

Health and wellbeing of people with intersex variations

Information and resource paper

The Victorian Government acknowledges Victorian Aboriginal people as the First Peoples and Traditional Owners and Custodians of the land and water on which we rely. We acknowledge and respect that Aboriginal communities are steeped in traditions and customs built on a disciplined social and cultural order that has sustained 60,000 years of existence. We acknowledge the significant disruptions to social and cultural order and the ongoing hurt caused by colonisation.

We acknowledge the ongoing leadership role of Aboriginal communities in addressing and preventing family violence and will continue to work in collaboration with First Peoples to eliminate family violence from all communities.

Family Violence Support

If you have experienced violence or sexual assault and require immediate or ongoing assistance, contact 1800 RESPECT (1800 737 732) to talk to a counsellor from the National Sexual Assault and Domestic Violence hotline. For confidential support and information, contact Safe Steps' 24/7 family violence response line on 1800 015 188. If you are concerned for your safety or that of someone else, please contact the police in your state or territory, or call 000 for emergency assistance.

To receive this publication in an accessible format, [email the Diversity unit](mailto:diversity@dhhs.vic.gov.au) <diversity@dhhs.vic.gov.au>

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Message from the Minister

The Victorian Government is committed to equality for all Victorians.

It is a key responsibility of the Victorian Government to keep people safe. This includes Victoria's LGBTI communities. The *Health and wellbeing of people with intersex variations: information and resource paper* is one of the ways in which we are addressing stigma and discrimination for people with intersex variations.

This information and resource paper is a critical step toward improving health and wellbeing outcomes of children and adults with intersex variations and their families, with Victoria at the forefront of national efforts in this area.

In releasing this paper, the Victorian Government acknowledges that people with intersex variations have had negative experiences in their interactions with health, education, employment and other settings, and confirms its commitment to protecting the right to informed consent and bodily integrity for people with intersex variations.

Through issuing this information and resource paper, the Victorian Government confirms its support for the development and implementation of evidence-based policies, programs and services for people with intersex variations.

The information and resource paper was developed with the assistance of the Victorian Government Intersex Expert Advisory Group and other community advocates. I would like to thank them for their contribution.

Jenny Mikakos MP
Minister for Health

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In particular, the department thanks those involved in the 2016 project overseen by Gay and Lesbian Health Victoria (GLHV), including project leads Associate Professor Tiffany Jones (La Trobe University and the University of New England) and William Leonard (Director GLHV), strategic advisors Anna Brown and Lee Carnie (Human Rights Law Centre) and research assistants Renee Zborowski and Joe Latham.

The 2016 project also benefitted from the input of a range of stakeholders, including members of the Department of Health and Human Services 2016–2017 Intersex Expert Advisory Group (IEAG), clinicians, researchers and other health and education experts. Thanks also to participants of the further consultations undertaken in 2017.

This information and resource paper, and the suite of related materials, were revised and updated by Jason Rostant Consulting. They benefitted from extensive input from members of the Department of Health and Human Services 2017–2018 IEAG, human rights advocates, members of the Inter-Departmental Project Reference Group, and clinicians. Thanks to all contributors, not all of whom are named, including Ro Allen, Tony Briffa, Dr Meg Brodie, Anna Brown, Paul Byrne-Moroney, Lee Carnie, Andrea Kapteinis, Dr Ruth McNair, Kristiina Siiankoski, Trace Williams, Sarah-Jane Miles, Michele O'Connell and Dr Agli Zavros-Orr.

1. Introduction

Participants highlighted the importance of timely access to appropriate health services, especially for ... children and adults with intersex variations.

Access to surgical, mental health and service providers with expertise in presenting conditions was also identified as important. Support programs and services, including peer support groups, were highlighted as crucial for individuals experiencing isolation, helplessness and anxiety. (Victorian Government, 2014, p.13.)

- This information and resource paper provides the context for a suite of materials targeted to a diverse range of people involved in the treatment, care and support of people with intersex variations.
- The Victorian Government commissioned this paper to support the development and implementation of evidence-based policies, programs and services, and to further understanding of the needs and interests of people with intersex variations in Victoria.
- This paper has been developed with input from members of an Intersex Expert Advisory Group and other stakeholders who provided advice on a wide range of issues, including research limitations, current clinical practice, and appropriate and respectful terminology.

1.1 Rationale

The Victorian Government values and celebrates diversity. It affirms the right to equality, fairness and decency for people with intersex variations and is committed to removing discrimination from Victorian laws, services and society, including hospitals and other health care settings. This commitment extends to improving the health and wellbeing outcomes and experiences of people with intersex variations in Victoria, helping them live lives free from stigma and discrimination, and upholding their rights to informed consent and bodily integrity.

In recent years, community understanding about intersex variations and the experiences of people with intersex variations has improved. In medical, legal and other settings there has been impetus to shift towards rights-based treatment, care, support and decision making that privileges individual autonomy, choice and control.

Victoria has been at the forefront of these efforts nationally, including through the development of *Decision-making principles for the care of infants, children and adolescents with intersex conditions* (Victorian Department of Health, 2013). While the principles have been broadly endorsed and accepted, the lack of transparent evidence of their adoption and consistent application has also been highlighted as a significant shortcoming and has attracted criticism.

Many people with intersex variations continue to describe negative experiences in their interactions with health, education, employment and other settings, and in the community generally. These experiences lead to poorer physical and mental health outcomes for some people with intersex variations, and their families, and have been the focus of continuing efforts by intersex advocates to effect system and practice reform.

The Victorian Government recognises that more research about intersex variations and experiences of health services is needed and that improving health outcomes for people with intersex variations also depends on efforts to improve community awareness and understanding of their needs.

1.2 Purpose and audience

The primary aim of this paper is to support the development and implementation of evidence-based policies, programs and services for people with intersex variations. It seeks to support increased awareness, knowledge and understanding of their health and wellbeing experiences, and to deliver improved service access and quality, treatment practices, and health and wellbeing outcomes.

To that end, the paper brings together current international, national and state policy; clinical and sociological research; and other perspectives offered by people with intersex variations.

This information and resource paper is presented as a primer for individuals and organisations involved or interested in the delivery of health-related services to people with intersex variations in Victoria. It also provides the background for a suite of more targeted resources described in section 1.3.

1.3 Resource development

In 2013, the Victorian Department of Health developed the *Decision-making principles for the care of infants, children and adolescents with intersex conditions*. The principles were an Australian-first tool to help Victorian hospitals apply best practice decision making to the treatment, care and support of people born with intersex variations.

In 2016, the Victorian Department of Health and Human Services commissioned an update of its earlier work, overseen by Gay and Lesbian Health Victoria (GLHV). The project involved an extensive legislative, policy and literature review and delivered a lengthy draft background paper. Supported by input from a broad range of stakeholders including the Department of Health and Human Services IEAG, the work also relied heavily on data drawn from an Australian intersex study undertaken in 2015. The Jones study was an online survey of 272 people with intersex variations which explored experiences and perspectives primarily, though not exclusively, in relation to education (Jones, 2016a).

Further consultation throughout 2017 with the IEAG and select clinicians proposed a range of products drawn from this draft background paper, including the development of a suite of resources targeted to particular audiences:

- *Information and resource paper (Executive summary)*: a summary companion to this document intended for the wider health and human services sector and community.
- *Revised principles for decision making*: incorporates changes to reflect recent policy and legislative reforms. The *Revised principles* are primarily intended for health service providers and other government and non-government bodies within Victoria and nationally.
- *Guide for parents on health care options*: incorporates changes as described above and is targeted to respond to the information needs of parents and families of children born with variations of sex characteristics.
- *Future directions paper*: recognising that policy, legislation and research relating to people with intersex variations continues to evolve, the *Future directions paper* identifies system challenges and development needs, and other issues for further exploration in the shorter and longer terms. It is primarily intended for audiences with an interest in future reforms, including government agencies, health service providers and intersex organisations.

This information and resource paper draws on this earlier work and feedback, as well as a more recent review of the current and emerging legal and human rights context undertaken by the Human Rights Law Centre in 2018. It has been developed with input from a range of stakeholders including members of the 2016–2018 IEAG and a project reference group comprising members from the departments of Health and Human Services, Justice and Regulation, and Premier and Cabinet.

1.4 Emerging framework

Since the Victorian *Decision-making principles* were developed in 2013, several policy and legislative shifts have occurred at international, national and state levels, and further sociological and clinical research has been undertaken.

These policy and legislative shifts have been strengthened by the inclusion of intersex voices through statements such as The Darlington Statement (see section 3.2), which have supported a shift towards the depathologising of intersex variations, the privileging of intersex lived experience, and the importance of individual self-determination, autonomy and bodily integrity.

This paper summarises the current policy and legislative landscape and emerging health and wellbeing perspectives of people with intersex variations and provides background context to support the suite of resources outlined above in section 1.3.

Together these resources support Victoria's current exploration of options for the development of a new systems approach to the care, treatment and support of people with intersex variations and their families.

Discussed in more detail in [Chapter 6](#) and in the *Future directions* paper, this new approach, if developed, would be underpinned by a human rights approach that:

- is consistent with client-centred principles of choice and control, autonomy and self-determination
- affirms and values intersex variations as a natural expression of human diversity
- prioritises informed consent of people with intersex variations or their legal guardians through their active participation in the planning and delivery of treatment and care.

1.5 Key terminology

'People with intersex variations' is an umbrella term for people born with congenital, atypical sex traits. The variations may be chromosomal, hormonal and/or anatomical in nature. The term is non-stigmatising, person-first and consistent with the language many people use to describe themselves (Davis, 2015a). Some people with intersex variations may also describe themselves according to their individual variation or using other context-dependent language.

There are many other terms currently in use in certain contexts. In clinical settings, use of language linked to an individual's specific variation is common, whereas terms such as 'differences (or divergence or disorders) of sex development' (DSD) and 'conditions affecting reproductive development' (CARD) have emerged for the purposes of diagnostic and treatment classifications, development of standards of care, and conduct of research. In consultations planned for 2018, the Australian Human Rights Commission will refer to 'people born with variations in sex characteristics'.

Other terms such as 'people with disabilities' or 'LGBTI people' have sometimes been applied to this group. People with intersex variations do not generally view themselves as disordered, do not generally have disabilities, do not generally identify as transgender, and primarily identify as heterosexual (Jones, 2016a).

For legal consistency and to assist in the development of health policy, programs and services, this paper uses the umbrella term 'people with intersex variations' to describe overlapping intersex variations and the health issues they raise. However, it is important that use of an umbrella term does not mask the complexity and significant differences that exist among people with intersex variations or promote the myth that all people with intersex variations share a singular perspective or experience.

A glossary of key terms includes descriptions of a selected range of more than 30 intersex variations (see [Appendix 1](#)).

1.6 Structural outline

This document is divided into six chapters. Each chapter opens with a stakeholder quote and a summary of the main points, followed by themed subsections providing more detail and references:

- Chapter 1: **Introduction** explains the document's background context and development, its intended purpose and audience, its limitations and key terminology.
- Chapter 2: **Understanding intersex** defines and explains 'intersex', considers population estimates for people with intersex variations, distinguishes between impacts on sex compared to impacts on gender and discusses appropriateness of terminology.
- Chapter 3: **Legal and policy contexts** summarises relevant policy at the international, national, state and institutional levels.
- Chapter 4: **Health and wellbeing** provides a brief overview of the physical, mental, sexual and reproductive health and wellbeing issues that may be experienced by people with intersex variations. It does not provide detailed information about the health and wellbeing issues and experiences of people with specific intersex variations, a further summary of which can be found in the appendices.
- Chapter 5: **Delivering quality treatment and care** examines different approaches to the treatment, care and support of people with intersex variations, including in the Victorian context, and considers opportunities for improving quality and outcomes for them and their families through improved information, peer support and other forms of psychosocial support
- Chapter 6: **An evolving approach for Victoria** provides an overview of an evolving systems approach to the treatment, care and support of people with intersex variations and their families that positions the *Revised principles* as an underpinning support for a new treatment and care typology, outcomes and standards of care framework, and range of system enablers.

The document concludes with a **glossary** and **appendices** providing further discussion of health issues relevant to specific intersex variations.

1.7 Limitations

This paper recognises that people with intersex variations have diverse health and wellbeing needs and experiences. It also recognises the significant complexity that derives from current clinical and research limitations, which include small sample sizes, poor longitudinal focus, difficulty attracting and maintaining participants, selection bias, limited data especially for the less common intersex variations or for those often diagnosed later in life (if ever) (for example, Warne, 2012; Kohler et al., 2014; Reiner, 2005; Rattan et al., 2010) and, in some cases, conflicting and inconclusive evidence. A lack of funding to support the establishment of prospective longitudinal databases to enable further intersex research has also been highlighted as a significant shortcoming.

The paper responds to these complexities and limitations in part by drawing on narrative / anecdotal evidence that privileges the voices of people with intersex variations to supplement gaps in the clinical and sociological research.

The paper also recognises that a significant contributing factor to poor health and wellbeing outcomes for people with intersex variations and their families is the widespread lack of treatment, experience and outcome data. These issues are explored in more detail throughout this paper, particularly in Chapter 5.

Finally, this paper is not intended to, and does not, provide detailed clinical and treatment information relating to specific intersex variations. Instead it explores health and wellbeing issues and experiences commonly reported by people with intersex variations in Victoria, nationally and internationally, and how health providers and systems can deliver improved treatment, care and support through rights-based, person-centred care.

2. Understanding intersex

A surgeon removed my internal testes in 1997, when I was 17 years old. The surgery was an attempt to normalize my ‘abnormal’ body because testes don’t belong in a female body. I thought the doctor was removing premalignant underdeveloped ovaries, but as I later learned that was a lie he told me allegedly to ensure that I would see myself as the girl I had been raised to be. ... I wish he knew that the surgery he performed created a new set of abnormalities in my life. Having my body surgically modified for a medically unnecessary reason, I came to feel that my core was, from the beginning of my life, damaged. I felt like I was a freak of nature. For years I wondered how different my life would be had my body been left intact, and rather than lied to about my diagnosis, I had been told I was a unique, and, most importantly, natural variation ... (Davis, 2015b, p. 87)

- People with intersex variations are born with congenital atypical sex traits (whether chromosomal, hormonal or anatomical). Many have two or more variations.
- It is estimated that 1–2 per cent of the population have intersex variations but these estimates may be conservative because of the physical invisibility and failure to diagnose some intersex variations.
- Most people with intersex variations identify as female or male while a smaller number may identify as non-binary (neither female nor male) or both male and female.
- Having an intersex variation does not determine or restrict an individual’s gender identity or gender expression.
- This paper uses ‘people with intersex variations’ as an umbrella term. However, use of a person’s preferred terms when discussing their intersex variations, body, sex and gender is recommended.

