SAFE & EQUAL ACCESS

Submission to the Australian Commission on Safety and Quality in Health Care

Consultation on the National Safety and Quality Standards for Assisted Reproductive Technology Services

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INTRODUCTION

Equality Australia appreciates opportunity to make a submission to the Australian Commission on Safety and Quality in Health Care's (**the Commission**) consultation on initial draft of the National Safety and Quality Standards for Assisted Reproductive Technology Services (**the Standards**).

Equality Australia is a national LGBTIQ+ organisation dedicated to achieving equality for LGBTIQ+ people. Equality Australia brings together legal, policy and communications expertise, along with thousands of supporters, to address discrimination, disadvantage and distress experienced by LGBTIQ+ people. In recent years, Equality Australia has advocated for equitable pathways to parenthood and made several submissions to law reform processes concerning surrogacy and assisted reproductive technology.

We welcome the Commission's development of nationally consistent standards for assisted reproductive technology (**ART**) services. ART is an area of healthcare in which consumers can face significant financial, physical and emotional costs, often over an extended period. The quality and safety of ART therefore depends not only on clinical safety, but also on whether consumers can access services equitably, receive accurate and clear information, provide genuinely informed consent, and have their individual circumstances and family structures respected and accommodated.

In particular, the Standards should recognise that ART consumers include same-sex couples, solo parents by choice, trans people, intersex people, and people with diverse family structures and parenting arrangements.

Clinics also owe duties to gamete donors, many of whom are recruited from LGBTQ+ communities. While there is limited information available on the sexual orientation of clinic-recruited donors in Australia, research from UK found a high proportion (nearly 20%) were gay or bisexual men. [1]

They should also recognise that ART services have responsibilities to donor-conceived people and their families that extend well beyond the clinical treatment itself.

This submission provides feedback and recommendations on specific sections in the draft Standards.

Our key recommendations are that the final Standards should:

- expressly incorporate equitable access, accessibility and non-discrimination as components of safety and quality;
- expressly refer to consumer needs based on gender identity, gender expression and sex characteristics, in addition to sexuality, relationship status and parenting arrangements, where relevant;
- strengthen complaint handling, consumer feedback and participation mechanisms**;**
- strengthen requirements for accurate, transparent and accessible information about ART services, costs, donor availability and waiting times;
- strengthen requirements for accurate, secure and accessible healthcare records, recognising the lifelong importance of records and information for donor-conceived people and their families;
- ensure ART providers have appropriate workforce training and capability to provide inclusive, non-discriminatory and culturally safe care to diverse consumer populations;
- ensure counselling is inclusive and appropriately tailored to the circumstances and needs of individual consumers and families;
- strengthen specimen identification and matching safeguards to minimise the risk of errors involving reproductive material;
- strengthen requirements concerning donor records, donor limits and the proactive communication of significant medical information; and
- encourage data collection on diverse populations while ensuring the use of demographic information is transparent and based on informed consent.

[1] Tuppy Freeman, Vasanti Jadva, Emma Tranfield and Susan Golombok, 'Online Sperm Donation: A Survey of the Demographic Characteristics, Motivations, Preferences and Experiences of Sperm Donors on a Connection Website' (2016) 31(9) Human Reproduction 2082.

INCORPORATE EQUITY AND NON-DISCRIMINATION PRINCIPLES

The draft Standards contain a number of important references to particular consumer populations and to individualised care. However, equitable access and non-discrimination are not sufficiently prominent as overarching principles.

This should be addressed at the beginning of the Standards under Item 1.01.

We recommend that the Standards expressly state that ART providers are expected to provide safe, high-quality and equitable care, without discrimination, and to identify and address barriers to access and differences in outcomes experienced by particular consumer populations.

Barriers to healthcare created by exclusion and discrimination are themselves a safety and quality issue. Where a consumer avoids care, delays treatment, receives inappropriate treatment or cannot access appropriate treatment because of discrimination or a failure to understand their needs and circumstances, this can result in poorer health outcomes.

The available academic literature demonstrates the need to prioritise equitable access and non-discriminatory practice.

