

health

Decision-making principles
for the care of infants, children
and adolescents with
intersex conditions

February 2013

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conditions

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Contents

| | |
|--|-----------|
| Acknowledgements | iv |
| Introduction | 1 |
| Understanding intersex | 1 |
| The need for a decision-making resource | 2 |
| A resource for decision making | 3 |
| Principles for decision making | 3 |
| 1. Principles for supporting patients and parents | 3 |
| 2. Medical management principles | 4 |
| 3. Human rights principles | 4 |
| 4. Ethical principles | 5 |
| 5. Legal principles | 6 |
| Applying the principles | 6 |
| References | 10 |
| Related policies | 11 |
| Support groups | 11 |
| Appendix 1. Further information on the principles | 12 |
| 1. Principles for supporting patients and parents | 12 |
| 2. Medical management principles | 14 |
| 3. Human rights principles | 16 |
| 4. Ethical principles | 18 |
| 5. Legal principles | 21 |
| List of acronyms | 24 |

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A note on the resource

This resource is aimed at achieving the best possible outcomes for infants, children and adolescents with intersex conditions who are cared for in Victorian hospitals.

- It is intended for use by all parties responsible for, or contributing to, decisions about the healthcare of patients with intersex conditions only and does not apply to decision making about any other conditions.
- It will not replace specific advice given to parents by health professionals about their child's condition.
- It will not provide clinicians or parents with directives or clinical protocols for treatment of individual cases.

While the principles outlined in this resource are current best practice, it is important to acknowledge that medical management, human rights, ethical and legal considerations, standards and approaches to treatment for intersex conditions are constantly evolving. Hospitals and community members are encouraged to provide feedback on the resource as necessary to assist the Department of Health to update the document. This process will ensure that it continues to promote best practice in the healthcare of infants, children and adolescents with intersex conditions in Victoria.

Introduction

Making decisions about the healthcare of infants, children and adolescents with intersex conditions involves the intersection of a complex range of medical management, human rights, ethical and legal considerations. Everyone involved in the healthcare of patients with intersex conditions wants to make decisions in the best interests of the person receiving the care. However, it can be a confusing and difficult time for patients and parents, and an ethically and legally challenging area for hospitals, particularly when decisions that have life-long implications must be made without the patient's full and informed consent due to their age.

This document is a resource for Victorian hospitals responsible for the healthcare of infants, children and adolescents with intersex conditions. The Victorian Department of Health, in collaboration with leading experts in the field, has developed this resource to assist decision makers to make the best possible decisions in this complex area. The resource synthesises the advice of the Victorian Government, medical, human rights, ethical and legal experts, and community advocates, and outlines best-practice principles to be applied to decision making. It is intended to assist decision makers to safeguard the best interests of patients.

The principles contained in this resource apply to decision making about all cases where an intersex condition is assessed in a Victorian hospital or health service. All decisions about the healthcare of all infants, children and adolescents with intersex conditions in Victoria should be made while supporting patients and parents, and according to the current best practice medical management, human rights, ethical and legal decision-making principles in this resource. The final decisions should be those that reach a balance of the principles in light of the individual circumstances of the case, and that are in the best interests of the patient.

Understanding intersex

Sex is determined by a number of biological factors, including physical attributes, chromosomes, genitals, gonads and hormones. In this resource, the term 'intersex conditions' refers to any set of physical or biological conditions that mean a person cannot be said to be exclusively male or female.

Two of the more common conditions are congenital adrenal hyperplasia and androgen insensitivity syndrome, both of which can result in ambiguous genitalia detectable from birth. Some intersex conditions are not detected until later in life, for example, when a child does not progress through puberty in the usual manner. In addition, some intersex conditions are difficult to classify and can be misdiagnosed as non-intersex conditions (for example, some complex hypospadias).

Further information about when a condition should be considered to be an intersex condition, and therefore become subject to the decision-making principles in this resource, is available in the *Consensus Statement for Management of Intersex Disorders* (Lee et al. 2006) and *Disorders of Sex Development: An Integrated Approach to Management* (Hutson, Warne and Grover 2012).

There is a lack of definitive data regarding the incidence of intersex conditions. Recent estimates suggest they may occur as frequently as one in 280 births (Warne and Hewitt 2012). In 2011, Victorian hospitals reported seeing approximately 40 new cases of infants with identified intersex conditions per year, and involvement in follow up and monitoring for 240 patients into childhood and adolescence.

The majority of infants, children and adolescents diagnosed with an intersex condition in Victoria are referred to either the Royal Children's Hospital (RCH) or Southern Health's Monash Medical Centre (MMC) Clayton for assessment and healthcare. RCH and MMC are paediatric hospitals in Victoria that have the necessary infrastructure and clinicians with the experience, skills and expertise required to treat intersex conditions.

There is considerable debate about the appropriate terminology to use to describe intersex conditions. The Australian Human Rights Commission in its 2009 paper, *Surgery on Intersex Infants and Human Rights*, uses the term 'intersex' to describe people who are not born, or do not develop, as exclusively male or female. Most Victorian advocates for people with intersex conditions endorse the continued use of the term 'intersex'.

Intersex was also endorsed as the preferred terminology by an expert advisory group of Victorian clinicians, with input from intersex community representatives, convened during the initial stages of development of this resource (Victorian Department of Human Services 2009). However, it is important to note that while individuals with intersex conditions may identify as intersex, not all do, nor might a person consider their condition to be an intersex condition, or indeed a 'condition' at all.

Since the publication of the *Consensus Statement on Management of Intersex Conditions* (Lee et al. 2006) there has been a growing international consensus within the clinical community to refer to intersex conditions as 'disorders of sex development' or DSDs. In response to this term, a number of Australian and international intersex advocates and academics have voiced their opinion that intersex conditions should not be described as 'disorders' or 'conditions' because they are part of human variation due to genetic, chromosomal or hormonal factors. This resource predominantly uses the term 'intersex conditions' with the acknowledgement that there is no agreement across sectors on appropriate terminology.

The need for a decision-making resource

The definition of intersex conditions and how these conditions are treated can be controversial. There is considerable pressure for people with intersex conditions to conform to cultural and social expectations of physical appearance and gendered behaviour. In the past, the birth of an infant born with an intersex condition was viewed as a medical and social 'emergency'. In some cases parents report not having been given adequate information, time or options to provide informed consent or make informed decisions on behalf of their children. For some infants, children and adolescents who received treatment, the stigma, shame and secrecy surrounding their condition sometimes negatively affected the decisions that clinicians and parents made on their behalf.

Some patients who are now adults regard the decisions made when they were infants, children or adolescents as not being in their best interests. For example, patients have reported significant negative consequences of decisions where they ultimately feel that the wrong gender was assigned, where irreversible surgery was performed, and where the effects of surgery such as loss of sensation or loss of potential fertility have had lasting consequences for the person's quality of life. In some cases, these outcomes occurred because the risk of embarrassment about difference and the related stigma was given undue weight in the decision-making process.

More recently, the medical sense of urgency to treat intersex conditions has decreased. Emphasis is now more commonly placed on establishing an accurate diagnosis and making considered decisions about any medical or surgical treatment for intersex conditions where patients cannot give full informed consent. However, while practices in relation to diagnosis, technology, surgical techniques, patient information and disclosure have improved significantly, decision-making about healthcare remains challenging.

Those responsible for, or contributing to, decision making, including parents, families, clinicians, ethicists, lawyers, advocates and others may have different and sometimes conflicting views on the approach to take to achieve the best outcomes for patients.