2.1 What does ‘intersex’ mean?

People with intersex variations are born with physical, biological or chromosomal sex characteristics that do not fit the typical expectations for male or female bodies.

Despite a large body of research demonstrating significant variability in biological sex, sexual development and bodily forms (Ainsworth, 2015), everyday and professional understandings of human biology and sexual development are dominated by a two-sex or **binary** model. In this model sexual development and adult sexual roles are assumed to display unambiguous and congruent characteristics of one sex and one sex only – female or male. Although changing, this binary model has guided our understanding, diagnosis and treatment of people with intersex variations.

It is important to recognise the diversity of human experience and the limitations inherent in a binary understanding of sex and gender that can cause harm to people with intersex variations and their families.

As discussed in section 2.3, it is also important not to assume that people with intersex variations identify their sex and gender in ways that are non-binary – some may do so, but many do not. Sex and gender should not be conflated.

Intersex variations include **naturally occurring** chromosomal, hormonal and/or anatomical traits that do not entirely conform to a binary model of sex or binary categories of female or male. The appended glossary describes more than 30 intersex variations.

Some people with intersex variations do not develop primary and secondary sex characteristics indicative of one sex or the other and some combine features of both sexes.

Some intersex variations are detectable prenatally, at birth or during infancy. Some become apparent around puberty, particularly those that involve differences in reproductive functions. Other intersex variations may go undetected during a person's lifetime.

Sex characteristics are determined by a combination of chromosomes, hormones and anatomy:

- **Chromosomes:** A binary model assumes two sex-specific chromosomal patterns: 46XX for females and 46XY for males. People with intersex variations may have atypical chromosomal patterns and combinations including a fewer or greater number of chromosomes (such as 47XXY, 47XYY, 45XO, 47XXX, 48XXXX and 49XXXXX) or chromosomal mosaics – cellular combinations of two different chromosomal patterns (such as 46XY/45XO or 46XY/47XXY). Some intersex people may have been assigned to one sex but have the chromosomal pattern of the opposite sex (male presentation and 46XX chromosomes or female presentation and 46XY chromosomes), while others may combine characteristics of both sexes. These natural variations mean that sex chromosomes alone are an unreliable determinant of sex and gender.
- **Hormones:** A binary model assumes hormone levels and ratios in which females have greater levels and sensitivities to oestrogen than males, and males have greater levels and sensitivities to testosterone than females. And yet, some people with intersex variations produce hormones in greater or lesser amounts than is common to the sex they have been assigned or exhibit more or less sensitivity to hormones than is common for their assigned sex (such as androgen insensitivity syndrome). Some people with intersex variations may have hormone levels and ratios that lead to a delay or absence of puberty or to developmental impacts that are atypical for their assigned sex.
- **Anatomy:** A binary model assumes development of clearly differentiated primary sex characteristics (ovaries, a clitoris and vagina for XX females, and testes and a penis for XY males), as well as secondary sex characteristics such as height, vocal cord length and/or tenor, facial and bodily hair distributions and thickness, breast development, jawline prominence, muscle mass and other features. People with intersex variations may experience atypical primary sex characteristics relating to differences in the development, size, appearance and/or absence of internal and external genitalia. The development of secondary sex characteristics may also differ as a result of an intersex variation.

2.2 How common are intersex variations?

Reliable data on the number of people with intersex variations is difficult to obtain. A recent Australian Senate inquiry noted that estimates range from 0.1–2.0 per cent of the population in a report by the UK National Health Service, while the Australasian Paediatric Endocrine Group estimates ranged from one in 125 to one in 4,500 births (Senate Community Affairs References Committee, 2013).

A number of factors contribute to this variability and paucity of data. These include, for example, the invisibility of some variations at birth or throughout the life course and different approaches to classifying specific variations under the intersex umbrella. Studies may rely on very narrow, biomedical definitions of intersex and intersex variations or small sample sizes where results for a particular cohort may be generalised to a whole population. Larger studies can also be impacted by methodological challenges including recruitment, sampling and self-reporting biases. Few jurisdictions maintain accurate data on babies born with intersex variations and their medical and other treatment.

Mixed sex chromosome variations are the most commonly diagnosed intersex variations. These include 47XXY (Klinefelter syndrome), which is estimated to occur in boys at one in 448 births (Herlihy et al., 2011); 47XYY, which occurs in boys at roughly half that rate; 47XXX (triple X syndrome), which appears in girls at approximately one in 1,000 births (Otter et al., 2010); and 45 X (Turner syndrome), which occurs in approximately one in 2,500 girls (Stochholm et al., 2006). Most people with mixed chromosome

variations do not have atypical genital appearance. Some mixed chromosome variations are not identified at birth or even later in life (Bojesen et al., 2003).

Intersex variations associated with atypical genitalia are much rarer. The most common form (a form of congenital adrenal hyperplasia) is estimated to occur in as few as one in 16,000 births (Senate Community Affairs References Committee, 2013). Other conditions, such as polycystic ovary syndrome (PCOS), that may impact on primary and sometimes secondary sex characteristics, may or may not be understood as intersex variations. Without adequate Australian data, these less frequently identified variations are underrepresented in estimates and the people who have them may not access health-related services of potential benefit to them.

Intersex advocates commonly estimate that one to two per cent of the population has an intersex variation, arguing that other estimates are likely to be conservative given the lack of visibility, diagnosis and exclusion of some intersex variations (Jones, 2016a; Carpenter, 2013a; Intersex Human Rights Australia [IHRA], 2013). A number of these include minor variations of genital development (for example, mild degrees of hypospadias) that do not result in significant long-term interactions with health systems, in ongoing health needs or in the person considering themselves to have an intersex variation. For others, there may be two or more atypical chromosomal, hormonal or anatomical characteristics associated with their variation (Jones, 2016a).

2.3 Do intersex variations influence sex and gender?

Intersex variations, like a person's sex, are commonly understood as matters of biology or anatomy, whereas gender is generally understood as an identity and the social expression of differences between male and female bodies, whether naturally and biologically derived or socially determined.

In Australia, how 'sex' may be registered in official documents varies from state to state. The option to record sex as X, unspecified, indeterminate, non-binary or intersex is a very recent development and signals a growing recognition of non-binary variations in sex. Most people with intersex variations have a sex and gender identity that is either male or female.

In a recent Australian survey of people with intersex variations, most participants identified as female or male regardless of having one or more atypical sex characteristics. Australian data show that while most people with intersex variations are comfortable with either a female or male sex marker, nearly one fifth correct their assigned sex marker over time, most commonly those assigned male at birth (Jones, 2016a).

Having an intersex variation does not preclude an individual from expressing their gender in any number of ways, including ways that conform to or challenge a binary model.

Many people with intersex variations express their gender in ways that match the expectations of a binary model and report intense pressure from family, medical professionals and society to do so.

According to the Australian intersex study by Jones et al., 44 per cent of respondents (who were aged 16–87 at the time of survey completion) reported having received 'gender-behaviour' counselling or training from health professionals including doctors and psychologists, and 43 per cent from parents.

Some reported intense pressure to dress or act in more gender 'appropriate' ways. Those assigned male were encouraged to be physically stronger, attend a gym, style themselves in culturally-specific masculine ways including wearing pants, be less emotional, and be capable of sexually penetrating a partner in the context of a heteronormative marriage. Those assigned female were encouraged to be more submissive, style themselves in culturally-specific feminine ways including wearing dresses and skirts, engage in domestic duties, and be capable of being penetrated sexually in the context of a heteronormative marriage (Jones, 2016a).

Some people with intersex variations describe themselves as non-binary and express their gender in ways that are neither feminine nor masculine, or that combine elements of both. Eight per cent of participants in the Australian intersex study identified as transgender, which may have included people who identified their sex **and** gender as non-binary and others whose gender expression was at odds with the sex they were incorrectly medically assigned at birth.

For most people with intersex variations, their variation is not visible or noticeable to others in everyday, social interactions. People whose intersex variations are visible may experience problems associated with other people's (and sometimes their own) perceptions of these variations.

It is important that people with intersex variations and those who are involved in their treatment, care and support know that it is against Australian law to discriminate against someone on the basis of their gender identity or expression or intersex status in a number of areas of public life, including employment, education and the provision of goods and services. Health, education and other settings should ensure that people with intersex variations are not pressured to adopt a particular gender identity or role and are supported to express their gender as they see fit.

2.4 What terminology is appropriate?

There is considerable tension around the use and appropriateness of terminology to describe and refer to people with intersex variations.

A review of recent health-related resources reveals a strong division in the literature. Publications favouring a sociological or community narrative approach tend to apply the term 'intersex' to describe specific variations, whereas clinical and biomedical publications tend to refer to patients with disorders or differences of sex development (DSD). There remain occasional references to descriptions that many people find insulting, including 'hermaphroditism' or 'abnormal' vs. 'normal'.

While most stakeholders (but not all) no longer use terms regarded as stigmatising, like 'hermaphrodite', there remain strongly held views about other forms of language that continue to evolve.

Participants in the Australian intersex survey quoted throughout this paper were asked to choose their preferred terms for describing their own variations (Jones, 2016a). Overwhelmingly they preferred use of 'intersex' and related terms (intersex variation, intersex condition) compared to non-intersex related terms (diagnosis, my chromosomes, difference of sex development and disorder of sex development).

Many people identified feeling pressured to use terms they did not prefer in order to access health-related services, and many strongly opposed the use of DSD for its implication of pathology and something inherently in need of 'repair' (for example, Baratz et al., 2006; Briffa, 2009, 2014; Feder, 2008; Reis, 2007).

Clinicians first proposed use of DSD in 2005 and later 'conditions affecting reproductive development' (CARD) primarily for use in clinical and research settings. Clinicians report that DSD and CARD underpin a detailed classification system important for the development of internationally consistent diagnostic and treatment standards of care and research and are not intended to be used interchangeably with other terms. They report that it is more common to talk with individual patients in terms that reflect their specific variation rather using terms like intersex or DSD, although anecdotally practice is inconsistent.

In 2013, the Senate inquiry report recommended health professionals and health organisations should favour use of the term 'intersex' or 'differences of sexual developments' and confine the use of 'disorders of sex development' to appropriate clinical contexts (Senate Community Affairs References Committee, 2013).

Given many participants' preference to describe their own variations using terms related to intersex, this document uses and recommends the use of 'people with intersex variations' as a non-stigmatising option when discussing this group.

The term allows flexibility in how people define their relationship to sex and gender identities and the binary categories of 'female' and 'male'. Very few people use 'intersex' as a third or non-binary identity, with most identifying as exclusively female or male and describing themselves as **having** a particular intersex variation.

This document also supports the general use of terms like 'atypical' and 'variation' because, unlike 'ambiguous/ abnormal' and 'disorder', they do not imply that intersex variations are pathological and that people with such variations are in need of repair.

However, the paper also recognises that not all people with variations in sex characteristics identify with the term 'intersex' and that language is continuing to develop and evolve. In 2018 for example, the Australian Human Rights Commission will undertake consultations using the term 'people born with variations in sex characteristics'. Equally, not all people with variations in sex characteristics recognise their particular condition as belonging in any intersex-related 'umbrella group'.

Given this diversity in terminology and the individual preferences of people with intersex variations, it is important that health providers ask people how they would like to describe their variation, body and self. This helps people feel acknowledged and heard in any professional encounter and ensures that care is grounded in an individual's own understanding of their intersex variation.

3. Legal and policy contexts

Intersex people must be supported to be the drivers of social, political and legislative changes that concern them ... to end discrimination against intersex people and to ensure the right of bodily integrity, physical autonomy and self-determination. (Third International Intersex Forum, 2013)

- International human rights law provides a range of protections to people with intersex variations.
- Australia was the first nation to include intersex status as a protected attribute in national anti-discrimination legislation. Nonetheless, problematic interventions continue.
- Victoria was the first state to develop intersex policies in education and health and the state's Charter of Rights protects people with intersex variations against medical treatment without full, free and informed consent.
- There is an increasing focus on developing specific intersex policies in health-related services, with preliminary policies having recently been developed in aged care, mental health and medical services.
- The current legal and policy context is primarily applied in Victoria through the *Decision-making principles for the care of infants, children and adolescents with intersex conditions* (the principles).

3.1 International context

In recent years consensus has emerged in international human rights and related fora about how international law should be applied to protect and promote the rights of people with intersex variations. The *International Covenant on Civil and Political Rights* (United Nations [UN] General Assembly, 1966a), the *International Covenant on Economic, Social and Cultural Rights* (UN General Assembly, 1966b), the *Convention against Torture* (UN General Assembly, 1984), the *Convention on the Rights of the Child* (UN General Assembly, 1989), the *Convention on the Rights of Persons with Disabilities* (UN General Assembly, 2007) and other human rights treaties are relevant for understanding human rights protections for intersex people.

The United Nations is clear that intersex infants must not be subjected to enforced medical correction and that people with intersex variations must be given appropriate and non-discriminatory health-related services and education. In reports by multiple UN committees, people with intersex variations who have experienced so-called 'normalising' surgery or treatment have been recognised as 'victims of abuses and mistreatment'; medical treatments have been described as 'harmful practices', and it has been made unequivocally clear that no child should be subjected to medically unnecessary surgery or treatment during infancy or childhood.

In 2011, the United Nations Educational, Scientific and Cultural Organization (UNESCO) *Rio Statement* called for better treatment of young people with intersex variations in global education sectors (UNESCO, 2011) and in 2012 *Born Free and Equal* confirmed that the legal obligation of nations to safeguard the human rights of people with intersex variations was well established in international human rights law (United Nations, 2012).

In 2013, the UN Human Rights Council called upon all states to repeal laws allowing intrusive and irreversible treatments for children with intersex variations. The list of treatments included forced genital-normalising surgery and involuntary sterilisation without the free and informed consent of the person concerned (UNHRC, 2013).

On Intersex Awareness Day 2016, several UN committees and experts released a joint statement making informed consent a requirement for any cosmetic interventions for people with intersex variations (United Nations, 2016):

Intersex children and adults should be the only ones who decide whether they wish to modify the appearance of their own bodies – in the case of children, when they are old or mature enough to make an informed decision for themselves.

