InterAction
for Health and
Human Rights

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Submission on the General Treatment Plan for 45,X0 Turner syndrome

29 August 2025

1 Contents

2 This submission

Thank you for the opportunity to make a submission on the General Treatment Plan Application for 45,X0 Turner syndrome.

We warmly welcome the commencement of these public consultation processes for General Treatment Plans, and the opportunity to provide feedback.

InterAction for Health and Human Rights is a national charity and Public Benevolent Institution. Our name is new, introduced on the merger of Intersex Peer Support Australia into Intersex Human Rights Australia. Legally we remain registered as Intersex Human Rights Australia, a Public Benevolent Institution.

We provide psychosocial and peer support services, and engage in training, information and education, and policy work. InterLink is uniquely a professional, peer-run psychosocial support service providing individual and group counselling for people with innate variations of sex characteristics (intersex variations/differences of sex development) and family members delivered by an intersex community-controlled organisation. It is designed and led by Bonnie Hart. Intersex Peer Support Australia is now a program of InterAction, engaging in peer support and community development work. Kylie Bond leads the delivery of these services. Our policy program is led by Dr Morgan Carpenter. Morgan Carpenter wrote this submission, with input from Kylie Bond and Bonnie Hart, and review by our board and staff teams.

Please contact us at info@interaction.org.au in case of any queries or follow-up. We are happy for this submission to be published in full.

2.1 Statement on competing interests

Dr Morgan Carpenter led the drafting of this submission, while he is also a member of the Restricted Medical Treatment Assessment Board and some of its subcommittees. As a small organisation, we have not been able to address any perceived competing interests by allocating the drafting task elsewhere. However, the task of preparing this submission has been approached by focusing on the proposed GTP application itself, the evidence and approach it articulates, and our organisational values.

3 Irreversible treatment with neither assent nor consent

The GTP states that hormone treatment will produce irreversible consequences, without either assent or consent. The application states on page 9:

> "Treatment delayed until the individual is competent to provide her own assent or

> consent would be an acceptable, although suboptimal choice; the timing and dosage of estrogen replacement are paramount, as the benefits of early low-dose treatment cannot be replicated by later initiation of higher dose treatment."

While noting irreversible changes on page 5:

> "The effects of estradiol in stimulating breast and uterine maturation are not reversible, although some reduction in volume and breast softening may occur on withdrawal of treatment. Menses are reversible with cessation of regular estrogen replacement; however, this will result in endometrial atrophy, the usual consequence of which is irregular vaginal spotting or bleeding"

These produce a situation which is not acceptable. We cannot support any GTP that *builds in* the possibility of irreversible treatment that modifies sex characteristics without either assent or consent when acceptable alternatives exist. Lack of assent and consent is a fundamental problem with the described preferred approach to pubertal induction.

However, this does not imply a need to wait until the child reaches age 16 or 18. Our expectation is that most children and adolescents with 45,X0 Turner syndrome will be able to understand the nature of the treatment proposed, and have and express a view on it, between age 11-13, with the support available from the ACT's hospital Psychosocial Support Service and community-based peer and psychosocial support.

In our view, then, some delay is "optimal" and, in our view, a requirement of the guiding legislation in the ACT, to enable the patient to either assent or consent, *so long as* delay does not cause adverse consequences, and *so long as* treatment can commence during the typical window for pubertal commencement.

In our view, the possibility of irreversible treatment with neither consent nor assent arises directly out of a failure of the GTP drafters to contemplate, understand and articulate the core role of professional psychosocial support services in helping children to understand their bodies and diagnoses, and freely develop and express their own values and preferences for treatment (Liao 2022a; 2022b; Roen 2019; Liao and Roen 2019).

A treatment plan is not required to treat people who are able to consent, meaning that there is no sound rationale for this application, however, we address other issues with the application below.

4 Identity, values and preferences for treatment

The application states on page 2:

> "Gender identity is also typically female in TS, as demonstrated in a large study performed by the German DSD-Life consortium (Kreukels 2018). However, 4 cases of gender variance in TS have been reported (Eitel 2024; Pinheiro 2024). Although

> there is no published prevalence estimate for gender variance in TS, the fact that only 4 such cases have been reported among the many thousands of patients followed in clinics and large databases over almost a century since the initial publications describing the condition (Turner 1938; Ullrich 1930) indicates that the prevalence is unlikely to exceed that observed in girls without TS."

The application also states:

> "Because individuals with TS have chronic systemic estrogen deficiency, the primary goal of the proposed treatment plan is to replace the missing estrogen and restore age-appropriate physiologic serum estrogen concentrations."

And on page 10:

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

This material is poorly stated and appears likely to produce adverse outcomes for people with non-typical gender identities. It proposes a "one size fits all" approach which does not take individual values and preferences into account; the possibility of such differences is effectively disregarded.

