A Gender Agenda

Submission on the General Treatment Plan Application for the Clinical Management of Turner Syndrome under the ACT *Variation in Sex Characteristics (Restricted Medical Treatment) Act 2023.*

25 August 2025

Contents

Acknowledgements

This Submission

A Gender Agenda, henceforth referred to as 'AGA', thanks the ACT Government for the opportunity to make a submission under the public consultation provision of the *Variation in Sex Characteristics (Restricted Medical Treatment) Act 2023* legislation.

We welcome the opportunity to provide our feedback and input into the consultation process concerning the proposed general treatment plan for the innate variation in sex characteristics known respectively as Turner Syndrome (TS), 45 X, monosomy X, and 45, X0 among other clinical and diagnostic terminology.

We will refer to the specified variation as *45, X* throughout our submission, as an intentioned commitment to the de-pathologisation of our language. This also acknowledges community opposition to the use of the term '*syndrome*' as a descriptor of this, and other, innate variations in sex characteristics representing natural bodily diversity.

Our submission has been drafted by our Intersex Projects Coordinator, Gabriel Filpi, and has been reviewed and approved by our Executive Director, Dr. Vik Fraser.

Our Organisation:

A Gender Agenda is a Canberra-based, community-led and community-controlled charity, whose origins stem from grassroots community activism and self-advocacy.
For the past 20 years we have, and continue to, provide a wide range of peer and psychosocial support services, personal and community advocacy, systems navigation, education and training. Our work centers around supporting the needs and interests of intersex, transgender and gender diverse communities, and their families in the ACT and surrounds. We work closely with individuals, families, community organisations, professional bodies, and government to advocate for the needs and rights of the communities we serve.

AGA acknowledges the Ngunnawal and Ngambri peoples as the traditional custodians of the land on which we work. We pay our respects to the Elders of the Ngunnawal and Ngambri Nations, both past and present. We acknowledge and respect their continuing connections to land, water, and community.

As an organisation, AGA fundamentally operates from a human rights-based framework, respecting and celebrating the uniqueness and diversity of human experiences. We believe that there is no 'right' way to be male or female, masculine or feminine, and that all people are entitled to autonomy over their bodies, gender identity, and gender expression.

Our Submission

Overview

AGA would like to express our conditional support of the proposed General Treatment Plan, should our feedback be addressed and recommendations integrated in a revision of the proposed document.

This assessment is contingent on the proposed treatment being presented as an option provided to the individual and their families, alongside all relevant information required for the individual and their family to make an informed decision regarding treatment.

Such information includes communicating the relevant clinical detail included in the proposed General Treatment Plan application, around the risks and benefits of undertaking or not undertaking the treatment in an age-appropriate way with the individual, and in a way that is intelligible for the individual's family/guardian(s)/decisionmaker(s). Currently this is captured in the plan where it is stated that:

> "[the patient] *will be offered estrogen (and later, progesterone) replacement, after appropriate discussion with the patient and her caregiver(s) to optimise understanding of, and agreement with, the treatment plan".*

We recommend that this wording be amended, and consideration given to reflect the primary goal of providing the individual and their family with all relevant information to "*optimise understanding of…the treatment plan"*, as opposed to with the intent to *"optimise … agreement with, the treatment plan".*

This ensures that there are fair and equitable opportunities for alternative avenues or refusal, should the individual or so choose. Current framing presupposes that agreement to treatment is the desired outcome.

Our assessment is also contingent on flexible and accessible means of treatment discontinuation, in line with the following description in Part 2:

> *"At each review the question of comfort or discomfort with treatment effects will be addressed, and the girl and her caregiver(s) will have the opportunity to suspend or discontinue treatment at any time."*

Overall, AGA would like to acknowledge the considered and balanced nature of the proposed general treatment plan, specifically regarding concerns around the gender Identity of the individuals for whom treatment is proposed. We believe that the proposed treatment in this submission is well evidenced for the described subset of people with 45, X, that meet the conditions of the proposed plan.

We also believe that given the stipulations as to whom the plan applies and how it would function, that there is not a significant risk of harm or infringement on a person's rights and future decision-making, were the treatment to be offered or undertaken.

Given our conditional support of the application, we wish to address some areas we believe warrant further clarification and consideration. It is our position that these would need to be adequately addressed, and our recommendations incorporated in a revised version of the plan, before we could fully support its approval. Our thoughts and feedback have been detailed below.

Part 1. Details of the class of prescribed people.

Below we will outline our feedback on the criteria outlined in Part 1. Overall, the criteria in this section are considered and clearly outlined, particularly in relation to the sex characteristics of the individual, however we wish to raise points around points 2 and 3 in this section. Additionally, we wish to propose a fourth criterion be added, based on detail included later in the application.

Point 2

"2. for whom estrogen replacement is proposed"

As it is currently presented, we feel this inclusion criterion to be too vague. No definition is presented here to determine what constitutes an indicative a need for estrogen replacement therapy. More detail surrounding this can be intuited from information presented later in the application i.e. in Part 2 – Proposed treatment where estrogen replacement is recommended for those who have:

> *"chronic systemic estrogen deficiency"* and *"those who have evidence of ovarian dysfunction (elevated follicle stimulating hormone [FSH], with or without elevated luteinizing hormone [LH], with or without elevated anti-Mullerian hormone [AMH]..."*

We recommend that reference be made in Part 1, point 2, to define, or point to where definition of this criterion is provided. Without this clarity it could be reasonably assumed that a proposal for estrogen replacement therapy could be made arbitrarily.