In 2017, the *Yogyakarta Principles plus 10* were released. A revised and updated version of an earlier document, The *Yogyakarta Principles plus 10* are informed by international human rights and represent an international best practice standard, particularly relating to legal protections on the basis of sex characteristics (Yogyakarta Principles, 2017).

The European Commission has followed the UN's lead and made numerous statements in support of the human right to non-discrimination for people with intersex variations (Council of Europe, 2015; European Commission, 2011).

The Council of Europe recommended that member states undertake further research, ensure no one is subjected to unnecessary medical or surgical treatment that is cosmetic rather than vital for health during infancy or childhood, and guarantee bodily integrity, autonomy and self-determination (Council of Europe, 2013).

Notwithstanding these statements, legislation, policy and practice varies widely across Europe (European Union Agency for Fundamental Rights, 2015), with 20 European states reported in late 2016 as reviewing their laws and policies in relation to gender identity and sex characteristics (European Commission, 2016).

In 2015, Malta became the first EU member state to pass national legislation banning discrimination on the grounds of 'sex characteristics'. The *Gender Identity, Gender Expression and Sex Characteristics Act 2015* provides a range of other protections to people with intersex variations, including a prohibition on deferrable treatments and surgery on children until they can provide informed consent (European Union Agency for Fundamental Rights, 2015).

The legality of genital surgeries completed on infants without their informed consent is increasingly being tested, with damages having been awarded in several jurisdictions. In 2012, the Swiss National Advisory Commission on Biomedical Ethics recommended that:

on ethical and legal grounds, all (non-trivial) sex assignment treatment decisions which have irreversible consequences but can be deferred should not be taken until the person to be treated can decide for him/herself. This includes genital surgery and the removal of gonads unless there is an urgent medical indication for these interventions. (Swiss National Advisory Commission on Biomedical Ethics, 2012)

People with intersex variations and their support organisations have been key advocates for health, legislative and social reform in the international arena. In 2013, an international consensus statement called for people with intersex variations to be empowered to make decisions affecting their own bodily integrity, physical autonomy and self-determination. The statement called for an end to non-consensual 'normalising' genital surgeries or other treatments; use of preimplantation genetic diagnosis, prenatal screening and treatment and selective abortion; and sterilisations of people with intersex variations (Third International Intersex Forum, 2013).

The statement called on health-related service stakeholders to:

- de-pathologise intersex variations in medical guidelines
- register intersex children as females or males (understanding that they may later identify with a different sex or gender)
- ensure access to full information and medical records and history
- ensure adequate training for professionals and healthcare service providers
- recognise that medicalisation and stigmatisation result in trauma and mental health concerns
- provide autonomous, non-pathologising psychosocial and peer support.

3.2 National context

In Australia, existing legal frameworks regulate medical interventions for people who do not have the legal capacity to consent in particular contexts. In Australian common law, the 1992 High Court case of *Department of Health and Community Services [Northern Territory] v JMB and SMB* ('Marion's Case') has been an authoritative precedent examining the intersection between consent for treatment of children and requirements for court authorisation.

In Marion's Case, the High Court considered who could lawfully authorise the sterilisation of an intellectually disabled girl.

For the reasons set out by the High Court in Marion's Case, a person under 18 years of age can consent to medical treatment if they have sufficient intelligence and maturity to understand the nature and consequences of the particular medical treatment, which has been assessed using the Gillick competence test.

In the absence of an assessment of Gillick competence, parents may consent to **therapeutic** treatments but must seek Family Court authorisation for **non-therapeutic** treatments that are invasive, irreversible and considered 'major'; are not for the purpose of curing malfunction or disease; where there is significant risk of making the wrong decision; and the consequences of a wrong decision are particularly grave.

The **therapeutic/non-therapeutic** classification for determining the scope of parental authority in Marion's Case has drawn some criticism from commentators. Specifically, intersex and human rights advocates have suggested that in practice the criterion has failed to distinguish between interventions that are strictly clinically necessary and those that are not; between interventions based on culturally-specific social norms and gender stereotypes and those that are not.

Human rights lawyers have focused their critique on the Family Court's application of the test in cases involving intersex children. They have highlighted deficiencies in the way these matters are brought before the court – especially the presentation of arguments **against** the proposed treatment or applications seeking appeal to a higher court.

These limitations were particularly evident in the 2016 case of *Re Carla (2016) 54 Fam LR 576* ('Carla's Case'), which attracted widespread criticism and caused alarm within the intersex community for its misapplication of the Marion principles. In Carla's Case, the court held that the proposed medical treatment (a gonadectomy) was therapeutic and necessary to avoid adverse psychological consequences, whereas critics argued the decision was based on superficial gender stereotyping and failed to clearly consider the available medical literature, less intrusive alternatives or the consequences of rendering Carla infertile (Overington, 2016).

Only a small number of cases have been brought before the Family Court for authorisation and it remains unclear from publicly available data how many surgical and medical interventions are carried out on children with intersex variations. However, media reports, intersex advocates and informal discussion with clinicians and parents suggest that people with intersex variations continue to undergo cosmetic

treatments to change their appearance where informed consent was not given or possible due to their age or lack of consultation and information (Carpenter, 2013a).

In 2013, Australia became the first country to protect people with intersex variations from unlawful discrimination (Australian Parliament, 2013), and in the same year undertook an inquiry into the involuntary or coerced sterilisation of intersex people (Senate Community Affairs References Committee, 2013).

The Senate inquiry report was based on extensive consultations with people with intersex variations and health service practitioners. It too noted the distinction between therapeutic and non-therapeutic treatment criterion is poorly defined and recommended that:

... all medical treatment of intersex people take place under guidelines that ensure treatment is managed by multidisciplinary teams within a human rights framework. The guidelines should favour the deferral of normalising treatment until the person can give fully informed consent and seek to minimise surgical intervention on infants undertaken for primarily psychosocial reasons (p.xiii).

The report also recommended that the Commonwealth fund multidisciplinary teams to ensure 'intersex medical care has dedicated coordination, record keeping and research, and comprehensive membership from medical and non-medical specialism' (p xiii). To date, such funding has not been forthcoming.

The report made a series of further recommendations to improve decision making oversight and transparency for people with intersex variations who are unable to make informed decisions regarding their own treatment (pp. xiii-xv):

- All proposed intersex medical interventions for children and adults without the capacity to consent require authorisation from a civil and administrative tribunal or the Family Court.
- Civil and administrative tribunals in all states and territories have concurrent jurisdiction with the Family Court to determine authorisation for intersex medical childhood interventions.
- Complex intersex medical interventions be referred to the special medical procedures advisory committee for consideration and reported to whichever body is considering the case.
- The provision of information about intersex support groups to both parents/families and the patient be a mandatory part of the health care management of intersex cases.
- Intersex support groups be core funded to provide support and information to patients, parents, families and health professionals in all intersex cases.
- The Commonwealth Government support the establishment of an intersex patient registry to track and evaluate interventions and directly fund research that includes a long-term prospective study of clinical outcomes.
- The administration of dexamethasone for prenatal treatment of congenital adrenal hyperplasia (CAH) ceases, only taking place as part of research projects that have ethics approval and patient follow-up protocols.

Many of the report's recommendations have not been accepted, endorsed or implemented, and evidence suggests people with intersex variations in Australia continue to be subjected to cosmetic and other treatments without informed consent and access to appropriate information and support (Kennedy, 2016; Overington, 2016).

In 2017 and 2018, several UN committees expressed concern about children with intersex variations in Australia being subjected to treatment without full, free and informed consent. They called on Australia to provide relevant statistics and remedies for those who had undergone such treatments and to take steps

to implement the Senate inquiry recommendations (UN Human Rights Committee, 2017; UN Committee on Economic, Social and Cultural Rights, 2017; UN Committee Against Torture, 2017).

A number of these issues were canvassed in the 2017 Darlingtong Statement, an Australian and New Zealand companion to the 2013 international consensus statement. The Darlingtong Statement calls for, among other things, improved oversight of medical interventions, development of rights-based standards of care, improved access to peer support and information for people with intersex variations and their families, and improved data and research (Androgen Insensitivity Syndrome Support Group Australia [AISSGA] et al., 2017).

In Australia, a number of non-health related national policies also have the potential to affect the health and wellbeing of people with intersex variations.

Sex determination tests have been applied in a growing number of legal contexts including, for example, marriage and sport. Conversely, there has been a push at the national level for simpler amendments to sex and gender identity markers on identity documents.

In 2011 for example, provision was made for three sex marker options for passports – F, M or X – and in 2013 broader guidelines simplified processes for consistency across identity documentation to include male, female and indeterminate/intersex/unspecified sex marker options (Australian Government, 2013).

Many intersex advocates do not support the creation of a separate intersex option and have noted that attempts to classify intersex people as a third sex/gender do not respect their diversity and self-determination. These advocates have instead argued for the elimination of legal sex and gender classification systems (AISSGA, 2017). They also argue that if legal classification is to be retained, gender descriptors other than male or female (for example non-binary or male and female) should be made available but that these gender descriptors should not be assigned to children.

Since the development of the Australian guidelines, state governments in South Australia and the ACT have also legislated to introduce non-binary categories of legal sex/gender for birth certificates.

While there have been improvements in Australian legislative and policy provisions for people with intersex and other types of bodily variations, including the 2014 High Court decision in the case of *Norrie* that sex can be non-binary (High Court, 2014), advocates have argued that more can be done to align laws and policies with international human rights standards.

3.3 State context

Since 2000, Victorian anti-discrimination legislation has prohibited discrimination on the basis of sex and gender identity in areas of public life including employment, education and the provision of goods and services. While there are some criticisms of the current legislation's lack of a specific protected attribute of intersex status or sex characteristics, the current Act does contain protections that could cover circumstances where people face unfair treatment because of their intersex variation. For example, protections against discrimination on the basis of 'gender identity', 'physical features' or 'sex' could be relevant.

In 2006, Victoria became the first Australian state to enact human rights legislation providing protection from medical or scientific experimentation or treatment without full, free and informed consent (s. 10(c)). The *Charter of Human Rights and Responsibilities Act 2006* also protects rights to freedom from discrimination and equality before the law (s. 8 (2) and (3)); the right to life (s. 9); to privacy and reputation (s. 13); and protection of families and children (s. 17). Finally, the charter creates obligations on public authorities to act compatibly with human rights and to give proper consideration to human rights when making decisions (s. 38) (Victorian Parliament, 2006).

In 2007, Victoria created the first non-discrimination guidelines for people with intersex variations in education (Victorian Department of Education and Early Childhood Development, 2007). VicRoads has also adopted the national guidelines for sex marker options when issuing Victorian driver's licences.

In February 2013, the Victorian Department of Health published *Decision-making principles for the care of infants, children and adolescents with intersex conditions* ('the principles') (Victorian Department of Health, 2013). Another Australian first, the principles are supported by Victorian clinicians and by some members of the intersex community but have also been criticised for allowing 'non-therapeutic' reasons to guide decisions about whether genital surgery may be appropriate.

Similar to the discussion in the earlier section, a lack of publicly available data about the treatment and care of people with intersex variations makes it difficult to assess the practical application and effect of both the Charter of Human Rights and Responsibilities and of the principles. This lack of implementation evidence and data on current Victorian practices and inconsistencies in publications between the department and clinicians has also been criticised (Carpenter, 2016a & b).

Supported by repeated and ongoing consultations with a wide range of stakeholders, including people with intersex variations and their advocates, health-related service providers and researchers in the field, the Victorian Government has committed to continue to support the rights of people with intersex variations by ensuring its approach is reviewed against emerging best practice and evidence-based guidelines.

This commitment is reflected in the emerging model of care and *Revised principles* that are being updated to better reflect international, national and state legislation, inquiry recommendations and community consensus statements.

3.4 Health-related service/institutional contexts

A range of other national and state policies and procedures, strategies and position statements are relevant to quality of treatment, care and support provided to people with intersex variations. These include, for example, in maternal and child health services, aged care, mental health and generalist medical care settings.

In 2008, the *Australian Charter of Healthcare Rights* was adopted by state and federal health ministers. The charter describes the rights of patients, consumers and other people using the Australian healthcare system including in relation to access, safety, respect, communication, participation and privacy (Australian Commission on Safety and Quality in Health Care [ACSQHC], 2008).

In 2016, the Victorian Government developed the *Rainbow eQuality guide* to help mainstream health and community service agencies identify and adopt inclusive practices and become more responsive to the health and wellbeing needs of lesbian, gay, bisexual, trans, gender diverse and intersex (LGBTI) individuals and communities. The guide recognises that inclusive practice is an essential part of the delivery of health and human services, not an add-on or afterthought (Victorian Department of Health and Human Services, 2016)

The *National lesbian, gay, bisexual, transgender and intersex (LGBTI) ageing and aged care strategy* (Department of Health and Ageing, 2012) privileges the use of affirming terms preferred by people with intersex variations and promotes more education for staff.

The National LGBTI Health Alliance's framework for promoting the mental health of LGBTI people highlights the need for representative data on intersex people and for services and professionals to address trauma associated with 'medical examinations, treatment, and, for some, recurrent surgical interventions' (Leonard & Metcalf, 2014).

In 2014, the Victorian Equal Opportunity and Human Rights Commission (VEOHRC) published guidelines for GPs noting that people with intersex variations may experience discrimination when accessing health services (VEOHRC, 2014), including:

- failure by clinicians to fully disclose diagnosis details or doing so in a disrespectful manner or ways that prejudice treatment paths

- failure to fully inform about treatment options, risks and outcomes, including options to delay or avoid interventions
- suggesting that they must identify as a specific gender or must have genital surgery, hormone or other treatment
- focusing on the sex of the patient, including binary definitions of sex, on intake and patient record forms (for example, tick-boxes that only offer two options: 'male' or 'female').

In recent years a range of professional bodies have released policies and position statements that acknowledge health care access and treatment issues for people with intersex variations, and the need for improved care and treatment options (for example, Australian Medical Association [AMA], 2014; Australian Medical Students Association [AMSA], 2016; Public Health Association of Australia [PHAA], 2015; Royal Australian and New Zealand College of Psychiatrists [RANZCP], 2016).

In 2016, the National LGBTI Health Alliance released a national LGBTI mental health and suicide prevention strategy that made numerous recommendations in relation to data collection, research and person-centred approaches to the care and treatment of people with intersex variations (Jacobs & Morris, 2016).