A systemic review of the experience of LGBTQ+ people and their partners treated for fertility-related care (considering 25 studies from around the world - 16% of which were Australia-based research) identified significant issues regarding access to equitable care. Concerns identified through these studies included:

- standardised forms designed for opposite-sex couples
- insufficiently tailored information and education for same-sex couples and non-binary patients
- discrimination, negative interactions with staff and "gatekeeping".[2]

A 2024 Canadian study also identified similar barriers within the fertility care context. This included the use of inappropriate terminology and questionnaires, misunderstanding of social infertility, and assumptions about gender and relationships, a lack of tailored services, and non-birth parents feeling neglected in the process.[3]

Particular attention should be drawn to the experience of trans people accessing ART, as there is evidence that trans people experience significant barriers and discrimination in healthcare. Discriminatory treatment can lead to disengagement or avoidance of medical care altogether.

In a national survey of 928 trans Australians, 26% reported discrimination when accessing healthcare.[4]

Research involving more than 1,600 trans Australians found that experiences of gender insensitivity in healthcare were common, including in general practice and hospital settings. Experiences of gender insensitivity were associated with lower uptake and less frequent HIV/STI testing, demonstrating that discriminatory or inappropriate healthcare experiences can directly affect health-seeking behaviour and health outcomes.[5]

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[2] Abrirami Kirubarajan, Priyanka Patel, Shannon Leung et al, 'Cultural Competence in Fertility Care for Lesbian, Gay, Bisexual, Transgender, and Queer People: A Systematic Review of Patient and Provider Perspectives' (2021) 115(5) Fertility and Sterility 1294.

[3] Zoé Benoit, Natalie O Rosen, Mathilde Renaud, Sophie Bergeron, Audrey Brassard and Katherine Péloquin, '"Doctors Asked if We Are Sisters or Friends": Experiences of 2S/LGBTQIA+ Couples in the Context of Medically Assisted Reproduction' (2024) 33(3) *Canadian Journal of Human Sexuality* 429.

[4] Ingrid Bretherton, Emily Thrower, Sav Zwickl, Alex Wong, Daria Chetcuti, Mathis Grossmann, Jeffrey D Zajac and Ada S Cheung, 'The Health and Well-Being of Transgender Australians: A National Community Survey' (2021) 8(1) *LGBT Health* 42. Available at: https://journals.sagepub.com/doi/10.1089/lgbt.2020.0178.

[5] Shoshana Rosenberg, Denton Callander, Martin Holt, Liz Duck-Chong, Mish Pony, Vincent Cornelisse, Amir Baradaran, Dustin T Duncan and Teddy Cook, 'Cisgenderism and Transphobia in Sexual Health Care and Associations with Testing for HIV and Other Sexually Transmitted Infections: Findings from the Australian Trans & Gender Diverse Sexual Health Survey' (2021) 16(7) *PLOS ONE* e0253589. Available at: https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0253589.

While research specifically examining inclusion in Australian ART services is limited, there is clear evidence that trans people face barriers even in accessing general healthcare, including a lack of knowledgeable providers, discriminatory treatment and complex referral pathways.[6]

Barriers to health care identified in the systemic review of international research on access to ART for trans and non-binary patients included:

- experiences of distress and discomfort at the inappropriate use of pronouns and gendered documentation
- challenges with appropriate care for those on hormone treatment
- distress around "routine" care such as transvaginal ultrasounds, indicating a need for greater patience and understanding by clinicians working with this cohort of patients. [7]

RECOMMENDATION

Amend Items 1.01 and 1.05 to require ART service providers to promote equitable access to ART services, provide care without discrimination, and identify, monitor and address barriers to access experienced by consumer populations including LGBTIQ+ people.

Standards 1.09 and 3.23 appropriately require ART providers to identify consumer populations at greater risk of avoidable differences in health outcomes, and requires support for workforces to meet individual needs of certain cohorts. These are stated to include people with disability and people with diverse backgrounds, sexualities, relationship statuses and parenting arrangements.

While 'diverse backgrounds' is appropriately defined in the draft Standards to include sexual orientations, gender identities, gender expressions and sex characteristics, the definition is buried at the end of the document, and there is some inconsistency in which cohorts get a mention in primary text and those that are only included in the broader definition. This may inadvertently infer a hierarchy of importance.

