Oral Submission to the Health Select Committee

Gene Technology Bill

The Nathaniel Centre for Bioethics

The **Nathaniel Centre for Bioethics – Te Kupenga** is an agency of the NZ Catholic Bishops Conference. We speak on behalf of the Catholic Church in Aotearoa New Zealand.

As highlighted in our written submission, we are open in principle to the use of Genetic Engineering (GE). The challenge facing us is how to get the best out of GE technology while limiting its negative effects, keeping in mind two closely inter-connected goods – the good of humanity *and* the good of the environment.

At the heart of debates about biotechnologies such as GE lies a tension between what has been described as the Scylla of technological risk and the Charybdis of public reaction and overregulation. We recognise that regulations must facilitate and not inhibit appropriate research and technological advancement. However, we also recognise that there are approaches to managing this inherent tension that give insufficient attention to what happens at the intersection of scientific innovation and society.

We have outlined various serious concerns about the Gene Technology Bill in our written submission and these stand alongside tour oral submission. Today, however, we will focus on one issue; the importance of a regulatory scheme that is open to all disciplines. We believe that biotechnologies have significant consequences at a societal level and that they need to be critiqued and regulated according to the interplay that results between society and science, rather than apart from societal input. We believe this requires consultation with a wide range of perspectives other than the scientific and economic.

Our specific concern with this proposed legislation is the narrowness of the frameworks that sit behind it – the frameworks within which risks and benefits are identified, and which shape the questions deemed relevant.

Our key message today is that it must be **society as a whole** that ultimately owns and determines the regulation of new innovations, the alternative being a process that is primarily the domain of scientists, technological entrepreneurs and/or politicians. This leads us to identify two specific problems with the proposed Bill: (i) that it potentially gives too much control to groups with a vested economic or scientific interest; and (ii) that it construes democratic consultation and oversight as irrelevant if not a potential threat to scientific innovation.

Fifty years ago, a number of leading molecular biologists gathered in Asilomar, California, to evaluate the risks of the then novel and emerging technology of recombinant DNA and to set guidelines to govern research. This meeting and its model of risk management has often been held up as an exemplar of how to manage the risks of new biotechnological developments. It continues to be promoted by many who support its approach without recognising its inherent biases. The Asilomar model has rightly been criticised over recent decades for the fact that it rests on certain flawed assumptions, most notably that it reflects a science-first, ethics-second, paradigm.

These days, those who are critical of the Asilomar model include many scientists. The point is made that the Asilomar approach prioritises scientific freedom and autonomy to the exclusion of other principles. This, in turn, means that the questions around risk management are too narrowly linked to scientific and technical concerns. Within this model, the public are regarded as uneducated and fearful – a potential threat to scientific progress. Consequently, consultation around new

innovations is restricted to an elite, primarily technical, group while many philosophical, ethical, cultural and spiritual considerations are excluded.

Reacting to the biases of the science-first paradigm, critics such as the Global Observatory for Genome Editing hold the view that new biotechnologies like GE raise important questions about the meaning and purpose of human life. Consideration of these questions provides an important corrective to the dominant science-first, ethics-second, approach which overly privileges the scientific and technical.

To properly acknowledge that the implementation of biotechnologies influences our perceptions of what it is to be human is simultaneously to acknowledge the need for, and importance of, cultural, ethical and spiritual forms of wisdom.

That the proposed Gene Technology Bill is a paradigmatic example of the reductionist, science-first approach is clear from the shape of the Bill as well as from the various commentaries around it which speak exclusively about "the scientific management of risk". Moreover, it seems to us that this approach is clearly intentional.

For example, the MBIE authored Cabinet paper titled "Regulation of gene technology – policy decisions (10 December 2024) speaks of the new GE regime being more enabling than that of the Hazardous Substances and New Organisms Act (HSNO) because its "narrow, scientific scope will prevent applications being declined for subjective or speculative reasons". The paper categorically asserts that the "Regulator is not able to take into account unscientific calls for prohibition because they are outside the scope of the regulatory decision-making framework." The same paper then speaks, pejoratively and paternalistically, about public deliberation: "the predictable result of public consultation will simply be unscientific calls for prohibition."

This type of science-first approach is highly unacceptable to our minds, not to mention that it fails to establish a true partnership model with Māori as demanded by the Treaty.

It is worth noting that key scientists and science bodies in Aotearoa New Zealand, including the Royal Society of New Zealand, readily embrace the type of broad approach to public consultation that we are advocating for. For example, the Royal Society's recent commentary on Gene Editing, includes ethical and māori cultural considerations, alongside medical, legal, social, environmental, and technical/scientific considerations.[1] Speaking of the need to support public confidence in decision-making (Recommendation 4), it also asserts that "regulation needs to be informed by wide engagement with the public" (Recommendation 5).

