristics in order to be within the scope of the scheme's protective mechanisms. One participant said there was a fine line between puberty suppressants and other hormone treatments, and it may be difficult to distinguish in practice between treatments which suppressed one hormone but allowed another to take over. Other participants noted that the distinction meant that invasive genital examinations could repeatedly occur without personal consent, because they may not permanently change a person's sex characteristics.

One participant said that the proposal to ensure a review of the scheme is done within 5 years of its operation was important because medical treatments and procedures could change over time. For example, procedures or treatments which may be considered irreversible or invasive now, may be considered reversible or non-invasive in the future.

Hormone treatment

Several participants with variations of sex characteristics supported the inclusion of hormone treatments in the scheme's protective mechanisms, given their effects could be just as life transforming as surgical interventions. Several participants reflected on instances where gender incongruent hormones were prescribed to a person or

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[15] Consultation paper, p. 15.

[16] Id, p. 15 and fn23.

[17] Id, p. 15.

[18] Id, pp. 17-18.

where they were provided incorrect advice regarding hormone treatments by endocrinologists who were not familiar with their variation. One participant described having been given hormones because they were not *'female enough'* to the point that their body became dependent on them.

Vaginal dilation

Participants with variations of sex characteristics had differing views on whether vaginal dilation should be captured within the proposed scheme's protective mechanisms. Several participants considered that it should be covered, while another did not.

One reason given for including dilation was so that the oversight body could respond to instances of pressure or coercion placed on people to undergo this procedure, especially given its consequences – including psychological consequences. Another participant said that dilation sometimes enforced heteronormative standards around sexuality, which was another reason to ensure its use could be overseen by the oversight body.

However, for the participant who thought dilation should be excluded from the scope of the scheme, they said that it was different to surgery or hormonal treatment in that it could be entirely self-administered. So, if the oversight body refused to allow dilation as part of an individual care plan, a person could still undertake the dilation process (or be coerced to) on their own without medical support or supervision. On the other hand, if the panel allowed dilation as part of an individual care plan, it would place pressure on the person to undergo dilation even if they later decided that they did not want to. In this participant's view, providing support would be a better way to approach the issue than having the oversight body decide on its use.

Parts of a treatment

Several participants who generally supported an oversight scheme said it was important that the scheme allow the oversight body to consider each part of a proposed procedure when deciding if any (or all) parts of a procedure were deferrable. Some participants said that different parts of their surgeries were presented to them as one procedure, when some parts of their procedures may have been unnecessary and could have been deferred until they were old enough to consent. For example, an orchiopexy could go onto becoming a gonadectomy or hypospadias 'repair'.

Pre-natal treatment

Some participants who supported an oversight scheme in principle noted that the scheme did not cover prenatal treatments, however they said that they did not have suggestions on how such treatments might be addressed. Such treatments also raised more complex issues of consent.

Consistency with *Medical Treatment and Planning Decisions Act*

One participant noted that the *Medical Treatment and Planning Decisions Act 2016* (Vic) already had a definition of medical treatment involving both the treatment and the purpose of the treatment.[19] Although that Act had a broader application, it may be worth considering whether the definitions could be aligned.

People in opposition in principle

People who were in opposition to the draft proposal in principle did not tend to provide further detailed comments on the definitions of 'in scope' treatments, instead rejecting the draft proposal as a whole. As discussed in the

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[19] The *Medical Treatment and Planning Decisions Act 2016* (Vic) defines 'medical treatment' as *'any of the following treatments of a person by a health practitioner for the purposes of diagnosing a physical or mental condition, preventing disease, restoring or replacing bodily function in the face of disease or injury or improving comfort and quality of life—*

(a) treatment with physical or surgical therapy;

(b) treatment for mental illness;

(c) treatment with prescription pharmaceuticals;

(d) dental treatment;

(e) palliative care—

but does not include a medical research procedure'.

sections that follow, they opposed any medical treatment being captured by a scheme at all, or at least a scheme as proposed.

CRIMINALISATION

Section 4(a) of the draft proposal suggested that the prohibitions on certain medical interventions modifying a person's sex characteristics be achieved by way of two criminal offences.[20] One offence would principally apply to treatments performed without personal consent in Victoria, while another would apply to situations where someone were taken outside Victoria for the purpose of obtaining treatments that were otherwise prohibited in Victoria.[21] All offences would be subject to exceptions allowing treatment with personal consent, in emergencies, when allowed by the oversight body, and for male circumcision.[22]

Criminalisation generally

Several participants, including clinical and legal participants, who were both supportive of and opposed to the draft proposal, were concerned about the potential impact of criminalisation. One participant who supported a civil prohibition considered that the criminal prohibition should apply only to wilful conduct not recklessness, and suggested we review the proposed criminal offences, including in respect of the burden of proof for the defences. Another participant said that criminal prohibitions on female genital mutilation had proven to be ineffective to prosecute in practice and preferred a civil regulatory compensatory scheme. Several clinicians expressed a concern that criminalisation would lead to clinicians, especially surgeons, taking a cautious or protective approach, which could have a significant impact on a patient's wellbeing and lead to a *'scarcity of care'*. Another expressed a view that clinicians should be protected from misconduct if they provide treatment they consider to be in the best interests of a patient at the time.

One participant born with a variation of sex characteristics said that, while they agreed with a civil prohibition, they did not support a criminal prohibition. They did not think that criminalisation was a good way to deal with social issues, including because it involved police who were not well equipped to deal with such issues. They were concerned about the prospect of the criminal law *'hanging over the heads'* of medical practitioners, parents or other decision-makers making important decisions, leading to more conservative decision-making.

One clinician felt that a better option to criminalisation might be to put in place resources for informed consent, standardised pathways, and psychological and peer support; and then follow up results around satisfaction with surgery for 15 years. This clinician said there was a lack of evidence around deferability, including whether it led to better outcomes. They said that a blanket prohibition would be damaging to children and families. Another clinician suggested rolling out a pilot scheme which was limited in time and scope, rather than commencing with the whole proposal which they said was *'experimental'*. Several clinical participants did not support any legislative model at all, including because *'strong regulatory requirements'* on surgical practice already adequately protected the autonomy of patients.

However, another participant said they strongly supported criminalisation because it was effective in changing behaviour (including because of its effect on medical insurers) and because what was being criminalised was sufficiently clear. Another clinical submission echoed this, agreeing that the proposed prohibitions are clear and workable for medical professionals. One participant said, if anything, the criminal offences should be clearer in prohibiting feminising or masculinising surgeries without personal consent.

Extraterritoriality

One clinician expressed a concern about the extraterritoriality element, in particular the criminalisation of someone removing a child from Victoria for treatment. This person felt that parents seeking treatment for a child with hypospadias may already be waiting for some time; that going to an oversight body might not be well received, or add to the families' distress.

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[20] Consultation paper, pp. 14-15.

[21] Ibid.

[22] Ibid.

However, some participants with variations of sex characteristics reflected on surgeries being offered overseas, particularly in the US, by what was described as one participant as *'predatory operators for profit'.* They were worried about surgery being seen as an easy option, and that people were not made aware of its problems.

(c) Exceptions to the prohibitions

Apart from the processes overseen by the oversight body (discussed below), the draft proposal suggested two standing exemptions to the proposed prohibitions: one for emergency treatment and one for male circumcision.

EMERGENCY TREATMENT

The draft proposal suggested that any prohibition include an exception allowing medical treatment modifying a person's sex characteristics without personal consent in strict emergency circumstances.[23] The proposed emergency treatment exception was modelled on section 53 of the *Medical Treatment Planning and Decisions Act 2016* (Vic). Among its elements were the requirement for the medical treatment to be both urgent *and* necessary to save a person's life, prevent serious damage to a person's health or prevent the person from suffering or continuing to suffer significant pain or distress. This proposed exception was also subject to a mandatory reporting obligation, meaning that any use of the emergency treatment exception could be monitored by the panel.

Many participants who otherwise opposed medical treatment without personal consent expressed support for this exception, although some questioned its potential scope. Some participants were concerned that the word 'distress' would be read broadly, to justify treatment based on psychosocial rationales (such as concerns regarding stigma or discrimination). Others were concerned that the word 'urgent' would be read to justify treatment on account of potential cancer risks which were contested.

Examples of treatments that might fall within the scope of this exemption were raised by several participants with variations of sex characteristics, including:

- the closure of the bladder for a person born with bladder exstrophy;
- cortisol to address salt wasting CAH.

MALE CIRCUMCISION

Several participants queried the exception in the draft proposal allowing male circumcision (or, more accurately, removal of the foreskin of the phallus) to continue with the consent of parents and without oversight.[24]

One submission said that religious reasons for such circumcisions only account for a small minority of the circumcisions performed in Australia, with the vast majority said to be performed to suit parental social and aesthetic preferences. This submitter wished to see a prohibition on all non-consensual, medically unnecessary interventions that alter the sex characteristics of children regardless of their sex or gender, including circumcision performed for purely cosmetic purposes.

Some parents and clinicians who opposed the draft proposal in principle said the circumcision exception showed a double standard at play: namely, that alterations of sex characteristics performed for religious reasons were being excluded from the scheme's scope, while those performed for clinical purposes were being put under greater scrutiny. One clinical participant said they had seen problems with circumcisions performed in non-medical settings, showing the risks inherent in the procedure and highlighting the double standard. Another clinician said that treatment for 80% of patients with hypospadias involved removing the foreskin, which is not that different to circumcision.