In a Victorian context, there are a range of current government policies and strategies relevant to the care and treatment of people with intersex variations. The most critical of these is the implementation of the *Medical Treatment Planning and Decisions Act 2016* (the MTPD Act) which came into effect in March 2018. The MTPD Act provides a single framework for making decisions about medical treatment when people do not have the capacity to make their own decisions. It focuses on respecting people as individuals and enacting their treatment preferences and values, rather than allowing others to impose their values or understanding of what is best for someone else. It is part of a broader shift towards empowering and supporting people to make their own treatment decisions.

Other examples include:

- **Health 2040, Advancing health, access and care:** Recognising some groups and communities suffer a much higher risk of preventable disease, Health 2040 commits government to measuring and reporting on health disparities, ensuring gaps drive investment, and focusing efforts on designing and testing approaches in partnership to ensure health information and prevention services are easy to understand, relevant and culturally appropriate (Victorian Department of Health and Human Services, 2016).
- **Victoria's 10-year mental health plan:** Recognises that background or identity can contribute to poorer health outcomes for different populations, including people with intersex variations, the plan commits government to working with LGBTI leaders and communities, community-controlled services and other experts to continue and expand proven strategies that build resilience, address discrimination and minimise the factors that threaten good mental health (Victorian Department of Health and Human Services, 2015).
- **Partnering in healthcare framework:** In development, the framework supports health service quality in areas related to person and family centred services, care and outcomes; participation and shared decision making; equity, diversity, inclusion and responsiveness; and health literacy, information and communication (Department of Health and Human Services, 2017).
- **Targeting zero: supporting the Victorian hospital system to eliminate avoidable harm and strengthen quality of care:** Makes a number of recommendations to support improved hospital clinical governance, safety and quality improvement, decision-making transparency and accountability, and focus on patient needs (Duckett et al., 2016).

4. Health and wellbeing

... [I]ntersex infants, children and adolescents are subjected to medically unnecessary surgeries, hormonal treatments and other procedures in an attempt to forcibly change their appearance to be in line with societal expectations about female and male bodies. When, as is frequently the case, these procedures are performed without the full, free and informed consent of the person concerned, they amount to violations of fundamental human rights ... (United Nations, 2016)

- Most people with intersex variations are physically healthy.
- People may experience physical, mental, sexual and reproductive health and wellbeing issues related to their particular intersex variation.
- Some people with intersex variations report health and wellbeing issues resulting from the treatments they have received throughout their lifetimes.
- Health practitioners need to understand the range of health issues affecting people with intersex variations and how these issues differ according to an individual's particular variations.
- It is important to adopt a non-pathologising approach to the treatment and care of people with intersex variations regardless of an individual's particular variations and health needs.

4.1 Physical health and wellbeing

Most people with intersex variations are physically healthy. Nearly 80 per cent of participants in the recent Australian intersex survey considered themselves 'moderately' to 'extremely' healthy. Of those who didn't, negative health experiences were only sometimes linked to features or treatment of their variations (Jones, 2016a).

While most people with intersex variations report experiencing good health, some physical health issues or disabilities are associated with specific intersex variations. A number of people with intersex variations also report physical and mental health and wellbeing issues specifically arising from the treatments they have received throughout their lifetimes, and particularly in infancy and childhood. These issues are explored in more detail in [Chapter 5](#).

Reported physical health issues may relate to bone density, weight, heart and joint problems, fertility, and risk of certain cancers. There is also an increased risk in association with some intersex variations for kidney and liver dysfunction, autoimmune conditions such as hypothyroidism/under-active thyroid, and hearing problems. See [Appendix 2](#) for a summary of potential health issues for the most commonly diagnosed intersex variations.

Optimal health care for people with intersex variations should take into account the educational needs of health professionals and the significant differences in physical health risks, functional capabilities and experiences that may be associated with each intersex variation (Tyler, 2004).

Sixty-four per cent of respondents in the Australian intersex study by Jones et al. reported learning about their variation when they were under 18 years of age from a doctor, parent or guardian, and frequently in the context of a medical appointment. Many participants commented on the secrecy around intersex variations within their families, and a desire to know more about their family history. It is important to note that this study included adults within a broad age range (18 to 87) and so should not be interpreted as indicative of current practices. Open disclosure and sharing of health-related information (in age appropriate language) to children with intersex variations was introduced in the 1990s and is standard practice at the Royal Children's Hospital (RCH) Melbourne.

A failure to identify some intersex variations in some people can result in them not getting the physical or mental health support they need. It is unclear whether non-diagnosis arises as a consequence of lower needs associated with particular intersex variations or poor awareness and identification by health professionals.

4.2 Mental health and wellbeing

In the recent Australian intersex survey quoted throughout this paper, most respondents (60 per cent) rated their mental health as 'good' to 'excellent' (Jones, 2016a). The most commonly reported mental health diagnoses included depression, anxiety and post-traumatic stress disorder (PTSD).

However, 42 per cent of participants had thought about, and 26 per cent had engaged in, self-harm because of issues related to having an intersex variation. Sixty per cent had thought about suicide and 19 per cent had attempted suicide (compared with less than three per cent of the broader Australian population).

Research suggests there may be substantial differences in quality of life and wellbeing depending on an individual's sex and their particular intersex variations. Mental health and wellbeing can be affected by clinical conditions specific to a person's intersex variations, as well as by medical interventions and other non-clinical factors (Kasiannan, 2012).

Clinical factors specific to certain intersex variations might include, for example, issues related to physical and sexual functioning and fertility; behavioural, learning and literacy difficulties; and higher rates of bipolar disorder, schizophrenia and attention deficit hyperactivity disorder (ADHD).

For some of these people (for example, people with Turner syndrome, XXY/Klinefelter syndrome and other X and Y sex chromosome variations), psychiatric and other medical interventions affirming early intervention and support may be required throughout a person's life as part of their management of cognitive and executive functioning issues and challenges.

Australian research participants identified non-clinical factors, including unnecessary medical interventions and other people's comments and attitudes, as drivers of their reduced mental health and wellbeing, often more than the intersex variation itself (Jones, 2016a).

Mental health and wellbeing issues stemming from other people's negative attitudes and experiences of direct and indirect discrimination may lead to poor self-esteem and body image; experiences of stigma and discrimination: family rejection and school bullying; feeling isolated; and loss of romantic relationships or tension in relationships including those linked to fertility.

Australian research participants reported significantly reduced mental health at the time of learning about their diagnosis. Negative impacts related to how the information was communicated and experiences when accessing mental health services (Jones, 2016a).

Some people with intersex variations report experiences of secrecy, shame and stigma related to their diagnosis, of not being informed of their diagnosis and its implications, or of being told fabricated stories about why they were being operated on (Diamond, 2004). In Australia, some clinicians have led open disclosure practice since the 1990s (Hutson & Warne, 2012).

Some people reported that the medical interventions they underwent had a negative impact on their wellbeing. Some identify a loss of autonomy and grief associated with traumatising or unwanted surgery, others of the emotional impact and sense of feeling 'unlike themselves' when commencing hormone therapies.

The dominant binary understanding of sex and gender can also be a driver of social stigma and alienation. Some research participants identified mental health stress associated with being unable to express or understand their own gender identity, feeling pressure to resolve personal questions of masculinity and femininity, or feeling pressure to confirm to expected binary sex and gender norms:

I feel abnormal because I had to be fixed, not for the truth about my body ... Being born without a vagina was not my problem. Having to get one was the real problem ... People don't fail to meet the definition of normal gender, but the confines of the definitions fail to meet the people (Morris, 2001).

Constructions of sex and gender can also be influenced by other cultural and religious influences. In some cultures, female infertility precludes marriage, creating a bias towards rearing an infertile child as male (Warne & Bhatia, 2006); in others, raising boys perceived as dysfunctional stigmatises the child and family (Kaggwa, 2015).

Adolescents may experience anxiety as they move toward adult gender roles and sexual maturity. This can be in relation to sexual adequacy, sexual orientation or gender identity; entering into intimate relationships; hormone treatments that induce bodily changes; and other medical interventions such as vaginal dilation (Simpson, 2013; Ogilvie et al., 2006; Kasiannan, 2012; Warne, 2012).

It is important that mental health support is offered to this group from the time they learn about their intersex variation and at other life transition periods (such as adolescence or adulthood). Information must be presented in an affirming manner.

The *Consensus statement on management of intersex disorders* recommends that to maximise health and wellbeing outcomes for people with intersex variations, psychosocial care should be provided by mental health staff with specialist intersex training and expertise (Lee et al., 2006).

These services are best placed as part of multidisciplinary teams that can deal with the range of medical, social, familial and legal issues that affect the mental health and wellbeing of people with intersex variations. Specifically, teams must address continuing good practice evidence gaps (Cohen-Kettenis, 2010) in which psychosocial support often remains peripheral to surgical management (Liao & Simmonds, 2013).

In addition to accessing quality professional mental health support, people with intersex variations report that engaging with peer support groups helps improve their overall wellbeing (Jones, 2016a). The importance of individually-tailored, expert assistance for parents has also been highlighted (Swiss National Advisory Commission on Biomedical Ethics, 2012) with counselling and peer support helping them meet their child's (and their own) needs.

Parents and carers may be particularly vulnerable when receiving news of an intersex diagnosis. The type of information they receive has been found to significantly affect their decision making, with medicalised information tending to promote surgical pathways (Streuli et al., 2013). In cases where surgical techniques change over time, parents and children do not always fully understand they are being asked to consent to de facto experimental treatments they may later come to regret (Liao & Simmonds, 2013; Liao et al., 2015).

Parents and carers need additional support to understand the wider social dimension of a diagnosis, including information to help them understand the lifelong experiences of people with intersex variations. Peer support is crucial but is currently under-resourced. Further, current resources are not always designed to reduce stigma and minimise any sense of isolation or shame. Broader education of the general public as to the existence of variations in sex development will be critical to ensuring more widespread understanding and acceptance of these variations as part of the normal spectrum of diversity.

4.3 Sexual and reproductive health and wellbeing

Participants in the national Australian intersex study reported hearing a number of widely held community myths regarding their sexualities and sexual expression (Jones, 2016a). These included conflicting beliefs that all people with intersex variations are gay or exclusively heterosexual; asexual or

hypersexual; and married or single. The study showed that having one or more intersex variation is not linked to an individual's adult sexual life, interests or orientation:

- 48 per cent of respondents identified as 'heterosexual' with the remainder describing their sexual identities in various ways
- 62 per cent of respondents were currently involved with one or more partners and the majority of respondents had never formally or legally married
- 65 per cent of respondents reported that their variation or related treatments had affected their sexual life, including their sexual desire and ability to engage in certain sexual acts
- while participants engaged in a wide range of sexual activities, penetrative sex was not as common as kissing, touching, digital and oral sex
- most participants found safe sex devices (condoms, dental dams etc.) adequate, but a few did not and 14 per cent had previously contracted one or more STIs
- just over half of respondents believed that people with intersex variations require specific sexual and reproductive health information (particularly young people) to avoid common misconceptions such as the belief that infertility was synonymous with immunity from STIs.

The available evidence finds no association between intersex variations and sexual experience, activity or interest, but it does suggest that sexual functioning is different among people with intersex variations compared with the population as a whole. Overall, people with intersex variations report higher levels of sexual dissatisfaction, with impaired sexual functioning associated with particular intersex variations and also with medical interventions.

The majority of participants in the Australian intersex study reported difficulties or barriers to their fertility (Jones et al., 2016). Forty-eight per cent of respondents could not reproduce without assistance due to their intersex variation, 17 per cent could reproduce only with difficulties, and 15 per cent could not reproduce due to treatments or surgeries associated with their variation. Some respondents did not see barriers to fertility as a major issue in their lives while others had a deep emotional response to these barriers.

Advances in medical technologies are increasing fertility and parenting options for people with intersex variations. Fertility counselling is a key support for people with intersex variations and their significant others who may be considering ways to increase their fertility. Clearly, these options only apply to individuals who have not been surgically sterilised.

It is important that health service professionals affirm, in a non-discriminatory manner, a broad range of sexual possibilities for people with intersex variations. This includes assisting individuals consider and, where possible, meet their specific sexual needs rather than working to predetermined and fixed assumptions about what those needs are and will be in the future.

5. Delivering quality treatment and care

I celebrate everything about my child, including his intersex variation. But it is complex and sometimes extremely hard as a parent: this has nothing to do with difference, diversity or the chromosome variation that makes him an exception to (social) precepts of binary sex. I grieve because of the co-morbidities which he already experiences or may experience. I spend hours with medical professionals planning the best possible support and early intervention plans. However at the end of the day, my partner and I have to be the advocates. There is no interdisciplinary care, except for what we self-manage. We must continually educate health professionals and fight against persistent ignorance and stigma in many environments. Victorian families currently experience the absence of consistent, functioning support and referral and this is crucial for the care of our children with intersex variations. We need change in how we care for our kids and transition them into adulthood as loved, valued and supported members of the Victorian community. (Anonymous consultation participant)

- Many Australians with intersex variations report receiving little or no information about their variation, treatment and options, including the option to not have treatment.
- Communicating openly, early and in affirming ways with people with intersex variations and their families, and providing opportunities to link with peer supports, can help promote acceptance and positive body image and reduce the risk of poor health and wellbeing.
- Evidence shows health professionals may need training to better understand diversity and difference and apply a human rights and critical patient-centred approach to the treatment and care of people with intersex variations.
- While there have been many improvements in the treatment and care of people with intersex variations in Victoria and elsewhere in recent years, there are many opportunities for improvement that are being explored and implemented.

5.1 The treatment experiences of people with intersex variations

A recent Australian intersex survey sought to understand participants' experiences of medical interventions. Sixty per cent reported having undergone medical interventions related to their intersex variation, with most having experienced at least two such interventions (Jones, 2016a).

The most common interventions across all age groups were hormonal treatments, followed by genital surgeries of varying kinds, including genital construction, gonad removal and movement of undescended testicles into the scrotum. More than half of the reported medical interventions occurred when participants were under 18 years of age, often during infancy.

The majority of participants listed at least one negative outcome from their treatments. The most common problems associated with surgeries were scarring from genital or chest surgeries, followed by a decrease or loss of sensation and sexual pleasure (including climax), and infections.

The most commonly reported problems associated with hormonal therapies were decreased bone density and osteoporosis; moodiness, aggression and depression; weight gain; fogginess; and de-contextualised sexual stimulation. It was anecdotally reported that a few people had experienced mobility issues, life-threatening blood clots, and homicidal and suicidal ideation.

