Assisted Reproductive Technology Bill 2024

Statement of Compatibility

Prepared in accordance with Part 3 of the *Human Rights Act 2019*

In accordance with section 38 of the *Human Rights Act 2019*, I, Shannon Fentiman, Minister for Health, Mental Health and Ambulance Services and Minister for Women, make this statement of compatibility with respect to the Assisted Reproductive Technology Bill 2024.

In my opinion, the Assisted Reproductive Technology Bill 2024 is compatible with the human rights protected by the *Human Rights Act 2019*. I base my opinion on the reasons outlined in this statement.

Overview of the Bill

Background

Regulation of Assisted Reproductive Technology

Assisted reproductive technology (ART) refers to treatments or procedures that address human fertility. It can include artificial insemination, in-vitro fertilisation (IVF), gamete intrafallopian transfer and other related treatments or procedures. ART helps those with fertility issues, genetic risks and diverse genders and sexualities to have children they might not otherwise conceive and is increasingly part of how many Australian families are formed.

The *Research Involving Human Embryos Act 2002* (Cwth) requires ART clinics to be accredited by the Reproductive Technology Accreditation Committee (RTAC) of the Fertility Society of Australia and New Zealand (FSANZ). However, there is no Commonwealth legislation in place regulating ART services in Australia. The following national professional accreditation framework and guidelines govern ART services:

- National Health and Medical Research Council (NHMRC) *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research* (the NHMRC Guidelines); and
- RTAC *Code of Practice for Assisted Reproductive Technology Units* (RTAC Code of Practice).

The NHMRC Guidelines provide an overarching framework for the conduct of ART in clinical practice and research. They are intended to be read in conjunction with federal and state or territory legislation to create a robust framework for the conduct of ART in Australia.

The RTAC Code of Practice provides a framework and sets criteria against which ART providers are audited to maintain their accreditation with RTAC. ART providers are audited annually for critical criteria and every three years for good practice criteria.

Queensland has a relatively large ART industry. As at May 2024, there were 24 RTAC-accredited clinics operating in Queensland, accounting for one in four of the national

total of 96 clinics. Medicare claims data published by Service Australia suggests that, in recent years, over 20,000 ART treatment cycles were undertaken on average in Queensland clinics per year.

However, there is no dedicated legislation in Queensland regulating ART services, and Queensland has relied solely on the national self-regulatory framework. These are professional accreditation, not legal requirements, meaning there is no robust enforcement mechanism for compliance. In contrast, five other Australian jurisdictions (the Australian Capital Territory, New South Wales, South Australia, Victoria and Western Australia) have implemented legislation to regulate the provision of ART.

In mid to late 2023, several issues came to light involving the services of Queensland ART providers. The cases included alleged use of incorrect donor gametes, resulting in children from the same family not being biological siblings and alleged use of donor sperm many more times than is now acceptable practice, resulting in the potential for a large number of children born in Queensland to the same donor and the flow-on risk of consanguineous relationships.

Donor conception information

On 31 August 2022 the then Legal Affairs and Safety Committee (the Committee) tabled its Report No. 33, 57th Parliament – *Inquiry into matters relating to donor conception information* (the Report).

In conducting the Inquiry, the Committee considered the rights of donors and donor-conceived people and found that a donor-conceived person's right to know their genetic origin outweighs a donor's right to privacy. The Committee was clear that a register of donor conception information should be established, and that all donor-conceived people should have access to identifying and medical information about their donor.

Under the current national self-regulatory framework, the NHMRC Guidelines are intended to prevent ART providers from using donated gametes unless the donor has consented to the release of their identifying information to any persons born as a result of their donation. Prior to the NHMRC Guidelines coming into effect in 2004, there was no accreditation or other requirement for ART providers to obtain consent from donors to release their identifying information, and many donors donated on the condition of anonymity.

The NHMRC Guidelines outline that a donor-conceived person 18 years or older may approach the ART provider where the gametes were donated to obtain identifying information about the donor. In such circumstances, the ART provider must review whether the donor has consented to the release of their identifying information. If the donor has consented (which should be the case for all post-2004 donors used by ART providers), then the ART provider should provide the donor-conceived person with information about their donor. If the donor has not consented to the release of the information (which may be the case for some pre-2004 donors), the NHMRC Guidelines outline that the ART provider should make reasonable efforts, consistent with the original consent document and the privacy rights of the donor, to contact the gamete donor and request their consent to the release of their information. Under the Guidelines, information about the donor should not be released to the donor-conceived person unless the donor has consented.

Anecdotal evidence provided to the Committee as part of its Inquiry outlined that donor-conceived persons who were conceived using gametes donated prior to 2004 have difficulty obtaining identifying information about the donor through ART providers. Donor-conceived people may use at-home DNA testing kits or social media to obtain information about the donor and other relatives, including donor siblings.

In its Report, the Committee made six main recommendations and 20 sub-recommendations. Key recommendations were that:

- a central register of donor conception information should be established in the Registry of Births, Deaths and Marriages (RBDM) (recommendation 5.1);
- operation of the register should be retrospective and all donor-conceived people should be provided with the legislative right to access identifying and medical information about their donor when they turn 18, regardless of when they were born (recommendations 1 and 2.1);
- clinics involved now and historically with donor conception practices should be required to retrieve, check and submit all donor information to the register (recommendations 3.2 and 5.2);
- contact between donors and donor-conceived people, and contact between donor-conceived people and their siblings should be facilitated by consent (recommendations 2.4 to 2.6);
- donors should have access to non-identifying information about any person born as a result of their procedure (recommendation 2.1);
- the register be available voluntarily to those who have pursued donor conception in private procedures (recommendation 5.3 and 3.4)
- the Queensland Government considers funding counselling and support services for donor-conceived people, recipient parents and donors to facilitate positive outcomes from recommendations of the report (recommendation 4); and
- birth certificates of all donor-conceived people, including those already born, should be annotated to note the fact of donor conception (recommendation 3.3 and 3.4).

The Queensland Government response to the Committee Report, tabled on 28 February 2023, supported all recommendations in principle noting that implementation would be subject to further consideration of resourcing and operational needs, as well as ongoing targeted consultation. The Bill implements the intent of recommendations made by the Committee.

Objectives

The main objects of the Act are to:

- protect the welfare and interests of people who use ART and people born as a result of ART;
- regulate the use of ART; and
- provide and regulate access to information relating to people born as a result of ART.

The Bill also provides that the welfare and interests of children who are born as a result of ART are, throughout their lives, of paramount importance in the administration and operation of the legislation.

The Bill will achieve these purposes by providing for the regulation of ART through:

- a State-based licensing regime for ART providers, including eligibility requirements, application processes, powers to impose licensing conditions, notification requirements, a public register of licensed ART providers, enforcement and inspection functions and powers;
- requirements relating to accessing ART services, including the provision of information between the ART provider and the ART recipient and/or gamete provider, counselling and consent;
- requirements relating to the use of gametes and embryos, including prohibited uses, limits on the use of donated gametes and embryos, storage, export, and disposal of gametes and embryos, and posthumous retrieval and use of gametes;
- information requirements, including: collection and retention of information about donors and ART patients, a prohibition on destruction of ART records, disclosure of information for medical purposes and information sharing between ART providers and relevant agencies;
- fees and regulation-making powers; and
- transitional arrangements.

The Bill will also achieve these purposes by providing for access to information about donor conception by:

- establishing a donor conception information register (the Register) in RBDM which is to be maintained and operated by the Registrar-General, RBDM (the Registrar);
- from commencement, requiring ART providers to collect and provide relevant information about donor conception ART procedures to the Registrar, which will include identifying and non-identifying information about donors, donor-conceived persons and their parent/s;
- requiring ART providers or other persons to provide information about donor conception ART procedures that were carried out pre-commencement to the Registrar for inclusion on the Register, which may include identifying information about donors, donor-conceived persons and their parent/s;
- allowing persons who have undertaken private donor conception procedures in Queensland to voluntarily provide information to the Registrar;
- allowing all donor-conceived people aged 16 years or older to access identifying and non-identifying information about their donor that is held on the Register, regardless of whether the donor has consented to the release of the information;
- establishing a framework to allow donor-conceived people, their parents, donors and others to access other information held on the Register; and
- facilitating contact between persons by consent by allowing a person to provide their contact information to the Register and consent to the information being provided to a particular person or persons.

In addition, the Bill will require the Registrar to issue an addendum to a birth certificate if a donor-conceived person born in Queensland applies to RBDM for their birth certificate and the Registrar is aware that information about the person is held on the Register. The addendum will state that further information about the person's birth is available through RBDM. The provisions will apply prospectively to donor-conceived people born after the commencement of the Bill, as well as donor-conceived people born before the commencement of the Bill if there is information about the person held on the Register. It will then be the choice of the person as to whether they contact RBDM for information.

Human Rights Issues

Human rights relevant to the Bill (Part 2, Division 2 and 3 *Human Rights Act 2019*)

In my opinion, the human rights that are relevant to the Bill are:

- right to recognition and equality before the law (section 15 of the Human Rights Act);
- right to protection from torture and cruel, inhuman or degrading treatment (section 17 of the Human Rights Act);
- right to property (section 24 of the Human Rights Act);
- right to privacy and reputation (section 25 of the Human Rights Act);
- right to protection of families and children (section 26 of the Human Rights Act);
- right to a fair hearing (section 31 of the Human Rights Act);
- rights in criminal proceedings (section 32 of the Human Rights Act); and
- right to health services (section 37 of the Human Rights Act).

The Bill actively supports and promotes several rights, but where rights are potentially limited by the Bill, this is identified and an analysis and justification of any potential limitations is provided.

If human rights may be subject to limitation if the Bill is enacted – consideration of whether the limitations are reasonable and demonstrably justifiable (section 13 *Human Rights Act 2019*)

Human rights potentially limited by licensing requirements

Right to property (section 24)

Right to privacy and reputation (section 25)

(a) the nature of the right

Property

Section 24 of the Human Rights Act states that all persons have the right to own property alone or in association with others and must not be arbitrarily deprived of their property. Case law

has defined 'arbitrariness' in this context as conduct that is capricious, unpredictable, or unjust, or interferences that are not proportionate to a legitimate aim.

'Property' includes all real and personal property recognised under general law (such as interests in land, chattels and money), and may include statutory rights such as the right to use, licence and restrict access to a thing.