However, one participant with a variation of sex characteristics was concerned about the exception for circumcision precisely because it could be used to authorise procedures for hypospadias, given the foreskin can be used in the reconstruction of a urethral opening.

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[23] Consultation paper, p. 15.

[24] Ibid.

Several other participants said they were content with the exclusion of male circumcision, given a prohibition on male circumcision in the context of the scope of this legislation would then only apply to people born with intersex variations, and a broader debate needed to occur about male circumcision generally. One participant said that the exclusion should cover circumcision performed for both religious and non-religious purposes, given it would be anomalous to put circumcision for medical purposes under a greater degree of scrutiny than circumcision for religious purposes.

(d) Oversight body – establishment and composition

SUMMARY OF THE DRAFT PROPOSAL

Sections 6(a) to 10(a) of the draft proposal concerned the proposed establishment and work of an oversight body.[25]

Section 6(a) of the draft proposal covered the establishment and composition of the oversight body, including panel comprised of a specific mix of 9 members being:

- a chair who was a senior lawyer or former judge,
- 3 health professional representatives (being 2 clinicians and 1 allied health professional);
- 3 community representatives (being 2 people with variations of sex characteristics and 1 family member of a person with variations of sex characteristics);
- 2 other representatives (being 1 bioethicist and 1 human rights or children's rights expert).[26]

Proposed oversight panel

Chair (senior lawyer or former judge)

3x health professional representatives

3x community representatives

Bioethicist

Human rights or children's rights expert

The draft proposal including the following proposed operative provisions:

- that the Minister for Health would appoint the permanent panel members and an additional reserve pool of members if satisfied that the person had the knowledge, experience or skills relevant to their role. Members would be paid and appointed for renewable terms of 3 years subject to their resignation or termination by the Minister;
- that the chair be allowed to substitute panel members from a reserve pool of members if a permanent panel member were unable to attend a meeting or if the issue before the panel required an area of expertise or lived experience which was not represented by the permanent members on the panel;
- that decisions of the full panel would require a majority of the panel to agree with a quorum of at least 7 out of the 9 members. Further, at least one community representative and one health professional member would need to be part of that majority;
- that a sub-panel consisting of three members (including 1 health professional and 1 community representative) could be assembled by the chair to decide individual cases. However, decisions of a sub-panel would need to be made unanimously or the matter would be referred back to the full panel for a decision. Further, all sub-panel decisions would be appealable to the full panel:
- that all decisions of the full panel can also be reviewed by a court if the panel failed to comply with the legal requirements of the scheme.[27]

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[25] Id, pp. 22-36.

[26] Id, p. 22.

[27] Id, pp. 22-23.

GENERAL SUPPORT FOR AND AGAINST A PANEL

Most people with variations of sex characteristics, some parents and other consultation participants in community, policy, legal or human rights areas supported the idea of an oversight panel but had detailed comments on the proposed operative provisions regarding its size, composition, appointment and ongoing professional development. These views are set out thematically in the following relevant headings.

However, as discussed in section 4 above, many of the parents and most clinical participants did not support the proposal for a panel, whether at all or as proposed in the draft proposal. While parents came to the issue with a range of views, most clinicians (but not all) were strongly opposed to the panel proposal.

Some parent views on the panel proposal

Several parents, particularly those of children with CAH, rejected the proposal for a panel altogether. One parent told us that a panel process would add extra stress at an already stressful time when parents were deciding whether or not to proceed with surgery for their children. This parent told us they were already angry about the number of people looking at babies with variations (although they understood that clinicians needed to learn). They said that, for people with CAH, this was not a decision about choosing a child's gender but that their daughter was a girl from the start, although *'androgen had affected her physical side'*. This parent said that the expert advice they had received from the hospital had helped them make their decision to go ahead with surgery. A number of parents supported this view, saying they would be upset if their decision were taken away from them and given to a *'random'* panel or group chaired by a lawyer or judge. They felt they were in the best position to make decisions about the best interests of their children after consultation with subject matter experts who understood CAH. They expressed strong trust in their existing medical and surgical teams. Another participant with CAH, who also opposed the proposal for a panel, said parents make the best decisions they can with the amount of knowledge they have at the given time, and so would the panel. The biggest difference was that a parent's decision would be based on love while the panel's would be based only on information. A panel could never have the *'heart of a parent towards a child'*.

However, another parent told us that they thought the panel was a good idea. They said that they did not initially feel that they had been given enough support to make an informed decision about their child with CAH, so they did lots of research and got a second opinion before proceeding with their child's surgery. While they thought 9 panel members may be too overwhelming for parents (see further Size of panel below), they thought that it would be better than the process their family went through which involved an ethics committee approval without them being provided an opportunity to attend the meeting or speak.[28] However, this parent also said that they would not like to see a blanket prohibition on surgeries, or approvals that were hard and stressful to get. They said their *'take home'* was not to make the scheme intimidating or overwhelming, and to make sure it was timely and considered the psychological worries parents have for their children.

Another parent who supported the idea of a panel told us that, although the panel's role would have to make some difficult decisions around what surgeries were urgent or not, they felt that *'in many ways'* the proposal was excellent. They said that the power of the process was that it would not leave parents by themselves but *'bring in the community to help'*. They said that, even going back a generation, this help was simply not available, and parents were left with very difficult judgement calls, particularly if they were presented with risks of malignancy which were not clear cut (such as risks of cancer in the order of 15% as opposed to 70%). In respect of taking away decision-making from parents, this parent said that what we should be thinking about what is best for the child. It may well be that some parents would like the decision left in their own hands. However, they were not sure that was the right thing for the child. This was because the panel could look to the full gamete of variations among children and come to a consensus view which, while uncomfortable for the parents themselves, might be best for the child.

Some clinical views on the panel proposal

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[28] The importance of ensuring parents had a right to have a say was a point raised by another parent, who also did not oppose the idea of a panel.

Most clinical participants were opposed to the panel proposal and gave a range of reasons for their opposition in workshops, interviews and through the anonymous questionnaire.

The reasons stated for their opposition were:

- existing multidisciplinary forums already exist and provide oversight. For example, one survey respondent said that current models already provided robust, transparent and good medical practice which were holistic, multidisciplinary, and guided by lived experience and evidence as it becomes available. They said that such models had already been shown to result in the deferral of surgery in appropriate cases. In support of this statement, reference was made to a 2021 article published in the Journal of Paediatrics and Child Health reviewing the work of multidisciplinary teams in Melbourne and Sydney;[29]
- there would be a negative effect on the wellbeing of a child having to go through such a process. For example, one clinician said that, in other areas of healthcare, we had moved away from legally bureaucratic processes towards patient-centred care, and that this was a step back. In respect of the proposal for individual care plans (see section 5(g) below), one clinician was concerned that care plans these would become a *'pro forma'* and would reduce the opportunity for individualised conversations. Another clinician said that each child is *'medically unique'* and their family are unique, and that children with a multitude of different diagnoses should not be encompassed under such a *'large umbrella'* of legislation. Another said that the proposal would delay important treatment, such as for undescended testes which protect fertility and prevent future cancer risk. One submission said that an unintended consequence of the scheme might be to delay necessary treatment because it is easier to defer than go through the exemption process;
- the proposal is not evidence-based. For example, one clinical respondent said that all studies on people with feminising genioplasties report that the vast majority of those with CAH preferred surgery done in infancy rather than later;
- parents would be further frustrated and distressed by a panel process, with one clinician also saying that parents already insist on procedures being done now and sometimes it was clinicians who tried to tell them it was better to wait;
- the approach to this issue was exceptional and arbitrary lines were being drawn. For example, one clinician said that, given we allow parents to consent to surgery on a child with *'bat ears'* and to have birthmarks treated, what made genitals so special that a panel was needed? Another clinician said that parents were already subject to legal limitations regarding the healthcare decisions they can make for their child, so there was no need for a panel at all;
- the proposal was unworkable and would impose a huge workload. For example, one clinician said that up to 5% of boys were born with undescended testes, so requiring a panel to consider each case would mean a panel sitting full-time. Another said that hypospadias has one of the highest incidences of *'all congenital abnormalities at 1 in 300 children (1 in 150 boys)'*. Another said it would take enormous resources and time for the panel to determine whether a person had capacity to consent, given it currently takes a minimum of 3 sessions with health professionals at present;
- the 'burden of proof' required of clinicians to prove the harm of delaying a procedure is both unreasonable and difficult to meet;
- the proposal would lead to clinicians becoming disengaged from this work which would mean access to care becomes even more limited. For example, one clinician said that it would not be professionally rewarding for clinicians to *'have to do reports all the time'*. Another said that clinicians would lose their clinical skills as surgeries were delayed until the next generation of

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[29] Vora et al (2021) 'Role of cross-campus multidisciplinary team meetings in decision-making for children and adolescents with differences of sex development/intersex', *Journal of Paediatrics and Child Health,* 30 April.

children were old enough to consent. Another said that providers would be less willing to see intersex patients due to medicolegal risk and time investment;

- it was not the best use of healthcare resources. For example, one participant said that additional funding would be needed to address the additional workload clinicians would face in applying to the panel. Other clinicians felt that finite healthcare resources could be better used in different ways: for example, funding for peer support, the creation of standardised resources to assist parents, and funding for mental health professionals who specialise in people with variations of sex characteristics;
- the proposal has been motivated by a few patients who are upset about past practices which are acknowledged not to meet the standards of today. However, they do not speak for the *'quiet majority of individuals who have received excellent medical care in childhood and are living fulfilling adult lives'*;
- lawyers and individuals with lived experience are not able to judge the nuances of clinical situations better than clinicians. The prospect of non-medical representatives making decisions on medical issues disempowers clinicians, is radical, and/or insulting. The panel would be able to *'override'* medical evidence;
- the 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;
- it will lead to 'backyard' procedures or a 'blackmarket' in procedures performed overseas without oversight.

