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ACT Government  
Chief Minister, Treasury and Economic Development Directorate  
Office of LGBTIQ+ Affairs  
GPO Box 158  
Canberra ACT 2601

Email: [intersex@act.gov.au](mailto:intersex@act.gov.au)

250–290 Spring Street  
East Melbourne VIC 3002 Australia  
Telephone +61 3 9249 1200  
[www.surgeons.org](http://www.surgeons.org)  
ABN 29 004 167 766

Dear Chief Minister,

**RE: *Variations in Sex Characteristics (Restricted Medical Treatment) Bill 2022***

**Introduction**

We thank you for the opportunity to provide feedback on Variations in Sex Characteristics (Restricted Medical Treatment) Bill 2022.

The Royal Australasian College of Surgeons (RACS) is a non-profit organisation training surgeons and maintaining surgical standards in Australia and Aotearoa New Zealand. As the leading advocate for surgical standards, professionalism in surgery and surgical education in Australia and Aotearoa New Zealand, the Royal Australasian College of Surgeons (RACS) is committed to taking informed and principled positions on issues of public health at both state and federal levels. RACS represents more than 7000 surgeons and 1300 Surgical Trainees and International Medical Graduates (IMGs) across Australia and Aotearoa New Zealand.

I am the Chair of Health Policy and Advocacy Committee (HPAC) at RACS, and it is the duty of our committee to provide strategic support on national and binational policy and advocacy issues, for RACS through the offices of the President and Vice President, and the Council. We lend our support to the paper submitted by the RACS ACT Committee (RACS ACT) who had requested that HPAC also provide a submission.

**Executive Summary**

HPAC fundamentally agrees with RACS ACT's submission and that "all individuals with variation in sex characteristics should be protected from harm and be free from external coercion, as well as receiving a high level of fully funded medical and psycho-social support."<sup>1</sup> HPAC also agrees that "the decision-making process and medical management plan for these individuals should be managed in a multidisciplinary team involving parents, legal guardians, clinicians and psycho-social

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<sup>1</sup> RACS ACT Committee., *RACS ACT response to proposed reforms to provide better care and support for people with variations in sex characteristics draft legislation*, 8 July 2022, p.1



experts.” The points of contention that we will examine in line with the questions provided are as follows.

- There needs to be an effective use of a multi-disciplinary team (MDT)
- The list of variations in sex characteristics provided needs to be refined and corrected
- Criminality of intervention; punitive measures such as imprisonment are too harsh
- The Issue of consent
- There needs to be more engagement with the parents of a patient child is required as too much is left to an independent body with veto powers
- There is no appeals mechanism for parents
- The selection of an expert panel and committee members is unclear

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

The general principles under section 10 do provide a framework, however complications still exist when we examine the clinical and legal parameters relating to ‘protected people’. RACS understands and acknowledges that where possible to medically defer a procedure under section 10(f) it is appropriate to do so until the child reaches an age of consent taking into account the physical and psychosocial welfare of the child. But we are concerned with respect to who defines what conditions/procedures are to be deferred? RACS notes that the term ‘deferrable medical treatment’ has been abandoned in this process as not being “legally precise.”<sup>2</sup> As phrased by our RACS Victorian Committee in a similar consultation held in 2021 “universal deferability” is an “assumption that does not consider the potential harms, physical and/or psychological, of deferring treatment.”<sup>3</sup> Furthermore, how is personal consent measured?

Most children with ambiguous genitalia cannot give consent, and it is damaging psychologically to a child not to have a gender assigned in some way using existing multi-disciplinary team (MDT) processes with the child (if able), parents (who are completely overlooked in this policy), surgeons, and psychologists being at the centre of that decision which is to be in the best interests of the child. The Urological Society of Australia and New Zealand (USANZ) informed RACS that now the human genome has been mapped, the diagnosis is often made using genetic testing identifying gene abnormalities leading to variations in the development of the gonad. With the development of the new terminology, the pair of clinicians managing a patient has evolved to a multidisciplinary team including a surgeon, an endocrinologist, a psychologist, a geneticist, and an ethicist.<sup>4</sup>

The current list has to be refined as many of the conditions are not disorders of sexual differentiation. Conditions such as hypospadias, epispadias and bladder exstrophy medically need to be corrected due to potential for lower urinary tract and renal damage and are not gender differentiation issues. As such, the legislation should be aimed at those who truly have disorders of sexual differentiation. The legislation should not include those with variations in sex characteristics (hypospadias, epispadias, bladder exstrophy) that can come to harm by treatment delays, and do not and should not need approval by an oversight committee as there are not gender or ethical issues to consider.