A resource for decision making

This resource is a tool to assist Victorian hospitals to apply current best-practice principles in decision making. The objectives of this resource are:

- to present current best-practice principles to assist those who are responsible for decision making about the healthcare of infants, children and adolescents with intersex conditions in Victoria
- to safeguard the best interests of patients by ensuring that decisions are balanced and not unduly influenced by perceived or actual social stigma, shame or secrecy
- to promote statewide consistency in understanding and application of the principles that should underpin decisions made about healthcare of infants, children and adolescents with intersex conditions in Victoria.

By applying the principles in this resource consistently, robustly and transparently to decisions about healthcare for infants, children and adolescents with intersex conditions, the intention is that Victorian hospitals will maximise the likelihood of achieving the best possible outcomes for patients, be able to explain their decision-making processes and justify any decisions taken.

Principles for decision making

The following section summarises the principles to apply to decision making about the healthcare of infants, children and adolescents with intersex conditions in Victoria, including:

- principles for supporting patients and parents during decision making
- medical management principles
- human rights principles
- ethical principles
- legal principles.

Further information about each set of principles, intended to assist decision makers to apply the principles to individual cases, is supplied in Appendix 1.

1. Principles for supporting patients and parents

The following principles were developed by an expert advisory group of Victorian clinicians (Victorian Department of Human Services 2009) with input from community representatives. The principles are based on the *Consensus Statement for Management of Intersex Disorders* (Lee et al. 2006).

Support for patients and parents¹ is paramount in the difficult time surrounding decision making about any medical or surgical treatment of an intersex condition. In most cases, parents provide consent and are the legal decision makers about the healthcare of their child. The health and wellbeing of infants, children and adolescents is dependent on their parents, and therefore parents need support, information, time and understanding in order to consent or not consent on behalf of their child to the healthcare options presented.

In cases where the patient is a child or adolescent capable of providing consent (see 'Gillick competence' in the Legal principles section of this document), it is important that they receive appropriate support, information and time to understand their condition, and what is being proposed to manage it. Even in cases where the patient is not able to provide consent, they should be supported, according to the following principles, to contribute to decision making within their capacity.

¹ Parents also includes legal guardians

Principles for supporting patients and parents

In order to achieve international best practice, Victorian hospitals should aim to provide patients and parents with:

- honest and complete disclosure of the diagnosis, risks, options, issues and treatments
- sufficient time and opportunity for discussion of all options for healthcare and a balanced review of risks and benefits
- intensive support, education and counselling during the decision-making phase
- standardised, age-appropriate resources for parents, children and adolescents that provide education about sex and gender diversity
- information about, and referral to, support groups for both parents/families, and the patient
- assistance for parents with informing their child in stages about their condition, and with seeking their child's consent for any medical or surgical intervention
- ongoing follow up and referral to psychological support for patients and their parents throughout the patient's life.

Further information on applying these principles to decision making is in Appendix 1.

2. Medical management principles

In 2006, the American Lawson Wilkins Pediatric Endocrine Society and the European Society for Paediatric Endocrinology convened an international group of 50 experts on intersex conditions in medical and related fields, including two representatives from Victoria. The outcome was the *Consensus Statement on Management of Intersex Disorders* (Lee et al, 2006) that, in addition to guidance on clinical decision making for specific conditions, provides general principles of care for patients with intersex conditions.

Medical management principles

In order to achieve international best practice, Victorian hospitals should aim to manage the care of infants, children and adolescents with intersex conditions according to the following principles:

- Gender assignment must be avoided before expert evaluation in newborns [Note that the term 'gender assignment' refers to assigning a gender label of male or female to an infant, in order to raise the child as that gender. Gender assignment does not necessitate surgery or other medical treatment.].
- Evaluation and long-term management must be carried out at a centre with an experienced multidisciplinary team.
- All individuals should receive a gender assignment.
- Open communication with patients and families is essential, and participation in decision making is encouraged.
- Patient and family concerns should be respected and addressed in strict confidence.

Further information on applying these principles to decision making is in Appendix 1.

3. Human rights principles

Victoria has domestic responsibilities with regard to human rights under the *Charter of Human Rights and Responsibilities Act 2006* (Vic) (the Charter Act). The Charter Act aims to protect and promote human rights, and it contains a number of rights that are modelled on rights recognised under international law. Victorian public hospitals are public authorities and, as such, have responsibilities under Section 38 of the Charter Act. Section 38 states that it is unlawful for a public authority to act in a manner that is incompatible with a right contained in the Charter Act, or, in making a decision, to fail to give proper consideration to a relevant human right, unless required to do so by law.

Victorian Charter Act human rights principles

The healthcare of infants, children and adolescents with intersex conditions raises four relevant Charter Act human rights against which decisions should be tested, including:

- the right to protection from medical treatment without consent (s. 10 (c))
- the right of children to protection (s. 17 (2))
- the right to privacy (s. 13 (a))
- the right to equality (s. 8).

Further information on applying these rights to decision making is in Appendix 1.

Australia is also a signatory to international human rights instruments and therefore has obligations under international law to uphold these rights, including the *United Nations Convention on the Rights of the Child*, the *International Covenant on Civil and Political Rights* and the *International Covenant on Social, Economic and Cultural Rights*. These instruments contain rights relevant to decision making about the healthcare of infants, children and adolescents with intersex conditions, in addition to those described in the Victorian Charter Act.

While these international human rights are not binding on public authorities, they may contribute to decision making as part of the overall human rights and ethical discussion. These rights may also be taken into account by courts when interpreting legislation. Further information on these rights is available in Appendix 1.

4. Ethical principles

Associate Professor Lynn Gillam, Dr Jacqueline Hewitt and Professor Garry Warne from the Royal Children's Hospital in Victoria have developed ethical principles for decision making about the healthcare of patients with intersex conditions that were endorsed by the 5th World Congress on Family Law and Children's Rights in Canada in August 2009. The wording of the principles as endorsed at the congress is used in this resource.

Gillam, Hewitt and Warne published their first six principles in *Ethical Principles for the Management of Infants with Disorders of Sex Development* (2010). A seventh principle was recently added to take into account the views and wishes of children and adolescents who are capable of contributing to decision making about their healthcare (Gillam, Hewitt and Warne 2012).

According to Gillam, Hewitt and Warne (2010), 'These principles can be understood as describing in precise terms the nature of clinicians' basic ethical obligation, which is to act in the best interests of the child in this situation, taking into account the views and wishes of the parents' (p. 2).

Ethical principles

To act in the best interests of the patient, decisions should be tested against the ethical principles developed by Gillam, Hewitt and Warne (2010; 2012), including:

- minimise physical risk to child
- minimise psychosocial risk to child
- preserve potential for fertility
- preserve or increase capacity to have satisfying sexual relations
- leave options open for the future
- consider parents' wishes
- take into account the views of the child.

Further information on applying these ethical principles to decision making is in Appendix 1.

5. Legal principles

The question of who may consent to the medical treatment of an infant, child or adolescent when they are not able to consent themselves is integral to the decision-making process from a legal and ethical perspective. The Australian legal authority as to whether, and in what circumstances, court authorisation is required for treatment decisions, was examined in the High Court case of *Department of Health and Community Services [Northern Territory] v JMB and SMB* ('Marion's Case') (1992)². Marion's Case continues to be the most authoritative precedent regarding the issue of consent for treatment of children.