The licensing requirements in the Bill may limit the right to property by:

- restricting the provision of ART services to licensed ART providers. Clause 12 of the Bill limits the provision of ART services to licensed ART providers. The maximum penalty for non-compliance is 200 penalty units or two years imprisonment. Eligibility criteria reflects the current requirement in Commonwealth legislation for RTAC accreditation and includes new requirements to not be completely prohibited from providing ART services by a prohibition notice, and others prescribed by regulation (clause 57). These restrictions will prevent any person who does not meet these requirements from offering ART services in Queensland; and
- enabling the Director-General to take compliance action against a licensed ART provider or applicant which may require them to reduce or cease operations, temporarily or permanently. The Director-General may issue a licensed ART provider an improvement notice (clause 62) or prohibition notice (clause 63), impose or vary a licence condition (clause 59) or cancel or suspend a licence (clause 64).

Privacy and reputation

Section 25 of the Human Rights Act provides that a person has the right not to have their privacy arbitrarily or unlawfully interfered with, or their reputation unlawfully attacked. The scope of this right also includes the protection of personal information and data collection.

Only lawful and non-arbitrary intrusions upon privacy, family, home, correspondence and reputation may occur. The concept of lawfulness in the context of the right to privacy means that no interference can take place except in cases envisaged by the law, while the concept of arbitrariness extends to interferences that may be lawful but that are capricious, unpredictable, unreasonable, and disproportionate.

The licensing requirements in the Bill may limit this right by:

- requiring applicants to provide personal information to the Director-General about themselves and each registered medical practitioner and other key personnel who will perform or be engaged in the provision of ART services by the applicant (clause 57), and to notify the Director-General of changes in their RTAC accreditation (clause 61);
- enabling the Director-General to consider whether a person has breached ART legislation, including in another states and territories, on licence application (clause 58) and throughout a licence (clause 63);
- enabling the disclosure of confidential information to regulatory bodies in other Australian jurisdiction and law enforcement (clause 140), which may include information about the compliance history of licensed ART providers;

- requiring licensed ART providers to notify Queensland Health of serious adverse events (which may include events such as patient hospitalisation as a result of a complication of ART treatment or a mix-up of gametes) within a specified time (clause 61). These notifications may include disclosure of personal and medical information of patients or service providers; and
- requiring the Director-General to maintain a public register of licensed ART providers, including the names of all registered medical practitioners and key personnel involved in the provision of ART services by that ART provider (clause 65).

(b) the nature of the purpose of the limitation to be imposed by the Bill if enacted, including whether it is consistent with a free and democratic society based on human dignity, equality and freedom

Property

The purpose of the limitation on property rights in the licensing requirements is to protect the health and safety of people who use ART and people born as a result of ART.

ART procedures involve risks to the health, safety and wellbeing of people undertaking treatment and donating gametes or embryos, and the people born as a result, and the objective of the Bill is to protect their welfare and interests.

Promoting the safety of ART is consistent with a free and democratic society based on human dignity, equality and freedom. It is also consistent with the government's obligation to take steps to protect the lives of individuals, thereby promotes the right to life (section 16 of the Human Rights Act).

Privacy and reputation

The purpose of the limitations on the right to privacy and reputation is to similarly improve safeguards for ART consumers and people born as a result of ART.

As explained above, protecting the health and safety of those who use ART and those who are born as a result of ART is a proper purpose and is consistent with the State's obligation to promote the right to life.

(c) the relationship between the limitation to be imposed by the Bill if enacted, and its purpose, including whether the limitation helps to achieve the purpose

Property

There is a direct relationship between the limitations to the right to property posed by the licence requirements and regulatory actions outlined in the Bill and its objectives to protect people born from or receiving ART treatment.

Regulatory schemes with licensing requirements are used widely used in settings where there is risk of harm to the public. Queensland Health currently administers a range of licensing schemes to regulate industries with risks to the health and safety, including the manufacture and sale of medicines and poisons, use of pesticides, private health facilities, radiation and, more recently, suppliers of smoking products. A requirement for a licence ensures that high-risk activities are not conducted unless personnel have been appropriately screened, and

the application of regulatory action ensures the regulator can enforce compliance with safety requirements.

The limitations will ensure that ART providers who do not hold current accreditation or have not complied with the legislative obligations cannot offer ART services to the public, and that Queensland Health can require ART providers to cease offering ART services (temporarily or permanently) to reduce the risk to people using ART services and people born as a result of ART services. The compliance action enabled under the Bill will permit the Director-General to act in response to any risk identified at the licence application stage or during the licence term, commensurate with the potential impact of the risk.

This will promote the safety of ART by preventing non-compliant ART services from being continued to be offered to consumers and pose a risk of harm, or threaten the welfare and interests of ART patients and their families.

Privacy and reputation

The limitations on the right to privacy and reputation relate directly to the purpose of improving safeguards to protect the health and safety of people who use ART and people born as a result of ART.

The licensing requirements ensure Queensland Health has oversight of the industry and can effectively enforce the scheme and achieve the Bill's objectives.

The requirements for personal information to be provided to Queensland Health on application and throughout the licence term is to ensure that Queensland Health maintains up-to-date information about the personnel involved in the delivery of ART treatment and who are obliged to comply with the requirements in the Bill. This will ensure that only appropriate people can provide ART services in Queensland. It will also enable Queensland Health to undertake prompt and appropriate compliance action in response to risks of harm.

The purpose of enabling the Director-General to access information about relevant contraventions of ART related legislation is to similarly improve safeguards for ART consumers. While the scheme will be new in Queensland, most Queensland ART providers operate nationally, including in states that have had similar legislation in place for many years. These provisions will enable the Director-General to assess whether contravention in those jurisdictions may be relevant to operations in Queensland, and take appropriate action in response to limit risks.

The ability to disclose relevant information to other regulatory bodies and law enforcement will similarly enhance the overall safety and oversight of the ART services. This is necessary in the Australian context where ART providers offer the same services across state and territory borders, and some patients may travel interstate to access treatment.

The purpose of requirements for serious adverse event reporting is to enable Queensland Health to proactively monitor current and emerging risks to the community from ART treatments. ART providers currently report serious adverse events to RTAC as part of accreditation requirements. This data will directly support the objectives of the Bill by ensuring that Queensland Health, as the state regulator, can access this data and take compliance action if needed to support the objectives of the Bill.

The purpose of the public register is to provide assurance to ART patients, their families and the community that ART providers have been assessed as appropriately qualified and compliant with the consumer protections outlined in the Bill. Inclusion of key personnel will also reassure patients that the staff involved in their treatment are known to Queensland Health and can be held accountable for compliance with their legislative obligations, and therefore promote public confidence in the provision of ART services.

Not including someone on the register may reflect poorly on their reputation. However, this impact is outweighed by the need to provide clarity to the community about the status of an ART provider or person under the scheme at a point in time, to enable them to make decisions about their treatment.

By enabling Queensland Health to maintain an accurate knowledge of key personnel in the delivery of ART services, potential risks posed by past compliance history, it will be able to take appropriate and timely action to reduce the risk of harm from delivery of ART services.

(d) whether there are any less restrictive (on human rights) and reasonably available ways to achieve the purpose of the Bill

Property

The licensing requirements in the Bill are the least restrictive way of protecting the welfare and interests of people accessing ART services and born as a result of ART treatment.

Queensland Health considered alternative options, including education programs for consumers and industry or continuing to rely on industry self-regulation. However, these alternatives are unlikely to achieve the purpose of the Bill and are not the approach that is taken in most other Australian jurisdictions.

The Bill also includes important safeguards to protect the property rights of licensed ART providers, thereby ensuring the limitations are the least restrictive possible to achieve the purpose. The Bill sets an appropriate bar for taking licensing action. For example, a licence can only be cancelled or suspended for specified reasons, including that the licensed ART provider ceases to have RTAC accreditation or is prohibited from providing ART services. Further, licensing decisions, including decisions to refuse to grant a license, to issue a prohibition notice or to cancel or suspend a licence, are reviewable decisions. Thus, there is oversight of these decisions by the Queensland Civil and Administrative Tribunal.

Privacy and reputation

Powers to obtain, consider and disclose (subject to limitations) personal information, such as names, history of contraventions of relevant legislation and adverse events, are the most robust and consistent way for Queensland Health to verify whether an ART provider is eligible to hold a licence and is complying with their obligations in the Bill, and to monitor risks to the public. Alternatives such as requesting ART providers to voluntarily provide this information are likely to result in the necessary information being provided unevenly across the industry, or not at all, and undermine Queensland Health's ability to equitably enforce the requirements in the Bill.

The Bill also includes appropriate limitations on the collection, use and publication of personal information, consistent with a free and democratic society based on human dignity, equality

and freedom. The Bill requires the Director-General to refrain from publishing particular information on the public register if requested, and they are satisfied that publication may endanger the safety of any person (clause 65(4)). Queensland Health will handle and use all personal information collected for these purposes securely and only for the purposes of its administration of the Act. Collection and use of personal information will also remain subject to the requirements of the *Information Privacy Act 2009*, including the Information Privacy Principles that require the agency to make the individual aware of the purpose of the collection of information and its potential disclosure.

(e) the balance between the importance of the purpose of the Bill, which, if enacted, would impose a limitation on human rights and the importance of preserving the human rights, taking into account the nature and extent of the limitation

In my opinion, the Bill strikes a balance between the competing rights of individuals and the requirement for enhanced safeguards for the provision of ART services, that is reasonable and demonstrably justifiable in a free and democratic society.

ART services have the potential to pose a high risk to the health, safety and wellbeing of ART patients, their families and people born as a result. Given the potential intergenerational impacts of the requirements to be enforced through the Bill, it is appropriate to impose moderate limitations on the rights to property and privacy and reputation on parties involved in delivering these treatments. These interferences are proportionate to the purposes of the Bill.

(f) any other relevant factors

Nil.

Human rights potentially limited by inspectors' powers

Right to property (section 24)

Right to privacy and reputation (section 25)

(a) the nature of the right

As discussed above, section 24 of the Human Rights Act states that all persons have the right to own property and must not be arbitrarily deprived of their property. The right does not include a right to compensation if a person is deprived of their property. Section 25 provides that a person has the right not to have their privacy arbitrarily or unlawfully interfered with. Only lawful and non-arbitrary intrusions upon privacy, family, home, correspondence and reputation may occur.