While some clinicians said there was nothing about the draft proposal that they liked, others also said that:

- they thought that the addition of an oversight panel for *'serious and complex disorders'* was reasonable, as was the idea of having community representatives in combination with medical ones;
- the development of robust guidelines and principles for management of children and adolescents with intersex variations was, in principle, a good idea;
- they recognised the value of lived experience, although saying that they considered there to be a significant bias in the representation that had informed this proposal;
- they liked the structure which considered the wellbeing of an individual and which required an approach to a committee, although they were concerned about the limited number of medical people on this panel;
- they recognised the intent of protecting a vulnerable patient group and the overall goal of improving outcomes, including a recognition of the need for more data;
- they welcomed the prospect of additional funding and resources being added to a space in which there is significant need, especially in psychological support and in the development of databases to document care.

One health professional, who did not support the draft proposal, suggested an alternative model. That model included:

- the development of standardised resources to ensure consistency in information provided to parents, including discussion of all possible pathways (including the pros and cons of both no intervention and possible interventions);
- the development of decision support tools for shared decision-making between clinicians and families (parents and/or child);
- adequate time for parents and young people to consider their options;
- appropriate mental health support and peer support;

- a multidisciplinary team, including people with lived experience, to discuss complex scenarios or a narrower list of pre-determined scenarios that could make recommendations and provide written feedback to families outlining the discussion and envisaged pros and cons of particular pathways. Parents and their child's clinical team would then come to their own preferred conclusion regarding what is best for their child;
- follow-up for all children with standardised assessment at pre-defined timepoints and the inclusion of health, wellbeing and patient-reported outcomes.

Other stakeholder views on the panel proposal

Other interested stakeholders involved in the consultation generally supported the idea of a panel. For example, one interested stakeholder who responded to the survey supported the idea of a panel because it offered a more open and balanced approach. Another respondent said they liked the diffusion of decision-making power, which would be valuable in combating undue deference to medical opinion (including by lawyers) that has given rise to human rights abuses in this area.

SIZE OF PANEL

Among supporters of a panel, there were a range of views about the number of sitting members.

Several participants liked the prospect of a 9-member panel, as they felt it would include a good range of views. A couple of other participants said they liked the size of the panel and the requirements on decision-making which provided *'safeguards against capture'* and prevented the body being *'stacked'* only with people favouring surgery or clinical solutions.

However, other participants with experience in administrative decision-making bodies said 9 members was too many. First, it would be intimidating to a family appearing before the panel to have an audience of 9 people. Second, a 9-member panel would be slow to arrive at its decisions – it would only be as fast as its slowest member. Third, the prospect of a 5-4 majority decision was an unattractive proposition. One suggestion was for the chair to have some flexibility to constitute a panel depending on the matter involved with a minimum number and a maximum number of panel members allowed, depending on whether decisions had to be made unanimously or by majority. Another suggestion was to have a pool of potential panel members with a larger panel constituted for making class exemption orders and a smaller panel constituted for individual decisions. Participants said that more decision-makers did not necessarily mean better decision-making, and different views could be taken into account through other means than by placing them on the panel. A couple of participants who had experience in similar decision-making processes said that decision-making bodies tended to attempt to reach for consensus first in any event and said that the culture of the body was just as – if not more – significant than the number of people on the panel. While the diversity of views was important, ultimately administrative decision-makers had obligations to give procedural fairness, which meant following the rule against bias.

One participant said that, while they could appreciate a panel of 9 members may be difficult to bring together, they did not wish to see a panel with less than 7. They did not like the idea of a smaller panel of 3 or 4 members as they were concerned that it could circumvent a full proper process. They also did not like the idea of decisions being made by majority but preferred the panel trying to operate by consensus as much as possible.

However, other participants were less concerned with the number of members who sat on the panel so long as the chair could bring in additional members or obtain other support to inform its decision-making. Importantly, many participants emphasised the importance of balance – having the same number of clinicians as community members, as discussed further below.

PANEL COMPOSITION

The composition and appointment of panel members was a significant topic of discussion among many consultation participants.

Panel dynamics

Many people expressed views about who they felt should be included or excluded on the panel, with many expressing a concern about certain perspectives they did not agree with dominating the makeup of the panel. This was a broad concern among many consultation participants who both supported or opposed the idea of a panel, highlighting an underlying concern among many participants about the ability of potential panel members to work well together and approach their task impartially. These were concerns raised by all stakeholder groups (i.e. people with variations of sex characteristics, parents, and clinicians), both about each other and about individuals from within their respective groups.

For example, some participants with variations of sex characteristics were concerned about the panel being *'stacked'* with people who were *'pro medicalised'*, leaving those who were marginalised or dissenting off the panel. Meanwhile, other participants with variations of sex characteristics felt they had a more constructive relationship with medical professionals and wanted to see that fostered by working together through building relationships and trust. One participant with a variation of sex characteristics objected to their healthcare being decided by people who did not have medical training, or others with a different variation to their own.

One participant's suggestion to the concern of the panel being dominated by one view or another was to ensure the panel's processes required people to be told *'both sides of the story'*.

Appointment of panel members

One participant with a variation of sex characteristics said appointments should be made transparently. This participant suggested that the Victorian Minister for Equality should have a role in appointments, and that there should be some community input or oversight around the selection of the panel, including the chair. However, another participant with experience in decision-making bodies said that appointments could become politicised and preferred an open selection process.

Participants were also worried that the pool of people with expertise and/or lived experience was likely to be small and may mean the government drawing upon the same pool of people it had previously relied on.

Representing lived experience on the panel

Many people, particularly those with variations of sex characteristics, emphasised that it was essential for people with lived experience to be on the panel, although getting an appropriate balance of different variations and genders was also important. For example, some participants were concerned about people with more common variations of sex characteristics dominating those with less common variations. Others said that different variations and genders had different experiences, and that it was important to ensure a balance of voices so that different experiences were appropriately represented on the panel.

Several participants, particularly people with variations of sex characteristics, liked the idea of a pool of panel members with a range of variations, so that a person who had the same or similar variation as the person whose individual care plan was being considered by the panel could form part of the panel.

Representing clinical expertise on the panel

We heard a range of suggestions regarding the clinical experience and expertise necessary for including on the panel, including the need for mental health professionals, sexual health professionals and fertility specialists depending on the nature of the decision before the panel.

Some participants said that bioethicists should be treated as health professionals, given that many work in clinical settings. This participant suggested that the panel spot for a bioethicist should fall under the banner of an allied health professional representative, leaving scope for two human rights or child's rights specialists in the proposed 9-member panel. One survey respondent said that an ethicist should always be part of the panel.

The chair

Many participants reflected on the significance of the appointment of a chair. Participants made comments regarding who that person might be and the kind of qualities they should have.

Several participants said that the chair would need to have gravitas to establish trust and confidence in the panel's processes, encourage panel members to work together, as well as set the culture for a process which had as little legalism and formality as possible. The chair would need to have sufficient gravitas to manage silos that may emerge if people who were intransigent in their position.

Several participants with relevant experience in administrative decision-making supported the idea of a senior lawyer or judge as chair, given the person will need to understand the principles of procedural fairness and would have a significant role in managing the operation of the panel.

However, whether the chair should be a senior lawyer or former judge (and which one) was a topic of some discussion. One participant suggested the chair should be a human rights lawyer, while another said it was important that the chair had respect for lived experience. Another participant suggested that the person should be a judge who had experience deciding cases involving children with disabilities. Another participant said it should not be a judge at all, as they would preside over the panel as if it were a court. However, two other participants with legal backgrounds said they would not necessarily rule out a former judge, given the benefit of experience and gravitas that would come with such a person. However, one of these participants also said that the chair should not be a former Family Court judge, given the criticism the Family Court had received in respect of its past decisions in approving interventions.

PROFESSIONAL DEVELOPMENT

Several participants reflected on the need for training panel members, including on medical and non-medical pathways and in the areas of administrative law and decision-making. This should include training in the principles of procedural fairness, which required decision-makers to exercise their roles impartially and afford affected persons a right to be heard. Several participants also supported provisions allowing the termination of panel members, including a requirement that members with clinical or legal expertise be required to maintain their registration or accreditation. The chair might also have a disciplinary role if complaints were received about a panel member.

One participant with experience in administrative decision-making bodies said that the chair would need to ensure a suite of policies, procedures, guidelines, and a complaints system were in place. This participant said that, in their experience, one of the most difficult challenges for people on a decision-making body with specific expertise was their tendency to want to generate evidence themselves rather than ask questions. As an example, while a clinical member of the panel might bring their expertise to bear in asking relevant questions, they could not engage in the role of a diagnosis themselves as this might raise apprehensions of bias. Panel members would need induction and ongoing training, including in how to evaluate evidence and how to question people in a way that was not confrontational.