According to the principles of Marion's Case, a child or adolescent under 18 years of age can consent to medical treatment when that child or adolescent has sufficient intelligence and maturity to understand the nature and consequences of the particular medical treatment. In Marion's Case, the High Court applied the test of the House of Lords in *Gillick v West Norfolk Area Health Authority* [1986] AC 112 (referred to as 'Gillick competence') to determine whether a child or adolescent can consent to medical or surgical treatment. See Appendix 1, section 5 (a) for further explanation of assessing Gillick competence.

In cases where a person is not deemed to be Gillick competent and therefore cannot consent to medical or surgical treatment, a parent may consent. However, **certain medical and surgical treatments are sufficiently serious according to law that a parent may not consent**. In those circumstances, parents and medical practitioners must seek court authorisation to proceed with the proposed treatment. There are four threshold questions shown in the Legal principles box below that should be used to determine whether a proposed treatment is one that a parent **cannot** consent to and therefore requires court authorisation.

Legal principles

Court authorisation is required for decisions made on behalf of infants, children and adolescents with intersex conditions, who cannot give consent if all of the following four threshold questions apply to a particular treatment, being that:

- the proposed treatment is non-therapeutic; and
- the proposed treatment is invasive, irreversible and considered 'major' treatment; and
- there is a significant risk of making the wrong decision about the best interests of the child; and
- the consequences of a wrong decision are particularly grave.

Court authorisation may also be required where there is disagreement between decision-making parties about the characterisation of a particular treatment against these principles.

Further information on applying these legal principles to decision making is in Appendix 1.

Applying the principles

The principles in this resource apply to decision making about all cases where an infant, child or adolescent with an intersex condition is assessed in a Victorian hospital. All decisions about the healthcare of infants, children and adolescents with intersex conditions in Victoria should be made in the best interests of the patient, according to current best practice principles for supporting patients and parents, and in consideration of the medical management, human rights, ethical and legal decision-making principles as described above.

Appropriate time and resources are necessary to adequately consider the principles and to document the decision-making process. Hospitals should be aware of the possibility that patients may in the future request their records, and that a justifiable explanation of any treatments performed must be able to be provided, particularly if the patient was not able to give full, free and informed consent at the time.

² Although Marion's Case did not involve a person with an intersex condition, the principles of consenting to treatment apply.

Applying the principles

The application of the principles for decision making should be:

- **robust** – all sets of principles should be considered in all cases and the application of the principles should be thorough
- **transparent** – the application of all principles to decisions made should be documented to be clearly explained and justified to the patient in future
- **consistent** – all the principles should be considered for all cases of intersex conditions managed in Victoria.

In Victorian hospitals, the patient's treating clinician is responsible for developing a management plan consistent with the principles in this resource. The management plan would contain decisions about which, if any, treatment is recommended for a patient's particular condition. The patient or their parent/s are then responsible for making decisions about whether they will consent, or not consent, to the proposed treatments in the plan.

Due to the number of possible intersex conditions, the complexity of each case, the evolving nature of clinical best practice in the field and the relatively low number of cases of each type of condition presenting each year in Victoria, it is likely that treating clinicians will need to confer with and seek advice from other experts when developing management plans for most, if not all, cases. Collaboration should be sought from medical, ethical and legal professionals with expert knowledge and experience in decision making about the healthcare of infants, children and adolescents with intersex conditions.

Developing a management plan in collaboration with colleagues, in light of the principles in this resource may take time. However, it is important that any sense of urgency to minimise distress for patients and parents is not given precedence over gathering the necessary information to make robust, transparent and consistent decisions. While developing the plan as swiftly as possible, treating clinicians should support patients and parents through the initial period of uncertainty, and foster an environment in which considered decisions that are in the best interests of the patient can be made.

To assist clinicians to apply the principles robustly, transparently and consistently, hospitals are strongly encouraged to establish formal specialised advisory groups of experts, such as multidisciplinary medical management groups and clinical ethics committees with specialist expertise in decision making about the healthcare of patients with intersex conditions. These formal mechanisms should be accompanied by processes, policies and procedures to guide clinicians on when and how to use the advisory structures. In addition, accurate and sufficiently detailed records of previous decisions and patient outcomes, in accordance with relevant information privacy policies, are also helpful as an information source for future decisions.

The extent of the advice or discussion with colleagues needed to ensure best practice in the management of a particular case (including the amount of advice, number of advisors and formality of the advice) will increase with the level of inconsistency of any proposed treatments with the principles in this resource. Other factors that will affect the extent of discussion and nature of the advice required include, but are not limited to, the complexity of the individual case, the experience that the treating clinician has with applying the principles, and the level of agreement that parties to the decision have on the best type of healthcare for the patient.

In order to achieve statewide consistency in understanding and application of the principles, medical, ethical and legal professionals in Victorian hospitals are strongly encouraged to share expertise and information within the bounds of patient privacy and confidentiality. Expertise could, for example, be shared between hospitals through formal advisory mechanisms, such as joint clinical review groups and ethics committees.

In addition, hospitals are encouraged to create formal opportunities for dialogue and collaboration between healthcare professionals and support groups as partners (Victorian Department of Health 2011). For example, formal opportunities could be arranged for support group members to share their lived experience of having an intersex condition, or having a child with an intersex condition, with members of clinical or ethics teams. Collaboration as partners is also encouraged as international best practice in the *Consensus Statement on Management of Intersex Disorders* (Lee et al. 2006).