Evidence exists of situations where Australian biomedical clinicians have commenced sex hormone therapies in line with sex registration even in contexts where the patient has a gender identity at variance with sex registration (*Re: Kaitlin* 2017; Carpenter 2018), and where prior engagement with psychosocial support services could have pre-empted this harm.

In every population there is a need to attend respectfully and appropriately to the needs of the subset of people in this population with identities that do not align with birth registration. Biomedical clinicians should never take gender identity, values and preferences for granted, and should not seek to undertake assessment of these matters themselves. Assessment of these matters should occur through long-term engagement between patients and psychosocial clinical professionals.

Clinical research in this space is subject to many forms of bias and methodological inconsistency and so has limitations that are not disclosed in the GTP. Reporting rates may not reflect actual frequency, in that individuals may not report their gender identity to clinical practitioners in paediatric settings, or not report their identity at all in clinical settings. Multiple different conceptions of gender identity, gender identity disorder, gender distress and gender dysphoria exist with different clinical criteria and reporting. Further, engagement by people with innate variations of sex characteristics with clinical research has been limited, hampering long term follow-up, in particular due to adverse experiences in clinical settings, and non-disclosure of diagnostic information and clinical histories (Lee et al. 2016).

Values and preferences for treatment extend beyond gender identity. Individuals may have values and preferences for physical appearance and sexual and reproductive health that should be ascertained by qualified, professional psychosocial clinicians, and not by biomedical clinicians.

5 The role of psychosocial and peer support

The 2006 and 2016 Consensus Statements and their appendices (Hughes et al. 2006; Houk et al. 2006; Lee et al. 2016) establish an important role for peer and psychosocial support, including in delivery of healthcare services.

Despite this, biomedical clinicians are known to have limited understanding of the role of psychosocial and peer support (Liao 2022a; 2022b; Liao and Roen 2019). This means that psychosocial support is often seen as a crisis intervention tool, to be called upon if a child, parents or carers experience distress that a biomedical professional feels unable to address, or if a patient appears to experience gender dysphoria. Peer and psychosocial support are not understood as long term, core components of healthcare for people with innate variations of sex characteristics and our families (Carpenter 2024; Hart and Shakespeare-Finch 2021). These errors are evident in the application, which 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."

In our view, this section of the application is entirely inappropriate. It places a psychosocial assessment in the hands of a biomedical professional who lacks the professional expertise of the hospital service – actually termed the VSC *Psychosocial* Support Service. It regards this as standard practice when a specialist, professional Psychosocial Support Service exists and is charged with providing a combination of targeted psychological, social work and informational supports to patients and family members. It treats a biomedical clinician as the centre of all healthcare delivery to the patient and family. It treats the psychosocial support service as if it is a gender dysphoria service, or a crisis intervention service - once a biomedical clinician considers that such a crisis exists. It treats utilisation of the Psychosocial Support Service as an optional extra.

The hospital Psychosocial Support Service must not be sidelined. must be engaged early and participate fully in multidisciplinary discussions around diagnosis, treatment and follow up care. The biomedical staff must rely on the Psychosocial Support Service for assessment of values, preferences, and age-appropriate discussion around bodies, social roles, and disclosure of diagnostic information. The Service can also assist in addressing concerns about

disclosure to third parties, particularly given that patches may be visible in the course of school and social activities.

On page 8, the application states:

> "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."

Puberty is a challenging and sometimes discomforting time for all adolescents, irrespective of whether or not they have an innate variation of sex characteristics. These issues, including "education" must be treated as the role and purview of the Psychosocial Support Service, complemented by community-controlled psychosocial and peer support.

6 Hospital and community-controlled services are complementary

Hospital and community-based services, and local and national services are complementary. The ACT government does not fund community-controlled services for people with innate variations of sex characteristics (i.e. InterLink and Intersex Peer Support Australia), but practices should nevertheless integrate them into service delivery.

As peer support workers and community advocates, we believe psychosocial and peer support are foundational to health and wellbeing for individuals with 45,X0 (Turner syndrome). Our lived experience and community knowledge offer insight into the complex emotional, and social challenges which are too often clinical or misunderstood. Psychosocial care is often only recommended when distress becomes apparent, this distress can be prevented when psychosocial and peer support is a proactive inclusion.

In our view, both peer and psychosocial support must be regarded as core services - including community-controlled psychosocial and peer support services as well as hospital services. We envision psychosocial support at the heart of service delivery. For parents and carers this means supporting them to understand their child's diagnosis and long-term implications, and supporting them to live with a child whose body and health needs may be different from their expectations. For children and adolescents with innate variations of sex characteristics, this means supporting them to understand their diagnosis and body in age-appropriate ways, and to help them to freely develop and express their own values and preferences for any treatment. Access to national community-controlled psychosocial and peer support services increases the probability of connecting with individuals and parents with the same diagnosis and healthcare concerns.