CONFLICTS OF INTEREST

One participant noted the potential for actual and perceived conflicts of interests (for example, people on the panel who treat patients at the same hospital) that required careful management and consideration.

SITUATING THE OVERSIGHT BODY

Finally, several participants with variations of sex characteristics reflected on their desire for the oversight body to be independent, sit within a human rights body (such as a human rights commission) and be taken away from a medical setting. It was important for these participants that the oversight body be situated in a neutral place.

(e) Oversight body – functions and powers

SUMMARY OF THE DRAFT PROPOSAL

Section 7(a) of the draft proposal broadly set out the proposed functions and powers of the oversight body.[30] These included critical functions in respect of the preparation and registration of individual care plans; the consideration and making of class exemption orders; and the receipt and consideration of mandatory reports from health professionals – each of which are addressed in detail below. However, apart from these functions, the oversight body was proposed to have a range of other functions including powers to:

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[30] Consultation paper, pp. 24-25.

- refer possible contraventions of the scheme to relevant enforcement and regulatory bodies;
- promote compliance through the provision of information and the issuing of guidance;
- analyse and research the operation of the scheme and provide advice and reports to the Minister for Health and Department of Health.[31]

EDUCATIVE, RESEARCH AND ADVISORY FUNCTIONS

A few participants addressed the educative, research and advisory functions of the proposed panel.

One participant supported the research function proposed as part of the oversight body's role. They said this would allow the body to keep up with emerging knowledge, including in respect of particular treatment options.

One participant said that more could be made of the panel's educative powers in driving a change of practices. However, another participant cautioned that the more educative and guidance functions given to the oversight body, the more it will be accused of bias. Expressions of policy positions could hamper its impartiality as a decision-maker, as well as perceptions of its impartiality.

Several participants emphasised the importance of the panel having clear periodic reporting requirements (whether to parliament or the Department of Health), so that it there was a level of transparency, trust building with the community, and accountability for its decisions. Periodic reporting would also allow the presentation of aggregated data regarding its decisions, reducing the risk of identifying particular people.

The participants envisaged that periodic reports would include key aggregated statistics on its decisions and outcomes, including the number of matters heard, what decisions were made, and whether treatment had been recommended or not.

One clinical submission, which expressed some concerns with the draft proposal, said that, given the oversight scheme would be the first of its kind in Australia, the scheme should have robust reporting requirements, as well as triggers for a review into its operation and the implementation of necessary changes.

(f) Oversight body – decision-making principles

SUMMARY OF THE DRAFT PROPOSAL

Section 8(a) of the draft proposal set out the proposed overarching principles that the oversight body would be required to meet whenever it made decisions about individual care plans or class exemption orders.

The proposed decision-making principles required the oversight body to:

- make decisions lawfully and in compliance with the Victorian Charter of Human Rights and Responsibilities (the **'human rights framework principle'**); and
- only make decisions if a person did not have the capacity to make those decisions themselves, and only after giving them reasonable support to express any views and taking those views into account (the **'principle of self-determination**); and
- ensuring its decisions did not allow medical treatment modifying a person's sex characteristics unless that treatment could not be deferred without causing or being likely to cause harm to the health of the person (the **'principle of deferability'** including the **'harm to health test'**); and
- ensuring its decisions did not presume without substantive evidence that a person with variations of sex characteristics would experience any social or psychological benefits from having their sex characteristics function or appear in a matter which conforms with norms for persons without that variation (the **'principle of non-discrimination'**).

These four critical principles were the backbone of the scheme and set the boundaries of the oversight body's powers. They emphasised that decisions of the oversight body had to be made within a human rights framework

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[31] Id, p. 25.

and in a manner which preserved the rights of an individual to make their own decision about any medical treatment if they had the capacity to do so. If a person did not have capacity, then the oversight body could allow medical treatment which modified a person's sex characteristics without their personal consent if deferring that treatment would likely harm their health. However, when considering whether deferring treatment would likely harm a person's health, the oversight body could not discriminate on the basis of that person's variation, by simply presuming without evidence that a person would be better off if their body functioned or appeared as if they did not have that variation.

Given the centrality of these propositions to the proposed scheme, many participants had views regarding these key principles.

THE HUMAN RIGHTS FRAMEWORK PRINCIPLE

Only a few participants made comments regarding the principle that decisions made by the oversight body must be made lawfully and in compliance with the *Charter of Human Rights and Responsibilities Act 2006* (Vic).

The draft proposal clarified that the oversight body would become a public authority under the *Charter*.[32] This meant that, subject to the statutory requirements of the scheme, the oversight panel would have to act consistently with the human rights contained in the *Charter* and consider relevant rights when making decisions about individual care plans and class exemption orders.[33]

One legal participant said this meant that decisions of the oversight body would not be entirely immune from court appeals which considered the merits of a panel's decision. For example, a court could still look into whether certain jurisdictional facts had been satisfied to enliven the panel's decision-making powers and test the legal reasonableness of the panel's satisfaction of those facts in accordance with the principles in *Minister for Immigration and Citizenship v Li* [2013] HCA 18. Courts could also consider whether the *Charter* had been complied with, including whether the panel had regard to the rights of families and children to protection under section 17 of the *Charter*. While courts might start from a position of giving deference to the expertise of a specially constituted panel, it would not prevent them entertaining appeals where consideration was not properly given to human rights. This participant said, this was part of the reason why you would want a former judge with some gravitas as the chair of the panel, so that due deference would be given to its decision-making by the courts on appeal.

THE PRINCIPLE OF SELF-DETERMINATION

To maximise a person's self-determination, the draft proposal suggested that the panel's decision-making powers be limited to instances where a person does not have the capacity to give consent to treatment modifying their sex characteristics.[34] That is, the panel would have no role in deciding on treatment for a person, if that person could otherwise make their own decision.

The quality of consent

Several participants (including people with variations of sex characteristics, parents and policy experts) said that limiting the work of the panel to people who lacked capacity to consent raised issues for people, particularly children and young people, who may well have the capacity to consent but whose consent may not be fully informed because of information which has been (or has not been) provided to them. This approach assumed that people with variations of sex characteristics know where to get information independently and are confident enough to do so.

Some participants said that even when information was sought, that information could be framed in *'biased ways'*, which significantly influenced decision-making for those with capacity to consent. For people with certain cultural and religious backgrounds, information could also be understood or interpreted in particular ways, such as one parent who told us that they initially believed their child's variation to be a *'punishment'* for having *'done something*

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[32] Id, pp. 10-11.

[33] *Charter of Human Rights and Responsibilities Act 2006 (Vic)*, s 38. See Consultation paper, p. 11.

[34] Consultation paper, p. 25.

wrong in my life'. Other family members told us that their loved ones felt pressured to make decisions, including driven by pressures to conform, even later in life.

Finally, for variations that may not be discovered until adolescence, such as MRKH, the quality of information given in order to obtain consent was the more significant concern for participants with these variations than the capacity to consent.

The strong concern about the context and environment in which consent is given or preferences are expressed was borne out in the lived experiences of many consultation participants. Several people with variations of sex characteristics told us of procedures or treatments that they ostensibly consented to, but not in a fully informed way. Others told us of feeling pressured or coerced into giving consent. For example, one participant said she was told by a surgeon as an adolescent that surgery was needed on her genitalia. She said she did not understand then what a clitoris was, and that her surgery involved several procedures which were presented to her as one procedure (*'while you're under, you may as well do this'*). She said, although she was happy that she had the surgery, she was not happy about the way it happened, including assumptions being made about her sexuality (*'essentially needing to accommodate a penis'*) and the process made her feel like a *'freak'*. She remembered looking down at herself after the surgery and crying: *'I don't look like me anymore'*. She also did not remember having any discussion about the need to use a dilator until the surgeon presented it to her after the surgery; an experience that another participant who underwent surgery in her teens also told us occurred to her. Several people with variations of sex characteristics told us about how they found out basic information about their variations or the reasons for treatment after surgeries had already happened, or that they had only received stigmatising and negative information about their variation. Others felt entirely unprepared for their diagnosis and felt their gender identity being questioned.

The prospect of obtaining consent in fully informed ways and without coercion or undue pressure was all the more challenging when participants felt burdened with secrecy and shame. As one participant put it, *'shame and secrecy are ingrained in us'*. They said that they had for a long time misdescribed their surgery to others as a *'mini hysterectomy'* and had *'made excuses'* to avoid *'facing up to who I was'*. Another participant told us their variation was kept from their siblings and they tried not to talk about it with their parents to avoid upsetting them. Another participant told us that her mum had told her not to show her body to anyone.

In order to realise one's own capacity to consent without coercion or pressure, several participants said that it was important for children to grow up with reassurance that all people were different and that there were others like them. However, not all parents were able to provide this for their children, and not all parents had the capacity or opportunity to guide their children towards the acceptance and affirmation of their differences. Participants with expertise in education emphasised the importance of starting to explain concepts to children, in an age-appropriate way, as they grow up, increasingly involving them in decisions about themselves, and supporting them on their journey from a young age.

It was for these reasons that a number of participants were interested in ways in which the oversight scheme could go further to aid in destigmatising people with variations of sex characteristics (for example through a requirement for information or mandatory referrals to peer support) even for people with capacity to consent. Another suggestion was whether the oversight body could be given the responsibility to commission some standard documentation for parents, available in a range of languages, with a requirement that these be provided to parents. Another suggestion was including a requirement on health professionals to document the reasons and actual written consent forms provided to people or their parents when consent was obtained.

