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Dear Dr Alderson,

Re: Non-Consensual Genetic Testing (Model Criminal Law Officers' Committee)

Thank you for the opportunity to comment on the above discussion paper. The Victorian Council for Civil Liberties (Liberty Victoria) is one of Australia's leading human rights and civil liberties organisations and works to defend and extend human rights and freedoms in Victoria.

The Model Criminal Law Officers' Committee (MCLOC) discussion paper on non-consensual genetic testing proposes the creation of several criminal offences to protect individuals from non-consensual collection and testing of their genetic material. As noted in the discussion paper, Australia's existing laws (privacy, health, torts) do not provide adequate protection against the non-consensual collection and testing of bodily materials.

Scope of Offences

Of primary concern is the failure of the proposed offences to protect individuals from other types of testing of their bodily material. For instance, the collection and testing of bodily material for non-genetic diseases or other acquired illnesses is not protected. Moreover, it may not cover 'genetic' diseases which have not been acquired genetically.¹ The proposed offences should be expanded to protect against any non-consensual analysis of bodily material to derive personal health information about an individual.

From the definition, it is unclear whether 'bodily material' includes waste material such as urine or fecal matter. Liberty believes bodily material should include all material produced or discharged by a human body.

Collection

The proposed provision does not extend to non-consensual collections where the intention of the person collecting the material is anything other than to perform a genetic test. For instance, it would not catch those who collect material with the intention of performing non-genetic tests (i.e. drug testing) or selling the material. To be effective, this provision should make it an offence to collect (without consent) the bodily material of another with the intention of causing testing or analysis to be carried out upon it.

¹ Various environmental factors may lead to the acquisition of what is generally considered a genetic disease (e.g. diabetes, MS, etc).

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Further consideration should also be given to making an attempt to commit this offence a crime (carrying a commensurately lower penalty or fine).

Use

Similarly, the proposed 'use' provision fails to prevent anything other than genetic testing. This provision should be broadened to make it an offence to cause any analysis or testing to be carried out on bodily materials unless either done with consent or otherwise authorised by law.

It should also be an offence (carrying either a financial penalty or lower order penalty) to attempt to commit the same offence.²

Disclosure

Once again, this offence should be broadened to apply to the disclosure of health information obtained as the result of a test or analysis conducted on bodily material obtained without consent.

However, this offence should be limited to the intentional (or reckless) disclosure of such information. At present, it applies to any disclosure of non-consensually obtained and tested genetic information.

Finally, clause 5.3.4(2) provides that the provision does not apply to the disclosure or use of information that does not identify any person. It should be noted that even where information does not directly identify a person, it is often possible to determine who the information relates to.³ Indeed, enterprising journalists could easily disclose health information that did not identify the individual, but which provided sufficient detail that his or her identity could be surmised.

Liberty recommends that this clause be removed and, if necessary, replaced with one that protects the use and disclosure of aggregate health information which does not and cannot be used to identify any individuals. Unfortunately even this approach may result in small groups (i.e. families) being identifiable. Liberty believes that the lawful authority defence provides adequate protection to the proper use and disclosure of such information.

Penalties

The penalties appear to be generally consistent with other similar provisions. However, the collection of bodily material is arguably a lower order crime than the testing and disclosure of the information that bodily material contains. Collection on its own (regardless of the intention behind it) will not reveal any health information about the individual. Thus the testing and later disclosure of health information about the individual constitute a greater invasion of privacy. Consideration should be given to imposing relatively higher penalties on the testing and disclosure of health information.⁴

Liberty also believes that financial penalties should be available in conjunction with other sentencing options.

Defences

Liberty strongly agrees that each offence must include a fault element. Where there is no intention to obtain the bodily material for future testing, no offence will have occurred. As

² Where bodily material is covertly obtained, it is more likely to be contaminated or otherwise impossible to test or analyse; this likely eventuality should not detract from the criminality of the actions underlying it.

³ For instance, in small towns or where other circumstances make it easy to identify the data subject.