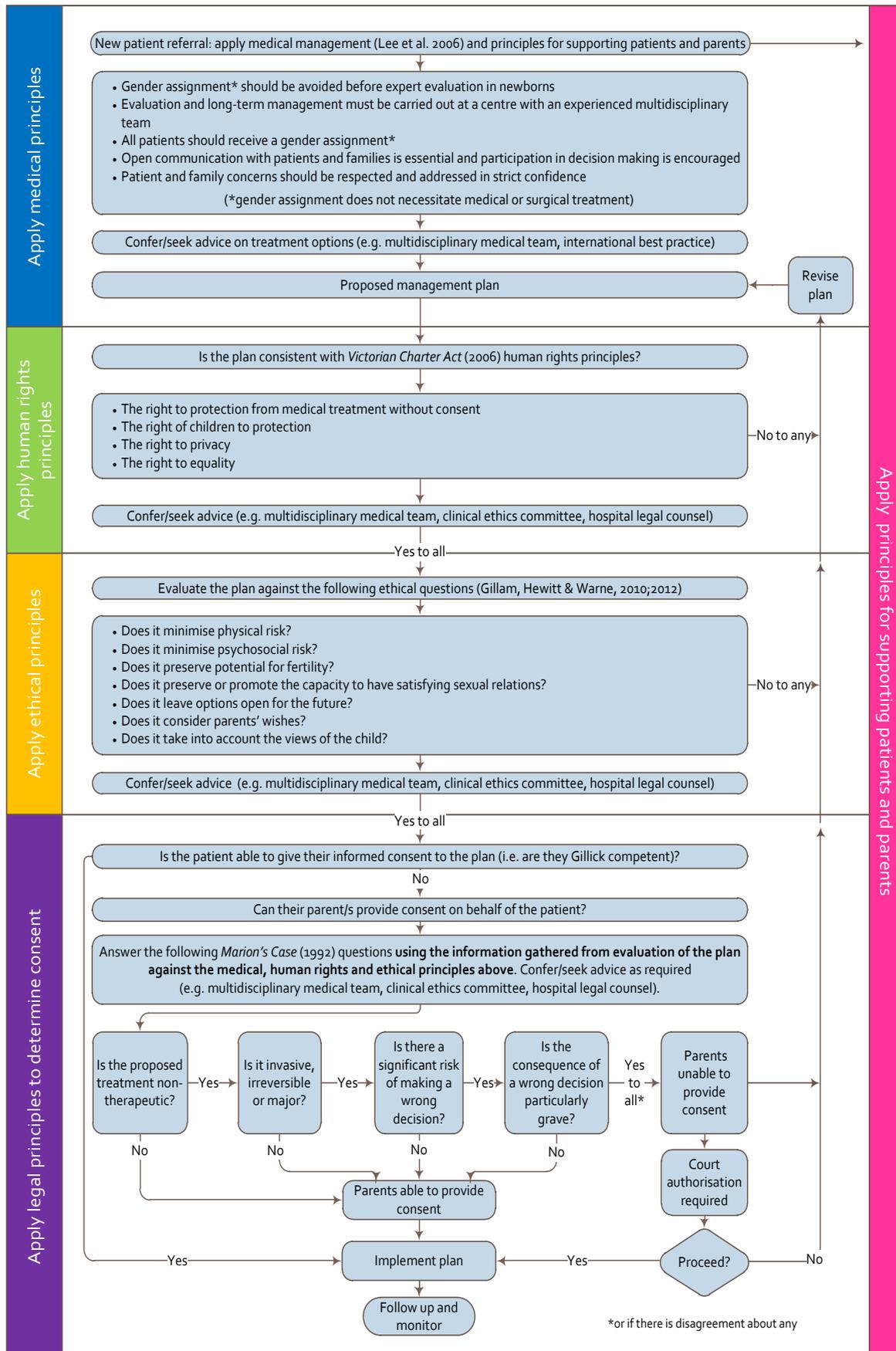
Seeking advice

In order to make robust, transparent and consistent decisions:

- clinicians should confer with or seek advice from medical, ethical and legal experts, including through formal advisory mechanisms, when applying the principles to decision making
- the extent of advice and discussion required for a particular case will depend on the level of inconsistency of the proposed management plan with the principles
- medical, ethical and legal expertise should be shared between hospitals in order to achieve statewide consistency in the application of the principles
- support groups should be involved in dialogue and collaboration as partners in order to achieve international best practice in Victoria.

Figure 1 shows the principles and suggested sources of advice for those tasked with applying them to a particular case. Note that the application of the principles to a particular case may occur in any order and is not restricted to the suggested order shown here. The key point is that all principles are applied to all cases. However, answering the questions posed by the medical management, human rights and ethical principles in the suggested order will assist in answering the questions of whether parents can provide consent for the management plan or whether it requires court authorisation.

Figure 1. Summary of decision-making principles



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Warne G, Hewitt J 2012, 'The medical management of disorders of sex development'. In: Hutson J, Warne G and Grover S (eds), *Disorders of sex development: An integrated approach to management*, Springer, Heidelberg, p 159–172.

Related policies

Victorian Department of Human Services 2009, *Well proud: A guide to gay, lesbian, bisexual, transgender and intersex inclusive practice for health and human services*, Victorian Government Department of Human Services, Melbourne.

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Victorian Department of Health 2011, *Doing it with us not for us: Strategic direction 2010–13. Participation in your health service system: Victorian consumers, carers, and community working together with their health services and the Department of Health*, Victorian Government Department of Health, Melbourne.

Support groups

Androgen Insensitivity Syndrome (AIS) Support Group Australia
<http://home.vicnet.net.au/~aissg/>

Congenital Adrenal Hyperplasia Support Group Australia
<http://www.cah.org.au/v2/>

Organisation Intersex International Australia
<http://oiiaustralia.com/>

Appendix 1. Further information on the principles

The following section outlines the principles in more detail, to assist those involved in decision making about the healthcare of infants, children and adolescents with intersex conditions in Victoria to apply them to individual cases. Decision makers include, but are not limited to, treating clinicians, multidisciplinary medical teams, ethics committees, legal advisors and hospital management who may all contribute to decisions about the care of a particular patient. The information in this section is reproduced from the original sources as accurately as possible. However, decision makers are also encouraged to review the original sources.

1. Principles for supporting patients and parents

a. Honest and complete disclosure of the diagnosis, risks, options, issues and treatments

Patients and parents should be made aware in the first instance that a diagnosis of an intersex condition does not necessarily mean that medical or surgical treatment is required. If medical or surgical treatment is recommended, then it is important that those providing consent to any proposed treatments on behalf of an infant, child or adolescent are made fully aware of the diagnosis, risks, options, issues and treatments available.

In the past, some parents have been asked to give consent to treatments where they felt they did not have sufficient information, or where other options (including no treatment or delayed treatment options) were not explained or explored. Further, informed consent requires awareness of potential negative, as well as positive, outcomes. Those responsible for seeking consent from patients or parents are therefore advised to ensure that all risks, options, issues and treatments are presented. Presenting all options is particularly important where there is no standard care protocol for the particular condition, and where other clinicians in the field are known to have a different approach. It is also important that the presentation of these options is well documented, in order to ensure an informed consent process.

b. Sufficient time and opportunity for discussion of all options for healthcare and a balanced review of risks and benefits

Parents giving consent to treatment for an intersex condition on behalf of their child, or patients giving consent for their own treatment, can experience intense social and time pressure to resolve the situation. This pressure may impact on their ability to make decisions that are in their or their child's best interests. Sometimes, patients' and parents' initial feelings of helplessness, confusion or anxiety can lead to premature requests for medical or surgical treatment (Swiss National Advisory Commission on Biomedical Ethics 2012).

Those responsible for providing information to parents should assist them to manage these initial reactions, and create an environment of calm and careful decision making. It is important to note, and to emphasise to patients and parents, that a diagnosis of an intersex condition does not mean that a decision about treatment is necessarily urgent.

The task of those responsible for seeking consent from patients or parents is therefore to ensure that they are given sufficient time and opportunity to discuss the options, ask questions and gain a clear understanding of the management plan that they are consenting to, and the possible implications for their or their child's future health and wellbeing. This responsibility includes use of accredited interpreters and translated resources for patients and parents who require them. Although those responsible for the patient may have a preferred direction for their care, it is important that patients and parents are given a balanced view of the risks and benefits, including those for the options of no treatment or delayed treatment.

c. Intensive support, education and counselling during the decision-making phase

The diagnosis of an infant, child or adolescent with an intersex condition can be a distressing event for patients and parents. There is a need at this time for intensive support to enable patients and parents to make the difficult and life-changing decisions that will ultimately be in their or their child's best interests. The role of those responsible for the care and support of patients and parents is to ensure a robust, transparent and consistent decision-making process, so that patients and parents have access to the best options available. However, the consent decision lies with the patient or their parents, who need to be supported by those in the multidisciplinary team who have specialist counselling and support skills, and knowledge (such as psychologists and social workers) to make an informed decision.

The aim of counselling and support during this phase should be to facilitate the formation of a close and loving bond between the parent/s and their child and to create an appropriate environment for reasoned decision making (Swiss National Advisory Commission on Biomedical Ethics 2012). Support, education and counselling should be available even if the patient has been discharged home.

d. Standardised, age-appropriate resources for parents, children and adolescents that provide education about sex and gender diversity

In the decision-making phase, patients and parents need to quickly understand very complex information in order to make decisions in their or their child's best interests. The provision of clear and informative resources can assist this communication, and it is recommended that hospitals collate or develop standardised, age-appropriate resources for this purpose.

It is important that these resources include education about sex and gender diversity, that is, different understandings of sex and gender experienced by adults with intersex conditions. This information is particularly important where there is a possibility that the patient may identify in the future with a different gender to the one assigned to them in infancy.

It is important to emphasise to parents that there are resources and support available for families if the patient chooses to re-identify their gender, and that in many cases, gender re-identification can be a self-empowering action for people with intersex conditions.

