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Submission on Use of genetic testing results in life insurance underwriting

Intersex Human Rights Australia (IHRA)

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2 Introduction

We thank the Treasury for developing the Consultation Paper on Use of genetic testing results in life insurance underwriting. Intersex Human Rights Australia (IHRA) welcomes the opportunity to provide feedback and comments and make recommendations.

Life insurance is a mechanism for aggregation and distribution of costs associated with mortality and morbidity risks. Pooling risk benefits the insured by spreading costs associated with death, illness and injury amongst all the insured. Pooling risk also contributes to community cohesion when insurance in community risk-rated (Armstrong 2001). When insurance is individual risk-rated, this generates a variety of perverse incentives and harmful consequences, which are further explored below. The fact that voluntary life insurance can be individually risk rated, while default insurance provided through a superannuation fund or employer is not individually underwritten, also creates a two-class system that in itself, is detrimental to social cohesion.

This submission therefore argues that life insurance in Australia should operate in accordance with community rating principles similar to the those forming the basis of Australia's health insurance system. IHRA does not argue that there should be no exceptions to a general principle of community risk rating in life insurance. It does argue that such exceptions need to be justified on their own terms, and should not detract from community cohesion or underlying principles of accessibility and portability. Other principles on which universal health care systems are based such as universality and comprehensiveness should also be considered.

2.1 About this submission

IHRA is a national charitable organisation run by and for people with innate variations of sex characteristics, formerly known as Organisation Intersex International (OII) Australia. We registered as a not-for-profit company in 2010 and became a charity in 2012. Since December 2016 we have been funded by foreign philanthropy to employ two part-time staff to engage in policy development and systemic advocacy work.

We promote the health and human rights of people with innate variations of sex characteristics, including rights to bodily autonomy and self-determination. Our goals are to help create a society where intersex bodies are not stigmatised, and where our rights as people are recognised. We build community, evidence, capacity, and provide education and information resources. Our staff and directors engage in work promoting consistent legislative and regulatory reform, reform to clinical practices, improvements to data collection and research. We also work to grow the intersex movement and the available pool of advocates and peer support workers, and address stigma, misconceptions and discrimination.

Our work is conducted in line with a 2017 community-designed platform, the *Darlington Statement*, which sets out priorities for the intersex movement in our region (AIS Support Group Australia et al. 2017). Together with Intersex Peer Support Australia (IPSA, also known as the AIS Support Group Australia) we comprise the Darlington Consortium.

We are willing to meet and discuss our submission, if Treasury would find this helpful. This submission may be published.

2.2 Authorship

This submission by IHRA has been written by Alice de Jonge. It incorporates material previously written by Morgan Carpenter, and has been supported through review and feedback by our board of directors.

Dr Alice de Jonge is a senior lecturer in law at Monash Business School. She has been a director on the board of IHRA since December 2021. She is author of four books and over 50 peer-reviewed journal articles and book chapters. Her research focuses on issues of human rights, equity and social inclusion in national and international law.

3 Examples and experiences of innate variations of sex characteristics

The purpose of this section is to provide sufficient understanding to enable consideration of the impact of policies, policy proposals, and practices affecting people with innate variations of sex characteristics. We consider these practices to be relevant to discussions about discrimination, including in relation to discrimination in the availability and terms of life insurance.

Respondents to a large Australian sociological study of people born with atypical sex characteristics in 2015 (Jones et al. 2016) had more than 35 different variations, including 5-alpha-reductase deficiency, complete and partial androgen insensitivity syndrome (AIS), bladder exstrophy, clitoromegaly, congenital adrenal hyperplasia (CAH), cryptorchidism, De la Chapelle (XX Male) syndrome, epispadias, Fraser syndrome, gonadal dysgenesis, hyperandrogenism, hypospadias, Kallmann syndrome, Klinefelter syndrome/47,XXY, leydig cell hypoplasia, Mayer-Rokitansky-Küster-Hauser syndrome (MRKH, mullerian agenesis, vaginal agenesis), micropenis, mosaicism involving sex chromosomes, mullerian (duct) aplasia, ovo-testes, progestin induced virilisation, Swyer syndrome, Turner's syndrome/45,X0 (TS), Triple-X syndrome (XXX).