Services like InterLink and Intersex Peer Support Australia, now part of InterAction, provide trusted safe spaces for understanding, connection and affirmation. They enable individuals to meet with others who share experiences of living with innate variations of sex characteristics, who share their lived experience or health concerns, sometimes for the first time outside of a clinical setting, and this experience is often transformative, fostering empowerment and wellbeing.

National community-controlled peer and psychosocial support services, provides greater access to peers, and create national and international connectivity. These services, especially those that are community controlled, play a central role in preparing and supporting young people and their families through these life stages. The best outcome is when medical and community services collaborate, when consent is truly informed, and people with 45,X0 are supported to understand and advocate for their own bodies.

7 Assessment and review deficiencies

The application states on page 5:

> "Regular clinical follow-up (which may include physical examination, laboratory investigations and transabdominal pelvic ultrasound) will be undertaken to assess response to treatment and occurrence of any expected or unexpected outcomes. 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."

The application is not clear about which practitioners will be party to these reviews. Psychosocial matters, including comfort and discomfort, must be addressed through long-term engagement with, and review by, staff with the appropriate professional specialisms, including the hospital-based Psychosocial Support Service.

The child/adolescent must also be given opportunities for engagement with psychosocial support staff independently of parents.

8 Research and evidence deficiencies

The application states on pages 4-5:

> "Because no estrogen formulations are specifically designed or approved for children and teenagers, the protocols recommended by the Guidelines (Gravholt 2024) and others (Donaldon 2019; Dowlut-McElroy and Shankar, 2022) use an approach of tailoring the adult estrogen formulations for the needs of younger, smaller girls. The most convenient approach is the use of fractionated matrix patch systems, if acceptable to the patient (Ankarberg-Lindgren 2014; Donaldson 2019). The process involves cutting the estrogen matrix patch, such as Climara®,

> Estraderm®, Estradot® or Estramon®, into fractions to provide the lower dosages required in the early stages of puberty … If transdermal estradiol is unavailable or unacceptable, oral estradiol valerate (Progynova®), which is converted to 17β-estradiol by the liver, may be used, but this form of estrogen is more difficult to administer in ultra-low doses, poses a greater likelihood of increasing clotting proteins due to its effects on the liver"

Further, on page 7, the application states:

> "Transdermal estradiol matrix patches are approved by the Australian Therapeutic Goods Administration (TGA) for treatment of symptoms of estrogen deficiency associated with menopause. There is no estrogen replacement preparation specifically formulated or approved for use in paediatric patients. […] The risks of treatment with estrogens in general, and transdermal estradiol in particular, derive from experience of use in much older women, who have an entirely different risk-benefit profile from the patients to whom this treatment plan applies."

This describes quite a remarkable failure in clinical research and practice, where children are treated as if they are simply small adults, and this framing has simply been adopted into routine clinical practice despite the risks to child health arising from inaccurate dosage.

We further note an inadequate attention in clinical research to long-term outcomes of hormone treatment commencing in puberty.

Research on psychosocial and long-term outcomes is neglected and any approved GTP must place greater emphasis on these matters.

Given the limited evidence base for treatment, treatment with gel should be available as an alternative to patches for adolescents and their parents or carers when they are able to administer these with greater dose accuracy.

9 Referencing deficiencies

The references are predominantly old and inappropriate sources, dating back to the 1970s. In and of itself, this is remarkable given the deficiencies in clinical research identified in our review of this GTP proposal.

We acknowledge that data in relation to innate variations of sex characteristics is scarce, due to a history of non-disclosure to patients and adverse outcomes impacting participation in research (Lee et al. 2016), and limited resourcing for community-based participatory research. We also understand that these issues may contribute to an absence of clinical research on the use of hormone treatment to induce puberty.

Bearing these in mind, and with the exception of 2006 and 2016 clinical "consensus statements" (Hughes et al. 2006; Lee et al. 2016), we recommend that sources more than one

decade old should be rare and should not be relied upon to determine or justify current biomedical treatment decisions.

The materials predominantly focus on biomedical aspects of health. Psychosocial experts should be cited for matters relating to psychosocial and mental health, including matters relating to disclosure, body appearance and function, and values and preferences.

10 Application drafting deficiencies

We would like to see a succinct, single sentence description of the target population for this GTP.

The application has clearly been written by a biomedical expert. Biomedical drafters of applications for treatment must ensure collaboration with the hospital psychosocial support service in drafting and submitting applications, to ensure adequate and professionally appropriate division of responsibilities and attention to psychosocial support needs.

We strongly recommend that all applications drafted by staff of Canberra Health Services be developed and submitted will the full and collaborative participation of the hospital Psychosocial Support Service.

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