The presentation of this information will need to be tailored to the particular circumstances of the case, such as the likelihood of gender identity issues in the particular condition, and the social and cultural context of the family. Referral to support groups would be appropriate for further information and advice on these issues.

e. Information about, and referral to, support groups for both parents/families and the patient

Support groups play an important role in supporting patients and parents through diagnosis, treatment and ongoing management of intersex conditions (see also the medical management principles below). Support groups can assist those responsible for the care of patients and parents to apply the supporting principles in this resource.

According to the international *Consensus Statement on Management of Intersex Disorders* (Lee et al, 2006), (the consensus statement), the role of support groups in providing information to families is most effective when dialogue and collaboration occurs between healthcare professionals and support groups as partners. This relationship between support groups and those responsible for the care of patients and parents should be actively sought and encouraged for the benefit of patients and their parents and families.

f. Assistance for parents with informing their child in stages about their condition and with seeking their child's consent for any medical or surgical intervention

In cases where the patient is not an infant, they will need to be informed about their condition and involved in decision making about their healthcare. The need for information disclosure and involvement in their healthcare increases with age (see the legal principle of Gillick competence in section 5 (a)).

Parents will also often require assistance in explaining medical concepts to their children. It is the responsibility of those caring for the patient and their parent/s to assist with information appropriate to the patient's age and developmental stage.

g. Ongoing follow-up and referral to psychological support for patients and their parent/s throughout the patient's life

The healthcare of a patient with an intersex condition is often a process that occurs over a period of time. In some cases, treatment may be deferred until a child or adolescent can contribute to decisions about their treatment. For example, treatment may only become medically necessary at a later stage in the child's or adolescent's development. It is also the case that the impacts of some procedures performed or treatments given in infancy can only be determined at a later date in the patient's development, such as when they reach puberty or become sexually active. It is therefore important that medical follow-up and psychological support is available for patients and their families throughout these life stages.

2. Medical management principles

This section outlines the principles included in the *Consensus Statement for Management of Intersex Disorders* (2006) (the 'consensus statement') and additional explanation based on current best practice in Victorian hospitals (Victorian Department of Human Services, 2009).

a. Gender assignment must be avoided before expert evaluation in newborns

The term 'gender assignment' refers to assigning a gender label of male or female to a child, in order to raise the child as that gender. It is important to note, and to emphasise to patients and their parent/s, that assigning a gender label **does not necessitate undertaking treatment such as surgery or other medical treatment**. Although initial uncertainty can be distressing for parents, it is important in cases where ambiguity exists that experts carefully evaluate the newborn's condition before assigning a gender. The decision is one that will have life-long consequences for the patient and, therefore, should not be made before consideration of all the available evidence.

Assigning a gender label of male or female to a child, rather than no gender label, does not mean that the label is immutable or that the patient will necessarily identify with that label in future. It is important to provide information about sex and gender diversity to patients and parents as appropriate (see Principles for supporting patients and parents section above).

The consensus statement recommends explaining to patients and parents that, while 'the best course of action may not initially be clear, the healthcare team will work with the family to reach the best possible set of decisions in the circumstances' (p. 555). Those responsible for the care for the patient should emphasise that intersex conditions are not shameful and focus on the potential for positive long-term outcomes. In particular, initial contacts with patients and parents during this period are crucial, because the response of clinical staff to the situation can leave a lasting impression.

b. Evaluation and long-term management must be carried out at a centre with an experienced multidisciplinary team

The consensus statement recommends that optimal care for infants born with intersex conditions requires an experienced multidisciplinary team that ideally includes paediatric specialists in endocrinology, surgery or urology, or both, psychology, psychiatry, gynaecology, genetics, neonatology, social work, nursing, and medical ethics. The consensus statement emphasises the importance of psychosocial care provided by mental health professionals with appropriate expertise to facilitate team decisions about gender assignment or reassignment, timing of surgery and sex hormone replacement.

The consensus statement also notes the specific responsibility that the multidisciplinary team has to educate other healthcare staff in the appropriate management of initial contacts with infants, children and adolescents presenting with intersex conditions and their families.

c. All individuals should receive a gender assignment

The consensus statement acknowledges that initial gender uncertainty can be unsettling and stressful for families, and recommends a swift but thorough assessment and decision-making process. Assigning a gender label based on the available evidence, rather than no gender label, is current best practice in most cases, but it should not be a process that is rushed at the expense of careful decision making. It is also important to note again that assigning a gender does not necessarily mean that the patient requires any medical or surgical treatment, or that treatment is necessarily urgent. In some cases, it may be in the patient's best interests to delay decisions about treatment to affirm an assigned gender or decide not to treat at all, depending on the patient's circumstances.

Where parents choose to delay or decide against medical or surgical treatment or gender assignment, this decision should be facilitated with access to appropriate counselling and support. Ongoing support from healthcare providers is particularly important in cases where a child or adolescent chooses to re-identify their gender or seeks related medical or surgical treatment at a later stage of their development. Where re-identification of gender is a possibility for the patient's particular condition, it should be presented as an option that will be supported as far as possible by the patient's treating clinician, multidisciplinary team and hospital, as appropriate.

The consensus statement lists the factors that influence gender assignment, including the diagnosis, genital appearance, surgical options, need for life-long replacement therapy, potential for fertility, views of the family and the culture in which the child will be raised. The statement also discusses long-term outcome factors to be considered when making healthcare decisions, including external and internal sex organs, physical health, including fertility and sexual function, social and psychosexual adjustment, mental health, quality of life and social participation.

The consensus statement advises that, before making any recommendations, the multidisciplinary team should develop a management plan with respect to these factors. This resource is designed to assist in development of the management plan (see Figure 1. Summary of decision-making principles).

d. Open communication with patients and families is essential, and participation in decision making is encouraged

The consensus statement advises that parents need to be informed about sexual development when making decisions for their child. Best practice in Victoria is that parents are routinely given the results of all investigations and an interpretation of what they mean, even when the test results are inconclusive and a clear diagnosis is not possible. Parents should receive comprehensive information on the implications of the proposed medical or surgical interventions, including evidence of the long-term impact and of gaps in the available research.

In addition, support groups have a particularly important role in providing information to patients and parents during the decision-making phase and beyond. The consensus statement encourages dialogue and collaboration between healthcare professionals and support groups, as partners in delivery of care to patients and their families.

e. Patient and family concerns should be respected and addressed in strict confidence

The consensus statement emphasises that ample time should be given for ongoing discussion with patients and parents about options for healthcare. One member of the multidisciplinary team, who has appropriate communication skills, should be nominated to act as the primary liaison. The decision-making process should provide opportunities for parents to review information with the primary liaison and other team members as appropriate. In addition, the primary liaison should discuss with the parents what information to share with their family members and friends in the early stages of diagnosis and decision making.

3. Human rights principles

This section outlines in further detail the relevant human rights principles contained within the Victorian *Charter of Human Rights and Responsibilities Act 2006* (the 'Charter Act') and additional international human rights principles not covered by the Charter Act. Legal advisors on individual cases should balance these rights by taking into account the facts of each case. Australian Human Rights Commission publication *Surgery on Intersex Infants and Human Rights* (2009) and the *Yogyakarta Principles* (International Commission of Jurists, 2007) on the application of international human rights law in relation to sexual orientation and gender identity may also be of assistance with these decisions.