Below we detail the characteristics and experiences of people with several distinct innate variations of sex characteristics due to their higher frequency, and/ or their value in illustrating potential or actual discriminatory practices in life insurance underwriting.

3.1 Androgen insensitivity

Persons with androgen insensitivity syndrome ('AIS') have XY sex chromosomes (typically associated with men), testes (typically intra-abdominal), and a phenotype or physical appearance that may vary. The majority of people with complete AIS appear to be cisgender women and a high proportion are heterosexual (Warren 2017). People with partial AIS grow up to understand themselves in diverse ways, including many women and girls with a largely typical female phenotype, and people who look and understand themselves in different ways.

Diagnosis may take place at any point during infancy or childhood (for example, if testes are mistaken for herniation) or during puberty (due to lack of menstruation). Commonly a diagnosis of AIS based on physical characteristics and symptom is then confirmed through diagnostic genetic testing.

Once diagnosed, people with AIS are frequently subjected to gonadectomies, or sterilisation. Historically, rates of potential gonadal tumour risk have been overstated, particularly in the case of complete AIS. Current papers suggest a low gonadal tumour risk of 0.8% associated with the gonads of people with complete AIS (Pleskacova et al. 2010), while risk levels associated with partial androgen insensitivity have reduced from an exaggerated high of 50% in a 2012 paper quoted in submissions to the Senate Community Affairs References Committee in 2013 (Warne and Hewitt 2012; Senate 2013) to '~7%' in 1 2021

report (O'Connell et al. 2021, 7). Following sterilisation, individuals require hormone replacement to maintain bone health, libido and general health.

It was only very recently, in 2019, that a team of clinicians in the United States published a first management protocol for preservation of gonads in individuals with AIS (Weidler et al. 2019). We have no data on whether such protocols are being taken up in Australia. In 2019, a clinical team in Brisbane published a review of cases managed by the Paediatric and Adolescent Gynaecology Service where, likely following age of diagnosis, 'In CAIS, bilateral gonadectomies were most often done at infancy'; all individuals with PAIS were also subjected to gonadectomies (Adikari et al. 2019).

3.2 Congenital adrenal hyperplasia

Children with congenital adrenal hyperplasia (CAH) may necessitate immediate medical attention from birth to manage salt wasting. Salt wasting is potentially fatal and neonatal bloodspot screening is being introduced nationally to identify and treat children at risk (Department of Health 2020).

3.3 17-beta hydroxysteroid dehydrogenase 3

Infants with 17-beta hydroxysteroid dehydrogenase 3 (17β-HSD3) have XY chromosomes and may have genitals that appear at birth to be somewhere between typically female and typically male. In cases where visible genital variation is evident at birth, the currently proposed World Health Organization *International Classification of Diseases* ICD-11 beta suggests that gender assignment be made based on a doctor's assessment of the technical results of masculinising genitoplasty, and that genital surgeries must occur early. Elimination via selective embryo implantation during IVF is also stated as possible.

In 2006, a clinical 'consensus statement' described the risk of gonadal tumours associated with 17β-HSD3 to be 28%, a 'medium' risk, recommending that clinicians 'monitor' gonads (Hughes et al. 2006). A more recent clinical review published in 2010 reduced risk levels to 17% (Pleskacova et al. 2010) and a German multidisciplinary team advised Amnesty International in 2017 that, in any case, 'cancer risk even for the high risk groups is not so high. We can monitor with ultrasound and for tumour markers' (Amnesty International 2017). However, like the WHO ICD-11 classification (World Health Organization 2022), current medical journal articles on this trait (for example, Lee et al. 2016) recommend gonadectomy with female gender assignment, and not on the basis of cancer risks.

In 2008, in the Family Court case *Re Lesley (Special Medical Procedure)*, a judge approved the sterilisation of a young child with 17β-HSD3 (Family Court of Australia 2009). While sterilisation was not predicated on clinical urgency regarding cancer risk, but rather to surgically reinforce a female gender assignment, risks of gonadal tumour were stated to be 'significant' (at [40]). Similarly, in the 2016, Family Court decision *Re: Carla (Medical procedure)*, the judge concluded that parents could authorise the sterilisation of a pre-school (5-year old) child with 17β-HSD3, claiming that 'it would be virtually impossible to regularly monitor them for the presence of tumours' (at [20]) (Family Court of Australia 2016). IHRA notes that this does not accord with the German experience, or material in a

2006 clinical ‘consensus statement’ that calls on clinicians to ‘monitor’ gonads of people with this trait (Hughes et al. 2006).