The current wording risks treating gender diversity as implicit within "diverse backgrounds" or "sexualities". Gender identity is distinct from sexual orientation and should be identified as such. Diversity of sex characteristics is also another distinct difference.

For example, a trans man or non-binary person may require fertility treatment and have particular needs to address. They may for instance have been taking gender-affirming hormones and may need individualised clinical advice about pausing or changing hormone treatment in connection with fertility treatment.

Further, people with innate variations in sex characteristics (also known as 'intersex') may be seeking treatment because of medical infertility specifically related to their variation, such as people with an MRKH diagnosis, where options like IVF, surrogacy and uterine transplants may all need to be considered.

RECOMMENDATION

Provide a more consistent approach to identifying priority consumer populations in Standards 1.09 and 3.23. This could be achieved by moving the definition of 'diverse backgrounds' to appear under these Items, or by expanding the text of these two standards to ensure that gender identities, gender expressions and sex characteristics are included alongside the reference to sexualities.

FEEDBACK AND COMPLAINTS

ART consumers may be reluctant to complain where they are financially, emotionally or clinically dependent on a provider, and some consumers who have negative experiences may simply leave the service rather than complain.

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[6] Bridget Gabrielle Haire, Eloise Brook, Rohanna Stoddart and Paul Simpson, 'Trans and Gender Diverse People's Experiences of Healthcare Access in Australia: A Qualitative Study in People with Complex Needs' (2021) 16(1) *PLOS ONE* e0245889. Available at: https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0245889.

[7] Zoé Benoit, Natalie O Rosen, Mathilde Renaud, Sophie Bergeron, Audrey Brassard and Katherine Péloquin, '"Doctors Asked if We Are Sisters or Friends": Experiences of 2S/LGBTQIA+ Couples in the Context of Medically Assisted Reproduction' (2024) 33(3) Canadian Journal of Human Sexuality 429.

The Standards (Items 1.07 and 1.08) should therefore require providers to actively encourage and support feedback and complaints, including from people who have stopped using the service, and make clear that consumers must be able to raise concerns without fear that doing so will adversely affect their treatment or access to care.

The Standards should also require providers to analyse feedback and complaints to identify systemic issues and avoidable differences in experiences and outcomes between consumer populations, including discrimination or barriers experienced by LGBTIQ+ people.

Complaints should be used not only to improve individual services but to identify and address broader risks to safety, quality and equitable access.

Consumers should receive appropriate information about the outcome of their complaint and any action taken in response. The effectiveness of feedback and complaints systems should also be regularly reviewed to ensure that they are accessible, responsive and delivering meaningful improvements.

The Standards currently have a gap where complaints have identified the need to progress disciplinary processes where the outcome of an investigation of the complaint indicates that staff behaviour has been inappropriate or unsafe. More clarity on the human resource investitive process could be added to address this.

RECOMMENDATION

Amend Standards 1.07 and 1.08 to include requirements that ART service providers:

- actively encourage and support consumers and people conceived through ART to provide feedback and make complaints through accessible and confidential complaints mechanisms;
- take all steps necessary to ensure that making a complaint does not adversely affect a consumer's access to, or treatment by, the service;
- analyse feedback and complaints to identify systemic issues, discrimination and avoidable differences in access, experiences and outcomes between consumer populations;
- use feedback and complaints to improve safety, quality and equitable access to care;
- provide complainants with timely and appropriate information about the outcome of their complaint and any action taken; and
- regularly review the effectiveness of their feedback and complaints management systems.

The Standards should address a situation where the investigation of a complaint or incident necessitates a human resource response, where staff conduct has been identified as falling below the expected standards.

COLLECTION AND USE OF INFORMATION ABOUT CONSUMER POPULATIONS

Standard 1.10 requires ART providers to use information about their consumer populations to inform planning and delivery of services.

We support this requirement. However, the Standards should also address how such information is collected and used, and which personnel have direct access to the information.

Information concerning sexual orientation, gender identity, sex characteristics and family structure can be sensitive personal information. Consumers should understand why information is being collected, how it will be used and who will have access to it, and what information will be de-identified.