The Bill limits the rights to property and privacy by providing powers for entry, search and seizure and to obtain information. Part 5 of the Bill outlines provisions for the appointment and powers of inspectors to monitor and enforce requirements for the provision of ART services, use of gametes and embryos and information collection. Clause 77 establishes powers of entry, subject to consent or authorisation by warrant. Clause 89 provides the general powers of inspectors after entering places, including powers to search any part of the place, inspect and seize items, place marks, and take photographs and notes. In practice, this will mean that inspectors will have the ability to deprive a person of their property during an inspection, and this may include personal information. For example, documents and records that are the

property of an ART provider could be seized by an inspector. Inspectors will also have powers to require personal details, including name and residential address (clause 106), and to make documents or their certified copies available for inspections (clause 108). The Bill also provides for the forfeiture of property in limited circumstances (clause 102 through 105).

(b) the nature of the purpose of the limitation to be imposed by the Bill if enacted, including whether it is consistent with a free and democratic society based on human dignity, equality and freedom

The purpose of limiting the rights to property and privacy is to ensure the ongoing protection of the health and safety of people who use ART and people born as a result of ART. Protection of the health and safety of individuals is a purpose that is consistent with a free and democratic society based on human dignity, equality and freedom.

(c) the relationship between the limitation to be imposed by the Bill if enacted, and its purpose, including whether the limitation helps to achieve the purpose

The limitations on property rights and privacy will ensure that Queensland Health has oversight of the industry and can effectively enforce the scheme and achieve the intended purpose of promoting safety in the provision of ART services.

The purpose of the powers is to enable inspectors to obtain critical information relating to the conduct of ART activities and ongoing compliance with obligations specified in the Bill. Powers to enter places, seize evidence and obtain information in specified circumstances will enable inspectors to perform their role, and more broadly achieve the objectives of the Bill. These powers are necessary to support a robust regulatory system and enable effective monitoring and enforcement of compliance with the legislation. They will ensure that an evidence-based investigation can be conducted in a timely manner. This will ensure that licensed ART providers are complying with requirements in the Bill and their licence conditions. Without limitations on the right to privacy and property, the monitoring and enforcement functions and the overall aims of the Bill would be undermined, and offences may not be able to be effectively investigated and prosecuted.

(d) whether there are any less restrictive (on human rights) and reasonably available ways to achieve the purpose of the Bill

The proposed provisions are the least restrictive way of protecting the interests of people accessing ART services and people who are born as a result of ART treatment. Without powers of search and seizure, Queensland Health would need to rely on providers to voluntarily respond to information requests, which is likely to constrain its ability to conduct thorough and prompt investigations.

The functions and powers are conferred only to the extent reasonable and necessary to achieve this purpose and the Bill includes a number of safeguards to lessen the negative impact of these powers on the rights to property and privacy.

The Bill has incorporated limits on inspector powers appropriate in a free and democratic society. Inspector functions are limited to matters relevant to the Act (clause 69) and inspectors are subject to appointment eligibility criteria and terms of office (clauses 70 through 72).

Inspectors must present also present and keep visible their identity card prior to and while exercising any powers under the Act (clause 75).

The general power to enter places specifically excludes the part of a premises used by a licensed ART provider where a person resides (clause 77(2)). Further, the power of entry to a place only applies if there is consent to entry, the place is open to the public at the time of entry, or the entry is authorised by a warrant (clause 77(1)). Where a warrant is required, a magistrate must be satisfied there are reasonable grounds for suspecting there is, or soon will be, some thing or activity at the place that may provide evidence of an offence against the provisions of the Bill (clause 83). This ensures magistrate oversight of entries without consent or where a place is not open to the public or otherwise open for entry.

The Bill prescribes safeguards for seized property, including provision of a receipt (clause 99) and ability for the owner to inspect or (if it is a document) copy it at any reasonable time, free of charge (clause 100). Owners may also apply for the return of seized property after a period, or it must be returned after there are no longer reasonable grounds for holding it (clause 101). The Bill does not confer a power on an inspector to seize a gamete or embryo (clause 94).

For property forfeited under the Bill, the Director-General must provide an information notice about the decision (clause 103). They must not deal with forfeited property in a manner that could prejudice the outcome of a review and, if sold, must make reasonable efforts to return the proceeds to the immediately previous owner (clause 105).

In light of the relevant safeguards, the entry, search and seizure powers in the Bill are justified as they ensure that authorised persons can access and collect accurate and relevant information and evidence to monitor and enforce the Act, and achieve its objectives to protect the welfare and interests of people using ART treatments and those born as a result.

(e) the balance between the importance of the purpose of the Bill, which, if enacted, would impose a limitation on human rights and the importance of preserving the human rights, taking into account the nature and extent of the limitation

In my opinion, the Bill appropriately balances the objectives of the Bill and limitations of human rights related to inspector powers. The purposes of the Bill are to improve consumer safeguards in relation to the provision of ART services. The inspectors' role will be to investigate, monitor and enforce compliance with the Bill in pursuit of those objectives. The associated powers are limited by safeguards and strike an appropriate balance between the imposition on the right to property and privacy and the importance of ensuring inspectors can effectively monitor and enforce compliance with the Bill.

(f) any other relevant factors

Nil.

Human rights potentially limited by administrative decision-making powers

Right to a fair hearing (section 31)

(a) the nature of the right

The right to a fair hearing in section 31 of the Human Rights Act affirms the right of all individuals to procedural fairness when coming before a court or tribunal. The concept of a fair hearing is concerned with procedural (rather than substantive) fairness. It applies to both criminal and civil proceedings and guarantees that such matters must be heard and decided by a competent, impartial and independent court or tribunal.

The Bill may limit the right to a fair hearing by conferring certain decision-making powers on the Director-General. While these powers are administrative and not judicial in nature, the powers are sufficient to substantially affect the rights and financial circumstances of licensed ART providers. These powers can be exercised without first affording the impacted licence holder or applicant an opportunity to be heard, thus potentially breaching the requirements of natural justice.

Part 4 provides for the Director-General to make decisions on licence applications, licence conditions to be imposed or varied, the issuance of improvement and prohibition notices, and licence cancellations and suspensions. These provisions specify the decision-making criteria which must be applied by the Director-General and require an information notice containing the reason for the decision to be provided as soon as possible. For example:

- **licence applications and conditions:** the Director-General may refuse a licence application if they find the ART provider to be ineligible because they do not hold current RTAC accreditation or are completely prohibited from providing ART services by a prohibition notice (clauses 57 and 58). The Director-General may also impose or vary a condition on a licence (clause 59);

- **licence suspensions and cancellations:** the Director-General may suspend or cancel a licence if they find the licence was granted because of information that was false or misleading (clause 64);

- **improvement notices:** the Director-General may issue an improvement notice to a licensed ART provider if they reasonably believe it is necessary for the provider to rectify a matter to minimise the risk of harm to people receiving ART services or the persons born as a result of ART services. Improvement notices must detail the relevant matter and timeframe, and may prescribe the action to be undertaken (clause 62); and

- **prohibition notices:** the Director-General may issue prohibition notices if they reasonably believe a licensed ART provider should be prohibited from providing all or some ART services because they have contravened a licence condition, breached ART or ART related legislation or there is a risk to people receiving ART services or people born as a result of ART services. These notices may be limited to particular ART services, premises, areas or individuals (clause 63).

(b) the nature of the purpose of the limitation to be imposed by the Bill if enacted, including whether it is consistent with a free and democratic society based on human dignity, equality and freedom

The powers to grant or refuse a licence, impose a condition, suspend or cancel a licence or issue an improvement or prohibition notice without first giving the licence holder or applicant an opportunity to respond limits their right to a fair hearing. The purpose of the limitation is to protect the health and safety of persons receiving ART services and people born as a result of ART services. This is a proper purpose that is consistent with a free and democratic society based on human dignity, equality and freedom.

(c) the relationship between the limitation to be imposed by the Bill if enacted, and its purpose, including whether the limitation helps to achieve the purpose

The limitations on the right to a fair hearing directly support the intended purpose of protecting the health and safety of persons receiving ART services and born as a result of ART services by enabling the Director-General to take prompt, scalable action against ART providers, proportionate to the nature of the risk to be addressed.

For example, the power to impose a licence condition or issue improvement and prohibition notices targets action towards specific risks and ensures they are rectified or managed in an ongoing way without ceasing all ART services to the community.

In other circumstances, the power to suspend a licence will ensure ART consumers are protected while a matter can be investigated, and allow the licensed ART provider to further explain or remedy the issue where possible. This will protect the public by preventing the ART provider from continuing to operate under the licence in a way that may pose a risk to public health and safety.

The power to cancel a licence will ensure Queensland Health can respond to serious incidences of non-compliance with the Act, which are unlikely to be able to be remedied.

An alternative approach such as issuing a show cause notice and allowing the licence holder a period of time to respond would impair Queensland Health's ability to act quickly to address an immediate risk, potentially risking harm to more ART consumers and their families.

These limitations on the right to a fair hearing will therefore achieve the purpose of ensuring the Bill can be administered effectively, while also promoting the Bill's broader objectives of improved consumer safeguards.

(d) whether there are any less restrictive (on human rights) and reasonably available ways to achieve the purpose of the Bill

There are no less restrictive and reasonably available ways to ensure the efficient functioning of the licensing scheme.

An alternative option, as mentioned above, is to require a show cause notice for each decision to refuse a licence application or decision to set a condition on a licence and provide licence holders or applicants an additional opportunity to be heard before the decision is made. However, the internal and external review processes established in the Bill have the same effect. For example, ART providers who have received an improvement or prohibition notice

may apply to the Director-General for the notice to be revoked if they consider the relevant issues have been rectified or the notice is no longer justified. The Director-General must also give the licence holder or applicant an information notice about a decision as soon as possible, including the reasons for the decision and the person's ability to ask for a review of the decision. The licence holder or applicant may then apply for internal review of the decision (clause 121) and, subsequently, external review by the Queensland Civil and Administrative Tribunal (clause 125). Thus, there is impartial tribunal oversight available for administrative decisions.

Given that a decision to grant or to refuse, suspend or cancel a licence, impose a condition or issue an improvement or prohibition notice may be in response to a health and safety risk to people undergoing ART treatment, it is necessary to provide for immediate action to be taken, with review available once that action is in place.