3.4 47,XXY/Klinefelter syndrome

People with Klinefelter syndrome are clinically defined as men with an extra X sex chromosome (i.e. XXY sex chromosomes, or 47,XXY). Klinefelter syndrome is associated with small testes, hypogonadism (low sex hormone levels, in this case low levels of testosterone), and also may be associated with cognitive issues such as ADHD, and a range of other health risks (Skakkebæk, Wallentin, and Gravholt 2015).

A 2015 clinical review states that 90% of people with 47,XXY are diagnosed after age 15, and only a quarter of individuals expected to have this variation are ever diagnosed.

3.5 46,X0/Turner’s syndrome

Women with Turner’s syndrome are often diagnosed at puberty, when menstruation fails to occur. In such cases, a preliminary diagnosis based on physical characteristics (such as short stature, webbing of the neck and/or cubitus valgus) will typically be confirmed through diagnostic genetic testing. Diagnosis may occur in utero when genetic testing is undertaken to screen for preferred sex and/or unwanted genetic conditions such as Down’s Syndrome.

Turner’s syndrome is associated in the literature with significantly increased risk of heart disorders, such as aortic dissection, and has been associated with evidence of reduced life expectancy (Price et al. 1986). Early literature finding significantly increased risks of gonadal cancer have been challenged, and it is now more common for surgical removal to be confined to cases of mosaic Turner’s women with streak ovaries. Lifetime estrogen therapy is commonly prescribed for Turner’s women. Turner’s syndrome women can expect early hearing loss and may suffer the psycho-social side-effects associated with hearing loss.

4 The decision to proceed with a life insurance application

What the above examples all illustrate is that in the great majority of cases, when an intersex person reaches an age where they might consider purchasing life insurance, they may have some understanding of their specific diagnosis and its associated health risks. In many cases, the intersex person considering life insurance will have undergone surgery and/ or will be receiving on-going treatment. What this means is that there is no decision to be made regarding whether or not to proceed with genetic testing, as this will often have been done dyring childhood without personal consent. The only decision to be made is whether or not to complete an application for life insurance.

People with innate variations of sex characteristics applying for life insurance mostly do so knowing that they will be subject to adverse individual risk rating. This is because in nearly all cases it will not be possible to fulfil the insured's duty of honest disclosure without revealing the applicant's diagnostic status. Certainly, by the time the intersex applicant has completed a life insurance application form, they will be aware that they are providing information which can, and probably will be used by the insurer to justify an adverse risk assessment. Research on a variety of intersex variations, as noted above, may provide the life insurance provider with evidence of increased risk that can be used to justify a higher premium charge. This alone may be sufficient to deter the applicant from proceeding with the application.

The prevalence of genital and gonadal surgery amongst individuals with different variations of sex characteristics was described above. Life insurance application forms used in Australia all (or at least all those we have examined) contain a question asking the applicant to disclose whether they have "EVER had, been diagnosed with or taken treatment for: … Disorder of the Reproductive Organs?"

Applicants responding yes to this question (including people with many innate variations of sex characteristics) are then asked to provide details of their specific diagnosis, including:

When did you first have symptoms?

When were you diagnosed?

Do you currently experience symptoms?

Do you take any medication?

Have you had any treatment?

Are you waiting on further treatment or medical appointments?

Has your condition resolved?