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<sup>2</sup> Chief Minister, Treasury and Economic Development Directorate., *Proposed reforms to provide better care and support for people with variations in sex characteristics Draft Legislation Consultation 2022*, p.6

<sup>3</sup> RACS Victoria State Committee., *Consultation on Victorian intersex oversight panel proposal*, 30 July 2021, p.1

<sup>4</sup> Urological Society of Australia and New Zealand., advice provided to RACS 27 September 2021

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

There is no clear definition for example of the term ‘intersex’ and which will impact a surgeon in their own determination when it comes to asking what constitutes *restricted medical treatment* under Section 7. Internal advice given from our fellows suggests that the definition should be ambiguous genitalia, not hypospadias, Klinefelters or congenital adrenal hyperplasia (CAH).<sup>5</sup> There has been a variety of terms in the past with some variations, these being ambiguous genitalia, Intersex abnormalities, DSDs (Disorders of sexual differentiation); and most recently: VSC (Variations in sex characteristics).

As surgeons we provide excellent state-of-the-art service to people affected. We deliver proper wrap around support to address medical, surgical, social and psychological needs of people and we deal with issues around secrecy and information sharing with respect to children. So, it is vitally important to make some fundamental distinctions. The following was advice provided to us by the RACS Aotearoa New Zealand National Committee.<sup>6</sup>

1. NOT operating on conditions such as undescended testes or hypospadias in early child can cause harm to these children (e.g., reduced fertility, higher risk of cancer, psychological problems)
2. Surgery for undescended testes and hypospadias account for over 90% of all cases, so are the vast majority of VSC
3. Clumping all the VSC conditions together is extremely unhelpful (it is such a broad range of mostly unrelated conditions with a wide variety of causes). This amalgam is the cause of much of the confusion and mis-information that occurs.

This has been confirmed by the Urological Society of Australia and New Zealand (USANZ) in that intersex or termed as DSD (disorders of sexual differentiation or differences of sexual differentiation) is poorly defined within the population. Intersex should not include conditions such as hypospadias, undescended testis or bladder exstrophy. USANZ has provided much research on the topic. The International Intersex Consensus conference of 2006 revised the terminology and the classification changing it to DSD. The classification of the population of patients was also revised and now includes the headings of sex chromosomal DSD, 46 XY DSD and 46XX DSD. These terms were felt to be better since they did not imply a gender for the patient.<sup>7</sup>

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

The criminality associated with any form of intervention is a very harsh and blunt punitive instrument under section 5 and its reference to the *Criminal Code*. If there is the tiered system, then who has the authority to define what is a serious intervention? RACS’s concerns about the criminalisation of surgical procedures under section 5 when it is being done for the welfare of an individual, is completely unprecedented in Australian law and will undoubtedly lead to a contraction to care

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<sup>5</sup> Health Policy and Advocacy Committee., Chair’s advice provided, 20 September 2021

<sup>6</sup> RACS Aotearoa New Zealand National Committee., advice provided to RACS, 30 October 2021

<sup>7</sup> Urological Society of Australia and New Zealand., advice provided to RACS 27 September 2021

provided due to the fear of prosecution. Every person should have the right to additional opinions, and if a parent who lives in the ACT decides to take a child to NSW, receives a different medical opinion from a multidisciplinary team, and pursues treatment based on that recommendation, they should not be punished with the threat of 1 year imprisonment under section 14.

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

Clinical experience is an essential criterion for any committee member, especially when attempting to oversee any treatment plans. An independent body being able to veto the desire of the parents to assign a gender and allow a child to socially integrate based on "human rights" when they bear no responsibility for looking after the child clinically or psychologically is troubling. A parent of a child with ambiguous genitalia would want to ensure that their child has as normal an upbringing as possible, and to socially integrate. It would be disconcerting if an independent committee that didn't know the family or the child, vetoed their decision as a parent who would always have the best interests of their child foremost in the minds.

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

Concerns exist for RACS that the expert panel under section 15 may make decisions for a general treatment plan based on social agendas and not based on the welfare of the child or their family. As the president of the expert panel has the power to appoint a committee to prepare a draft general medical treatment by the Minister, concerns exist as to how and who will be making the decision about the welfare of a child and if they are properly trained and experienced to do so. More emphasis needs to be made under section 17 to a medical practitioner and expert in the field as well as the parents of the child. Parents have limited if any say in the decisions affecting their child, when they know the child better than anyone on the committee and undoubtedly have the best interests of their child first and foremost.