3.1 Victorian human rights

Section 38 of the Charter Act makes it unlawful for a public authority to act in a way that is incompatible with a human right. It also makes it unlawful for a public authority to fail to give proper consideration to a relevant human right in making a decision. However, these obligations do not apply if a public authority is required by law to act in a particular way. Therefore, even though a particular course of action may conflict with a human right, it will not breach the Charter Act if the action is required or permitted by another statute or common law. For example, conduct undertaken because of a common law duty of care owed by the clinician to the patient would not breach the Charter Act. Note that the exception does not apply if the public authority could, under law, have reasonably acted differently or made a different decision that would have been consistent with the Charter Act.

The human rights listed below are particularly relevant when making decisions about treatment on behalf of infants, children and adolescents with intersex conditions. The rights are based on international human rights charters including the *International Covenant on Civil and Political Rights* (ICCPR) and the *United Nations Convention on the Rights of the Child* (UNCRC). Any limitation to these rights should be reasonable and demonstrably justified in accordance with s. 7 of the Charter Act.

- a. **The right to protection from medical treatment without consent** (Charter Act s. 10 (c). Also see ICCPR, Art. 7)

This right reflects the broader position at law whereby it is unlawful to render medical treatment without the informed consent of patients who are competent to provide consent, except in limited circumstances. Decision-making parties must ensure that the patient (or if the patient is unable to provide consent, their parent/s) gives 'full, free and informed' consent to the proposed treatment. That is, the consent should be voluntary and the person providing consent should have been given sufficient information for an informed decision to be made. This would include information such as the nature of the person's condition and the treatment options available, including possible risks, side effects and benefits of any treatment.

- b. **The right of children to protection** (Charter Act s. 17 (2))

This right is based upon Art. 24 (1) of the ICCPR, which recognises the special vulnerability of children as a result of their age and expressly confers additional rights on them. This right is promoted by the procedural safeguards in this resource, which aim to ensure that decision making takes into account the rights and best interests of the child.

- c. **The right to privacy** (Charter Act s. 13 (a). Also see UNCRC Art. 16 and ICCPR Art. 17)

The right to privacy includes consideration of personal autonomy and human dignity. Where medical procedures, for example, hormonal treatment or surgery, are used to treat an intersex condition in a child or adolescent, this will engage the child or adolescent's right to 'bodily privacy' and autonomy to make their own decisions concerning their physical being. Information privacy (collection, storage and use of records) will also be relevant.

The right to privacy is not absolute, but rather conveys a right not to have one's privacy 'unlawfully or arbitrarily interfered with'. The concept of 'arbitrary' interference incorporates notions of reasonableness and proportionality. Decisions to treat children or adolescents for intersex conditions will need to take into

account the child's or adolescent's particular circumstances to ensure that any limit to the child's or adolescent's privacy is reasonable and justified.

An example of the application of this human right is that repeated genital examinations of people with intersex conditions should be minimised and genital photographs should be discouraged, and only taken with parental or patient consent. If photographs are taken, they should be securely stored and archived under strict adherence to the Privacy Act and not kept in a shared hospital file (Victorian Department of Human Services 2009).

d. **The right to equality** (Charter Act s. 8. Also see UNCRC Art. 2 and ICCPR Art. 26)

Every person is entitled to enjoy human rights without discrimination. Under section 3 of the Charter Act, discrimination is defined on the basis of attributes set out in the *Equal Opportunity Act 2010*, including age, impairment, sex and sexual orientation.

Decisions concerning the healthcare of children or adolescents with intersex conditions should accord equal weight to the child's or adolescent's rights, as they would to any other patient of equivalent age and competence. It is particularly important that decisions are not taken with undue weight on the potential for perceived or actual discrimination against the patient, either currently or in future, due to their intersex condition.

3.2 International human rights

As a signatory to various international human rights instruments such as the UNCRC, the ICCPR and the *International Covenant on Social, Economic and Cultural Rights* (ICSECR), Australia seeks to act in conformity with the following rights that may be relevant in the healthcare of intersex infants, children and adolescents.

a. **The best interests of the child shall be a primary consideration** (UNCRC Art. 3)

Decision makers should give primary consideration to the best interests of the child when considering healthcare for intersex conditions. To determine the best interests of the child, it is important to weigh up the risks and benefits of a proposed treatment, with consideration to the particular circumstances of the child, as well as current medical and ethical positions.

b. **The right to maximum possible survival and development** (UNCRC Art. 6)

A child's 'development' includes the child's physical, mental, spiritual, moral, psychological and social development. Decision makers should give consideration to all aspects of a child's future development when making decisions with regard to surgery or other treatment for intersex conditions.

c. **The right of a child to protect their identity** (UNCRC Art. 8(1))

Every child has the right to preserve his or her identity without unlawful interference. This includes sexual or gender identity. Gender-related treatment or genital reconstruction surgery on an infant to treat an intersex condition may engage the child's right to protection of their sexual or gender identity.

d. **The right of a child to freely express their views in all matters affecting them** (UNCRC Art. 12(1))

Decision makers considering treatment of children for intersex conditions should assess the capacity of the child to form an autonomous opinion, and should not assume the child is incapable of providing consent because of their age (see the legal principle of Gillick competence in section 5 (a)). Where a child is capable of expressing their own views, those views should be given due weight according to the child's age and maturity.

e. **The right to highest attainable standard of physical and mental health** (ICESCR, Art. 12 and UNCRC, Art. 24)

Everyone has the right to the highest attainable standard of physical and mental health, without discrimination. Sexual and reproductive health is a fundamental aspect of this right.

f. **The right to found a family** (ICCPR Art. 23 (2))

If a proposed treatment of an infant, child or adolescent with an intersex condition carries a risk of reducing their fertility or ability to maintain a pregnancy in later life, the decision to carry out that treatment may limit the right to found a family.

4. Ethical principles

Gillam, Hewitt and Warne's (2010; 2012) principles are intended to guide discussion about the issues related to the management of intersex conditions. The principles all have equal ethical weight and the order of the list does not reflect an order of importance. Decision making in relation to these ethical principles should additionally incorporate consideration of human rights and the legal principles of Marion's Case as outlined below.

Gillam, Hewitt and Warne (2010) note that the aim of applying these principles to decision making for individual cases is not to fulfil every principle in its entirety. The final decision should be one that reaches a balance of the principles in light of the individual circumstances of the case, and in the best interests of the infant, child or adolescent receiving the healthcare.

a. Minimise physical risk to child

This principle relates to the risk of physical harm to the child (both short and long term) that is directly attributable to their intersex condition, for example, urinary passage obstruction. Any treatments proposed in the management plan should be proportionate to the level of physical risk resulting from the patient's particular condition. Gillam, Hewitt and Warne (2010) suggest that the following questions should be asked when considering this principle:

- What is the magnitude of the risk? How much harm would be done to the child if the risk eventuated? Would it mean loss of life, damage to an organ or body system, or less serious consequences?
- To what extent could this harm or damage be corrected after it occurred?
- What is the probability of the risk? How likely is it that the harm will occur?
- What measures are available to reduce the risk?
- How successful would these measures be in reducing the magnitude and the probability of the risk in comparison to other measures?
- Do the risk-reduction measures carry their own risks or known negative consequences, and if so, are these less than the magnitude and probability of the risks that the measures were meant to protect against?

b. Minimise psychosocial risk to child

It is important that while psychosocial risk factors are given appropriate weight in the overall decision-making process, decisions should not be unduly influenced by decision makers' perceived risk of social stigma or their predictions about the patient or family's level of embarrassment, shame about difference or desire for secrecy.