(e) the balance between the importance of the purpose of the Bill, which, if enacted, would impose a limitation on human rights and the importance of preserving the human rights, taking into account the nature and extent of the limitation

In my opinion, the limitations in the Bill are appropriate and adapted to achieving the objectives of the Bill. ART is a health service that poses serious risks to the short- and long-term wellbeing of ART patients and their families, and the purpose of the Bill is to improve consumer safeguards. This requires the licensing scheme to operate efficiently and enable the Director-General to take decision in a timely manner appropriate to the nature of the risk – noting that an immediate response may be required in some circumstances.

The limitations on the right to a fair hearing are narrow in scope and apply only to licence holders and applicants. These decisions are subject to internal and external review processes, allowing licence holders and applicants an opportunity to be heard on the merits of the decision. The Bill therefore balances its objectives to improve consumer safeguards with the limitation on the right to a fair hearing.

(f) any other relevant factors

Nil.

Human rights potentially limited by reversal of onus of proof and deemed executive liability provisions

Right to a fair hearing (section 31)

Rights in criminal proceedings (section 32)

(a) the nature of the right

The right to a fair hearing affirms the right of all individuals to procedural fairness when coming before a court or tribunal. It also guarantees that such matters must be heard and decided by a competent, impartial and independent court or tribunal. In the criminal law context, an initial requirement is that there is a clear and publicly accessible legal basis for all criminal prosecutions and penalties, so the criminal justice system can operate in a way that is predictable to the defendant.

Section 32 of the Human Rights Act upholds several minimum guarantees for people charged with criminal offences, including the right to be presumed innocent until proven guilty, the privilege against self-incrimination, and the onus on the prosecution to prove the offence beyond a reasonable doubt.

The Bill limits these rights by creating offences containing a reasonable excuse provision, which is considered to reverse the onus of proof. For example, where the Bill prohibits a person from doing something in the absence of a reasonable excuse, it is generally appropriate for the accused person, rather than the prosecution, to provide the necessary evidence of the reasonable excuse.

Reasonable excuse provisions apply to:

- **Registrar notices:** an ART provider (or other person required to provide relevant information under the Bill) must comply with a notice by the Registrar relating to information in the Register, unless they have a reasonable excuse (clause 54);
- **notification requirements:** a licensed ART provider is not required to comply with requirements to notify the chief executive of certain events if they have a reasonable excuse (clause 61);
- **return of identity cards:** inspectors must return their identity card within 21 days of their office ending unless the person has a reasonable excuse (clause 76);
- **requirements at inspection sites:** unless they have a reasonable excuse, persons at inspection sites must comply with any requirement in relation to seized property (clauses 97 and 98) and refrain from interfering with it (clause 98) or obstructing an inspector from exercising a power or someone helping them to do so (clause 116). They must also provide reasonable help (such as producing a document or giving information) to inspectors (clauses 90 and 91), unless they have a reasonable excuse;
- **production of documents:** separate to requirements at inspection sites, the Bill includes requirements for a person to produce or make available for inspection documents relevant to the Act (clauses 108 and 109) or certify a copy made by the inspector (clauses 108 and 109), unless they have a reasonable excuse; and
- **information about offences:** if an inspector reasonably believes an offence has been committed, they may require a person to provide their name and residential address (clause 107) and further information about the offence (clauses 111 and 112). A person to whom these requests are made must comply, unless they have a reasonable excuse.

The Bill limits the privilege against self-incrimination by excluding this as a reasonable excuse for not complying with the requirement to provide a document or its certified copy (clauses 109 and 110).

A maximum penalty of 50 penalty units, or fewer in some provisions, applies to non-compliance with each of the above requirements.

The Bill also limits this right by evidentiary provisions that reverse the onus of proof. Clause 133 provides that a certificate purporting to be signed by the Director-General of the

council stating that, for example, a stated document is a licence to provide ART services, is evidence of the matter.

The Bill further limits these rights by providing for deemed executive liability for selected provisions (clause 138). If a corporation commits an offence against a deemed executive liability provision, an executive officer of the corporation is taken to have also committed the offence, if they authorised, permitted or knew of the relevant conduct, directly or indirectly (clause 138). This applies to provisions for the regulation of ART (all clauses in part 2), information held in the Register (all clauses in part 3 division 3) and providing false and misleading information (clause 139(2)). Provisions of this type create a presumption of guilt or responsibility, and effectively relieve the prosecution of the obligation to prove the elements of the offence for the person taken to have committed it.

(b) the nature of the purpose of the limitation to be imposed by the Bill if enacted, including whether it is consistent with a free and democratic society based on human dignity, equality and freedom

The purpose of limiting the right to a fair hearing and rights in criminal proceedings by requiring the accused to provide evidence of a reasonable excuse, is to ensure that evidence is provided by the individual best positioned to provide that evidence. The existence of a reasonable excuse exception will also ensure individuals are afforded an opportunity to raise an appropriate defence for failing to comply with an obligation.

The purpose of the evidentiary provisions is to enable the Director-General to put non-contentious evidence before the court without the need to call witnesses to ensure proceedings can efficiently proceed.

With respect to deemed executive liability, given that the objectives of the Bill are to regulate ART, it is appropriate that an executive officer who is in a position to influence the conduct of a corporation be required to ensure the corporation complies with the legislation. The executive officer who is responsible for a contravention of the legislation should be accountable for their actions and not be able to 'hide' behind the corporation.

(c) the relationship between the limitation to be imposed by the Bill if enacted, and its purpose, including whether the limitation helps to achieve the purpose

The limitation on the right to a fair hearing and rights in criminal proceedings will achieve its purpose of helping to ensure that evidence of wrongdoing or other contraventions is provided by the individual best positioned to provide that evidence. Creating a reasonable excuse exception in certain circumstances provides a person the opportunity to raise a 'reasonable excuse' for failing to comply with a requirement. Without a 'reasonable excuse' exception, the relevant offences would be unnecessarily strict and penalise individuals for non-compliance with obligations that they may be unable to comply with.

In the circumstances where a reasonable excuse exception arises, the facts giving rise to a reasonable excuse would be within the knowledge of the accused person. For example, clause 109 provides that a person must not contravene a document production requirement unless the person has a reasonable excuse. The reason for a person not complying with a document production requirement is a matter within their own knowledge that they can prove by giving evidence.

The limitation on the privilege against self-incrimination also supports the objective of the Bill to regulate ART and protect the welfare and interests of people using ART services and people born as result. ART treatment has long term, intergenerational impacts and the keeping of accurate records is essential to ensure the scheme operates effectively. To allow a claim of privilege for these documents or information may effectively facilitate a failure to keep the records, or their destruction or falsification.

The limitation on self-incrimination with respect to the production of documents is a necessary limitation as this material may be the only reliable evidence in an investigation. In its 2004 Report, *The abrogation of the privilege against self-incrimination*, the Queensland Law Reform Commission considered that, in the context of a legislative regulatory scheme where one of the requirements is to keep records and present them on request, a person's participation implies they have accepted the enforcement provisions and waived the privilege of self-incrimination. Other reasonable excuses are permissible.

This is also the sole limitation on this privilege in the Bill, which explicitly permits the privilege against self-incrimination in other scenarios. For example, self-incrimination is explicitly permitted as a reasonable excuse for not complying with the requirement to provide reasonable help to inspector, unless it is a document (clause 91), or to provide information about an offence (clauses 111 and 112).

The evidentiary provisions are narrowly tailored to relate to non-contentious matters and enable the Director-General to put evidence before the court about a range of basic matters (such as the existence of a licence) without the need to call witnesses.

The deemed executive liability provision achieves the objectives of the Bill to protect the public by deterring the conduct of executive officers who may authorise, permit or know of a corporation's conduct constituting an offence under the Bill.

(d) <u>whether there are any less restrictive (on human rights) and reasonably available ways to achieve the purpose of the Bill</u>

The provisions in the Bill are the least restrictive way to achieve its purposes. Without reasonable excuse exceptions, the inspector would be forced to prove the accused did not have a reasonable excuse. As the facts of the defence of reasonable excuse may be entirely within the defendant's knowledge, this may unnecessarily impede the investigation or redirect resources from its intended focus. The reasonable excuse exceptions in the Bill therefore strike a fair balance between the rights of the person subject to the offence and the purposes of the Bill.

With respect to self-incrimination, without cooperation by the person who has been given or is required to keep or certify a document under the Bill, it would not be possible for an inspector to obtain documents by alternative means, or to ensure their authenticity. This limitation is justified as the provisions enable inspectors to enforce the framework by ensuring their enforcement capability is not compromised. The limitation is mitigated as the Bill provides a limited immunity against the future use of the document given or certified in compliance with the requirement. The limited immunity does not apply in relation to a proceeding about the false or misleading nature of the document, or a proceeding against the individual for an offence under the Bill or an administrative action taken against them (clauses 109, 110 and 118).

There are also no less restrictive and reasonably available alternatives to the evidentiary and deemed executive liability provisions. As the leadership of ART businesses is critical in ensuring the safety and compliance of its operations, the offences reversing the onus of proof in these limited circumstances are justified.

(e) the balance between the importance of the purpose of the Bill, which, if enacted, would impose a limitation on human rights and the importance of preserving the human rights, taking into account the nature and extent of the limitation

In my opinion, the limitations on an individual's right to a fair hearing and rights in criminal proceedings are reasonable and proportionate to achieve a legitimate outcome. As the Bill deals with situations where there may be serious risk of harm to the health, safety and wellbeing of people using ART services and born as a result, the limitations on these rights are appropriately balanced.

(f) any other relevant factors

Nil.

Human rights potentially limited by requirements for accessing ART services that use donor gametes and embryos

Right to protection of families and children (section 26)

Right to health services (section 37)

Recognition and equality before the law (section 15)

(a) the nature of the right

Section 26 of the Human Rights Act says that families are the fundamental group unit of society and are entitled to protection, and section 37 says that every person has the right to access health services without discrimination.

The Bill sets out certain pre-requisites for ART treatments that use donor gametes and embryos, including:

- **counselling:** ART providers must provide counselling services to people seeking treatment using donated gametes or a donated embryo and their spouse, and to prospective donors (clauses 15(1) and 15(2)). Counselling is optional where the gametes are obtained from the couple (clause 15(3)). The Bill prescribes a maximum penalty of 50 and 25 penalty units respectively for non-compliance with these requirements; and

- **family limit:** the Bill limits the number of donor-related Australian families that can be created from gametes and embryos from the same donor to 10. ART providers must exercise due diligence that this limit is not exceeded, such as by searching their records, making reasonable inquiries of the donor and requesting information from other ART providers. The Bill prescribes a maximum penalty of 400 penalty units or two years imprisonment for non-compliance (clause 25).