Other therapies, such as mechanical dilation on sexually inactive young people, also caused problems, with a number who had undergone dilation procedures reporting they were painful, emotionally fraught, and nothing like the sexual acts they experienced later in life.

Some people reported being shamed by medical staff while others experienced extreme trauma and anxiety in medical settings associated with interventions they had not consented to. A few reported that they experienced surgical interventions as sexual abuse or that following the surgery they felt more susceptible to such abuse. Several people said that surgeries had divided them from their families and from the person they were 'supposed to be'.

Three-quarters of participants did not believe that children should 'have genitals that precisely match the sex they are reared as' and nearly 90 per cent disagreed that genitals that are not the 'normal' size should be surgically altered. More than 90 per cent of participants disagreed with doctors engaging in surgical interventions without knowing the long-term outcomes, while 92 per cent believed health providers should not undertake interventions that affected sex characteristics without a person's informed consent.

Nine per cent of participants reported only positive impacts from medical interventions. These included achieving hormonal balance; assistance in stimulating sexual feeling and development; physical or aesthetic changes to their sex traits that aligned with their sense of self; and a positive impact on how they were perceived socially.

Positive impacts tended to be associated with treatments required on health grounds that did not affect sex traits; being adult at the time of treatments that did affect sex traits; and treatments provided on request and with informed consent. A small number of participants commented on the positives of having no interventions. These included avoiding physical complications associated with certain procedures and the emotional impact they often had on family and being able to enjoy their bodies.

It is important to note that the above discussion focuses on people's experiences of interactions with the acute health system (for example, hospitals). For many people with intersex variations these interactions may be tied to diagnosis and early treatment, while for others they may not exist at all. For others, continuing engagement with acute health services may be tied to the long-term effects of earlier interventions, particularly those undertaken in infancy and early childhood.

Across the diversity of intersex variations and the range of health and wellbeing issues individuals will experience in their lifetimes, most interactions between people with intersex variations and the health system will be in primary care and community settings with GPs, mental health and disability providers, and other supports. Ensuring the delivery of respectful, accessible and responsive health services in these settings is essential.

5.2 Evolving perspectives on treatment and care

People with intersex variations may have bodies and ways of expressing their sex and gender that do not conform to the expectations of a two-sex model. They may be subject to pressure from family, friends, healthcare professionals and society to conform to the social and behavioural norms associated with one sex or the other. Conversely, some people with intersex variations may be pressured to challenge or transgress established sex and gender norms (Carpenter & Hough, 2014).

The former renders intersex variations invisible and reinforces the belief that there is something intrinsically wrong or disordered about intersex variations, which can lead to internalised shame and stigma for some people with intersex variations. The latter may foster resentment among those who do not want or reject cosmetic interventions toward those who have undergone (and provide) these procedures, seeing their decision as reinforcing the very beliefs and processes that lead to discrimination against people with intersex variations.

For those who believe that biological sex is binary or that conforming to a binary model is critical to individual health and wellbeing, intersex variations are seen as a problem that requires medical and social solutions.

Medical practice has been driven by a belief that conformity to a two-sex (heteronormative) model was crucial to the health and wellbeing of people with intersex variations. Sex marker assignment and normalisation surgeries minimised visible bodily differences and enabled people with intersex variations to present as either male or female (Senate Community Affairs References Committee, 2013).

From the 1950s, medical procedures were informed by the 'optimal gender policy' that aimed for the best combined prognosis for reproductive and sexual functioning; minimal medical procedures; an overall gender appropriate appearance; stable gender identity; and a reasonably happy life. This approach was supported by the widely-held belief that infants could, to a large degree, be successfully assigned any gender; a belief that remained current through to the 1990s.

During this period, early surgery was recommended to avoid discrepancy between a person's assigned gender and their genital appearance. In some cases, surgery was undertaken without parental consent or even knowledge. Non-disclosure reflected, in part, the professional ethos and paternalistic attitudes of the time, a belief that ordinary people would have difficulties understanding what intersex meant and be traumatised by the knowledge that their child or someone close to them had an intersex variation (Sandberg & Mazur, 2014; Senate Community Affairs References Committee, 2013; Warne, 2012).

Research on the optimal timing of surgery and other medical interventions in terms of longer-term physical and mental health outcomes is limited and has delivered mixed findings impacted by a broad range of factors, not least the nature of the variation itself.

For example, early surgical interventions to address issues of medical necessity in certain intersex variations have been found to deliver similar physical and mental health outcomes when compared with other cohorts requiring medical intervention and follow up over time – for example, people with diabetes and Hirschprung's disease (Warne et al., 2005).

On the other hand, there is little conclusive evidence that 'normalising' treatments intended to protect people against stigma and discrimination improve psychological wellbeing later in life (Preves, 2002; Hughes, 2005; Lee et al., 2016). Further holistic studies are essential to evaluate the effects of early verses later surgery (Hughes, 2005; Lee et al., 2016).

Even so, currently available data and practice wisdom does suggest an increased risk of negative health outcomes when people lack information, personal choice, autonomy and decision-making capacity. For younger people with intersex variations, these outcomes have been found to include reduced satisfaction and mental wellbeing and also social impacts such as early school dropout (Jones, 2016a).

As a consequence, there have been gradual changes in attitudes to 'normalising' surgeries and a decrease in support for surgical gender assignment in the absence of a demonstrable physical health need or benefit. However, significant differences in views remain. For example, the RCH, in its submission to the Senate Inquiry, favoured early surgery for infants with atypical genitalia:

It is our opinion that early surgery has psychological benefits for the child, as it allows them to grow up with more normally appearing genitalia, which reduces psychosocial and psychological stigma associated with DSD and also minimises parental anxiety (Royal Children's Hospital, 2013).

In contrast, Intersex Human Rights Australia (formerly Intersex International Australia), in its submission to the inquiry, argued strongly against the continuing use of infant surgery that is not medically necessary.

We believe that cosmetic genital surgeries, and the sterilisation of children who are assigned a sex that does not match to their gonads, must end ... Medical interventions based on psychosocial adjustment or genital appearance should no longer be considered 'therapeutic' (Carpenter, 2013b).

The concerns of intersex advocacy groups are consistent with the Senate report's findings that recommend minimising surgical interventions on infants for primarily psychosocial reasons, rather than on a consideration of medical need.

The Senate report also notes the importance of ensuring medical criteria are not used to mask treatment decisions based primarily on non-medical and sometimes contested beliefs. In particular, the report highlights the problematic use of probabilities of cancer risk, which rely on limited data and are not clinically proven, to justify decisions that may be based on non-medical criteria and personal belief, such as the desire to conduct normalising surgery. At the same time, an emphasis on the psychological benefits can mask data showing that for some people with intersex variations these surgeries result in long-term, negative physical health outcomes.

Among the approaches adopted to ensure a broader range of considerations are included in decision making about treatment, care and support of people with intersex variations is the adoption of multidisciplinary approaches. Increasing numbers of clinicians have sought to adopt a multidisciplinary approach to clinical practice that includes input from a wide range of professionals, people with intersex variations and their significant others (Pasterski et al., 2010; Hughes, 2005; Lee et al., 2016).

These changes have been supported by intersex advocacy groups, which have lobbied government, medical experts and others to ensure that people with intersex variations are included wherever possible in all aspects of decision making and that treatment, care and support options are built on an understanding of their lived experiences.

5.3 Respecting diversity, autonomy and voice

As discussed in Chapter 3, the United Nations and countries such as Malta have adopted a human rights based approach to the provision of treatment, care and support of people with intersex variations. Also adopted in Victoria, a human rights based approach is consistent with client-centred principles that:

- affirm and value intersex variations as a natural expression of human diversity
- prioritise informed consent of people with intersex variations or their legal guardians through their active participation in the planning and delivery of treatment and care.

Human rights and client-centred approaches do not prescribe particular treatment options and pathways. They do not pressure people with intersex variations or their legal guardians to make decisions based primarily on sex and gender norms or minimise the effects of stigma and discrimination. Rather, they aim to support informed decisions about what is best for people with intersex variations in the long term, supported by a multidisciplinary approach that involves people with intersex variations and their family, friends and significant others working in partnership with clinicians, psychologists, social workers and other healthcare professionals.

Client-focused approaches may safeguard against common experiences of dissatisfaction with treatment pathways and social supports; the negative impacts of lack of information and of early interventions conducted without consent; feelings of disconnection from healthcare processes; trauma and depression; infertility; decreased sexual function and pleasure; undesired sex-based presentations; and surgical

complications. Client-focused approaches rely on first person accounts of treatment, allow for analyses critical of dominant constructions of intersex as an identity and a diagnostic category, and give weight to individual and family experiences of treatment and care.

5.4. Supporting individuals and families

Access to information about diagnosis, treatment and support

Being well informed about one's intersex variation is associated with better wellbeing and is likely to improve satisfaction with treatment. Support at a family level is critical to help parents, guardians and other family members navigate concerns over social stigma and discrimination and ensure they can provide the most supportive environment for children to grow up in.

However, research indicates that health and other services do not always do these things well. The recent Australian intersex survey (Jones, 2016a), which collected data on participants' experiences over a wide historical range, reported that:

- 20 per cent of participants had been given no information about surgical or hormonal treatments they had received
- 46 per cent had received information on the ideal outcome of their treatments, 43 per cent on the processes involved, and 32 per cent on the risks/problems associated with their treatment
- 16 per cent were given information on the option of not having their treatments, 14 per cent on the option of alternative treatments, and 10 per cent on the option of deferring treatments until they were ready or willing to undergo them
- nine per cent were given information on the social history of their treatments (other people's good or bad experiences)
- seven per cent received information about a community-led support group, three per cent about a clinician-led support group, and two per cent about a parent-led support group
- nine per cent indicated their parents had been given adequate choices and information about their intersex variation when it was first diagnosed
- information received was often of poor quality or inappropriate and was often characterised as 'misinformation'.

Many participants talked about information overlooking details or choices in ways that hindered their informed consent, particularly for treatments experienced under 18 years of age. Many described being excluded from discussions between doctors and their parents/guardians about their bodies because the possibility of their input was not considered. Many participants described having to proactively gather information themselves by demanding it, conducting online research or leveraging medical connections.

Where participants had positive experiences of information provision about treatments, this tended to have occurred when they were adults. These participants greatly appreciated professionals providing a range of options, including the option not to proceed with treatments, discussing the different outcomes of different options, connecting them with other people with their variation or similar, and being able to ask questions and discuss example scenarios.

Inadequate information about variations has also been found to contribute to family and guardian uncertainty and distress. Parent dissatisfaction has been reported in relation to health communication, inadequate processes for informed decision making, and poor care coordination (Boyse et al., 2014), incorrect, misleading or worst-case information, outdated knowledge about treatment and management (Bourke et al., 2014); uncertainty about diagnosis, and a lack of accessible medical literature (Crissman et al., 2011).

People with intersex variations and their families need open, accessible, age- and ability-appropriate information, provided early and on an ongoing basis. This may include information about:

- the specific variation relevant to the individual or family
- potential features of the variation across the life course using affirming language, available statistics, and positive differences and associations not just 'worst case scenarios' from a medical perspective
- a broad range of treatment options, alternatives and processes
- ideal treatment outcomes (acknowledging that these may or may not reflect the ideals aimed for by the individual themselves)
- treatment risks and problems
- the option of no or deferred treatment
- the social history of various treatment paths where available (other people's good and bad experiences)
- referrals to clinician-, parent- and community-led support groups
- other types of information (such as the availability of online resources and research knowledge and gaps).

It is important that information is delivered in an affirming, supportive manner that promotes an individual's self-worth. Information should be provided by multidisciplinary teams suitably qualified to respond to all of the physical and psychosocial needs of the person and their families.

Parents, carers and people with intersex variations should be made aware that discrimination on the basis of their intersex variation is against Australian law.

Children may need regular explanations about things they encounter, such as why they need certain types of medication in childhood, hormone replacement at puberty, why they have surgical scars or why they have regular medical check-ups.

Over time, parents and children are likely to need repeated explanations with information adapted to each person's capacity to understand and their developmental stage (Cohen-Kettenis, 2010; Kasiannan, 2012). They need balanced information about physical and mental health implications to support informed decisions about medical interventions (Sandberg et al., 2012) that may influence highly sensitive spheres concerned with the core of the child's personality (Swiss National Advisory Commission on Biomedical Ethics, 2012).

Although the predictability of gender identity change is limited for some intersex variations (Cohen-Kettenis, 2010), families need to be informed and affirmed about the potential for changes in gender and sexuality identification or expression to avoid or minimise associated anxiety.

Anecdotally, consulting clinicians report that it can be challenging to fulfil the obligation of open disclosure when some individuals do not wish to receive information about their variations or options during appointments. In these and other circumstances, the ability to supply accessible written and referral information would support people with intersex variations to engage with information at their own pace, when they are personally ready.

An important additional consideration for some people with intersex variations and their families is that treatment experiences may also be inextricably linked with a requirement to engage with the Family Court or Victorian Civil and Administrative Tribunal (VCAT) to secure therapeutic treatment orders. In these circumstances it is important that the range of supports and information given to individuals and families recognises and responds to this additional level of complexity.

Access to peer support

Consistent with the growing recognition of the value of peer support networks, intersex support groups are increasingly advocating their role as an alternative or complementary source of advice to individuals and families.

Most participants in the recent Australian intersex survey had engaged with community organisations or social groups in relation to their intersex variation (73 per cent), with the majority (65 per cent) reporting it had improved their wellbeing because it:

- improved body image, self-esteem and self-worth
- challenged the isolating myth that people with intersex variations were 'one in a million'
- combated loneliness by creating a sense of belonging.

The study reflects other findings that peer support groups help people with intersex variations and their families reduce isolation and stigma by providing perspective; create an early feeling of normalcy; find the best quality care; and help in improving health services (Lee et al., 2006). The importance of peer support was also highlighted in an intersex report produced by the San Francisco Human Rights Commission (de Maria Arana, 2005).

The Australian intersex survey also highlights that information and referrals to social supports were only rarely used, and that the value of community knowledge and contact was not yet being widely affirmed by medical practitioners and institutions. The vast majority of survey participants who had found a support organisation had done so via the internet, through word of mouth or through family. Only a very small proportion were referred by a medical, psychological or counselling institution or another service (Jones, 2016a).

The recent Australian Senate inquiry recommended that provision of information about intersex support groups to families and patients be a mandatory part of the health management of intersex cases (Senate Community Affairs References Committee, 2013).