In particular, the risk of embarrassment about genital appearance and related stigma should not be given undue weight in the decision-making process at the expense of other human rights, ethical and legal principles. For example, using such psychosocial risk factors to justify the urgency of major and irreversible procedures in children who cannot consent, creates a risk to the ethical principle of leaving options open for the child's future autonomy and self-determination (see principle (e) below).

This principle relates to the types of psychosocial risks that Gillam, Hewitt and Warne (2010) suggest typically occur across different intersex conditions, including:

- risk of assigning the 'wrong' sex of rearing, meaning a gender that the child will later reject or feel uncomfortable with, potentially leading to depression or other mental health problems
- risk that the child will not be accepted by parents in the chosen sex of rearing, leading to impaired bonding and associated negative consequences
- risk of social or cultural disadvantage to the child, for example, reduced opportunities for intimate relationships, or reduced opportunity for meaningful employment and capacity to earn an income
- risk of social isolation, restrictions or difficulties, for example, caused by embarrassment or social stigma associated with having genitalia that does not match the gender in which the person lives.

Gillam, Hewitt and Warne (2010) suggest that the questions applied to the principle, 'minimise physical risk to child', also apply to determining the best course of action in terms of psychosocial risk. That is, assessing what the magnitude and probability of the risk is, and determining whether measures that could be taken to reduce the risk (including other types of support, as well as medical interventions), will be successful in reducing it.

c. Preserve potential for fertility

This risk is concerned with the socially-mediated concept of fertility, which has both physical and psychosocial components. Gillam, Hewitt and Warne (2010) note that the question to be answered is: 'What is the best course of action that will maintain fertility in a way that will be meaningful for the person with the intersex condition in their own social and cultural context?'. They also note that this is a subjective judgement that should be based on the prospective values of the person with the intersex condition, not those held by the decision makers.

The physical states related to fertility include having ovaries or testes, having viable gametes, and hence having the possibility of having one's own genetic children (whether conceived naturally or by assisted reproductive technologies), having the physical capacity for one's gametes to produce a pregnancy as a result of sexual intercourse and being able to carry a pregnancy (whether or not the foetus has been produced by one's own gametes). The psychosocial considerations relate to the potential for psychosocial harm to the person who is or will be infertile, which depends on the importance the person attaches to fertility, and their social and cultural context.

d. Preserve or increase capacity to have satisfying sexual relations

It is important in the decision-making process to give sufficient weight to the psychosocial adjustment of the future adult, rather than focusing on childhood only. One aspect of psychosocial adjustment in adulthood is the capacity to have satisfying sexual relations. Gillam, Hewitt and Warne (2010) emphasise that the capacity to have satisfying sexual relations is a complex matter involving values and subjective interpretations, not just medical facts.

It is recommended that those responsible for developing the management plan engage the advice of an appropriate professional who can bring perspective in relation to future sexual functioning, including on a non-heteronormative basis. Therefore, decisions about an infant's future sexual functioning should be informed by principles of sexual diversity, rather than being limited to addressing heterosexual sexual function only.

e. Leave options open for the future

This principle is related to the ethical obligation to minimise harm and maximise potential benefit for the person with the intersex condition. Gillam, Hewitt and Warne (2010) list ways to leave options open to provide for the future autonomy and self-determination of infants, children and adolescents diagnosed with an intersex condition, including:

- not removing gonadal tissue unnecessarily, even if it appears non-functional, to allow for the possibility that future advances in medical technology may provide an option for fertility in those previously considered infertile
- performing surgery in such a way that it leaves open the possibility of further surgery to change the assigned sex later on
- delaying surgery, which could be left until later in medical terms, so that the child or adolescent can have some input into decisions affecting their body.

f. Consider parents' wishes

This principle is one of the more difficult principles to balance, particularly if parents' wishes for the healthcare of their child are not in accordance with the management plan proposed by their treating clinician. The wishes and beliefs of parents hold significant weight in the decision-making process because they are guardians of the child, who have primary responsibility for protecting their child's best interests and will raise and care for the child.

Parents also have the final consent decision for any treatment where their child cannot provide their own consent. However, parents' wishes will not always be fully determinative in decision making, particularly in cases where their proposed approach may directly cause significant harm to their child.

Gillam, Hewitt and Warne (2010) recommend the use of a concept developed by Gold, Hall and Gillam (2011) called the 'zone of parental discretion', which not only recognises that the wishes of parents come first in relation to medical decision making for their children, but also places boundaries on their authority to make decisions. Specifically, 'the zone allows parents to make a wide variety of decisions on behalf of their child, even when such decisions may not strictly maximise benefit to the child, provided that they do not result in significant harm to the child' (p. 635).

The boundary of the zone of parental discretion is set where a decision may directly cause serious or significant harm to the child. This boundary is consistent with the legal principle that, in some instances, the proposed treatment is sufficiently serious that even parents cannot consent (see Legal principles in section 5). In these cases, it is recommended that hospitals advise parents that they must seek court authorisation for the treatment before it can proceed.

The following factors are relevant to this principle:

- How the child feels about themselves and their body is strongly influenced by parental attitudes and behaviours.
- The parent-child relationship is the basis of the child's overall wellbeing.
- Parents are the most knowledgeable about the family and social environment in which the child will be raised, and have the best sense of how others will react to him or her, now and in the long term.
- Parents have a primary ethical responsibility to protect and promote their child's interests and have the right to be allowed to carry out this responsibility.

g. Take into account the views of the child

This principle is relevant to cases where the patient is not an infant. As some patients require healthcare for an intersex condition in childhood, including at puberty, it is important that their thoughts, feelings, wishes and beliefs are taken into account when making treatment decisions. Gillam, Hewitt and Warne (2012) suggest that applying this principle will help respect a child or adolescents' developing sense of autonomy and promote their psychosocial wellbeing.

In relation to psychosocial wellbeing, Gillam, Hewitt and Warne (2012) recommend assessing gender identity, the way a child feels about their body and their social role from about the age of three. A child and adolescent mental health professional should play a central role in this assessment process. In relation to respect for the child's developing autonomy, Gillam, Hewitt and Warne (2012) recommend assessing the child's developing cognitive capacity to contribute to healthcare decisions, and giving these appropriate weight when making decisions (see the principle of Gillick competence in section 5 (a)).

5. Legal principles

In Marion's Case, the High Court found that court authorisation is necessary where a proposed medical or surgical treatment involves certain features, which indicate that, in order to best protect the child's interests, the decision to authorise the treatment should not fall within the ordinary scope of parental power to consent. It is important to note that the threshold questions posed by Marion's Case may themselves be the subject of debate and different opinions, and therefore require careful consideration. The tests of Marion's Case apply to all intersex conditions and to all contemplated treatments, not only surgical procedures.

a. Is the patient able to give their informed consent to treatment (Gillick competent)?

Decision makers should give consideration in each case as to whether a child or adolescent is Gillick competent. A young person under the age of 18 who is considered to be Gillick competent can consent to decisions about medical treatment on their own behalf, and these decisions are regarded with the same weight as would be given to adult patients. Competence to consent to or refuse medical treatment is an emerging competence, and should be assessed in relation to each medical treatment decision until the child is fully competent or reaches 18 years of age.

According to the Family Court of Australia (1998), to make an informed decision about whether to consent to a procedure, the child or adolescent must be able to:

- fully understand the circumstances
- generally understand the medical procedure or treatment proposed
- assess the medical treatments and alternative options
- freely wish to undergo the operation or treatment.

In cases where the child or adolescent receiving the healthcare is assessed as **not** being Gillick competent, their parent/s would usually provide consent on their behalf. In these circumstances, the child or adolescent's wishes should be considered as part of the body of evidence for decision making and given increasing weight according to their capacity to make informed decisions (Gillam, Hewitt and Warne, 2012).