The composition of the panel could be highly biased. Will it contain a person with a variation who has had a favourable outcome regarding their own care, or an unfavourable outcome? Is the psychologist one who has dealt with many successful treatments of children with variations or one who has seen only those who have had difficulty and have been more requiring of support? As such, the panel can be highly personally biased which could unfairly and inappropriately bias treatment decisions.

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

Current multidisciplinary teams are robust and considerate of the individual's needs now and in the future. They have been based on a medical team, together with psychologists and parents, who all have the child's welfare at heart. Oversight may be reasonable but there is also no mention of timelines that need to be met by the expert panel to reach a decision about the general or individual medical plan. There is however mention of a timeline for review after a decision has been made under section 37 of some 28 days.

If an untoward outcome occurs by not operating on an infant, then who bears the medicolegal responsibility for that poor outcome? Is it the expert committee or the surgeon who was not been allowed by law to operate when they felt that surgery was the appropriate medical management?

Appropriate medico legal protection for the treating surgeon needs to be in place and enshrined in the document.

Under Part 6 *Notification and review of decisions* the appeal mechanism seems long and arduous where the president of the committee can review the panel's decision (hence they are examining themselves which is hardly independent), only to then have to go to the ACT Civil and Administrative Tribunal (ACAT) often at expense for the family, stress and importantly time. Hence there appears to be no appeal mechanism for parents.

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

With respect to the rights of a child, this is a matter fraught with complexities which differs between states and territories. Any surgical procedure will have long lasting effects and may not be reversible. In SA the age is 16 for consent to medical treatment and healthcare. In fact, as far as we are aware only SA and NSW have such laws as to the medical treatment of children. But NSW veers into the issue of competence as well whereby a child of that age may lack.

- SA has *Consent to Medical Treatment and Palliative Care Act 1995* - ss6, 12
- NSW has the *Minors (Property and Contracts) Act 1970* - s49

Legally it would appear that a child younger than 18 years of age can independently provide consent for a medical treatment or refuse it. But this revolves around the 'Gillick competent' principle or a 'mature minor' (from the case of English House of Lords judgment, *Gillick v West Norfolk and Wisbech Area Health Authority* 1985 and *Secretary of the Department of Health and Community Services v JWB* 1992 is a leading decision of the High Court of Australia which adopts *Gillick*). Has this been properly considered by the government? Has there been a proper evaluation between consent or how young is too young, and competence or how to measure the mental capacity of a child to make up their own decision regarding their own medical care?

## Conclusion

RACS agrees that the management of patients with disorders of sexual differentiation or differences of sexual differentiation (DSD) or intersex subjects can be improved. It would appear that the introduction of this Bill is an attempt at doing so. Banning all procedures on patients with the diagnosis of the DSD is ill-advised because a patient can come to harm from not having an intervention done procedurally and within an optimal time just as much as they can come to harm from having a poorly performed intervention, a poorly timed intervention or an intervention that was not warranted.

RACS advocates for more studies to be undertaken to assess the outcomes of current management for this group of patients. It is likely that with the creation of a multidisciplinary team and joint decision-making, patient outcomes will be significantly improved without the need for any further intervention. It is also possible that genetic therapies will be developed, for example in congenital adrenal hyperplasia, to allow better outcomes and avoid the need for lifelong medication.<sup>8</sup> The involvement of a patient's parents is of equal importance.

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<sup>8</sup> Urological Society of Australia and New Zealand., advice provided to RACS 27 September 2021

RACS concurs with both the Society for Paediatric Anaesthesia in New Zealand and Australia (SPANZA) and the Australian and New Zealand Association of Paediatric Surgeons Inc (ANZAPS)'s argument that greater emphasis is needed to understand that "not all individuals have a named condition, and understanding of the chromosomal, hormonal and anatomical variation are key to considering what intervention, if any, may be appropriate."<sup>9</sup>

Yours sincerely,

Professor Mark Frydenberg  
**Chair, Health Policy and Advocacy Committee**

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<sup>9</sup> Society for Paediatric Anaesthesia in New Zealand and Australia (SPANZA) and the Australian and New Zealand Association of Paediatric Surgeons Inc (ANZAPS), Position statement, 27th April 2022, p.2