However, not all participants shared these concerns and a group of parents of children with CAH said to us that they had felt supported by medical experts in navigating decisions about their children's treatment. One parent said that parents worked closely with a limited group of paediatrics and endocrinologists who had their own ethics panels, and they were not sure why this proposal was needed at all. Another parent told us that their child's clinicians had been very open and honest with them, including about the upsides and downsides of surgery (such as the potential need for dilation in future). Another parent told us that the issue of scarring had been raised with them, but they had been told that if they did not perform the surgery on their infant child, their recovery would be harder, and the *'plasticity'* of their vagina would not *'bounce back'*. They said that, even though the surgery resulted in an *'amazing transformation'*, *'nothing was thrown away'*.

Testing the quality of consent – a role for the panel?

Among supporters of the oversight panel proposal, there were a range of views as to the extent to which the panel itself should have a role in overseeing decisions made by people who had capacity to consent – over and above any role it may have in providing education or guidance.

Some participants who supported the idea of an oversight panel asked whether the panel should have a role in testing the correctness (and neutrality) of information provided to a person who otherwise had the capacity to make their own decision. Participants were also concerned about how the panel might receive and analyse evidence from children on their views and preferences, if the child had not grown up in a supportive environment without *'biased information'* about their variation or medical options. For example, one participant said that when seeking the views of young people about proposed treatment it was important for them to be asked basic information about themselves by someone they felt comfortable with. Important questions included how they identified, whether they wanted children, how important it was for them to look a certain way, and whether they understood what the parts of their body being operated on were and what they did. Another person was concerned that the panel may be influenced in its decision-making when confronted with parents whose distress was both *'real and heartbreaking'.*

For several of these participants, access to independent peer support was critical in supporting an environment that encouraged children and young people to understand themselves and their bodies in positive ways, as was funding to ensure the viability of organisations providing this support. However, not every participant saw the value in peer support. One person said to us that they felt bullied in certain peer support groups which they considered to be homophobic and transphobic.

However, some participants who supported the idea of an oversight panel also said that medical professionals already had a duty to ensure they received informed consent prior to the provision of medical treatment, and therefore the quality of consent may be improved through training for medical professionals and peer support for people born with variations of sex characteristics. Some participants with variations of sex characteristics also emphasised the desire for the scheme to only feature the panel as a decision-maker of last resort with the principles of supported decision-making informing the scheme. As discussed below, the principles of supported decision-making do not support the panel substituting its own decision for the decision of a person who, after reasonable support is provided, can exercise their own capacity to consent. One participant said that the challenge was about how to frame a legislative scheme which recognised that people were entitled make choices for themselves, even if they were bad choices, but that the environments in which those decisions were made were not coercive.

THE PRINCIPLE OF DEFERABILITY

The principle that *deferrable* medical treatment modifying a person's sex characteristics should be left until a person had capacity to make a fully informed decision for themselves was discussed by most participants.

Views among people with variations of sex characteristics

Most participants with variations of sex characteristics supported the principle of deferability, and some described it as a *'non-negotiable'* aspect of the reform. As one person with a variation of sex characteristics put it: *'if the child can piss, poo, eat, drink and breathe, leave them the hell alone'.* Another participant said that given the limited research, we cannot be certain whether people will be happy with the decisions which have been made for them, and if we cannot be certain that people will not be harmed, we should not proceed in assuming the risk for someone else. Another participant told us that many decisions which are made are based on assumptions that are gendered, and that once people grow older, they start to question those assumptions – which was their own experience. This participant said to us that it was important not to lose sight of the ultimate aim of this reform, which was to protect the individual and their choice. They said that the reform had to be measured by three principles: whether it protected and promoted the individual's *'right to be'* who they were, *'right to belong'* and be part of a family and community that welcomed them, and the *'right to become'* who they wanted to be.

One participant who supported the principle of deferability provided us with their personal testimony. They said that, as a person who had multiple unsuccessful surgeries starting as a teenager, they felt they were coerced into doing something to *'fix'* themselves. Outside of life threatening or urgent situations which were better decided by a panel and not parents, they supported the right of a person to choose what happens to their own body at an age where a person understood and could be well informed of the outcomes. They thought that informed consent, including knowing the possible risks and consequences and outcomes was vital, as was knowing that there was a team considering all aspects of the individual's mental and physical health.

Another participant told us that most people they knew with their variation had some form of surgery when they were young. They said that parents and people with variations can still be in shock when they receive a diagnosis, and parents tend to go into 'fix-it' mode wanting to 'fix' things surgically following a specialist's recommendations.

Two participants with CAH opposed the principle of deferability saying they were happy their surgeries happened before they could remember or wished they could have happened when they were younger. One participant in her teens told us that she was glad that she never had to make the decision herself or know that she was different to her classmates. She said had not experienced any impact from the decision regarding surgery having been made for her by her parents when she was an infant. She said that, although she did not know if she wanted children, she said that her surgery had probably increased her chances of having children. She said that having surgery at a younger age allowed the tissue to heal and *'grow with her body'*, and that she had read that not having surgery can lead to other infections, including infections that could be life-threatening.

Another participant told us that she had surgery some time ago when she was young, that she was aware of her difference prior to her surgery and wishes she could have had her treatment earlier as an infant. She told us that as a child she was told by her mum that she was different, that she should not show her body to anyone, but that *'doctors would fix her'*. She recalled the doctor calling her abnormal in front of her mother, which had been a *'kick in the guts'* to her mother. She also reflected on experiences of exploitation and abuse, including being undressed as a little girl with a large number of doctors *'gawking'* at her and *'prodding'* her. However, she said that, for women with CAH, taking away the right of parents to consent to early surgery for their children, *'when it can be fixed'*, would be to deny *'a woman who is a woman the right to be a woman'*. She said she had not told people about her surgery, but that it did not matter because she was *'whole'* and that all *'142 stitches'* had made her a better woman. Her surgery had allowed her to have sexual relationships, and she thinks the sooner the surgery could have been done the better.

Several parents of children with CAH told us their children also opposed the principle of deferability. A parent told us that their teenage child, who would be having further surgery, was anxious in having to wait and wished the surgery had been done in one go. Another parent told us their teenage child was glad that the surgery had been performed on them as a baby, although they were not comfortable to talk with us about it.

However, another participant with CAH said that many adolescents have surgeries and it did not scar them for life. Another woman who had genital surgery during her early adolescence said that she would have been better prepared for the procedure and it would have come as less of a shock to her if she had a pre-established relationship with a psychologist leading up to it. She said that deferring surgery until adolescence was good as she had felt *'more normal'* about her body by then. But it was the lack of understanding she had about the procedure and the way it was done, rather than the fact that she was having surgery during her adolescence, that made the biggest difference. She supported deferring surgery until a person could give personal consent, emphasising the need for that person to be fully informed of what the procedure involved and ensuring there was post-treatment support.

Several other participants with variations of sex characteristics, who supported the principle of deferability, also said that early surgery did not necessarily discount the possibility of further surgery in future. So, the notion that there may be an alternative between early *or* later surgery proceeded on a false assumption that surgery would necessarily be a once-off event. Some participants told us of their own series of surgical treatments.

One participant said that all surgeries have side effects and once tissue is removed or cut, the effect is permanent, and it would be impossible to go back. Emphasising the very personal nature of the factors involved in decisions around surgery, one participant said in respect of people with variations of sex characteristics who advocated for access to earlier surgery: if you have never known what it is to feel sexual sensation, then how would you know what were you were missing?

One participant born with a variation of sex characteristics addressed the principle of deferability in a nuanced way. They told us that they did not feel any regrets about their parents' decision for them to undergo a gonadectomy at a very young age. They said the decision was influenced by fears that their undescended teste could later become cancerous. They said that the decision did not have a huge impact on their life and that the resultant infertility was not particularly consequential for them, given their views on family formulation. They said that, as a human rights principle, they agreed with the principle that treatment should be deferred until such time as a person had capacity to give consent. They said this *'sounded right, strong and convincing'.* However, they also said that they personally were glad that the decision was taken out of their hands; that they had no real recollection of the surgery, and it could have perhaps created traumatic memories for them to go through it themself; and that the alternative of a monitoring regime over a period of time to see whether the risk of cancer might have materialised could have itself been invasive. They also said that deferring medical treatment also raised its own unique series of ethical quandaries. They said that considerations such as the consequences of infertility were not important to them but could be important to others, but that had he been required to go on hormone replacements for the rest of their life that would have somewhat coloured their thinking regarding the procedure.

Views among parents

Some parents supported the principle of deferability, while others did not. In some cases, parents were already grappling with the principle when making decisions about treatment for their children. In other cases, parents reflected on their regret, or feeling pressured, to have made decisions for early treatment in the past. Some of the decisions had taken place sometime in the past, but not all of them. Some decisions were still under active consideration today.

One parent with a young child with CAH told us that they had made the decision to wait until their child was older, so that their child could make their own decision. However, they said that they were having second thoughts and were always second guessing whether they had made the right decision. They said they had a lot of medical professionals trying to convince them that a procedure needed to happen. Another person who provided peer support said that parents could feel a lot of pressure to assign a sex to their child and make decisions about treatment, particularly given the limited time for registering the birth of the child.