In some cases, however, the treatment proposed is sufficiently serious that even a patient's parent/s may not give consent. According to the principles derived from Marion's Case, court authorisation to proceed with a medical or surgical treatment of an infant, child or adolescent with an intersex condition is required if the answer is yes to ALL of the following threshold questions.

b. Is the proposed treatment non-therapeutic?

The first threshold question of whether a medical or surgical treatment is non-therapeutic or therapeutic can be complex and controversial, and requires careful consideration for all cases where an intersex condition is diagnosed, including those with established treatment protocols.

The characterisation of a treatment as therapeutic or non-therapeutic is a medical decision that is the responsibility of the patient's treating clinician, in collaboration with the multidisciplinary medical, ethical and legal experts assisting with the development of the management plan. Consideration of the management plan against the medical management, human rights and, in particular, the ethical principles in this resource is likely to assist in the characterisation of a proposed treatment as therapeutic or non-therapeutic.

Most of the international debate about the healthcare of intersex conditions has been concerned with the ethics of performing genital surgery on infants and children. Generally, the focus of concern is not on medically necessary treatment done to avoid physical harm that is proportionate to the level of physical risk that the condition poses to the patient (for example, ensuring a functioning urinary system). The focus of concern is in cases where treatments for cosmetic effect are carried out for conditions that pose little or no physical risk to the patient (for example, to 'normalise' the person's body to make it look more typically male or female).

Treatments where the medical imperative for intervention is not obvious include those performed to protect against potential psychosocial stress associated with 'looking different' and being known by others to look different. Some advocates for intersex people now firmly argue that protection against potential psychosocial stress associated with looking different alone should no longer provide a satisfactory rationale for surgical intervention, and no longer provide a basis for characterising a treatment as therapeutic. Instead, the focus of treatment should be on functional outcomes appropriate for the child's age (Swiss National Commission of Bioethics, 2012).

In Marion's Case, the court defined a 'therapeutic' treatment as a procedure or treatment that is carried out to treat 'a malfunction of disease', however, this definition is not exhaustive. The treating clinician, in collaboration with the multidisciplinary team, will need to characterise any treatment as medically therapeutic or non-therapeutic, on a case-by-case basis, based on their informed knowledge of medical best practice and medical ethics.

Clinicians need to apply their medical understanding of those terms, as well as their knowledge of the patient's condition, to the likely future development of the infant, the risks associated with treatment, no treatment or delayed treatment, the details of the proposed treatment, and how the treatment will affect the physical and mental health of the child, and the future adult.

If the proposed treatment is **therapeutic**, court authorisation is not required. However, the treatment should still uphold the other medical management, human rights, ethical and legal principles described in this resource, in order to be justifiable as being in the best interests of the patient. If a proposed treatment is consistent with these principles, it is more likely to be able to be justified. If the proposed treatment is *non-therapeutic*, the next threshold question (below) needs to be addressed.

In order for the treatment to require court authorisation, treatments that are deemed non-therapeutic must also be invasive, irreversible and major, **and** there must be a significant risk of making a wrong decision in the best interests of the patient **and** the consequences of a wrong decision must be particularly grave (see Figure 1. Summary of decision-making principles).

If there is confusion about whether a treatment is non-therapeutic or therapeutic, then treating clinicians and the multidisciplinary medical team are advised to seek advice from expert colleagues, through formal mechanisms provided by their hospital, such as clinical ethics committees and legal counsel. In some cases, it will remain difficult to characterise the proposed treatment as therapeutic or non-therapeutic, or there may be an unresolvable disagreement between parties to the decision about the correct characterisation of the proposed treatment. In these circumstances, authorisation for the treatment must be sought from the appropriate court, which would usually be the Family Court of Australia.

c. Is the proposed treatment invasive, irreversible and considered 'major' treatment?

The second threshold question of whether a proposed treatment is 'invasive' 'irreversible' or 'major', requires reference to medical knowledge. While a surgical procedure is more readily characterised as invasive and irreversible than non-surgical medical treatment, other non-surgical medical treatment can still be major (for example, radiation or pharmaceuticals). Consideration of the management plan against the medical management, human rights, ethical, and principles for supporting patients and parents will assist in the characterisation of proposed treatments in the plan as invasive, irreversible or major.

If the decision is that the treatment is not invasive, irreversible or considered to be major, court authorisation is not required. If the treatment is considered to be invasive, irreversible or major, the next question in the analysis must be addressed. Where there is unresolvable disagreement about whether the proposed treatment is invasive, irreversible and major, court authorisation should be sought.

d. Is there a significant risk of making the wrong decision about the best interests of the child?

The third threshold question from Marion's Case requires decision makers to consider whether, if performing a non-therapeutic, invasive, irreversible and major procedure on an infant, child or adolescent who is not able to give informed consent (Gillick competent), there is a risk of a wrong decision. The level of risk should be assessed in terms of the probability of a wrong decision based on the available evidence.

A wrong decision in this context is a decision that the infant, child or adolescent would in future not consider to be in their best interests. A decision that is consistent with the medical management, human rights, ethical, and principles for supporting patients and parents in this resource has less risk of being wrong. However, it is not possible to mitigate this risk entirely when making decisions on behalf of a patient who cannot provide full, free and informed consent.

The level of this risk is not possible to determine definitively, but consideration is required as to how likely it is that the decision will be against their best interests. For example, for some intersex conditions, there is a material risk that the gender assigned at birth will be inconsistent with the person's gender identity in future. In these conditions, there could be a significant risk of making a wrong decision about a treatment such as irreversible surgery to make the patient's genitals look consistent with the norms of their assigned gender.

For other conditions, where there is more certainty about future gender identity, the risk of making a wrong decision about such surgery would be less significant. If there is a significant risk of making a wrong decision about the best interests of the child, then the next threshold question must be addressed. Where there is unresolvable disagreement about whether there is a significant risk of making the wrong decision about the best interests of the patient, court authorisation should be sought.

e. Are the consequences of a wrong decision particularly grave?

The fourth threshold question from Marion's Case requires decision makers to consider, if performing a non-therapeutic, invasive, irreversible and major procedure on an infant, child or adolescent who is not able to give informed consent (Gillick competent), and where there is significant risk of a wrong decision, whether the consequences of a wrong decision would be particularly grave.

This question requires consideration of long-term outcomes for people with intersex conditions, such as those considered by Gillam, Hewitt and Warne's (2010; 2012) ethical principles. The consequences of a wrong decision are less likely to be particularly grave if the management plan has been developed in accordance with the medical management, human rights, ethical and principles for supporting patients and parents in this resource.

Some of the possible consequences identified by the Australian Human Rights Commission (2009) of treatment for intersex conditions (including surgery) include:

- the child not having an opportunity to express their gender identity
- the child experiencing psychological damage due to an incorrect imposition of gender
- with certain conditions, infertility being certain, as opposed to probable
- possible complications from surgery, such as haemorrhage.

The above factors considered, if it is identified that there is a significant risk of grave consequences of making a wrong decision about treatment, or if there is disagreement, court authorisation must be sought.

List of acronyms

| | |
|----------------|--|
| DSD | Disorder of sex development |
| ICCPR | International Covenant on Civil and Political Rights |
| ICESCR | International Covenant on Social, Economic and Cultural Rights |
| MMC | Monash Medical Centre |
| RCH | Royal Children's Hospital |
| the department | Victorian Government Department of Health |
| UNCRC | United Nations Convention on the Rights of the Child |