Australia and Victoria have a range of support sources for people with intersex variations and their families. A list of organisations is at Appendix 3.

Addressing complexities for families

Similar to the experience of people with intersex variations, many studies have shown that parents of children with intersex variations may also experience stress and reduced wellbeing. For parents these experiences may relate to unfamiliarity with intersex variations, perceived stigma, controversy surrounding clinical management, uncertainty regarding diagnosis, and concerns about their child's future physical, social and sexual development (Crissman et al., 2011). Parents may feel stress and pressure to ask for or consent to a range of social or medical interventions.

Parents and guardians are impacted by language and labels applied to their child. Evidence suggests that medicalised diagnoses and information may play a significant role in decision making and may lead to more medicalised interventions, including infant surgery (Streuli et al., 2013). Providing social supports alongside medical supports may help delay non-medically necessary decisions that impact sex traits or have irreversible outcomes until a time when the child can give informed consent.

Talking in ways that frame intersex variations as a natural part of human biological diversity from early in the diagnosis process may also be valuable in helping families work through their own immediate and longer-term needs.

Families may need support with a broad range of feelings on initial diagnosis, after diagnosis and over time. Feelings may include shock and concern; grief and loss; anger, sadness, depression and post-traumatic stress symptoms; shame, embarrassment and guilt; and feelings of isolation/disconnection and relationship difficulties. Parents and guardians may experience somatic symptoms, such as loss of appetite, insomnia and stomach upsets.

Some parents may experience difficulties understanding and accepting atypical sex traits, gender role behaviours and sexual diversity, and any discordance between their child's chromosomal sex and gender identity. Parents may experience stress and anxiety in relation to sex marker assignment.

Information and support to understand the potential symptoms associated with their child's intersex variation, including worst case scenarios that may never occur, may be needed. Parents may also need support to navigate complex health systems and clinical management recommendations and pathways.

Biological family members may wonder whether variations are hereditary or appear elsewhere within their family history, while non-biological guardians may seek to make such information available to their child.

Families may grapple with the ethics and value of genetic testing, which can add significant insight into intersex patterns within families but can also be used for more nefarious purposes. In the Australian intersex survey, 81 per cent of participants disagreed (or strongly disagreed) with the proposition that 'people should select against having intersex offspring through IVF and other selection techniques' (Jones, 2016a). Some parents may experience misplaced but long-lasting guilt around genetic hereditary traits where they exist; it may help to affirm that with the passing of genetic traits comes the gift of life itself.

Parents may experience stress about how to best balance openness about their child's intersex variation with privacy concerns. Parents will be motivated by a desire to protect their child from negative social attitudes, ridicule or stigma (Crissman et al., 2011) and while attempts to maintain privacy may be appreciated in many circumstances, trusted disclosures may also be of benefit. For example, maintaining strict privacy has been reported as very stressful and a contributor to unresolved parental feelings of guilt (Crissman et al., 2011), while family privacy has been regarded as a kind of secrecy, shame or silence by children with variations (Jones, 2016b). Appropriate disclosures may also be relevant for certain health professionals, school staff or people in the child's life to understand their specific needs if any.

Evidence suggests people with intersex variations largely want their families to be more open with them about their own variations and to respect their right to disclose them as needed (Jones, 2016a). Health services offering more explicit and extensive support to families about how and when to share information with family, friends and others could be beneficial.

Ultimately, it is important that human variety be affirmed to families as natural and in many cases healthy. Connecting families to support groups may enable destigmatising and ongoing support and alternate messaging beyond medical messaging.

5.5 Improving health systems and services

Understanding and respect for diversity and difference

The stories and statistics presented in this resource paper highlight the need for more respectful treatment and respect of diversity and difference in health and wellbeing service settings, and from society itself. The impact of past harms also needs to be openly acknowledged if these are to be remedied and treatment and care are to continue to be improved.

People with intersex variations do not have one set of characteristics or one set of needs but are as diverse in their requirements as other parts of the community. Difference is to be expected and catered to – one type of treatment path or set of ideal outcomes will not fit all people with a particular type of intersex variation, particular sex marker or gender identity, or particular set of physical characteristics.

Some people with intersex variations will also experience other forms of vulnerability related, for example, to being Aboriginal and Torres Strait Islander, of a culturally and linguistically diverse background, having a disability or being in foster, kinship or out-of-home care. For these people, the intersection between their experience of having an intersex variation and other life experiences may result in significantly amplified vulnerability, which must be considered.

It is important that professionals working in health and wellbeing settings are trained to expect and cater flexibly to the diversity present within the group – including diversity in variations, in expression of

specific variations, in abilities (including some disabilities or special needs), in sexual orientation and gender identity, and in cultural and family backgrounds and so on.

The aim is not to homogenise people's bodies or the treatment and care paths that are followed, but to apply a critical human rights and patient-centred approach that affirms a range of intersex variations as natural expressions of human biology and prioritises treatment and care paths determined by people with intersex variations themselves. Treatment and care must privilege the individual autonomy, needs and desires of people with intersex variations.

Training and education

Current evidence suggests that across the range of relevant health and wellbeing disciplines professionals are exposed to very little, if any, information and training in relation to intersex variations, needs and experiences in either undergraduate or postgraduate settings or as part of ordinary professional development.

As more research becomes available about the diversity of people with intersex variations in Australia and their individual experiences, it is essential that this work becomes part of training for health-related services and helps to inform their responses.

One available resource, developed by the Victorian Equal Opportunity and Human Rights Commission, provides guidelines for general practices for complying with the Equal Opportunity Act when providing services (VEOHRC, 2013). The guidelines recognise people with intersex variations may face particular types of discrimination in service delivery, including, for example, failure by clinicians to fully disclose diagnosis details or to do so in a respectful way without predetermining treatment; failure to fully inform patients of treatment options, risks and outcomes (including options to delay or avoid interventions); pressure towards specific gender identity / genital surgery / hormone or other treatment; and irrelevant insistence around patients' sex markers (for example, enforcing tick-boxes that only offer two options, 'male' or 'female', for adults who do not use either of those markers).

Research undertaken with primary healthcare providers in Western Australia found that a lack of understanding of intersex variations and experiences among staff was affecting service delivery for people with intersex variations (Somers et al., 2008). The disclosure of intersex variations was noted to be critical to the provision of appropriate treatment, but reliant on environments where people with intersex variations felt safe to disclose. The authors identified a need for greater awareness of the exclusionary effect of binary gender concepts and for education initiatives to improve awareness among health professionals.

The attitude of the diagnosing doctor and quality of interactions between doctor and patients with intersex variations has also been found to play an important role in influencing how people see themselves and their condition (Oakes et al., 2008).

In a Victorian context, health service and other providers might also consider accessing human rights training to support the development of rights-based practice, a culture of rights and compliance with Charter of Rights obligations on public authorities where they exist.

Multidisciplinary oversight underpinning standards of care

The important role of well-trained and resourced non-clinical, psychosocial supports for people with intersex variations and their families has also been highlighted (Hughes, 2005; Lee et al., 2016). Further investment is needed to establish dedicated resources. People with intersex variations have identified the need for:

- improved training for mental health practitioners and counsellors, including through undergraduate education and ongoing professional development

- appropriately skilled, multidisciplinary specialist teams within hospital, mental health and other health settings that support interprofessional equity
- support for and use of peer support groups and people with lived experience within and in addition to the multidisciplinary teams described above
- improved access to information and training resources tailored to the needs of the mental health workforce.

In Australia, intersex advocates and community organisations have argued for the establishment of multidisciplinary teams that include human rights specialists, child advocates and independent community representatives alongside clinicians and other health professionals (AISSGA, 2017). These teams should operate in line with transparent, human rights based, lifetime standards of care that are also recommended to be developed.

Also recommended are strategic efforts to foster respect for people with intersex variations in the broader community through widely available information in a range of accessible formats, including in educational settings.

Research, information management and data collection

This paper has identified a range of information, data and research gaps requiring further investment.

In the Darlington Statement developed in 2017, advocates noted limitations with current mechanisms to oversee medical interventions. They call for more transparent decision making through the establishment of standards of care, improved oversight mechanisms, full access to whole-of-life medical records and regular public disclosure of treatment data (AISSGA, 2017).

[Chapter 1](#) of this paper identified limitations associated with existing research and clinical studies. Further information is needed on the prevalence of intersex variations, evidence-based treatment and care, and the experiences of people with intersex variations and their families.

Firstly, more research is needed into issues with diagnosis, especially for intersex variations diagnosed later in life such as Klinefelter's syndrome and several others. This will ensure all people with intersex variations can share in the potential benefits of multidisciplinary health-related care and referrals to support groups.

Secondly, there is a need for more studies around associations between specific intersex variations and medical concerns, such as the association of Turner syndrome, bowel cancer and gonad malignancy. It is unclear to what extent some associations with cancer risks (such as for breast cancer in men with PAIS or certain gonadal cancers) have supported medical interventions for cosmetic reasons (such as mastectomies and gonadectomies). Clinicians have also called for larger methodologically-sound studies regarding the cancer risks for particular genetic diagnosis. Clarity on levels of association for people with different intersex variations could ensure their decision making is better informed.

Thirdly, there is a need for more studies on the outcomes for people with intersex variations who do not undergo interventions. This group is not represented strongly enough as a comparative group in clinical research, and their experiences may help inform decision-making processes for many stakeholders (individuals considering their own options, their families and clinicians).

Finally, most of the studies cited in this document were small scale and either cross-sectional or retrospective in design. It would be useful to prospectively gather more large-scale longitudinal data from a range of stakeholders' perspectives on issues around decision making, including influences, processes and outcomes. Calls for more research in this space are not new (Hughes, 2005). The predominant barriers to such work include the lack of a comprehensive database with clinically relevant information relating to Australian people with intersex variations, which would maximise inclusion of all available data in any study, reducing selection bias. Establishment of such a database is crucial if outcomes and natural history of different variations are to be more accurately described.

6. An evolving approach for Victoria

Despite changes in expert opinion about full disclosure of the nature of each patient's condition and recommendations to defer cosmetic surgical interventions, we do not know how much actual practice has changed over several decades. Moreover, discrepancies continue between the views of [those] who have these conditions and medical practitioners. Paediatrician (Frader, 2015)

- The Victorian Government is seeking to improve the delivery of client-centred health and wellbeing services to people with intersex variations and their families.
- This requires practices consistent with human rights principles that value intersex variations as a natural expression of human bodily and sexual diversity.
- This also needs diverse treatment and care approaches developed in partnership with people with intersex variations and their families and delivered by multidisciplinary teams.
- Improved care and outcomes for people with intersex variations requires development of a systems approach underpinned by a treatment and care typology, outcomes and standards of care framework, and a range of system enablers.

6.1 Putting principles into practice

The Victorian Government seeks to develop an approach to the treatment, care and support of people with intersex variations that reflects emerging evidence, policy and practice, and draws on a deepening understanding of the needs of people with intersex variations and their families.

Of particular interest is ensuring people with intersex variations receive high quality, lifelong treatment, care and support tailored to their needs. In the short to medium term, this means exploring options for more individual choice, autonomy and bodily integrity; increased community awareness and understanding; reduced discrimination and stigma; and greater consistency and oversight of treatment decisions.

Among the range of opportunities to deliver these outcomes is a focus on better access to information and support for individuals and families; greater access to peer support; enhanced gathering and reporting of diagnosis, treatment and outcome data; and continued development of clinical practice and standards of care.

In 2013, the Victorian Government released *Decision-making principles for the care of infants, children and adolescents with intersex conditions*. The principles were an Australian-first tool to assist Victorian hospitals to apply best practice decision making to the treatment, care and support of people born with intersex variations. The principles prioritise human rights and the informed consent of people with intersex variations or their legal guardians in all aspects of treatment, care and support, including whether to undergo treatment and what treatments are appropriate. According to the principles, irreversible medical treatments, including surgeries, should not be performed on people with intersex variations who are unable to give consent, unless the treatment is medically necessary at the time.

Decision making, including in relation to the allocation of sex markers at birth, considers a wide range of social, psychological and behavioural factors alongside clinical criteria. Decisions should be informed by multidisciplinary teams with an understanding that decisions to allocate a **'place-holder' sex marker** male/M or female/F may be provisional and may be corrected by an individual in the future through a simple administrative process.

While the principles have been endorsed by the Australasian Paediatric Endocrine Group (APEG) and accepted as the Australian guidelines by hospitals in Victoria and other states, their application in practice has been criticised by key intersex advocacy groups and other stakeholders due in part to the lack of transparent evidence of their adoption and consistent application.

In part, this criticism relates to a lack of clinical or directive protocols accompanying the principles and uncertainty around the degree to which clinical decisions have been subject to independent oversight. It also relates to differing interpretations of what constitutes medical need and what types of treatment are in the long-term interests of individuals.

Since the principles were developed, several policy and legislative shifts have also occurred at international, national and state levels, and further sociological and clinical research has been undertaken.