These requirements will impact all people and couples who undertake ART treatment with donor gametes and embryos, but will disproportionately impact single women and LGBTIQ+

couples. These groups undertake the majority of ART treatment cycles where donated gametes and embryos are used.

These additional pre-requisites may result in more time, complexity and cost for ART providers to offer treatments using donor gametes or embryos, which they may pass on to the patient in the form of increased costs. Some people may consider the requirement for counselling as intrusive and potentially a barrier to accessing treatment. The family limit may also prevent people from accessing gametes from their preferred donor and therefore restrict their ability to start a family in the manner of their choosing.

The right to recognition and equality before the law in section 15 of the Human Rights Act may be triggered when a policy or statutory provision, while stated in neutral terms, has the potential to have a disproportionate impact on a group in the community or members of the community who have a particular attribute. The family limit for the use of donor gametes may therefore limit the right to recognition and equality before the law by disproportionately impacting single women and LGBTIQ+ couples.

(b) the nature of the purpose of the limitation to be imposed by the Bill if enacted, including whether it is consistent with a free and democratic society based on human dignity, equality and freedom

The purpose of the limitation on these rights is to protect the welfare and interests of people accessing ART services and those born as a result. The purpose is not to control access to ART or determine the legitimacy of people's claims for treatment. Protecting the welfare of individuals is consistent with the purpose of the Bill and is consistent with a free and democratic society based on human dignity, equality and freedom.

(c) the relationship between the limitation to be imposed by the Bill if enacted, and its purpose, including whether the limitation helps to achieve the purpose

Limiting these rights will achieve their purpose by enabling Queensland Health to enforce counselling and family limits in the interests of people seeking ART treatments using donor gametes and embryos and the people born as a result.

The requirement for counselling before donor treatments is consistent with the NHMRC Guidelines. It recognises that all decisions about ART treatments, but especially those about the use of donor gametes and embryos, have the potential to impact key aspects of people's lives and relationships over the long-term. It is critical that people are informed and supported to process these matters and be equipped with the necessary tools to manage the impacts. The counselling process should complement their discussions with their treating fertility specialist.

A requirement for counselling for these services therefore promotes the right to protection from torture and cruel, inhuman or degrading treatment in section 17 of the Human Rights Act. This says that, inter alia, a person must not be subject to medical or scientific treatment without the person's full, free and informed consent. This right is promoted because the requirement for counselling will support people to make an informed choice about proceeding with ART treatment involving gamete or embryo donation.

The purpose of the family limit is to protect the donor-conceived person from the risk of consanguineous relationships and the psychosocial impacts of having many siblings. The Bill

also prescribes the limit in terms of families rather than the number of people who may use a donor's gametes and embryos so as not to disadvantage LGBTIQ+ couples where both partners wish to carry a pregnancy using the same donor. The family limit also engages and promotes the right to protection of families and children (section 26 of the Human Rights Act) by protecting the rights of donor-conceived people to form relationships and encompassing the range of families in Queensland.

The NHMRC Guidelines already include requirements for counselling for donor treatments and family limits. While already a well-recognised part of ART clinical practice, legislating these requirements will ensure that Queensland Health can monitor and enforce any potential non-compliance by ART providers. This will support their consistent application across the industry.

(d) whether there are any less restrictive (on human rights) and reasonably available ways to achieve the purpose of the Bill

There are no less restrictive and reasonably available ways to achieve the purpose of protecting people accessing donor treatments and the person born as a result. While these are current accreditation requirements, continuing to rely on industry self-regulation will mean that people seeking ART treatment and the people born as a result will have no recourse in the event of non-compliance.

(e) the balance between the importance of the purpose of the Bill, which, if enacted, would impose a limitation on human rights and the importance of preserving the human rights, taking into account the nature and extent of the limitation

In my opinion, the limitations on the rights to health services, protection of families and children and recognition and equality before the law are proportionate to the objectives of the Bill. ART treatments that use donor gametes and embryos have additional psychosocial risks not seen in other treatments. While the limitations necessarily impact some groups to a greater degree, and the potential risks are not uniform across different groups or individuals accessing donor treatments, the limitations will generally protect the people undergoing these more complex treatments and their families and promote other human rights.

(f) any other relevant factors

Nil.

Human rights potentially limited by requirements relating to the use of gametes and embryos

Right to protection of families and children (section 26)

Right to health services (section 37)

(a) the nature of the right

Protection of families and children

Section 26 of the Human Rights Act says that families are the fundamental group unit of society and are entitled to be protected by society and the State. Families take many forms and the right accommodates the various social and cultural groups in Queensland, including where

understanding of family may differ. Section 26(2) recognises that children have the same rights as adults, but with additional protections because they are children.

The Bill may limit this right by prescribing a point at which a gamete provider may no longer modify or withdraw their consent from their genetic material being used in an ART treatment (clause 20). For providers of donated gametes, they may no longer modify or withdraw their consent once an embryo has been created. For other scenarios, this point is when the gamete or embryo is placed in a person's body. This may restrict a gamete provider's ability to make decisions about their genetic family to some extent.

The Bill also prohibits ART providers, without the approval of the Director-General, from using donated gametes or donated embryos in an ART procedure if the gamete was obtained, or the embryo created, more than 15 years before the procedure. The Bill prescribes a maximum penalty of 100 penalty units for non-compliance (clause 27). This requirement may restrict a person's ability to make decisions about their family and future children.

Health services

As discussed above, section 37 of the Human Rights Act says that every person has the right to access health services without discrimination.

This Bill may limit this right by restricting some uses of gametes and embryos in ART procedures, including:

- where gametes used to create an embryo are from closely related family members, including a parent, child, sibling, grandparent or grandchild (clause 22);
- obtaining a gamete from a child (unless a medical practitioner certifies there is a reasonable risk of the child becoming infertile before becoming an adult) (clause 23); and
- where the family limit of the donor has been exceeded (clause 25).

The maximum penalty for each of the above offences in 400 penalty units or two years imprisonment.

The Bill also restricts sex selection of embryos for non-medical purposes (clause 24) and prescribes a maximum penalty of 240 penalty units or two years imprisonment.

As ART is a health service, by prohibiting some ART treatments, the right to health services will be limited to some extent.

(b) the nature of the purpose of the limitation to be imposed by the Bill if enacted, including whether it is consistent with a free and democratic society based on human dignity, equality and freedom

Protection of families and children

The purpose of the limitations regarding donors' consent and storage and usage of a donated gamete or embryo is to promote and protect the health and wellbeing of people undergoing ART treatment and persons born as a result of ART.

The purpose of restricting the time in which donated gametes or donated embryos may be used in an ART procedure is to promote and protect the health and wellbeing of people born as a result of ART.

These are proper purposes consistent with a free and democratic society based on human dignity, equality and freedom.

Health services

The purpose of restricting or prohibiting some uses of gametes and embryos is to protect the interests of the person born as a result of an ART procedure and the health and welfare of those undergoing ART procedures or donating gametes. The restrictions align with those in the NHMRC Guidelines currently being applied by clinics to guide the ethical practice of ART.

(c) the relationship between the limitation to be imposed by the Bill if enacted, and its purpose, including whether the limitation helps to achieve the purpose

The limitations imposed by the Bill are directly related to its objectives.

Prescribing a threshold for consent is essential to protect the interests and human rights of other parties involved in the ART treatment and remove ambiguity about whose interests may 'prevail'. If a provider of a donated gamete was able to modify or withdraw their consent after the gamete or resultant embryo was placed in a person's body, this could necessitate a termination of pregnancy, impacting the pregnant person's autonomy and reproductive freedom, and their human rights relating to family and medical treatment. In my opinion, these outcomes would be inconsistent with a free and democratic society based on human dignity and freedom. The limitation of the rights of the gamete provider caused by the threshold upon which a gamete provider is no longer able to withdraw consent is, in each case, a direct consequence of the threshold being necessary for the legitimate purpose of protecting the rights of the person undergoing ART treatment.

The restriction on using donated gametes or donated embryos obtained or created more than 15 years before a procedure is directly related to the health and wellbeing of persons born as a result of ART treatment. The restriction increases the likelihood that a person born as a result of ART treatment using donated gametes or embryos may, with consent of the individuals involved, be able to form a relationship with their biological parent/s.

With regard to restricting some uses of gametes and embryos, the NHMRC Guidelines recognise that some ART treatments offer the potential for greater influence of the desires of the intended parent/s than occurs with unassisted conception, and that treatment should commence only after serious consideration of the interests and wellbeing of the person who may be born as a result.

The NHMRC Guidelines are regularly reviewed and updated through the Australian Health Ethics Committee, with the most recent update in 2017 following two rounds of public consultation. That update considered the issue of non-medical sex selective ART procedures. The Australian Health Ethics Committee ultimately maintained the position that sex-selective ART procedures should not be used for non-medical purposes.

Overall, the Bill aligns with the NHMRC Guidelines in restricting a small number of potential services where the physical and psychosocial risks are considered to be more serious. This

includes having closely related biological parents, undergoing ART treatment as a child, having many siblings, and selecting embryos on the basis of genetic sex where there is no medical reason to do so.

The Bill provides for limited exemptions on medical grounds. Sex selection of embryos is permitted when necessary to avoid transmission of a genetic abnormality or disease to the child (clause 24(2)). ART providers may also obtain a gamete from a child if a medical practitioner certifies there is a risk to their fertility prior to adulthood, and the gamete is stored for the child's future benefit (clause 23(2).

The limitations promote the right to protection of children in section 26 of the Human Rights Act, which states that every child has the right, without discrimination, to the protection that it needs, and is in the child's best interests. Prohibiting a small number of certain ART procedures is intended to support this right by protecting people born as a result of ART from potential harm. The prevention of ART treatment on a child, unless certified by a medical practitioner as being in their best interests for future fertility preservation, also promotes this right.

In my opinion, the modest limitations on rights posed by restricting a small number of potential scenarios considered to have more serious impact is consistent with a free and democratic society based on human dignity and equality.