Answering such questions can be both confusing and distressing for individuals applying for voluntary life insurance. It may also put the insurer seeking the information in breach of s. 27 of the *Sex Discrimination Act* 1984 (Cth) which provides, in relevant part, that:

> *"It is unlawful for a person to request … another person … to provide information (whether by way of completing a form or otherwise) if:*
>
> *(a) The information is requested … in connection with, or for the purpose of, the first person doing a particular act; and*
>
> *(b) … it would be unlawful in particular circumstances for the first person, in doing that act, to discriminate against the other person on the ground of the other person's … intersex status … ; and*
>
> *(c) Persons:*
>
> *…. (ic) who are not of intersex status; …*
>
> *… would not be requested … to provide the information in circumstances that are the same or not materially different.*

It can be argued that intersex individuals are in the same position as persons diagnosed with genetic conditions such as Hereditary Breast and Ovarian Cancer syndrome (*BRCA1/2*), Lynch syndrome or Huntingdon's disease. The difference, of course, is that intersex status is a protected category under the *Sex Discrimination Act* 1984 (Cth). Section 22 of that Act provides, in relevant part:

> *It is unlawful for a person who, … provides … services … to discriminate against another person on the ground of the other person's … intersex status, …*
>
> *(a) By refusing to provide the other person with those … services …;*
>
> *(b) In the terms or conditions on which the first-mentioned person provides the other person with those … services … ; or*
>
> *(c) In the manner in which the first-mentioned person provides the other person with those … services…*

IHRA submits that intersex applicants for life insurance products are discriminated against by insurers. Intersex individuals are subject to higher life insurance costs whenever they are identified by the insurer as having intersex status, including where such identification is not based on genetic test results known to the insurer.

Life insurance providers may seek to justify treating intersex applicants individually based on published data relating to the applicant's innate variation of sex characteristics. As noted above, the accuracy of such studies has sometimes been called into question. More importantly, treating life insurance applicants with innate variations of sex characteristics

individually based on such studies fails to recognise the diversity existing between and within sex characteristic variations.

IHRA notes that section 41 of the *Sex Discrimination Act* provides that discrimination on grounds of sex by an insurer is not unlawful if reasonably based on actuarial or statistical data.[1] No such exception exists, however, in relation to discrimination on the grounds of intersex status.[2]

The Office of the High Commissioner for Human Rights expressly recognised that intersex people are subject to discrimination in access to services (OHCHR 2019), and this includes life insurance services. IHRA submits that legislation allowing or mandating for life insurance to be provided on a community risk-rated basis would help to ensure that insurers do not act contrary to the *Sex Discrimination Act*. It would have the added benefit of preventing many, if not most, other instances of discrimination in the provision of life insurance products in Australia that have been identified in the literature (see, for example, Tiller et al. 2023, 2020).

IHRA notes the care taken by life insurance companies offering products in Australia to avoid including in their application forms any questions relating to race or sexuality. It is submitted that the intimate nature of questions in life insurance application forms regarding the 'health' of the applicant's reproductive organs represents de-facto inclusion of a question requiring applicants with innate variations of sex characteristics to disclose their intersex status. Whether or not this represents a breach of section 27 of the *Sex Discrimination Act* remains for the courts to decide. Regardless, IHRA submits that such questions are experienced as intrusive and discriminatory by people with innate variations of sex characteristics, and in many cases may result in sufficient distress to deter the intersex applicant from proceeding with the application. In other cases, increased premium charges will be the deterrent. In either case, discrimination has been experienced.

This submission has argued that allowing (or even mandating) the provision of life insurance on a community risk-related basis enables insurers to avoid genetic discrimination against individual applicants. If such a solution is regarded as a 'step too far' for the life insurance sector however, we call, as an alternative, for genetic discrimination to be made unlawful, including in the provision of insurance. Importantly, adopting this alternative legislative strategy would address the significant community concerns about genetic discrimination in life insurance revealed in a number of recent studies.

Legislating a total or partial prohibition on the use of adverse genetic testing results by life insurers would also assist in smoothing risks across the community between those who have and those who have not been tested when the contract is made.

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[1] An addition requirement is that the insurer must make a copy of the relevant data available to the client.

[2] Noting also that discrimination on ground of sex and discrimination on ground of intersex status are clearly treated as separate categories of discrimination throughout the Act: See sections 5 and 5C especially.

IHRA notes that the intersex population includes those who have entered adulthood without knowing or being aware of their intersex status. This may be the result of a deliberate decision made by carers or healthcare providers not to reveal relevant information, or simply the result of failure to diagnose. If genetic testing occurs after a life insurance policy has been underwritten and commenced, the insured is under no obligation to hand the test results over to the insurer.