Another set of parents told us that they had consented to a series of surgeries for their child, who was still young. They said they were given a range of reasons for the various surgeries at the time, including so their child would be able to *'pee standing up',* to mitigate the risk of cancer, and to resolve a series of infections their child had been experiencing. They said they always felt uncomfortable with the decisions but felt pressured to make them and felt shut down when they wanted to ask questions. They said that their child's infections continued after the surgery and their child *'sits to pee anyway'.* They said they felt they needed to apologise to their child for the decisions they had made and felt regretful today. They are open with their child about their decision, who is angry about the decision.

Another set of parents told us they made decisions in the past that they probably would not make now. They had made those decisions with very little information, but in line with the best thinking at the time. They said that, while they did not feel anger about the past, they would be very sad to see people still making and living with wrong decisions. They said they felt it was a shame that things had not changed enough, and that legislation was required.

Another parent told us that they consented to surgery for their child some time ago because they were told their testes would become cancerous. Their child told us that no tests were done prior to the surgery and a pathology report afterwards showed there was no malignancy. The consequence of the surgery was the removal of their child's reproductive capacity. This parent still felt sorry about their decision. They said: '*let kids grow up and make their own decision'.*

However, not all parents agreed that they felt pressured to decide on surgery for their children and many of the parents opposed the draft proposal. One parent said that not allowing surgery when a baby or young person was least likely to remember it and instead leaving it to their teenage years presented more issues, including the risk of the child discovering *'they do not look what is considered normal'.* Another parent told us that, for young people with CAH who could not menstruate, deferring surgery might mean leaving the decision to a child who was only 10 years old, which was still very young for a person to decide that they want surgery for themselves.

While the possibility of deferring treatment was one factor considered by some parents, most said there were many reasons favouring early treatment. One parent told us that it was explained to them that their child's surgery was medically urgent and that their child would have problems with menstruation. This parent said that they made the decision for their child having consulted several doctors in different disciplines and being presented with information. They reported that their teen child was not comfortable talking about their surgery with us but was quite adamant that she was glad that the decision had been made for her as a baby. Another parent whose daughter had surgery as a child said they consulted with a number of doctors and it was unanimously decided that there were health related complications for their daughter that meant it was important for her to have the surgery when she was young. They said that doctors had told them that they could hold off but that there was no guarantee that there would not be further complications.

Another parent with a young child told us that they decided for personal reasons not to operate on their child because *'she was fine the way she was'*. They were told by doctors that they could wait and their child could have surgery later if she wanted. One of the reasons informing their decision was that surgery would not offer their child a complete vulva and there would still be a difference in her genitals anyway. However, this parent said that different doctors around the country had different perspectives, saying that they thought urologists were more pro-surgery while endocrinologists were more *'on the other end'*.

Views among clinicians and health professionals

Many clinical participants (but not all) objected to the principle of deferability being implemented in the form proposed by the proposed scheme, or in some cases being implemented as a general standard at all. By contrast, mental health professionals tended to support the principle of deferability.

Several clinical participants expressed disapproval for an *'assumption of universal deferability'*. They said that this assumption was untested, experimental and lacked any strong evidence base that it provided benefit. One clinician said that while there was evidence regarding the outcomes of early interventions, there was no evidence regarding the outcome for people who had their treatments deferred. Therefore, they said that there was a high potential for similar if not higher rates of dissatisfaction with the *'experimental'* deferral approach, which would not be known for another 15 years. Another clinical survey respondent said that the scheme did not take into account the possibility of later regret, anger or distress from procedures not being done in infancy or early childhood, and that all the evidence currently available suggests that a high proportion of adults who had procedures done in infancy were pleased that it was done early and did not wish for it to be left for them to decide later.

Other clinicians said that the principle of deferability would cause harm. They said that evidence suggested that most women with CAH preferred surgery earlier rather than later and that deferring treatment for hypospadias had negative impacts on psychological health. They also said that there was evidence that, in the case of undescended testes, earlier surgery improves the potential for future fertility. However, the benefits of early interventions were also disputed by other consultation participants, including among clinicians. For example, one participant said that evidence on the benefits of early treatment was limited and showed that poor outcomes were real and not insignificant risks, including negative impacts on sexual function, a significant likelihood of reoperation, and poor cosmetic outcomes. We were referred to some studies in this regard.[35] Another participant agreed that the evidence did support early surgery in the case of undescended testes but said that these surgeries would be good candidates for class exemption orders given they could be justified by evidence that deferring surgery would likely harm the future fertility of a person.

However, some clinical participants said that the lack of evidence in the field generally would make it difficult to rebut a presumption of deferability in practice, potentially leaving people without treatment that clinicians could not prove to be in their best interests. Another participant suggested that the principle could be expressed more neutrally; that is, not presuming the benefits of deferability but allowing its benefits to be factored into decision-making.

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[35] Including: van der Zwan et al (2012) 'Severity of virilisation is associated with cosmetic appearance and sexual function in women with congenital adrenal hyperplasia: a cross-sectional study', *Journal of Sexual Medicine*, 10(3):866-875; Warne et al (2005) 'A long-term outcome study of intersex conditions', *Journal of Paediatric Endocrinology & Metabolism*, 18(6):555-567; Crouch et al (2008) 'Sexual function and genital sensitivity following feminising genitoplasty for congenital adrenal hyperplasia', *Journal of Urology*, 179(2):634-8; Lean et al (2005) 'Cosmetic and anatomic outcomes after feminizing surgery for ambiguous genitalia', *Journal of Pediatric Surgery*, 40(12):1856-1860.

One clinical participant said that deferral was already common practice for certain conditions, particularly those where gonads were likely to function at puberty (even if that function is incongruent with the sex of rearing). Conditions where this may be the case include all forms of androgen insensitivity, 5-alpha reductase deficiency and 17 beta HSD.

In contrast to most clinical participants, mental health professionals generally supported the principle of deferability. Citing specific references,[36] one submission from a group of mental health professionals said that a variety of mental health issues can emerge as a result of unnecessary surgeries or hormone treatments performed on young children. Mental health challenges could also be further compounded by a lack of community understanding and awareness. They said that decisions and processes regarding medical interventions needed to focus primarily on the individual's wellbeing, over and above a concern for social integration which often means 'normalisation'. However, they also said that there was the potential for harm to mental health during the deferral period – due to living in an environment where parents may be of the strong view their child should be *'normalised'.* This could mean that a young person may be subject to coaching or coercion by parents or guardians during the deferral period. To mitigate those risks, the submission said there should be dedicated and evidence-based psychological support provided to families throughout the deferral period, including psychoeducation, support and evaluation of parental openness, and strategies to protect the young person's mental health.

THE 'HARM TO HEALTH' TEST AND PRINCIPLE OF NON-DISCRIMINATION

In addition to the exception allowing treatment in emergency situations (see section 5(c) above), the draft proposal suggested that the oversight panel could allow medical treatment modifying a person's sex characteristics if deferring that treatment would be likely to cause harm to the person's health. However, when considering whether deferring treatment would be likely to cause harm to the person's health, the principle of non-discrimination prevented the oversight body assuming without evidence that a person would be better off if their body functioned or appeared as if they did not have that variation. A number of participants addressed these aspects of the draft proposal in commenting on the rationales for treatment which they believed should and should not be allowed to influence decision-making.

Some participants said that the scheme needed to provide some clarity on the *'absolute non-negotiables'*, which several participants described as cosmetic treatment or surgery. Several participants, including people with variations of sex characteristics, parents and health professionals, said that an approach which strictly ruled out some procedures might be needed. Some participants were concerned that the harm to health test and non-discrimination principle may be too broad, specifically allowing a range of social and psychological considerations grounded in mental health claims to be considered.

On the other hand, some participants suggested the harm to health test and non-discrimination principle might be too narrow. One participant said that some procedures which were aimed at preserving future options for a child, including procedures designed to preserve fertility such as orchiopexy[37], should be allowed. Another person told us that if their parents could have done anything to save their fertility, they would have expected their parents to fight hard to keep it. One participant with a variation of sex characteristics also said that even cosmetic factors should not be entirely excluded given aesthetic considerations do matter when deciding on the preferred approach to procedures which attempt to achieve continence and maintain kidney function for people with cloacal and bladder exstrophy.

A participant with experience in administrative decision-making bodies felt very strongly that the notion of health had to include both physical and psychological health. Because the panel had to make decisions in respect of children with evolving capacities, it had to be able to make decisions that responded to their needs. While some of these children may not be old enough to formally consent, they might still know what they want, what they feel and

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[36] Rosenwohl-Mack et al (2020) 'A national study on the physical and mental health of intersex adults in the US', *PLOS ONE*, 15(10):e0240088; Kasiannan (2020) 'Psychological management in adolescence and beyond' in Hutson et al (eds) *Disorders | Differences of Sex Development*, Springer, Singapore, pp. 261-280; Victorian Government, Department of Health and Human Services, Jason Rostant Consultation & Intersex Expert Advisory Group (2019) *Health and wellbeing of people with intersex variations*, Victorian Government.

[37] A procedure to descend testes into the scrotum.

what they want to be. Some could come to the panel with mental anguish or suicidality. So, it was important that the panel could address their physical and psychological health needs, whatever they were.