Limiting the number of uses for gametes and embryos will also discourage these treatments except when medically necessary, and enable Queensland Health to monitor and enforce compliance. The limitations will also support consistent application of the requirements across the industry.

(d) whether there are any less restrictive (on human rights) and reasonably available ways to achieve the purpose of the Bill

There are no less restrictive or reasonably available ways to achieve the purpose of the Bill. The restrictions are targeted at serious risks to the wellbeing and interests of people seeking ART treatment and people born as a result. While these risks are currently being managed to some extent by clinics' compliance with the NHRMC Guidelines, continuing to rely on industry self-regulation would mean there is limited recourse for those affected if non-compliance occurs.

(e) the balance between the importance of the purpose of the Bill, which, if enacted, would impose a limitation on human rights and the importance of preserving the human rights, taking into account the nature and extent of the limitation

In my opinion, the limitations on rights imposed by these restrictions are necessary to provide a clear framework for ART to be conducted in a way that promotes other human rights of the parties involved in ART. This will achieve the objectives of the Bill to protect the welfare and interests of ART users and the people born as a result.

(f) any other relevant factors

Nil.

Human rights potentially limited by requirements relating to the posthumous use of gametes

Right to protection of families and children (section 26)

Right to health services (section 37)

Right to privacy and reputation (section 25)

(a) the nature of the right

Protection of families and children

As discussed above, section 26 of the Human Rights Act says that families are entitled to be protected by society and the State. Children have the same rights as adults, but with additional protections because they are children. Families take many forms. The right accommodates the various social and cultural groups in Queensland, including where understandings of family may differ.

Some couples face the extremely challenging situation where one person dies unexpectedly. Gametes retrieved from a deceased person in a timely manner can be used in ART procedures to assist the surviving partner to conceive a child. This is a complex area with significant ethical issues. The existing NHMRC Guidelines outline clinical and counselling considerations for these situations, however, a legislative framework for retrieval and use will provide clarity and certainty for all parties.

For retrieval, noting time is of the essence, the Bill provides for a process that streamlines what is already permitted under the *Transplantation and Anatomy Act 1979*.

The Bill permits retrieval from deceased or unresponsive persons (clause 29). 'Unresponsive' relates to circumstances where a person's respiration or blood circulation is being maintained in a hospital by artificial means, and a designated officer of a hospital (as defined under the Transplantation and Anatomy Act) certifies that the person would die if these artificial means of respiration or circulation were withdrawn (clause 28). Retrieval in these circumstances is likely to have better quality of gametes than waiting until life support is withdrawn, potentially improving the recipient's chances of conception and reducing the need for multiple treatment cycles.

Posthumous retrieval is authorised only where there is evidence the person had consented to the retrieval and use of their gametes, or had not expressly objected and is likely to have supported the use (clause 29). Parties who may request retrieval are limited to the surviving spouse or, in specified exceptional circumstances, another family member of the deceased or unresponsive person, acting on behalf of the spouse (clause 30).

Use of gametes that have been retrieved and stored posthumously are provided for separately. This is because different considerations apply to protect the interests of the people involved, including allowing time for grieving, counselling and consideration of the health and psychosocial implications for the people that may be born.

To use stored gametes that were retrieved posthumously, the Bill requires that the proposed use has been reviewed by an independent review body and that body or individual has certified in writing that it supports the proposed use (clause 31). The qualifications of the body or

individual will be prescribed in regulation, and are expected to include a clinic's ethics committee (if it has one) or an appropriately qualified fertility counsellor.

The Bill may limit rights to the protection of families and children by prescribing pre-requisites for the posthumous use of gametes in this manner. This may be interpreted as limiting this right for the intending parent and the person born. For the intending parent, their ability to start a family in the manner of their choosing and their right to health services will be limited as this is subject to independent review. If the procedure is endorsed and a person is born as an outcome, the possibility of their having a relationship with one of their biological parents is prevented.

Health services

As discussed above, section 37 of the Human Rights Act says that every person has the right to access health services without discrimination. A person seeking to use gametes that were retrieved and stored posthumously must satisfy additional pre-requisites that would not apply to their use of other gametes, or if their spouse was still living. Therefore, their access to ART treatment is arguably limited.

Privacy and reputation

As discussed above, section 25 of the Human Rights Act provides that a person has the right not to have their privacy arbitrarily or unlawfully interfered with, or their reputation unlawfully attacked. Only lawful and non-arbitrary intrusions upon privacy, family, home, correspondence and reputation may occur.

The Bill may limit the right to privacy by prescribing that people must seek endorsement from an independent body for the use of gametes that have been retrieved post-mortem. That body or individual's consideration will necessarily include personal information necessary for it to make a decision on whether use is appropriate in the circumstances, such as whether the surviving partner has participated in counselling and has the capacity to provide for the resultant child's emotional, intellectual and other needs. In addition, if a person's application is not endorsed, they may experience this as a negative assessment of their reputation.

(b) the nature of the purpose of the limitation to be imposed by the Bill if enacted, including whether it is consistent with a free and democratic society based on human dignity, equality and freedom

For the intending parent, the purpose of the limitations on the rights to protection of family and children, health services and privacy is to separate decision-making about pursuing ART treatment to create a pregnancy from the very difficult circumstances of an unexpected death. While it is beneficial to provide for a streamlined process to enable viable gametes to be retrieved and stored, decision-making about the subsequent use of gametes in an ART procedure in the immediate aftermath of bereavement may present risks to the wellbeing of parties.

The NHMRC Guidelines prescribe that clinics should not attempt ART treatment until sufficient time has passed so that grief and related emotions do not interfere with decision-making, the intending parent undergoes counselling and is provided with information about the potential psychosocial and health implications for the person who may be born. It

also promotes the right to protection from cruel, inhuman or degrading treatment in section 17 of the Human Rights Act, which states that a person must not be subject to medical or scientific treatment without the person's full, free and informed consent. This right is promoted because the requirement for counselling will support people to make an informed choice about posthumous conception, separate in time from the grieving process. This will promote the welfare and interests of people who use ART and the person born as a result, consistent with the objectives of the Bill.

The limitation on the right to privacy is a necessary step to ensuring the broader protection of rights and interests related to these provisions. Ensuring that the independent body or individual considering a proposed posthumous use of gametes has all relevant information will necessarily include some personal information from the applicant. However, it will promote informed decision-making by the independent body or individual during what can be a challenging process.

In my opinion, the limitations on the rights of both parties are necessary in order to achieve the objectives of the Bill to promote their welfare and interests and promote other related human rights.

(c) the relationship between the limitation to be imposed by the Bill if enacted, and its purpose, including whether the limitation helps to achieve the purpose

The limitations are directly related to the purpose of the Bill and will achieve its purpose. The limitations establish appropriate prerequisites in order to facilitate decision-making in the best interests of the surviving spouse and the person who may be born as a result of the use of gametes, including a providing a degree of independence from the clinic where the proposed use of the gametes will occur. While these occasions are expected to be rare, the provisions will also enable Queensland Health to enforce these requirements on clinics and therefore protect the welfare and interests of the parties.

(d) whether there are any less restrictive (on human rights) and reasonably available ways to achieve the purpose of the Bill

There are no less restrictive and reasonably available ways to achieve the purpose of the Bill. Queensland Health considered the alternative option of seeking authorisation from the Supreme Court for posthumous use, as applies in some other Australian jurisdictions. However, during consultation, stakeholders advised that this would be unduly onerous for an intending parent and would likely present a significant barrier to pursuing treatment.

(e) the balance between the importance of the purpose of the Bill, which, if enacted, would impose a limitation on human rights and the importance of preserving the human rights, taking into account the nature and extent of the limitation

In my opinion, the limitations on rights are commensurate and proportionate with the objectives of the Bill. The provisions are well targeted at supporting parties through the extremely difficult circumstances of an early, unexpected bereavement with the aim of promoting the best interests of the surviving spouse and the person that may be born. The limitations on rights provide a safeguard against premature decision-making that may otherwise risk the long-term welfare of the surviving spouse and their family, and are therefore consistent with the objectives of the Bill.

(f) any other relevant factors

Nil.

Human rights potentially limited by the Register and birth certificates of donor-conceived people

(a) the nature of the right

Privacy and reputation

As discussed above, section 25 of the Human Rights Act outlines that a person has the right not to have their privacy, family, home or correspondence unlawfully or arbitrarily interfered with, and not to have their reputation unlawfully attacked.

The right to privacy is broad and is intended to protect the underlying value of humans as autonomous individuals with power over their actions. The right protects privacy in relation to personal information, data collection and correspondence, as well as a person's private life more generally.

Only lawful and non-arbitrary intrusions may occur upon a person's privacy. An intrusion is considered to be arbitrary if it is conduct that is capricious, unpredictable or unjust, or interferes with the right in a way that is unreasonable (in the sense of not being proportionate to the aim).

Establishment and operation of the Register

The Bill will limit this right in relation to information privacy as the Bill will require the provision of information, including personal and confidential information about donors, donor-conceived people and their parent or parents, to the Register and will establish a framework that will allow disclosure of a donor's identifying information to a donor-conceived person.

Following commencement of the Bill, donors will have donated gametes with the knowledge that their identifying information will be provided to the Register and may be accessed through the Register by donor-conceived persons once the donor-conceived person is 16 years or older. The limitation on the right to privacy will be particularly relevant for donors, donor-conceived people and their parents in relation to donor conception ART procedures that were carried out prior to commencement of the Bill.

Clause 46 of the Bill will compel ART providers or other persons that have possession or control of information about donor conception ART procedures that were carried out prior to the commencement of the Bill to provide the information to the Register. This may include personal or confidential information about donors, donor-conceived persons and parents of donor-conceived persons (such as the person's name, date of birth, place of birth and relevant medical information about the person). Clause 53 of the Bill outlines that the information must be provided to the Register, regardless of whether the person to whom the information relates has consented to the provision of the information. This will limit the privacy of these persons

as their personal or confidential information will be provided to Register under the Bill without their consent.

Clause 48 of the Bill outlines that a donor-conceived person, upon turning 16, may apply for and access identifying information about the donor if it is held on the Register. The donor's identifying information, which will include the donor's name and date of birth, will be provided to the donor-conceived person regardless of whether the donor has consented to its release. This will limit the right to privacy of donors who donated prior to commencement of the Bill, as these individuals have not consented to their information being provided to the Register and disclosed through the Register to donor-conceived persons.