As life insurance is a guaranteed renewable product, once a policy has been underwritten and commenced, the life insurer cannot change or cancel a person's cover (provided premiums are paid when due). What this means is that genetic testing undertaken after commencement of the policy cannot be used by the insurer to increase premiums based on increased risks. Nor can such testing be used by an insured to argue for a reduced premium - for example by demonstrating that risks typically associated with a particular genetic feature or set of features are not present in the case of the insured. In either case, the result of the "guaranteed renewable product" rule is that premiums are not in fact reflective of risk. This may result in the life insurer deciding to adjust premiums across a risk pool – a practice akin to community risk-rating. IHRA suggests that the fairest and most consistent way to resolve such individual inequities is to apply a community-risk rating principle to all life insurance products. IHRA does not insist that there should be no exceptions to such a principle but does argue that any such exceptions should be justifiable on the basis of public interest principles.

IHRA notes that superannuation related life insurance products are not individually rated. As the coverage of compulsory superannuation throughout the Australian community spreads, more employees and former employees are likely to be covered by some form of superannuation life insurance. A two-class system may develop where those fortunate enough to be covered by superannuation have access to community-rated life insurance products, while those without superannuation access can only obtain life insurance on an individual risk-rated basis. IHRA submits that such a situation is discriminatory and undesirable.

In summary, when life insurance applicants are identified as having intersex status, whether or not on the basis of genetic test results, they are susceptible to irrational discrimination during the underwriting process. This is because of the complexity and variety of sex characteristic variations, a lack of reliable and reproducible data, the complexity of genomic linkages to different sex characteristic variations, the role of non-genetic factors, and the tendency to assign excessive probative value to published data about a class of persons.

The insurance industry has underwritten based on general medical information since its inception, but insurers have little knowledge or experience in dealing with information about variations of sex characteristics and their relevance in risk assessment for life insurance underwriting purposes. This is due both to the very small number of life insurance applicants with an innate variation of sex characteristics, and also due to the relative paucity of reliable data relevant to life insurance underwriting. As a result, policy and practice surrounding the treatment of intersex life insurance applications may be unfair, inconsistent and lacking transparent reasoning.

IHRA therefore submits that the problem for intersex individuals lies less in decisions relating to genetic testing – the decision whether or not to undertake such testing is often a decision that has been made on their behalf before adulthood. The problem is that members of the intersex community are assessed adversely whenever they apply for life insurance and are identified as having intersex status. This has the effect of deterring potential life insurance applicants from proceeding. It also means that intersex individuals must make a difficult decision before accepting any opportunity (employment, travel or 'adventure') where life insurance is a prerequisite. The person with an innate variation of sex characteristics must decline the opportunity or face higher costs relative to others seeking access to the same opportunity/ activity.

To address this discrimination, IHRA proposes that the law should be altered to allow and/ or require, life insurance products to be offered on a community risk-rated basis. The precise nature of such a change should be open to consultation and debate. One possibility would be for consumers to be offered different products on different risk-rating bases. Some life insurance products might be offered on an individual risk-rated basis only. Other products might be offered to allow consumers a choice, while yet others might be offered only on a community rated basis. Life insurance products could be allocated to different risk-ratings based on the type of product (Life cover; TPD; Trauma; income etc.) or based on the value of the product or a mix of both type and value of product.

If the option of broadening the use of community-risk rating in life insurance underwriting is not accepted, IHRA proposes that the law should be altered to prohibit genetic discrimination totally or in part. The approaches to genetic discrimination adopted in Canada (*Genetic Non-Discrimination Act* 2017) and/or the EU (different national legislation based on the Oviedo Convention on Human Rights and Biomedicine).

In relation to question 9 and 10 of the consultation paper, relating to the most appropriate enforcement body, IHRA submits that both the AHRC and ASIC have a valuable role to play.

ASIC plays a valuable role in ensuring that life insurers apply relevant prudential standards, including underwriting standards, consistently, fairly and in a transparent fashion. Where an insurer has failed to do so, consumers should be able to make a complaint to the AFCA.

Particularly in the event that the law is altered to prohibit genetic discrimination, AHRC has a valuable role to play in educating, promoting and raising awareness of this new element in Australian human rights law. AHRC should also continue to play a part in addressing and resolving claims of discrimination in insurance, and supporting individual complainants.

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