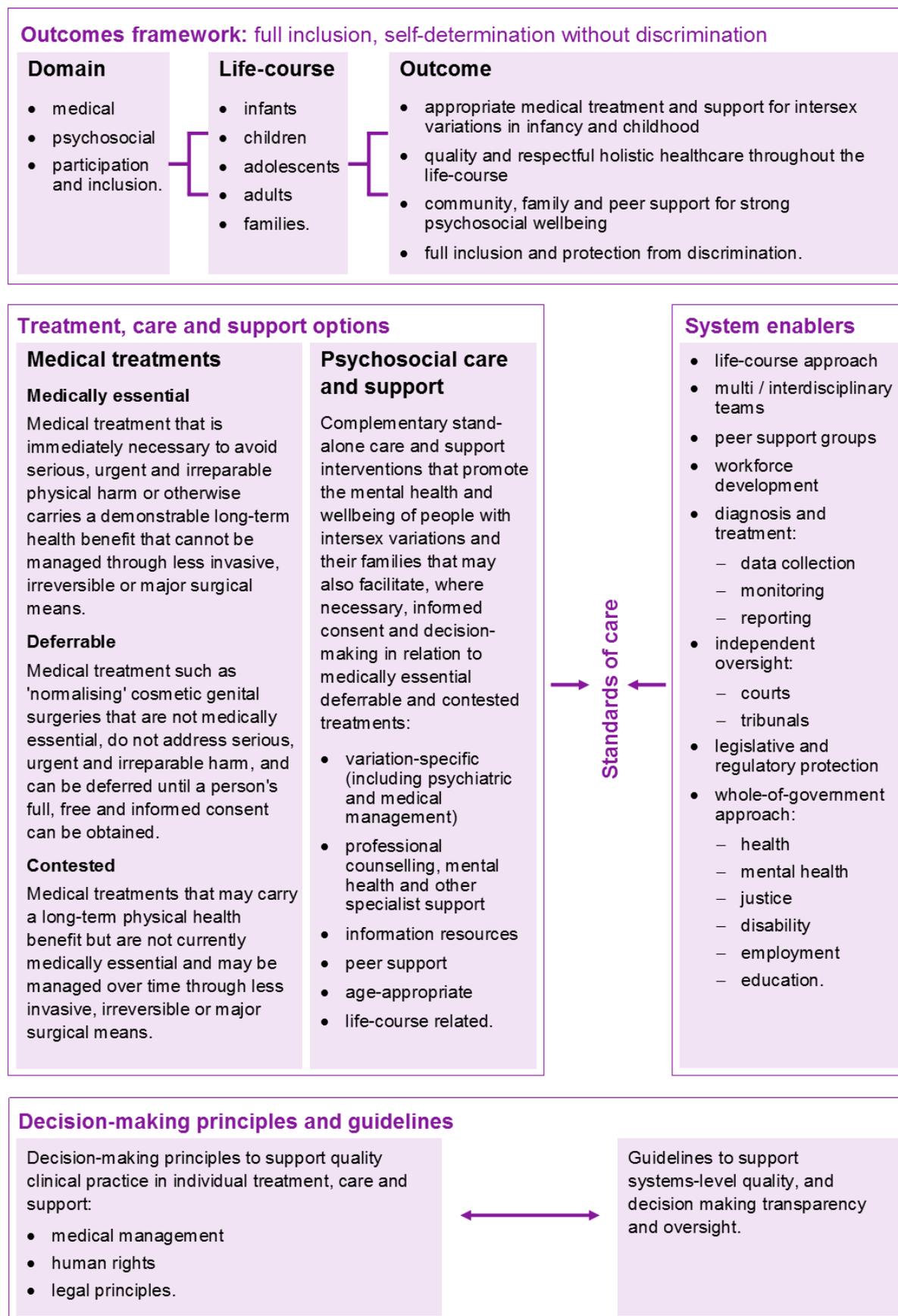
6.2 An emerging systems approach: future considerations

Recognising these recent developments, Victoria is updating its 2013 principles and will seek to document and explore options for other future directions, including the development of a potential new systems approach and model of care.

This potential new systems approach is presented below in Figure 1. It provides a frame against which key issues and perspectives may be mapped in order to support development of the updated principles and improved information for parents (part of the current suite of resources). It will also help to highlight key gaps and identify legislative, policy and program options within different parts of the overall system. Examples may include development of an outcomes framework (medical, psychosocial, participation and inclusion) across the life-course supported by clearly articulated standards of care, as well as other system enablers drawn from the 2013 Senate Inquiry, Malta Declaration, Darlington Statement and relevant aspects of the Victorian policy and legislative landscape (see [Chapter 3](#)).

Together these activities will ensure Victoria's approach continues to adapt and evolve over time, remains open to the lived experiences of people with intersex variations and their families, and reflects developments in clinical practice for different types of variations.

Figure 1: Systems approach to the treatment, care and support of people with intersex variations and their families



Appendices

Appendix 1: Basic glossary

(Jones et al., 2016, edited)

17-beta-hydroxysteroid dehydrogenase deficiency or 17 β -Hydroxysteroid dehydrogenase III deficiency: An autosomal difference including two carrier genes, one from each biological parent, which affects testosterone biosynthesis (by 17 β -HSD III) in people of any sex, such that sexual development is impacted. Individuals with these variations may be born with atypical external genitalia. An individual with this variation may also have impacts on their puberty or secondary sex characteristics.

47XXY/Klinefelter Syndrome (and more rare variations such as 48XXXY or 49XXXXY): This variation involves 'aneuploidy', an extra 'X' chromosome added to the more common two sex chromosomes, such that the individual has a karyotype 47 XXY (in rarer cases karyotypes have included 48XXXY or 49XXXXY). An individual with this variation may have testes with reduced size, increased firmness and no sperm production; impacts to their primary sex characteristics; puberty delays or absence); or atypical secondary sex characteristics. Some individuals may experience cognitive, developmental or health issues.

48XXXX/XXXX syndrome, Tetrasomy X, Quadruple X (and more rare variations such as 49XXXXX, XXXXX Syndrome, Pentasomy X): The presence of extra X chromosomes. Individuals with this variation experience impacts similar to those with Triple-X Syndrome/XXX, including increased height but also joint issues and other features that may be unnoticeable in the main or may require that the individual has care for their lifetime depending on severity. The individual may or may not experience puberty or cognitive difficulties. Perhaps 30 people have been found to have Pentasomy X. Individuals with this variation experience severe cognitive difficulties and are short with different facial features which may suggest misdiagnosis as Down syndrome. As with XXX and XXXX, heart issues, joint issues and so on may be present and more exaggerated.

5-alpha reductase deficiency or 5-ARD: An autosomal difference (on a chromosome other than the X or Y chromosomes) including two altered genes, one from each biological parent. It affects people with a Y chromosome only, impacting their androgen ratios (testosterone and DHT) and development in utero. An individual with 5-ARD has testes but they may have typically male, atypical or typically female external genitalia. The hormones of puberty may trigger the development of masculine traits (descending testes or enlarged clitoris, deepening voice, increased facial/body hair). Some individuals may produce sperm; none can carry pregnancies.

Amenorrhea: An impact of some variations; the absence of a menstrual cycle in those with a uterus.

Aphallia: Being born without external genitalia (generally a term applied to being without a penis), this variation impacts people with any type of genitals, who experience a halted development of the genital tubercle a few weeks after conception, such that their urethra opens on the perineum.

Bladder exstrophy or Ectopia vesicae: This variation or impact, involves some features similar to epispadias, and particularly the protrusion of the urinary bladder through the abdominal wall. Individuals with this variation may experience related impacts in the pelvic floor, rotation of the pelvis and/or in the presentation of their genitalia. Medical procedures to reconstruct the bladder can be completed (which can have known complications around loss of penile tissue) or staged across early years; sometimes these are teamed with other genital interventions and there can be complications.

Clitoromegaly or large clitoris: A clitoris that is larger than socially or medically 'expected' for the body part, whether it is slightly larger or larger to the point where it more strongly resembles a phallus.

Congenital Adrenal Hyperplasia or CAH: Various autosomal recessive differences resulting from particular expressions of genes for enzymes mediating production of cortisol by an individual's adrenal glands (steroidogenesis). This can involve greater or lesser production of sex steroids, altering the development of primary or secondary sex characteristics in people of various sexes/body types at different ages (milder versions may only impact fertility, stronger versions may produce impacts much earlier). CAH is most extreme (potentially fatal) when the individual has inadequate mineralocorticoids, involving vomiting leading to dehydration. An individual described as having excess androgens may experience no sperm production, atypical genitalia, an absent/delayed or advanced puberty, excessive facial hair, adolescent menstrual irregularity, and/or an enlarged clitoris and shallow vagina.

Complete Androgen Insensitivity Syndrome or CAIS: A complete inability of cells to respond typically to androgenic hormones, meaning that a person with XY chromosomes will develop along primarily female lines, including secondary sexual characteristics at puberty. People diagnosed with CAIS are almost invariably women and will experience typically female maturation except for the onset of menses, as the individual has internal testes rather than ovaries. People with this variation may have longer limbs/hands/feet, proportionally greater stature, larger teeth, minimal or no acne, dry eye syndromes, light sensitivity, and/or decreased bone mineral density.

Cryptorchidism: Usually understood to involve having one or more undescended testicle/s. One or both testicles are considered 'absent' from the scrotum, whether they are entirely absent, undeveloped, differently developed, or located elsewhere in the abdomen or thigh for example.

De la Chapelle or XX Male Syndrome: An unequal 'crossing over' between X and Y chromosomes during meiosis in the individual's father, which results in the individual's X chromosome containing the genetically-male SRY gene. An individual with this variation has an X chromosome with SRY from the sperm gamete which teams with the X from the egg during fertilisation, so that they present as typically male but are chromosomally XX. The individual may or may not have small testes, feminine characteristics, extra breast tissue, decreased facial hair or experience decreased libido.

Epispadias and Hypospadias: Variations involving formation of the genital tubercle and/or pelvic fusion in the first months in the womb, experienced by a range of individuals (male, female and genderqueer/non-binary). Impacts often include issues with the bladder neck and a shortened urethra. This can lead to an 'early' opening on the upper aspect of the individual's penis and/or potential difficulties in fertility for some; there can be more extreme variations where the external genitals are not attached strongly. It can alternately lead to 'early/forward' vaginal genitalia, an unfused clitoris and/or possible 'stress leaks' (urinating when one coughs or laughs).

Follicle-stimulating hormone insensitivity /FSH: An intersex variation where individuals do not respond to follicle-stimulating hormones (FSH), necessary for stimulation of typically female sex hormones. Impacts include hypogonadism, reduced or absent puberty (lack of development of secondary sexual characteristics), and/or infertility.

Fraser Syndrome, Meyer-Schwickerath's Syndrome, Fraser-François Syndrome or Ullrich-Feichtiger Syndrome: An intersex variation involving an autosomal recessive congenital condition and particular genes. An individual with this variation may have eyelids which do not separate in each eye and other impacts (in formation of the nose, fingers/toes, ears, larynx, renal system, or sometimes the mind), atypical genitals (e.g. micropenis or clitoromegaly) or urinary tract differences.

Gonadal dysgenesis (partial and complete): Intersex variations and impacts of the reproductive system which can impact people of any sex, involving progressive loss of germ cells on the developing gonads of an embryo. Individuals with these variations/impacts have gonads or ovaries mainly composed of fibrous, functionless tissue (sometimes called 'streak gonads') – they thus can experience arrested hormones, develop no secondary sex characteristics, infertility and an infantile typically female presentation. Associated with for example Turner syndrome/mosaicism; XX gonadal dysgenesis/pure

gonadal dysgenesis/46XX; Swyer syndrome/pure gonadal dysgenesis/46XY; Perrault syndrome, Mixed gonadal dysgenesis; and exposure to environmental endocrine disruptors.

Hypogonadism: Impacts of some intersex variations comprising of low levels of androgens/hormones. Individuals who are genetically female may not: menstruate, develop breasts, gain height, or have much libido or body hair. They may experience hot flashes if onset is late. Individuals who are genetically male may not: develop or retain muscles, gain height, retain erections easily or have much facial or body hair. They may develop breast tissue.

Jacobs or XYY Syndrome: An intersex variation involving an extra Y chromosome so that the individual's karyotype is 47XYY, stemming from an extra copy of the Y chromosome inherited via the sperm gamete. Individuals with this variation tend to be male and considered taller than average.

Kallmann Syndrome: An intersex variation affecting people of varying sexes; during the individual's embryonic development the neurons responsible for releasing gonadotropin-releasing hormone (GnRH neurons) do not migrate into the hypothalamus. Individuals with this variation either do not go through or complete puberty and have an absent or reduced sense of smell (taste).

Klinefelter Syndrome: See 47XXY.

Leydig Cell Hypoplasia: An intersex variation involving an autosomal recessive genetic and endocrine pattern. Individuals with this variation do not respond to luteinizing hormone (LH), necessary for the testes to produce testosterone and other androgen sex hormones. Impacts include reduced development of genitalia, hypogonadism, reduced or absent puberty (lack of development of secondary sexual characteristics), infertility, or issues with menstruation.

Micropenis: An intersex variation or impact usually understood to involve having a penis that is smaller than socially or medically 'expected' for the body part (the shaft is small with the urethra opening at the top, scrotum and perineum are present, testes may or may not be descended).

Mild Androgen Insensitivity Syndrome/MAIS: An intersex variation involving a milder androgen insensitivity than CAIS or PAIS, which impacts the genetically male individual such that they develop the typical external genitalia of a genetic male, despite being somewhat insensitive to androgens and having some secondary sexual characteristics develop less strongly at puberty for example.

Mosaicism or Chimerism involving 'sex' chromosomes: An intersex variation or impact involving different (not matching) karyotypes of sex chromosomes in some of an individual's cells, such that they carry two differing types of sex chromosomes. This can impact people of varying sexes, and stems from having a different pattern of cell division during early development. An individual with this variation may for example carry XX and XY cells, or other variations (X and XX, XY and XXY, XO and XY etc.). Mosaicism can occur in some forms of Turner or Klinefelter Syndromes.

Mayer-Rokitansky-Küster-Hauser Syndrome, MRKH, vaginal agenesis, congenital absence of vagina, Mullerian agenesis or Mullerian (Duct) aplasia: An intersex variation or impact which is characterised by the congenital absence of the upper two-thirds of the vagina and an absent or rudimentary uterus in females who have typical development of secondary sexual characteristics and a 46XX karyotype. It results from agenesis or hypoplasia of the mullerian ducts. Other organs can also be impacted including, kidneys, skeletal, and heart.

Ovo-testes (formerly 'true hermaphroditism'): An intersex variation or impact which involves having one or both of one's gonads combining testicular and ovarian aspects/tissues, experienced by people of any genetic sex. It is sometimes associated with gonadal dysgenesis, mosaicism, 47XXY, 46XX/46XY, or 46XX/47XXY. Individuals with this variation may present as mainly male, female, or otherwise. This variation was once mistakenly termed 'true hermaphroditism' because ovo-testes are a common feature of some hermaphroditic animals (e.g. slugs) but human ovo-testes do not fully function in both reproductive roles like actual (plant or animal) hermaphrodites.

Partial Androgen Insensitivity Syndrome (PAIS): An intersex variation involving a partial inability of cells to respond typically to androgenic hormones, meaning a person with XY chromosomes may develop external genitalia along a spectrum that is primarily female to atypical in appearance. Atypical presentation can include an enlarged clitoris, labial fusion or hypospadias. PAIS may also impact secondary sexual characteristics at puberty. Many people with PAIS are raised as girls, some are raised as boys.

Persistent Mullerian Duct Syndrome (PMDS): An intersex variation involving an autosomal recessive pattern and/or deficiency of anti-Müllerian hormone (AMH), in which a genetic male may be born with a uterus/uterine tissues and sometimes other Müllerian duct derivatives. Individuals with this variation tend to have male genitalia and may also have undescended testes (cryptorchidism). The uterine tissue may be discovered due to the experience of a bulge or hernia for example.