A parent who discussed with us their decision to consent to a clitoral reduction and vaginoplasty for their child in the last decade highlighted the intermingling of physical health, psychosocial and socioeconomic rationales that can influence a decision. Among the reasons for choosing early surgery for their child in this case were that:

- the child would need the surgery to menstruate at the onset of puberty;
- given where the surgery was being performed, there was an unlikely risk of the clitoris being impaired;
- the child would not remember the awkwardness of the surgery if done early;
- they understood that the child may need to dilate when they were older to be able to use tampons or be sexually active;
- a vaginoplasty was easier on a baby;
- research showed that the gender identities of people with CAH were mostly assigned correctly;
- the fear of stigma and bullying, particularly in the specific community and family that the child lived, which could have lasting psychological effects;
- the impact of the variation on the child's self-body image; and
- the availability of and access to healthcare based on where the family lived.

Another parent said the draft proposal wrongly focussed on preferencing that a body *'is not touched'* without personal consent over what was in the best interests of a child. This parent said that they did not want their child to have issues with their sexuality and mental health. They thought the focus of the scheme should instead be on ensuring people had the most fulfilling lives: confident as children and then later, as adults, who were confident in their own body image and sexuality. A parent survey respondent said that it was important to look at *'the real society we are living in to see what's really happening'*. They did not think potential prejudices towards people with variations of sex characteristics would be eliminated, even if the person were fully protected by laws, rules and regulations. However, one child with an intersex variation who we interviewed (with their parents) told us that people at their school knew that they were intersex and it was not an issue; they were not teased or bullied. In their view, the test should be: *'if [a person] can't give consent, it can't be done – unless it is going to kill them'*.

SUPPORTED DECISION-MAKING PRINCIPLES

Several participants, including legal and disability rights experts, expressed support for a scheme framed in accordance with supported decision-making principles. However, not all participants necessarily had the same understanding of what supported decision-making meant.

One human rights expert said that the scheme needed to accommodate the different human rights approach required for children and adults with disability. In respect of children, the starting presumption was that children did not have the capacity to consent until they reached maturity and someone else would have to make decisions on their behalf based on what was in their best interests. The *Convention on the Rights of the Child* required that the child's views be taken account as their capacity evolved when determining whether a decision was in their best interests. In respect of adults with disability, the 'best interests' consideration did not apply, and adults were assumed to have an inherent capacity to consent, regardless of what someone else thought was in their best interests. So, for adults with disability, the focus is on giving adults all the supports necessary to express their own will and preference. And if, after providing all necessary supports the adult is not able to express their own will and preference or express it fully, the requirement turns to determining what that person's will and preferences would likely be (for example, based on what they have expressed in the past). Disability rights experts told us that no Australian guardianship system currently incorporated all the principles of supported decision-making for adults with disability and that this proposal had gone further in incorporating those principles, including by its reference to ensuring those who could provide informed consent after reasonable support were able to exercise their own decision-making capacity.

(g) Oversight body – individual care plans and class exemption orders

SUMMARY OF THE DRAFT PROPOSAL

Sections 9(a) and 10(a) of the draft proposal proposed two ways in which the oversight panel could allow medical treatments modifying a person's sex characteristics to proceed without personal consent (in addition to the exception for emergency treatment and male circumcision). The first was to allow the registration of an individual care plan including that treatment.[38] The second was to make a class exemption order covering a class of treatments.[39] In both cases, it was proposed that the oversight panel would be required to apply the decision-making principles discussed in section 5(f) above: the human-rights framework principle, the principle of self-determination, the principle of deferability (including the harm to health test), and the principle of non-discrimination. Also, it was proposed that the oversight panel would be required to follow certain procedural requirements including those that ensured procedural fairness; the ability for the panel to consider and inform itself with evidence; timely decision-making; and transparency and accountability in decision-making.

'In principle' supporters of the draft proposal engaged with the individual care plan proposal. They provided comments on: what should be included in an individual care plan; how it should be prepared, considered and registered by the oversight panel; and how the plan could be implemented. A few participants also provided comments on the class exemption orders proposal.

THE SCOPE OF INDIVIDUAL CARE PLANS

Participants had a range of views and ideas about what should or could be included in an individual care plan.

One participant said that consideration should be given to requiring an individual care plan from birth, given documentation of the decisions made on behalf of an individual would allow accountability to that individual.

Several participants emphasised the importance of individual care plans including provisions on support before and after any treatment. For example, several interview participants told us that they had been left to *'fend for themselves'* after surgery with no support. One participant said that they would love to see psychological counselling support from people with understanding of intersex issues built into decision-making for young people, not just as a step in the process. Another participant said that counselling should be required as a minimum before any surgery.

One participant said that it was important that an individual care plan had longevity and was regularly reviewed, including at major milestones or changes in family circumstances. One suggestion was to rename the proposal an *'individual support and care plan'* to move the focus away from medical treatment and onto wholistic support which might be necessary at different life stages, such as puberty. Other participants also mentioned that for people with a disability, who may need ongoing support into adulthood, having one scheme that covered adults as well as children would give continuity of care.

However, one participant highlighted that if an individual care plan allowed for the provision of mental health support, but the scope of the panel's work was limited to people who did not have capacity to consent, this would result in unequal access to mental health support for those who did not go through the oversight panel process.

SUPPORT WORKERS

The draft proposal suggested that employed support workers facilitate the preparation of a draft individual care plan for consideration by the oversight panel. The reason for this proposal was to make the process as accessible and friendly to families as possible.[40]

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[38] Consultation paper, pp. 27-31.

[39] Id, pp. 34-35.

[40] Id, p. 32.

However, questions were asked about the role of these employed support workers. One survey respondent said more detail was needed on the role of the support worker, such as their qualifications, scope of role and clarifying who their primary *'client'* was.

One participant with relevant experience in similar decision-making bodies said that it was important that the support worker helped people through the process but did not advocate or put forward their own views, as this would give rise to procedural fairness issues. Support workers could do research and assist people going through the process but should not express policy positions. The other approach was to have the support workers employed by a different public body so that their role was distinct from the decision-making body.

In addition to support workers, one participant said that the process could be very emotionally driven, and they recommended putting in place a counselling model before and after the process.

CONSIDERATION BY THE PANEL

The draft proposal set out a detailed process and decision-making framework for the oversight panel to follow when making the decision whether to register an individual care plan.[41] Participants provided a range of views regarding these matters.

Evidence gathering powers

One participant said that the panel should have the power to appoint someone, such as a psychologist, to provide independent evidence to help inform its decisions. This participant also said that the panel's processes needed a degree of flexibility, including allowing decisions to be made *'on the papers'* without a formal hearing in an appropriate case.

One participant said that it while it was critical to ensure that people had a right to speak, they should not be forced to do so by the panel.

Independent advocate

Several participants raised the idea of having an independent advocate for the child on the panel or part of its deliberations, particularly where a child was too young to express their own views or where there were questions regarding their capacity to provide consent.

One participant said that, while most parents simply want the best for their children, they can be unduly influenced by cultural or faith pressures, struggle with language barriers or be simply disengaged. Especially if interventions were framed by a parent or medical expert as achieving 'normality', 'attractiveness' or 'fixing defects', young people could feel heavily influenced by their parents' expectation and there was a potential for coerced decisions that young people may subsequently regret. It was for this reason that it was very important for young people to be provided with an independent ally, separate from their parents who could provide unbiased information and who would have a seat on any panel as that child's advocate.

Legal representatives

One participant suggested that lawyers be allowed to appear only by leave of the panel. This was to avoid increased legalism in decision-making but would allow the chair to allow legal representatives to appear when, for example, there was a complex issue of law for the panel to consider.

Time for making decisions

One participant said that, at times, the panel would need to be convened quickly, while at other times more time would be available for making its decisions.

Several clinicians expressed concerns about the potential workload of the panel creating backlogs of cases and delaying decision-making, with one clinician noting that the timeframe of 14 days might be *'optimistic'*. Some

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[41] Id, pp. 30-31.

participants questioned the potential psychological impacts of delays on individuals going through the panel process.

REGISTRATION

When the oversight panel decided to register or refuse to register an individual care plan, the draft proposal suggested that the oversight panel be required to give written reasons for its decisions.[42]

One participant said that there needed to be more clarity around the registration of individual care plans, for example, who would keep the register and who would be able to access, search or edit the register.

One participant emphasised the importance of the panel's 'case notes', rationale and decision-making information to be retained and be made available to the individual upon request.

MATTERS FOR CLARIFICATION

One participant highlighted the need for operational and technical matters to be clarified in respect of the individual care plan proposal. The first question was: what is the effect of the body refusing to register an individual care plan? Would that mean that the treatments proposed could not proceed? The second question was: if the body had registered an individual care plan, who would have responsibility for its implementation? One possibility was that it acted as an authorisation allowing health professionals to provide the treatment. Another possibility was that it framed the scope of possible authority (including what treatments were prohibited), leaving the person with medical decision-making responsibilities under the *Medical Treatment Planning and Decisions Act* empowered to make decisions within the boundaries of what was permitted by the individual care plan. This would mean that the medical decision-maker, such as the parent or appointed decision-maker, would have the practical role of signing treatment forms, hospital forms, consents to anaesthesia, and evaluate the risk that an individual procedure may pose, within the boundaries of their authority. Finally, this participant said that it was not clear who was responsible for risk in the event something went wrong when putting the plan into effect. The risk could not be worn by the plan. Another clinical participant also asked questions about who would bear the liability for wrong decisions.