Personal information of consumers should only be shared with the explicit consent of a consumer with clinicians directly involved in clinical care. Particular care is required to prevent inadvertent disclosure or “outing” of a consumer to staff who do not need the information to provide their care.

The Standards should therefore require providers to collect demographic information only where there is a legitimate purpose, to explain that purpose to consumers, and to handle the information consistently with privacy obligations.

RECOMMENDATION

Amend Standard 1.10 to require ART providers to:

- obtain consent for the capture and sharing of sensitive information on sexual orientation, gender identity, sex characteristics and family structure;
- explain to consumers why demographic information is being collected;
- obtain informed consent for the use of information;
- collect only information reasonably necessary for service delivery, quality improvement, safety or other legitimate purposes;
- protect the privacy and confidentiality of that information; and
- use population data to identify and address inequities in access, experience and outcomes.

HEALTHCARE RECORDS AND ACCESS TO INFORMATION

Standard 1.11 requires healthcare record systems to facilitate a consumer's access to their healthcare record.

The Standards should make clear that obligations concerning access to records also need to take account of the rights and interests of people conceived through ART, particularly those born via donor conception.

Donor-conceived people may need access to information held by an ART provider many years or decades after treatment has occurred.

Identity-release donor information must be kept up to date, and information shared between all parties (donor, the family, the donor-conceived person) to the extent possible (depending on legislation, and personal preferences).

This can also require maintenance of contact and information-sharing preferences for all parties in states or territories that do not have a donor register. For example, it should be possible for parents (or an older donor-conceived child) to register interest with a clinic about contact with other donor-siblings, and for the clinics to make these connections. This is less of a priority in states/territories with existing donor registers, noting our preference would be for a national register to be created.[8]

RECOMMENDATION

Amend Standard 1.11 to expressly recognise the importance of accurate, complete, secure and accessible records for donor-conceived people and their families, and donors, including records necessary to facilitate access to donor and family medical information, including identifying information at the age of identity-release in accordance with applicable legislation and policy.

[8] We expect this issue to a priority consideration of the Australian Law Reform Commission its upcoming review of donor conception.

CLINICAL PERFORMANCE AND EFFECTIVENESS

This section is about the workforce having the knowledge and skills to provide safe and high-quality care – in our view this can only be achieved by tailoring services to the needs of diverse consumers, and this should be explicitly stated. While there is the important inclusion around meeting the needs of Aboriginal and Torres Strait Islander consumers in 1.16, this could be expanded with reference to other groups.

RECOMMENDATION

Amend 1.15 to include a requirement that the ART service provider identify the training needs of its workforce to ensure appropriate, non-discriminatory and sensitive provision of services to diverse consumer populations, including LGBTIQ+ people and others.

SUPPORTING INFORMED DECISIONS

We welcome the Actions under A07 regarding information required to be provided to consumers to inform decision-making in relation to ART services.

We recommend that this section also require ART service providers to have processes to identify when a consumer's ART treatment may interact with, or have implications for, other healthcare they are receiving, and to facilitate timely referral to an appropriately qualified health professional where specialist advice is required.

This is particularly important for trans consumers receiving gender-affirming healthcare concurrently with ART treatment. Consumers should be informed at the earliest appropriate opportunity about any potential interactions between ART treatment and their existing healthcare, including any implications of temporarily ceasing or changing gender-affirming hormones, the potential effects of doing so on their health and wellbeing, and any implications for fertility preservation or treatment options. Where the ART provider is not appropriately qualified to provide this advice, the consumer should be referred to their treating specialist or another appropriately qualified health professional.

Providing this information early is essential to genuine, informed consent. For example, the information may affect whether a consumer chooses fertility preservation, IUI or IVF, as well as the timing and nature of treatment. It should not be left until immediately before treatment, when the consumer may have limited practical ability to reconsider their options.

RECOMMENDATION

Amend A07 to include a requirement that the ART service provider identify whether a consumer's ART treatment may interact with or affect other healthcare they are receiving, and ensure that the consumer is provided with appropriate information and timely referral to a suitably qualified health professional where required.

COMMUNICATION WITH CONSUMERS

Standard 2.06 requires communication to be tailored to consumers' needs and preferences, easily understood and to address ongoing healthcare.