⁴ Either by dropping the penalty for collection to 1 year or increasing the penalty for use and disclosure to 3 years.

noted, this will apply in the myriad of instances in which unwitting or unavoidable collections occur.⁵

It is also appropriate that no criminal responsibility attach to public officials acting in the course of their duties where that conduct is reasonable in the circumstances.⁶ However, this defence as it stands is too broad. Its purpose is to protect incidental collections or conduct not expressly authorised by law. Thus accidental or incidental collection is defensible only where the public official takes immediate steps to destroy the sample once aware of the collection; criminal liability should attach where the public official goes on to use or otherwise disclose that material to another person without lawful authority.⁷

For instance, an officer arrests a celebrity and later realises hair from that person is stuck to his or her uniform. Rather than destroy or dispose of it, the officer now seeks to have it tested or sell it on e-bay. Such conduct should be a criminal offence, regardless of whether they are a public official or not.

The discussion paper states that 'grey' collections by public officials should be protected. Liberty disagrees. Covert collection and testing should only be protected where expressly authorised by law. Otherwise public officials will effectively be empowered to collect and test bodily material where not authorised to do so. A Government should not protect officers who act beyond their authority in circumstances where the public would be held criminally liable for the same conduct.

For the above reasons, Liberty believes that the 'lawful authority' defence, when coupled with the requisite fault element contained in each offence provides sufficient protection to individuals (public officials or not) who handle non-consensually obtained bodily material.

Onus of Proof

Liberty believes that for each offence, the onus of proof must lie with the prosecution. However, where a defendant seeks to rely on a lawful authority defence, he or she must first adduce some evidence to put the matter in issue (at which point the onus passes to the prosecution to prove its absence).

Consent

The established definition of consent is the appropriate test, but Liberty recognises that employers, insurers, clubs and other interested parties are increasingly asking individuals to undertake various forms of testing. For those individuals, consent is a condition of their continued involvement with the organisation (as an employee, insured party, club member, etc). Liberty believes this form of duress is a worrying trend which must be addressed in the medium to long term. Unfortunately the current proposal does little to protect individuals against non-consensual non-genetic testing or 'duress' consensual testing.

All forms of non-consensual intentional testing or analysis of bodily material should be a criminal offence unless authorised by law. Moreover, non-consensual testing should only be authorised by law in certain limited circumstances (i.e. where a reasonable suspicion of wrongdoing exists).

Liberty also believes that consensual collection, use and disclosure by organisations needs to be regulated. In many cases, individuals have little choice but to consent to testing which may reveal information which is simply not relevant. Accordingly, organisations should be

⁵ Such as when objects used by individuals (e.g. crockery, clothes, cars, etc) or areas frequented (e.g. offices, homes, public transport) are cleaned or personal services rendered (e.g. haircuts, day spas, etc).

⁶ Further, public official should not be limited to law enforcement officers as it is foreseeable that other public officials may incidentally collect or test bodily materials (e.g. pathologists, clerks, etc).

⁷ No criminal liability should attach to a law enforcement officer who deliberately (where expressly authorised by law), accidentally or incidentally collects bodily material from an individual (i.e. hair, skin, etc).

limited to collecting, using and disclosing only that health information which is directly relevant to the individual's involvement with that organisation.

Liberty therefore recommends the MCLOC give further consideration to how the collection, use and disclosure of health information can be limited to that reasonably required by an organisation or individual. The underlying purpose being to prevent organisations or individuals pressuring an individual into consenting to testing which is not reasonably required (or carrying out further tests once blanket consents are obtained).

Shared 'health' Information

Another consent issue lies with the family of individuals. Particularly in the case of genetic testing, information obtained will be highly relevant to other family members (especially children). For instance, an individual may consent to the collection, use and disclosure of genetic information, but his or her son or daughter may not (and vice versa or between siblings or even across generations). Thus consent by one party may conflict with a lack of consent by another. Liberty believes that strict disclosure laws are required to protect non-consenting parties from disclosures of shared health information. The current proposal does not adequately address this area and Liberty encourages the MCLOC to further consider how shared personal health information can best be protected.

We hope the above comments are of assistance to the MCLOC and please do not hesitate to contact Liberty Victoria should you wish to discuss this matter further.

Kind regards,



Georgia King-Siem

Vice-President
Liberty Victoria