CLASS EXEMPTION ORDERS

The draft proposal suggested a regime for allowing the oversight body to make exemptions for a class of treatments, subject to the decision-making principles discussed in section 5(f) above and certain procedural requirements.[43] The proposal allowed the oversight panel to stipulate conditions or circumstances that would limit the scope of these exemptions or require reporting to the oversight panel regarding their use.

One participant highlighted that a benefit of class exemption orders would be to allow streamlining based on risks. Low risk procedures could be authorised without individual applications. However, another participant said they were concerned that class exemption orders reduced accountability to the individual. Among the things that an individual should have access to is all the information pertaining to any decision made about their body, including answers to the questions of *'who, what, when, where and why'.*

We heard several examples of procedures that could be dealt with through carefully drafted class orders:

- fistula repair;
- orchiopexy and chordee repair;
- certain fertility preservation treatments;
- gonadectomies for evidenced high risk of cancer; and
- treatment for evidenced repeated urinary tract infection over a long term.

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[42] Id, p. 31.

[43] Id, pp. 34-35.

(h) Mandatory reporting obligations

SUMMARY OF THE DRAFT PROPOSAL

Section 11(a) of the draft proposal suggested imposing an obligation on health service providers to report certain details about the medical treatment they had provided relying on the permitted exceptions of the scheme. This would allow the oversight body to monitor compliance with the scheme. However, health professionals would be protected from any liability for complying in good faith with this reporting obligation.[44]

OBLIGATION TO REPORT

Several participants supported the mandatory reporting requirements proposed, with some participants suggesting that the obligations could be expanded or clarified. Those who were generally opposed to the draft proposal did not tend to provide further comments on this aspect of the proposal, although one clinical participant asked whether clinicians would be funded for the additional time taken to prepare reports.

Among supporters of the mandatory reporting requirements, some participants considered that the oversight body should be notified when the diagnosis of a person with a variation of sex characteristics occurs to address the lack of data on the prevalence of people with variations of sex characteristics. However, this view was not supported by all participants who supported mandatory reporting requirements generally. One participant said that the focus of reporting should be on treatments as reporting of diagnoses could have the unintended adverse effect of discouraging medical investigations to occur. Given the concern was with the potential for harm caused by treatments and not diagnosis, the reporting should focus on the area where the risks lay. Another participant also said that misdiagnosis frequently occurs anyway.

One participant said that the obligation to report should extend to past medical procedures taking place within at least the last 10-15 years. This would allow a comparison of the number of procedures performed before and after the inception of the oversight body, to test its effectiveness in changing medical practices and social norms.

Another participant suggested that the reporting obligation be extended to include information on any alternative treatments considered.

MANAGING PERCEPTIONS OF BIAS

One participant with experience in similar decision-making bodies said that it was important that the role of the oversight body as a decision-making body, and not a regulatory body, be preserved. This was to ensure it is not perceived as biased. Either the police or a professional registration body should have responsibility for enforcing the law. Accordingly, the oversight body should refer such reports to the right place but not engage in its own investigations.

(i) Confidentiality

Section 12(a) of the draft proposal suggested that it be a criminal offence for anyone to disclose any personal information about any individual connected to a treatment or proposed treatment being considered by the oversight panel. The draft proposal suggested limited exceptions to this confidentiality requirement, including where the person had given consent to the disclosure.[45]

Several participants reflected on the importance of privacy protections for people with matters appearing before the panel, and that this should be made explicit.

One participant with experience in similar decision-making bodies suggested that confidentiality requirements should allow the body to contact a mental health crisis team, such as if there a real risk of suicide or self-harm in respect of a person appearing before the body.

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[44] Id, p. 36.

[45] Id, p. 37.

Another participant said that periodic reports with aggregated information, rather than publishing individual decisions, could also better protect individual privacy.

(j) Interaction with other laws and systems

Section 14(a) of the draft proposal suggested consequential amendments to a number of other laws to ensure the proposed scheme operated harmoniously with existing laws and systems.

For a number of legal reasons, one participant disagreed with the proposal to remove the *parens patriae* jurisdiction of the Victorian Supreme Court in respect of matters which were in the jurisdiction of the oversight body. The first was that the jurisdiction was an ancient and protective one and it provided a last resort jurisdiction in difficult cases.[46] The second was that, given the similar welfare jurisdiction of the Family Court would remain in place, people should be given the option of either the Supreme Court or Family Court processes.

One participant said that the test in *Gillick*[47] may have been superseded by section 55(4) of the *Medical Treatment Planning and Decisions Act*, which appointed, as the medical decision maker for a child, a parent, guardian or other person with parental responsibility who is reasonably available and willing and able to make medical treatment decisions for a child. Accordingly, the civil protection proposal[48] would need to interact with this provision.

One participant with experience in relevant decision-making bodies supported the principle of carving out from other decision-makers, such as in the guardianship and child protection systems, decisions that would be left for the oversight body. This would recognise the specialist expertise of the proposed oversight body.

Another participant suggested that apart from the scheme's interaction with the *Medical Treatment Planning and Decisions Act 2016* (Vic) and *Guardianship and Administration Act 2019* (Vic), the proposal may need to consider its interaction with potential powers given to foster carers under child protection legislation and the status of appointments made under historical legislation including:

- a medical power of attorney under the *Medical Treatment Act 1988* (Vic);
- an enduring guardian under the *Guardianship and Administration Act 1986* (Vic);
- an enduring attorney for personal matters with powers to make decisions about health care or medical treatment under the *Powers of Attorney Act 2014* (Vic) between 1 September 2015 and 11 March 2018.

Finally, one participant said that statute of limitations legislation should be amended to provide clearer avenues to compensation and redress.

(k) Future nationalisation

Some participants mentioned that they would like to see the scheme implemented nationally. For example, one participant indicated that they ideally wanted to see nationally consistent laws, as they did not want to see border hopping. However, they were content with some states and territories moving forward with others following.

6. OTHER ISSUES

Some participants raised issues and ideas that went beyond the draft proposal, and these are addressed here.

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[46] For example, in those cases where blood transfusions were allowed by a court against the consent of a person or their parents. The jurisdiction allowed the Supreme Court to override the lack of consent of a person or their parents if necessary to save their life.

[47] *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 112, as affirmed in *Secretary, Department of Health and Community Services v JWB and SMB (**Marion's case**)* [1992] HCA 15.

[48] At section 5(a) of the consultation paper.

(a) Redress

Acknowledging that the proposed scheme would operate prospectively, several participants raised the need for redress in respect of historical practices. Among the redress measures raised with us were:

- an apology or acknowledgment that what was done previously was wrong, a betrayal of trust and a breach of rights;
- the need for simple answers as to what was done to a person, including access to health records or medical procedures that would help provide those answers;
- support for connection and contact with others in a similar position, particularly through funding peer support;
- financial support for psychological care or further medical treatment, including to fund corrective surgeries to reverse the negative effects of past medical procedures;
- clear avenues for compensation.

When asked what redress meant to one person who felt coerced to undergo surgery in her teenage years, she replied immediately with a single word: *'answers'*. She said that there were people in her peer support group who had scars from surgeries that they did not know about. She said that she first found out what was done to her by reading a medical journal which reported about her without her consent. She said that all she wanted was an MRI, so that she could know what was *'going on'* inside her own body after a history of misdiagnosis. Another participant shared with us a similar experience of not knowing what had happened to them until attempting to have a child later in life. They said that their experience was *'swept under the carpet'*.

Several participants shared with us traumatic accounts which occurred to them in medical settings. One parent shared with us memories of her young child trying to run away from hospital after waking up to find her dress had been lifted. Her now adult child recalled having to stand in a bath while nurses came to observe her genitals.

Finally, one participant said to us that it was important for Equality Australia to recognise the intersex activists that have been working for several decades to achieve legislative change, including those who contributed to the Darlington Statement. To add to the acknowledgements contained in the consultation paper and background paper, we have also done this at the front of this report.

(b) Need for education

Several participants reflected on the need for greater education about and awareness of people with variations of sex characteristics, including with health professionals such as GPs and the general public. This could help reduce the stigma faced by people with variations of sex characteristics, but also ensure parents were not confronted with a situation they were unfamiliar with.

Several participants said that, when faced with a child with a variation of sex characteristics, parents were not always well equipped to respond effectively; parents may throw themselves into the hands of *'saviours'* and were quick to believe all the things which were said. One parent told us that they would like to see more information with *'easy parental language'* rather than surgical language.

A person with CAH told us that it would be good for older people to have information about how CAH affects them in older life, including the consequences of over treatment and the proper management of steroids.

(c) Impact on relationships

A few participants with variations of sex characteristics and their parents and family members reflected on past procedures and the impact those decisions had on their familial relationships.

Several people invoked terms such as bitterness and guilt in describing the impact on their relationships. Several people with variations of sex characteristics and parents said they were not bitter but had made (or appreciated that their parents had made) the best decisions that they knew at the time. Some participants with variations of sex characteristics said they did not want their parents to feel guilty about those decisions. One participant with a variation of sex characteristics told us that they loved their mother, and their mother loved them, but it was something they could not talk about together, as it was traumatic for both of them. This participant said they did not ask their mother about was told to them or promised in respect of the outcomes of their surgery, but that they would not say that their mum made a bad decision.

We witnessed a number of tears from parents and partners who reflected on the impact of past decisions on their loved ones with variations of sex characteristics.