We support this requirement but recommend adding explicit requirements for accuracy, transparency and completeness.

In the ART context, consumers make decisions on the basis of information provided by providers about treatment options, success rates, costs, donor availability and other matters. Information that is technically accurate but incomplete or presented in a way that creates an unrealistic impression may undermine genuine, informed decision-making.

The Standards should therefore make clear that communication must not only be understandable, but also sufficiently accurate and transparent to enable informed decisions.

RECOMMENDATION

Amend Standard 2.06 to require communication with consumers to be:

- accurate;
- transparent;
- timely;
- complete in relation to material information;
- tailored to the consumer's needs and preferences; and
- free from misleading or coercive representations.

INFORMATION ABOUT ART SERVICES

Standard 2.07 requires providers to make information available about services, costs, access, eligibility and feedback mechanisms.

We support this requirement and recommend that it be expanded to include information particularly relevant to donor conception.

Consumers considering donor conception should have access to meaningful information before they commit financially to a provider or donor program.

This should include, where applicable:

- the number of donors currently available;
- anticipated waiting times where relevant;
- whether donor availability is subject to significant restrictions or wait times;
- whether there are storage limits applicable to the donor (depending on the jurisdiction), and how long is available to use the donor;
- if certain donor profiles are unavailable e.g. donors who match the family's make up e.g. racial background;
- the likely costs associated with accessing donor material;
- additional costs associated with storage, transport or treatment;
- whether donor material is imported or Australian-based;
- the number of donor-related families likely to be formed through donors offered through the program (depending on the legislation in the state/territory).

This is particularly important because donor availability can be a critical determinant of whether treatment can proceed at all. Clinics are not always forthcoming with information about the number of families that might be created through a single donor, and this is an important aspect of informed consent.

Further, some jurisdictions impose storage limits of 10 or 15 years from the date of donation, meaning the period during which a donor can be used may already be running before a family is allocated that donor. If a donor is allocated seven years after donation, for example, the family may have only a few years remaining to have all the children they planned. This should be made clear to consumers from the outset, including the date on which the donor's storage period will expire.

This can be particularly problematic for families who need to space pregnancies because of medical infertility issues, pregnancy or birth-related considerations, or other personal circumstances. Families should not discover only after commencing treatment that the donor they have chosen may no longer be available when they are ready to have a sibling.

Consumers should not be required to pay substantial fees for consultations, testing and entry into a donor program only to discover at a much later stage once already financially committed that there is no suitable donor available or that waiting times are substantially longer than reasonably expected.

RECOMMENDATION

Amend Standard 2.07 to require ART providers to make timely and accurate information available about donor availability, waiting times, relevant donor information, donor limits and all material costs associated with donor conception.

COLLECTION AND USE OF INFORMATION ABOUT CONSUMER POPULATIONS

Standard 3.22 currently requires providers to routinely ask whether a consumer is of Aboriginal and Torres Strait Islander origin and to use this information to optimise service planning and delivery.

The Standards should recognise the importance of collecting other relevant demographic information where this is necessary to identify inequities in access or outcomes. This would create better alignment with the definition of 'diverse backgrounds' where the Standards already recommend greater care is taken to ensure good outcomes for consumers.

This could include, where appropriate and with appropriate privacy protections and optional participation:

- disability (and possibly separately, neurodiversity);
- sexual orientation;
- gender identity;
- sex characteristics.

From this information providers should be able to identify whether particular groups are experiencing poorer access, poorer experiences or poorer outcomes and take action in response.

For the first time, all Australians were asked about gender and sexual orientation in the national Census, providing a valuable population-level benchmark against which ART consumer data can be compared.

RECOMMENDATION

Amend Standard 3.22 to include a requirement that ART service providers collect, where appropriate and with appropriate privacy protections and voluntary participation, relevant demographic information needed to identify and address inequities in access, experiences and outcomes for diverse consumer populations including LGBTIQ+ people.

COUNSELLING SERVICES

We support the requirement for access to counselling services for ART consumers (Item A12) when providing person-centred care.

However, counselling must be appropriately tailored to the individual circumstances of the consumer.