Poly-cystic Ovary Syndrome (PCOS) and Hyperandrogenism: PCOS is constructed by some people with the syndrome as an intersex variation where it involves androgen excess. This likely genetic condition involves growth of cysts on the individual's ovaries which can increase the production of androgens and therefore impact hormones overall. This can lead to irregular periods or stop ovulation/prevent fertility entirely, promote acne, lead to thinning hair on the scalp, and/or increase facial and body hair growth and other features.

Progestin Induced Virilisation: An intersex variation related to prenatal exposure to artificial/drug-related androgens (often progestin, a drug historically used to prevent miscarriage). There may be impacts to the individual's primary or secondary sex characteristics.

Streak Gonads: Impacts of some intersex variations can include gonads (testes or ovaries) mainly composed of fibrous, functionless tissue. These gonads do not produce or stimulate hormones such that individuals with streak gonads do not experience a puberty without aid, develop no secondary sex characteristics, and are infertile.

Swyer Syndrome or XY gonadal dysgenesis: An intersex variation involving the absence of functional gonads/sex glands, affecting genetic males (karyotype 46XY). Individuals with this variation present as females and have gonads termed 'gonadal streaks', fairly undeveloped tissue replacing the testes or ovaries. Individuals will not develop secondary sex characteristics generally due to the lack of gonadal/hormonal production.

Turner Syndrome, Ullrich-Turner Syndrome, Gonadal Dysgenesis, 45X0 or 45X: Intersex variations involving the absence/ difference of all or part of an X chromosome in genetic females (such that they have a karyotype 45XX sometimes called 45XO or 45X; meaning individuals have 45 rather than 46 full chromosomes with only one functioning X chromosome). Sometimes the chromosome is missing in all cells and sometimes only in some (with mosaicism/Turner mosaicism). Individuals with the variation generally do not have functional ovaries or menstruation and may experience infertility. They may be short, broad-chested, or have a low hairline and low-set ears, or have a webbed neck or experience swelling of hands and feet. Related health concerns may include heart and kidney issues, hypothyroidism, diabetes, obesity, vision or hearing concerns, and/or autoimmune diseases. Some individuals experience difficulties with memory, spatial or mathematical skills.

Triple-X Syndrome, XXX, triple-X, trisomy X, XXX syndrome, 47XXX aneuploidy: An intersex variation involving the presence of an extra X chromosome in all cells of a genetic female (or in some cells in the mosaic type). Individuals may inherit the extra X from either parent, and generally have the karyotype 47XXX, rather than 46XX. An individual with this variation can be affected to different extents depending on the ratio of XXX to XX cells, but usually has no noticeable visible impacts to their appearance. Since X chromosomes operate such that only one is largely dominant at a given time, impacts are mild or unnoticeable and females are usually unaware of their chromosomal difference. Impacts possibly include increased height, small head, vertical skinfolds over the eyes' inner corners, speech and language learning difficulties (e.g. dyslexia), and weak muscle tone for example.

XY/XO Mosaics: An intersex variation involving XO chromosomes in some cells. An individual with this variation may have female presentation with an enlarged clitoris and internal 'streak gonads' or may for example have male presentation and be fully fertile.

XY-Turner Syndrome: An intersex variation involving chromosomal difference. Individuals with this variation may have a chromosomal mosaic in the form 46XY/45X or other types. An individual usually doesn't have all the associated traits of TS and may experience other intersex features.

Appendix 2: Potential health issues for selected intersex variations

Complex hypospadias

Complex hypospadias are among the most commonly diagnosed intersex variations. When a male child is born with complex hypospadias, the urethra instead of opening at the tip of the penis opens near the junction of the penis and scrotum or at the perineum. Common associated health issues include:

- stigma and body image problems
- up to 32 per cent have been found to have an absent or undescended testicle
- inguinal hernia in nine to 15 per cent of people
- urinary tract infections can be common due to enlargement of the prostatic utricle
- erectile dysfunction and ejaculatory disturbances
- other impacts of multiple surgeries.

(Source: Kraft et al., 2011)

Congenital adrenal hyperplasia (CAH)

Congenital adrenal hyperplasia (CAH) is less common than chromosomal intersex variations, but is the variation most commonly associated with atypical genitalia at birth. CAH results from a lack of the enzyme steroid 21-hydroxylase and results in an inability to produce adequate cortisol or aldosterone. CAH requires glucocorticoid and mineralocorticoid supplementation that aims to ensure optimal growth and development for children and to prevent long-term adverse health consequences in adults. However, optimal therapeutic regimens are difficult to achieve, and associated negative health outcomes are common and serious. Potential health issues that people with CAH may require support for:

- adrenal crisis that may be life threatening
- high risk of testicular adrenal rest tumours in men
- reduced fertility in men and women
- polycystic ovarian disease
- pain and discomfort during penetrative intercourse for women
- reduced quality of life has been identified in a number of studies
- greater risk of lower urinary tract symptoms such as stress and urge incontinence
- irregular menses
- effects of infant genital surgery
- obesity, hypertension and insulin resistance (related to glucocorticoid therapy)
- metabolic syndrome (related to glucocorticoid therapy)
- osteoporosis (related to glucocorticoid therapy).

(Source: Ventura et al., 2013; Marumudi et al., 2013; Finkielstain et al., 2012; Arit et al., 2010; Simpson, 2013; Speiser, 2012)

Androgen insensitivity syndrome (includes complete and partial androgen insensitivity syndromes)

Androgen insensitivity involves a complete or partial inability of a person with XY sex chromosomes (typical male pattern) to respond to androgens. Genitalia can be typically female in appearance or atypical with features that range from typical female to typical male. Testes are present in all cases. Psychological difficulties are commonly the greatest health issues facing people with AIS. Other potential health needs include:

- increased risk of testicular cancer after puberty (estimated at three per cent)
- increased risk of osteoporosis
- difficulties with penetrative intercourse
- infertility
- rejection or discontent with the gender assigned at birth (PAIS)
- effects of infant genital surgery (PAIS).

(Source: Warne, 2012; Diamond, 2004)

Mayer-Rokitansky-Küster-Hauser syndrome, MRKH syndrome (Vaginal agenesis)

Often MRKH is not diagnosed until puberty when help is sought regarding failed menses. Females with MRKH will have either an absent vagina or incomplete vaginal canal, and possibly an absent uterus, cervix, and kidney. Important potential health issues include:

- skeletal issues such as scoliosis, in around 12 per cent of cases
- kidney problems in around 30 per cent of cases
- infertility
- some problems with sexual function can exist after surgery/dilation to create a vagina
- lower urinary tract symptoms have been noted in some studies
- hearing impairments have been reported in 10 to 25 per cent of cases (particularly for the atypical form)
- heart malformations have been reported but are not common
- effects of genital surgery.

(Source: Creatsas et al., 2010; Walch et al., 2011; Borkowski et al., 2008; Nadarajah et al., 2005; Morcel et al., 2007)

Triple X syndrome (47XXX)

Triple X syndrome describes females who have an extra X chromosome. It is estimated that only around 10 per cent of women with Triple X syndrome are diagnosed and significant variability exists in health and wellbeing needs. Health needs have been known to range from minimal to clinically significant requiring comprehensive interventions. Major medical problems are not present for many women with Triple X syndrome, however, as outlined below, a range of other health issues have been reported for this group of people. There are issues with data quality.

- kidney and urinary tract issues have been reported in some studies
- congenital heart defects have been described in some studies
- cardiovascular disease is more common
- varying rates of clinical seizures have been reported, 15 per cent in the largest studies
- anxiety, mood disorders, or other psychiatric symptoms are more common than the broader population
- gastrointestinal problems including constipation and abdominal pain may be more common
- low muscle tone (hypotonia) is estimated to affect over 50 per cent of infants
- premature menopause (primary ovarian insufficiency) and under developed or dysfunctional ovaries
- infants and children are at risk of developmental delays due to speech and language difficulties
- cognitive deficits and learning disabilities are more common than in the general population
- motor coordination and auditory processing disorders can be present
- ADHD is estimated to affect 25 to 35 per cent of people with this variation.

(Source: Tartaglia et al., 2010; Linden et al., 1988; Otter et al., 2010; Rare Chromosome Disorder Support Group, 2013)

Klinefelter syndrome (47XXY)

Klinefelter's syndrome (XXY) is one of the most common intersex variations, but more frequently than some other variations, may not be diagnosed until investigation is undertaken for another issue such as infertility. Clinical manifestations of Klinefelter syndrome vary significantly and may include:

- low muscle tone (hypotonia)
- osteoporosis (particularly where testosterone supplements have not been taken during adolescence/early adulthood) in up to 40 per cent of cases
- language and learning difficulties are common
- diabetes, cardiovascular disease, and metabolic syndrome are more common
- recurrent leg ulcers affect six to 13 per cent of people
- enlargement of breast tissue (gynecomastia) at puberty occurs in many boys
- higher rates of non-Hodgkin lymphoma, breast cancer and extra-gonadal germ cell tumours
- increased lung cancer risk has been identified in some studies
- autoimmune conditions, including rheumatoid arthritis, systemic lupus erythematosus, and Sjogren's syndrome
- impaired executive function occurs in some people with this condition
- erectile dysfunction can be an issue
- testes produce lower amounts of testosterone than typical in males and have very limited Sertoli cell function (hence reduced fertility)
- diminished function of the testes (hypogonadism) and infertility in 95 per cent of people.

(Source: Tyler, 2004; van Rijn and Swaab, 2011; Cederlöf et al., 2014; Jha et al., 2007; Diamond, 2004; Lee et al., 2011; Swerdlow et al., 2001; Bojesen et al., 2006; Ishikawa et al., 2008; Swerdlow et al., 2005; De Sanctis et al., 2013; Thukuntla and Kumar, 2011)

Turner syndrome (45X)

Turner syndrome describes females with a 45X chromosome karyotype, sometimes accompanied by other cell lines with two or more X chromosomes or a Y chromosome. Turner syndrome is commonly diagnosed in adolescence and can be associated with a range of serious and less serious health conditions. It has been associated with a substantially increased overall death rate. Conditions that can more commonly affect women with Turner syndrome include:

- congenital heart defects, mostly left-sided, are present in 30 per cent of people with Turner syndrome
- renal issues are present in 30 per to 60 per cent of cases
- recurrent middle ear infections and hearing loss can occur
- higher rates of obesity, hypertension and glucose intolerance
- coronary heart disease, stroke and diabetes are more common
- metabolic syndrome
- hypothyroidism (under active thyroid) is estimated to affect 50 per cent of adults
- gonadal cancer risk is increased where a Y chromosome mosaic is present
- inflammatory bowel disease
- bowel cancer risk is estimated to be five to six times that of other women
- neuroblastoma (a neuroendocrine tumour frequently originating in the adrenal glands)
- osteoporosis and scoliosis are more common

- premature menopause (premature ovarian failure) has been reported
- increased risk of liver disease and autoimmune diseases (including celiac)
- impaired nonverbal visual-spatial organisation and nonverbal problem-solving skills, as well as impairments in mathematics, memory, ability to formulate goals and attention span
- ADHD and impaired motor skills and coordination are more common
- lymphedema (fluid retention in hands and feet)
- social difficulties are common during childhood.

(Source: Oliveira et al., 2009; Tyler, 2004; Swerdlow et al., 2001; Stanhope, 2003; Turner Syndrome Support Society)

Appendix 3: Support and advocacy services

- [Androgen Insensitivity Syndrome Support Group Australia](http://www.aissga.org.au) (AISSGA) <http://www.aissga.org.au>
- [Australian X and Y Spectrum Support](https://axys.org.au) (AXYS) <https://axys.org.au>
- [CAH Support Group Australia](http://www.cah.org.au) <http://www.cah.org.au>
- [Genetic Support Network Victoria](https://www.gsnv.org.au) <https://www.gsnv.org.au>
- [Intersex Human Rights Australia](https://ihra.org.au) <https://ihra.org.au>
- [PCOS Australia](https://www.facebook.com/PCOSAustralia) (facebook) <https://www.facebook.com/PCOSAustralia>
- [Turner Syndrome Association of Australia](https://www.turnersyndrome.org.au) <https://www.turnersyndrome.org.au>

Appendix 4: Figure description

Figure 1: Systems approach to the treatment, care and support of people with intersex variations and their families

Outcomes framework: full inclusion, self-determination without discrimination

Domain

- medical
- psychosocial
- participation and inclusion

Life-course

- infants
- children
- adolescents
- adults
- families.

Outcome

- appropriate medical treatment and support for intersex variations in infancy and childhood
- quality and respectful holistic healthcare throughout the
- life-course
- community, family and peer support for strong psychosocial wellbeing
- full inclusion and protection from discrimination.

Treatment, care and support options

Medical treatments

Medically essential

Medical treatment that is immediately necessary to avoid serious, urgent and irreparable physical harm or otherwise carries a demonstrable long-term health benefit that cannot be managed through less invasive, irreversible or major surgical means.

Deferrable

Medical treatment such as 'normalising' cosmetic genital surgeries that are not medically essential, do not address serious, urgent and irreparable harm, and can be deferred until a person's full, free and informed consent can be obtained.

Contested

Medical treatments that may carry a long-term physical health benefit but are not currently medically essential and may be managed over time through less invasive, irreversible or major surgical means.

Psychosocial care and support

Complementary stand-alone care and support interventions that promote the mental health and wellbeing of people with intersex variations and their families that may also facilitate, where necessary, informed consent and decision-making in relation to medically essential deferrable and contested treatments:

- variation-specific (including psychiatric and medical management)
- professional counselling, mental health and other specialist support
- information resources
- peer support
- age-appropriate
- life-course related.

Treatment, care and support options and system enablers contribute to standards of care.

System enablers

- life-course approach
- multi / interdisciplinary teams
- peer support groups
- workforce development
- diagnosis and treatment:
 - data collection
 - monitoring
 - reporting
- independent oversight:
 - courts
 - tribunals
- legislative and regulatory protection
- whole-of-government approach:
 - health
 - mental health
 - justice
 - disability
 - employment
 - education.

Decision-making principles and guidelines

Decision-making principles to support quality clinical practice in individual treatment, care and support:

- medical management
- human rights
- legal principles.

These decision-making principles contribute to

Guidelines to support systems-level quality, and decision making transparency and oversight.

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