Since their commencement in 2004, the current NHMRC Guidelines are intended to prevent clinics from using gametes of donors who did not consent to the release of their identifying information to donor-conceived persons. Accordingly, the limitation on the right to privacy is expected to have less impact upon donors that donated after commencement of the NHMRC Guidelines, as clinics should have ensured the donors consented to the release of their identifying information to persons conceived using their donated gametes at the time of donation (though could not have consented to the information being provided to and held by the Register as it was not in existence at the time of the donation).

The limitation on the right to privacy is particularly relevant for donors who donated prior to the commencement of the NHMRC Guidelines in 2004, as there were no accreditation or other requirement for donors to consent to the release of their identifying information to donor-conceived persons and donated gametes were often used on the condition that the donor would remain anonymous.

While the Bill outlines that a donor's contact information will not be provided to a donor-conceived person unless the donor consents to the release of the information, a donor-conceived person may attempt to seek out the donor using the information they have received from the Register (such as the donor's name and date of birth). This may impact upon the donor's privacy in terms of their family and home if a donor-conceived person contacts the donor outside of the consent framework outlined in the Bill. For post-2004 donors, the limitation may not be as relevant as the donor has consented to and is aware that their identifying information will be accessible by the donor-conceived person, which may lead to the donor-conceived person attempting to contact the donor.

A donor may also choose to disclose to their spouse and/or raised family (being the donor's children that are not conceived through a donor conception ART procedure) that they have donor-conceived children where they otherwise may not have disclosed this information. In some cases, the donor may not be aware of how many donor-conceived children they have and may become aware of this by accessing information about their donor-conceived children through the Register, which may also impact upon the donor's family and home.

Implementation of the access to information framework may result in donors disclosing to their raised family that they have donor-conceived children or their raised families becoming aware that the person has donor-conceived children, which may not have occurred if the Register was

not established. This will impact the privacy of the donor as it may cause intrusions on their family and home.

Birth certificate addendums

Clause 154 of the Bill will amend the *Births, Deaths and Marriages Registration Act 2023* to outline that if a person applies for their birth certificate and the Registrar is aware that the person is donor-conceived and there is information about them on the Register, the Registrar must issue an addendum with their birth certificate which outlines that there is further information about the person on a Register. It will then be a matter for the person to contact RBDM to obtain further information. The amendment will implement the intent of the Committee's recommendation in relation to birth certificates, which is to provide an independent avenue for donor-conceived people to become aware that they are donor-conceived if they are not aware of the information.

The birth certificate addendum may limit the right to privacy of parents of donor-conceived people and donor-conceived people themselves if these parents have not disclosed to their child or children that they are donor-conceived. In these circumstances, the right to privacy will be limited in relation to family and home where the donor-conceived person becomes aware they are donor-conceived as a result of receiving an addendum with their birth certificate and contacting RBDM to obtain further information that outlines that they are donor-conceived. The disclosure of such information may impact upon a donor-conceived person's relationship with their parent or parents and their understanding of their own identity.

(b) the nature of the purpose of the limitation to be imposed by the Bill if enacted, including whether it is consistent with a free and democratic society based on human dignity, equality and freedom

The purpose of the limitations on the rights of individuals that will occur through the establishment and operation of the Register and the birth certificate addendum is to promote and protect the health and wellbeing of donor-conceived people. In relation to the Register, this will be achieved by providing all donor-conceived people, regardless of when they were conceived or born, with the ability to access information about their genetic origins. In relation to the birth certificate addendum, this will provide donor-conceived people with an independent avenue to determine that they are donor-conceived and to access information held on the Register, if they choose to do so.

Although historical donors may have been assured anonymity at the time they donated, these individuals made the decision to donate as a competent adult, in full knowledge that the donation of their gametes may result in the conception and birth of a child. By comparison, donor-conceived people had no choice in the method of their conception and subsequently should not be denied the ability to have access to information about their genetic origins due to the timing and circumstances of their birth.

In its Inquiry, the Committee received submissions which outlined that the ability of a donor-conceived person to access information about their genetic origins is integral to supporting the person's sense of identity and this information can assist donor-conceived people to manage their health and wellbeing. Submitters outlined that it is in the best interests of donor-conceived people to ensure all donor-conceived people, regardless of when the person

was conceived or born, have the same ability to access identifying information about donors and this view was supported by the Committee.

Providing for retrospective operation of the Register ensures that all donor-conceived people can access important information about their donor if it is held on the Register. The contact framework is also intended to allow a donor-conceived person to connect with and share information, including medical information, with donor-conceived siblings or the donor. Enabling the sharing of information, including medical information, can be important for informing a donor-conceived person's identity and self of self, and may be life-saving in the case of sharing of medical information. The Inquiry heard evidence that having access to the medical history of donors is important, not only for a donor conceived person's own health management and awareness of any predisposition to develop genetic diseases, but also for any children they may have.

Accordingly, the purpose is considered to support human dignity and equality by ensuring all donor-conceived people are provided with the same rights under the Bill and have the ability to access information that is available to non-donor-conceived persons. The purpose will promote the rights of donor-conceived people, including the right to equality before the law, and is considered sufficiently important to justify the limitation on the rights of other individuals, particularly the right to privacy of donors.

(c) the relationship between the limitation to be imposed by the Bill if enacted, and its purpose, including whether the limitation helps to achieve the purpose

The provision of information about historical donor conception ART procedures to the Register is critical to fulfilling the purpose, as donor-conceived people will not be able to access identifying information about the donor unless it is provided to and held on the Register. Similarly, disclosure of a donor's identifying information regardless of whether the donor has provided their consent to the disclosure of the information is necessary to ensure the donor-conceived person has access to information about their genetic origins.

The limitation on the right to privacy of individuals will achieve the purpose as it will compel ART providers and other entities to provide information about historical donor conception procedures to the Register, regardless of whether the donor has consented to the provision of this information to the Register.

(d) whether there are any less restrictive (on human rights) and reasonably available ways to achieve the purpose of the Bill.

A potential model for the Register includes a prospective model, which would place obligations for ART providers to collect and provide information to the Register from commencement onwards and allow donor-conceived people conceived after the commencement of the Bill to access identifying information about their donor through the Register. This model would be less restrictive on the right to privacy for donors who donated prior to commencement of the Bill, and who did not consent to their information being provided to or disclosed by the Register.

However, this model would restrict the rights of donor-conceived people, particularly the right to equality before the law and the right to protection of children and family, as the ability of donor-conceived people to access information about their donor would depend on when they

were conceived and born. Donor-conceived people conceived prior to commencement would not have the same ability to access important information about their genetic origins through the Register and would have to rely on existing access provisions under the NHMRC Guidelines to obtain information about the donor if the donor has consented to its release. As outlined in submissions to the Committee as part of its Inquiry, donor-conceived people have stated that they currently have difficulties accessing information through ART providers even where this information should be provided under the NHMRC Guidelines. Although this model would promote the right to privacy for donors that donated prior to commencement of the Bill, this model was considered to unjustifiably limit the rights of donor-conceived people.

Another potential model for the Register is one that could operate historically, with ART providers and other entities to provide all historical donor conception information to the Register, however the information would only be provided to donor-conceived people if the donor has consented to its release. Again, this model would promote the right to privacy of donors, and their identifying information would not be provided to a donor-conceived person without their consent. However, the model would largely maintain the status quo and would continue to limit the ability of a donor-conceived person conceived prior to commencement of the Bill to access identifying information about their donor if the donor does not consent to its release. This model was also considered to unjustifiably limit the rights of donor-conceived people.

The model outlined in the Bill includes safeguards intended to mitigate the limitation on the right to privacy of donors. Particularly, a donor's identifying information will only be released without the donor's consent to a donor-conceived person. The donor's identifying information will not be provided to another person, such a parent of a donor-conceived person, unless the donor consents to this. The Bill provides that RBDM must make reasonable attempts to notify the donor that the Registrar has provided identifying information to a donor-conceived person.

A donor's contact information will never be provided to a person unless the donor has consented to the release of the information. While a donor-conceived person could seek out a donor using their identifying information, submissions made to the Committee as part of its Inquiry outlined that donor-conceived people generally seek information about the donor to inform their own identity and sense of self, rather than using the information to contact the donor if the donor has not indicated that they would like to be contacted.

The model for the Register outlined in the Bill will provide an opportunity for donor-conceived people, their parents and donors to be put in contact with support and counselling services that may not otherwise have access to if the Register did not operate historically. It is anticipated that these services will support donor-conceived people and donors when confidential and personal information is accessed through the Register. The establishment of the Register will also be supported by the development of resources and a public awareness campaign to ensure donors, donor-conceived people and their parents are aware of the changes to the law.

The model for the birth certificate addendum is considered to be the least restrictive option with regard to the rights of donor-conceived people. The recommendation of the Committee was to annotate the birth certificates of donor-conceived people to state that the person is donor-conceived. This option was considered to unjustifiably limit the right to privacy of

donor-conceived people, as information about the fact of their donor conception would be disclosed without their control in circumstances where provision of their birth certificate is required (for example, school enrolment or employment).

The model outlined in the Bill is considered to mitigate the impact on a donor-conceived person's right to privacy, as the fact of their donor conception will not be outlined on their birth certificate and inadvertently disclosed to others where a birth certificate must be provided. The birth certificate addendum model is also intended to provide RBDM with an opportunity to put donor-conceived people in contact with support services if they contact RBDM to seek further information about their birth and are not aware they are donor-conceived.

(e) the balance between the importance of the purpose of the Bill, which, if enacted, would impose a limitation on human rights and the importance of preserving the human rights, taking into account the nature and extent of the limitation

The purpose of the Bill is to promote the rights of donor-conceived people by providing all donor-conceived people with the ability to access identifying information about their donor where this information is held on the Register, and to have an independent avenue of becoming aware of the fact of their donor conception. Enactment of the Bill will promote the right to equality and the right to protection of children and families for donor-conceived people, as the Bill will not impose differing conditions on access to information based on when a donor-conceived person is conceived.

Enactment of the Bill will limit the right to privacy for donors, particularly donors who donated prior to the commencement of the Bill and especially those who donated prior to commencement of the NHMRC Guidelines.