The reference to supporting consumers to understand the "implications" of treatment should be clarified, as the wording is not accessible and may be confusing. Counselling should assist consumers to understand the relevant medical, psychological, familial and social implications of the particular treatment or family-building pathway they are considering.

In the context of donor conception, counselling should focus on supporting families to provide children with age-appropriate information about their conception and genetic origins throughout their development. It should not operate as a "screening" process that seeks to assess whether prospective parents are suitable or unsuitable to raise a family.

Counselling must also be non-discriminatory and appropriately adapted to diverse family structures.

Examples of tailoring include the following:

- Counselling approaches developed around heterosexual couples experiencing infertility may not be

appropriate for same-sex couples or single people using donor conception.

- A same-sex couple who has always understood that donor conception and/or surrogacy would be part of their pathway to parenthood may not experience the same form of "grief" or loss associated with infertility that is assumed in conventional infertility counselling models.
- Same-sex couples who use reciprocal IVF should not have one partner treated as a “surrogate” when the child will be raised together in partnership.
- Information will need to be tailored depending on whether a family chooses a known donor or clinic-recruited donor as navigating ongoing relationships (when ongoing contact is intended – or even when it is not planned for) can be a particular challenge to be worked through in counselling.

Conversely, LGBTIQ+ people accessing ART may have particular issues requiring support, including decisions about donor selection, disclosure, donor relationships, legal parentage and supporting a donor-conceived child or child born via surrogacy to understand their origins.

Similarly, counselling for trans consumers should not pathologise gender identity or assume that gender identity is itself a problem requiring psychological intervention.

RECOMMENDATION

Amend A12 to require counselling services to:

- be non-discriminatory and inclusive;
- provided and communicated to consumers as an additional service to support the consumer and future child’s wellbeing, and not as a “screening” tool;
- be tailored to the consumer's circumstances, identity, family structure and reproductive pathway;
- support genuinely informed decision-making;
- address the particular implications of donor conception where relevant; and
- be delivered by appropriately qualified professionals with relevant expertise.

SPECIMEN IDENTIFICATION AND MATCHING

We support the requirements concerning accurate matching of specimens to consumers and procedures.

Given the profound consequences of errors involving mix ups of reproductive material, however, we encourage the Commission to consider whether the safeguards in A18 should be strengthened further.

We understand that insufficient staffing is one particular concern that could contribute to errors.

We are not best placed to comment on best practice and potential advancements in this space, but would recommend the Commission consider all recommendations to ensure that the systems are as robust as possible.

DONOR INFORMATION, DONOR LIMITS AND LIFELONG RESPONSIBILITIES

The provisions concerning donor information (A21 and A22) are among the most important elements of the Standards for donor-conceived people and their families. We consider that these provisions could be further strengthened and made more detailed as the current drafting represents only the minimum standard that should be expected. This is particularly important in a national ART environment where consumers may move between jurisdictions and where donor material may be accessed through different providers.

One omission is the requirement to update a donor-conceived person and/or their family (depending on the age of the person) about changes in health status of the donor – for example, the diagnosis of a serious health condition, or genetic disorder, particularly where it might affect the health of the donor-conceived person. E.g. the need to inform of genetic risk for a potentially inherited condition that may necessitate further health screening.

Further details should be added to ensure accurate up to date information is kept, particularly in jurisdictions without donor registers. For example, there is a need to ensure updated contact information.

While we understand it to be out of scope for this process, the reference to verification of information about donors ("where possible") underscores the importance of a national register so that information on number of donations and number of donor-siblings is accurately recorded.

RECOMMENDATION

Amend A21 and A22 to require systems that:

- maintain accurate and up-to-date donor records;
- enable donor-conceived people to access information to which they are entitled;
- proactively keep contact information up to date for all parties;
- maintain accurate information on contact preferences for consumers and donor-siblings, wherever stated;
- record donor limits and donations across the relevant jurisdictional or national systems;
- update records when significant new medical information becomes available;
- facilitate timely communication of significant medical information to affected donor-conceived people, families and donors (consistent with legislation, where relevant).

CONCLUSION

The development of nationally consistent ART Standards is an important opportunity to improve the safety, quality, transparency and consistency of ART services across Australia. We appreciate the opportunity to provide input.