Point 3

"3. who do not have Y-chromosomal material detected by current sensitive genetic techniques, including those with 45,X/46,XY mosaic karyotype (also referred to as mixed gonadal dysgenesis). Techniques used to ensure absence of Y-chromosome material in girls for whom estrogen replacement is proposed may include standard karyotype, chromosomal microarray or exome/genome sequencing (Gravhold 2024)."

While we welcome the inclusion of this criterion, and subsequent consideration of the sex characteristics of the individual this point raises two issues:

1. An absence of definition, or direction to the justification of the exclusion of people with detectable Y-chromosome material from this treatment plan, or any contraindications of the treatment for such individuals.
2. If, or how treatment would be approached for someone who meets all other criteria. has a female gender identity AND has detectable Y-chromosomal material (for whom such treatment may be desirable). For example, are there avenues for such individuals to be presented with relevant information about this treatment option if this may be something they desire?

In the interest of self-determination and providing individuals and their family/guardian(s)/decisionmaker(s) with access to information relevant to decision-making, AGA recommends seeking further clarity on these points. We further recommend the inclusion of the relevant detail in a General Treatment Plan, should one be approved.

Proposal: Point 4

In addition to the 3 criteria put forward in Part 1, AGA recommends the inclusion of a fourth criterion based on information around gender identity, and what has been labelled as *"gender variance"* throughout the application.

We believe that the information provided later in Part 1, and in detail in Parts 2, 3(c) and 6, warrants the explicit inclusion of a criterion stipulating an established feminine gender identity for persons to whom the treatment plan applies.

We suggest the following indicative text be added as a fourth criterion to this effect:

"4. Who has an established feminine gender identity (i.e. the individual identifies as a girl, woman, transfeminine etc.)"

While Parts 1 and 6 emphasise the rarity of gender identification outside of an expected *"typically female"* gender identity, there is also acknowledgment in Part 1 that:

> *"there is no published prevalence estimate for gender variance in TS"* and that *"that the prevalence is unlikely to exceed that observed in girls without TS"*.

Even if the prevalence of diverse gender identities in the 45, X population, aligns with that of the general female population, there is still a significant chance that prescribed persons in this category could have a gender identity that is not *"female",* warranting specific consideration[1].

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[1] Eitel, K.B., Zenno, A., DiBlasi, C., Fechner, P.Y., Hodax, J.K. (2024). Gender-diverse youth with Turner syndrome: special management considerations. *Journal of Clinical Endocrinological Metabolism Case Reports*, 2, luae076.

It is important to note here, in reference to our previous commentary on Point 3, that the presence of detectable Y-chromosome material, cannot, and should not be used as an indicator of diverse gender identity.

This recommendation is based on the proposed treatment in Part 2, that states that:

> "[people] *with TS who have confirmed female gender identity... will be offered estrogen (and later, progesterone) replacement."*

This is preceded by information that states:

> *"In keeping with standard practice for children with VSC under the care of the paediatric endocrinologists at Canberra Hospital, assessment of gender identity is undertaken and documented on an ongoing basis by the primary clinician at initial presentation and throughout the child's care. In addition, when clinically indicated based on suggestion of gender variance raised by the child or caregiver(s), supplemental gender assessment may be performed by appropriately trained staff of the VSC Psychological Support Service (VSC PSS) for any child whose family accepts referral to the service."*

This raises questions for individuals who have not received care through the paediatric endocrinologists at Canberra Hospital, public ACT Health services, and for families who do not accept a referral to the VSC PSS.

As such, we wish to address the need for a provision in the General Treatment plan that requires assessment of the individual's gender identity, prior to the provision of the proposed treatment, and clarification around the means and responsibility for this (i.e. does the prescribing doctor need to undertake this assessment or verify that this has been undertaken?).

This application also provides its own evidence and justification for the inclusion of this criterion in Part 3 where it is stated that:

> *"Discomfort associated with the physical changes of puberty could potentially occur as a psychological consequence of estrogen replacement. However, determination of female gender identity and appropriate planning and education prior to treatment initiation should reduce the chance of this outcome. If psychological distress were to develop, treatment could be paused, advanced more slowly to allow time for adjustment, or discontinued."*

This is again reiterated in Part 6 of the application:

> *"if concerns regarding changes to sex characteristics were to arise, estradiol/progesterone could be discontinued, and testosterone treatment could be undertaken after appropriate detailed assessment according to standards of care for gender variant individuals."*

We believe that this is an essential consideration that should be reflected explicitly in the criteria presented in Part 1 of the General Treatment Plan. This is further supported by Part 6 of the application that states definitively that:

> *"the child's female gender identity will be confirmed prior to treatment initiation."*

Given the clarity and certainty of this intent throughout the application, we believe that it is not unreasonable to include this outright in Part 1.

Thank you again for the opportunity to provide commentary on the application for this General Treatment Plan. A Gender Agenda is grateful for your time and consideration of our submission.

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