Balancing the rights of donors to privacy with the rights of donor-conceived people to have access to information about their genetic origins is sensitive and implementation of the model in the Bill will alter the conditions a donor may have donated under in relation to anonymity. However, the limitation on the right to privacy of donors is considered to be justified when considered in conjunction with the effect the establishment and operation of the Register will have in promoting the rights of donor-conceived people to have access to important information about their genetic origins.

The establishment of the Register under the model in the Bill will promote the right to recognition and equality before the law, as well as the right to protection of families and children for donor-conceived people.

Prior to the introduction of the Bill, the ability of a donor-conceived person to access identifying information about the donor has been dependent on when the gametes were donated. Donor-conceived people born from gametes donated prior to the commencement of the Guidelines in 2004 have a limited ability to access identifying information about the donor from an ART provider, as there was no requirement for the donor to consent to the release of the information to the donor-conceived person.

The Bill will promote the right to recognition and equality before the law by providing all donor-conceived people, regardless of when they were born, with the same legislative ability to access information about the donor, where this information is held by the Register. Under the Bill, the release of identifying information about a donor to a donor-conceived person will

not be dependent of the consent of the donor. This promotes equality before the law for donor-conceived people as it provides a consistent approach to allowing access to information.

At the Inquiry, many stakeholders supported donor-conceived persons having access to historical clinical records. For instance, in its submission to the Inquiry, Donor Conceived Australia advised that the current legislation and framework relating to people conceived after 2004 "creates different classes of donor-conceived people" and that "retrospective legislation will remove discrimination and afford donor-conceived people equality before the law irrespective of their parents' timing of treatment and treatment success."

The right to protection of families and children outlines that every child has the right, without discrimination, to the protection that is needed by the child and is in the child's best interests, because of being a child. The right is also linked to the United Nations Convention on the Rights of the Child (which has been ratified by Australia). Article 8 of the Convention states that State Parties undertake to respect the right of the child to preserve their identity, including nationality, name and family relations as recognised by law without unlawful interference. Where a child is illegally deprived of some or all of the elements of their identity, State Parties shall provide appropriate assistance and protection, with a view to re-establishing speedily their identity.

As outlined by the Committee in its Report, "evidence and the experiences of donor-conceived people indicate that a person not knowing their genetic origin may negatively impact on their sense of identity and wellbeing and that early disclosure of donor conception status is important to their formation of identity".

The establishment of the Register and allowing donor-conceived people to access identifying information about the donor is intended to provide all donor-conceived people with the ability to access information about their genetic origins which may inform the person's sense of identity. Although donor-conceived people will be 16 years or older upon accessing information held on the Register, the Bill will provide the person with a right from birth to have the ability to access identifying information about the donor. In addition, the Bill will allow the parents or another person with parental responsibility for a donor-conceived person younger than 16 years old to access non-identifying information about the donor. This information may be used to support the donor-conceived person's knowledge that they are donor-conceived in an age-appropriate manner. These provisions of the Bill will promote the right to protection of families and children by allowing a donor-conceived person to have access to information about their genetic identity and family history.

(f) <u>any other relevant factors</u>

The Bill will legislatively implement an access to information framework that is similar to the framework ART providers have been operating under since the commencement of the NHMRC Guidelines in 2004. The Bill will extend this framework to include information about donor conception procedures that were undertaken prior to the commencement of the NHMRC Guidelines, which will provide certainty for all donor-conceived people as to their ability to access information through the Register.

The retrospective model for the Register outlined in the Bill aligns with the model established in Victoria under the *Assisted Reproductive Treatment Act 2008* (Victoria) and the model that

is being established in South Australia under the *Assisted Reproductive Treatment Act 1988* (South Australia). The Australian Capital Territory Government has also committed to establishing a retrospective donor conception information register following consultation with stakeholders.

Human rights potentially limited by requirements for ART providers to collect, share and disclose information

Right to privacy and reputation (section 25)

(a) the nature of the right

As discussed above, the right to privacy and reputation has a very broad scope, including protection of personal information and data collection and a person's private life more generally. For example, this right protects against interference with an individual's sexuality, family and home, and their individual identity, including their appearance and gender. Any interference with privacy that is unreasonable, unnecessary or disproportionate would limit this right. Only lawful and non-arbitrary intrusions may occur.

The Bill has the potential to limit this right by requiring ART providers to collect personal information from gamete providers prior to obtaining the gamete. For all gamete providers, ART providers must collect prior to treatment their full name, contact details, date and place of birth and other information prescribed by regulation (clause 33). For providers of gametes to be donated, ART providers must obtain further personal information, including:

- their ethnicity and physical characteristics;
- relevant medical history;
- the sex and year of birth of each of their children (whether or not donor-conceived); and
- any other information prescribed by regulation (clause 33(b)).

ART providers share this information, along with records of consents, when transferring gametes and embryos (clause 34).

The Bill prescribes a maximum penalty of 200 penalty units for non-compliance with the above requirements.

The Bill may also limit this right by providing for the disclosure of health information about donors and donor-conceived people, to specified parties, if a medical practitioner certifies the disclosure is necessary to minimise risk of harm. For example, an ART provider may:

- disclose health information about a donor (or a relative of a donor) to a donor-conceived person, their parent (or someone with parental responsibility), someone pregnant as a result of an ART treatment using the donor's gamete or their spouse, someone with a donated gamete from the donor in storage, or descendant of the donor-conceived person (clause 38); and
- disclose health information about a donor-conceived person (or their relative) to the donor, a donor-conceived sibling, parent (or someone with parental responsibility) of a donor-conceived sibling, someone pregnant as a result of an ART treatment using gametes

from the same donor or their spouse, or someone who has donated gametes from the same donor in storage (clause 38).

Other parties to whom health information may be disclosed may be prescribed by regulation.

The Director-General may disclose this information if they are satisfied that the ART provider who has the information has not disclosed it, and the information should be disclosed (clause 39).

(b) the nature of the purpose of the limitation to be imposed by the Bill if enacted, including whether it is consistent with a free and democratic society based on human dignity, equality and freedom

Information collection and record keeping are already integral to the clinical practice of ART, as outlined in the NHMRC Guidelines. For all providers of gametes (donated and otherwise) and embryos, the purpose is to ensure a high standard of information collection and record keeping is maintained in order to promote the welfare and interests of people who use ART and the people born as a result.

For all gamete providers, it is essential that their personal information is accurately collected, stored and handled throughout ART treatment. This provides certainty for the intending parents about the origins of the gametes used in their treatment. It also provides certainty for donors that their donated gametes and embryos are being used in a manner that is compliant with the legislation and consistent with their consent. This promotes other human rights of protection of family and children (section 26) and the right to protection from cruel, inhuman and degrading treatment, which requires that consent for medical treatment be full, free and informed (section 17).

The right to privacy for providers of donated gametes and embryos is limited to a greater extent because the donor is not personally known to the intending parents and more information is collected. However, the additional personal information is collected only to the extent required and is reasonable so that intending parents can make decisions about the ART treatment in the best interests of their family and the person who may be born. The information about the number of people born to the donor is also required in order to enforce the family limits (clause 25) which will protect donor-conceived people from the risks of consanguineous relationships and having many siblings. The limitation is also necessary for the operation of the Register, which will fulfil the rights of donor-conceived people to access information about their genetic heritage.

The purpose of the limitations on rights associated with the disclosure of health information is to enable ART providers to share information in order to prevent or minimise harm. This would apply in scenarios where information about a heritable medical condition becomes known, that would benefit a donor-conceived person, their parent or donor. The provisions remove the ambiguity about how and with whom this information can be shared, for the benefits of their health.

ART providers' non-compliance with provisions about information collection and disclosure may have long-term health and psychosocial impacts for people who use ART and the people born as result. Accordingly, the Bill has created a new offence for the destruction of records commensurate with these impacts, with a maximum penalty of 400 penalty units (clause 37).

Therefore, in my opinion, the limitations on the rights to privacy and reputation are necessary in order to achieve the objectives of the Bill and promote public confidence in ART, which is consistent with a free and democratic society, based on human dignity.

(c) the relationship between the limitation to be imposed by the Bill if enacted, and its purpose, including whether the limitation helps to achieve the purpose

The limitations are directly relevant to the objectives of the Bill. The Bill prescribes the minimum personal information that ART providers must collect from gamete providers and donors to provide for safeguards during ART treatment that gametes and embryos are being used appropriately and in accordance with consent. The Bill also establishes a clear framework for the disclosure of information where it will benefit an individual's health, removing the ambiguity which may otherwise cause unnecessary delay. These limitations will achieve the purpose of the Bill of promoting the welfare and interests of people who use ART and people born as a result.

(d) whether there are any less restrictive (on human rights) and reasonably available ways to achieve the purpose of the Bill

There are no less restrictive or reasonably available ways to achieve the purpose of the Bill.

Clear, enforceable requirements for the collection, storage and sharing of personal information are essential to the operation of the licensing scheme and the Register. A legislative framework for the disclosure of health information in certain circumstances is also considered the most efficient way to enable it to be communicated, noting these disclosures may be time-sensitive.

Alternatives such as education or continuing to rely on industry self-regulation would mean that people who use ART or born as a result have no recourse in the event of non-compliance by ART providers.

(e) the balance between the importance of the purpose of the Bill, which, if enacted, would impose a limitation on human rights and the importance of preserving the human rights, taking into account the nature and extent of the limitation

In my opinion, the limitations on rights by the information collection and disclosure requirements in the Bill are appropriate and necessary in order to achieve the objectives of the Bill. The Bill provides for a limited and specific range of personal information to be collected and stored by ART providers, scaled to the relevant ART treatment (whether it be a couple's own gametes or donor gametes and embryos). It also provides a clear, legislative framework to enable ART providers to disclose serious health information in limited circumstances, in order to warn people of a serious medical condition and prevent harm. The requirements will facilitate the operation of the licensing scheme and Register, and ensure that people have recourse in the event of non-compliance. These outcomes are consistent with the objectives of the Bill.

(f) any other relevant factors

Nil.

Conclusion

In my opinion, the Assisted Reproductive Technology Bill 2024 is compatible with human rights under the *Human Rights Act 2019* because it limits relevant human rights only to the extent that is reasonable and demonstrably justifiable in a free and democratic society based on human dignity, equality and freedom.

THE HONOURABLE SHANNON FENTIMAN
MINISTER FOR HEALTH, MENTAL HEALTH AND AMBULANCE SERVICES
MINISTER FOR WOMEN