Furthermore, it needs to be noted that the proposed Gene Technology Bill not only fails in this regard but, sadly, represents a regression in terms of the way in which other current regulatory schemes and laws in Aotearoa New Zealand provide for ongoing and broad consultation inclusive of cultural, ethical and spiritual perspectives, the HSNO Act being an obvious example.

The example we wish to focus on, however, and one we have engaged significantly with for almost 20 years, is the Human Assisted Reproductive Technology (HART) Act (2004). We suggest that the HART Act offers a particularly useful and appropriate regulatory model for the Gene Technology Act (given that both human reproductive technologies and gene technologies have the potential for unintended negative human and/or environmental outcomes) and we strongly promote the HART

[1] See also Royal Society Te Apārangi "Gene Editing. Reflections from the Panel Co-Chairs. Scenario Summaries and Scenarios (Healthcare, Pest Control and Primary Industries. Legal and Regulatory Implications. August 2019). Gene-Editing-FINAL-COMPILATION-compressed.pdf

Act as an alternative and more robust regulatory model than what is currently being proposed for GE for the following three reasons:

(i) Notably, unlike the Gene Technology Bill, the HART Act rests on a clearly enunciated set of principles. In particular 4 (f) which affirms "the needs, values, and beliefs of Māori should be considered and treated with respect"; and 4(g) which clearly states that "the different ethical, spiritual, and cultural perspectives in society should be considered and treated with respect". This Bill does not do that.

(ii) Closely related to the two principles above, The HART Act also spells out the requirement for public consultation in the section titled *Guidelines and advice* (see in particular Sub-Sections 36, 39, 40, and 41).

(iii) The regulatory framework for the HART Act centres around an Advisory Committee that works closely in conjunction with an Ethics Committee that oversees particular procedures that have not, previously, been deemed as "established procedures" (see Appendix 1). (It is notable that the Australian regulatory scheme for Gene Technology includes an Ethics and Community Consultative Committee that "provides advice on ethical issues and matters of general concern to the community relating to GMOs".) We regard the lack of a similar Ethics Committee as a serious flaw in our proposed GE legislation. (See Appendix 2)

In the absence of mechanisms allowing broader interdisciplinary input and public input into decisions about GE, we believe the regulatory process, as proposed, risks alienating large sections of the public of Aotearoa New Zealand, undermining public confidence and leading to the possibility of significant public resistance.

To summarise, GE raises fundamental questions that go beyond scientific risk and economic benefit. The scientific and technological frontier is also a cultural, ethical, moral and spiritual frontier.

It demands an approach that focuses on the global common good, something that requires a broad focus on human and environmental well-being drawing on all forms of wisdom as an antidote to hubris and an excessive drive for growth and profit; an approach that employs a broad range of imaginations related to culture, ethics and spirituality; an approach which considers the impact of scientific developments on human institutions and environmental well-being as well as economic and scientific gains.

As the Waitangi Tribunal remarked in Ko Aotearoa Tēnei, WAI 262 (2011), biotechnological developments reflect

> the fact that humans have come to exercise control over the matrix of life itself. We now have powers that were once the exclusive preserve of the gods. Our technological developments must be matched by our moral and ethical capacity to make good decisions in deploying these technologies for ourselves and future generations (p.95).

This Bill, in its current form, does not enhance our moral and ethical capacities let alone consider that as being important.

Staff of the Nathaniel Centre for Bioethics – the NZ Catholic Bioethics Centre
14 March 2025

Appendix 1

HART Act (2004): *Guidelines and advice*

36 Advisory committee to publish and notify guidelines

(1) The advisory committee may issue guidelines only after it has,—

(a) on the basis of a discussion paper or an outline of the proposed guidelines, given interested parties and members of the public a reasonable opportunity to make submissions; and

(b) taken any such submissions into account.

39 Advisory committee to call for and consider submissions before giving significant advice

(1) This section applies to advice that—

(a) is given under section 37 or section 38; or

(b) although not given under those sections, is of significant public interest but is not required as a matter of urgency.

(2) The advisory committee may give advice to which this section applies only after it has,—

(a) on the basis of a discussion paper or an outline of the proposed advice, given interested parties and members of the public a reasonable opportunity to make submissions; and

(b) taken any such submissions into account.

(3) For the purposes of subsection (1)(b), advice is not required as a matter of urgency if it relates to the question whether or not a treatment or procedure should be declared to be an established procedure.

40 Public meetings on proposed significant advice

(1) If, in the opinion of the advisory committee, a significant number of persons wish to make oral submissions on a proposal to give advice of the kind to which section 39 applies, the advisory committee must hold as many meetings as are required to enable those submissions to be made.

(2) The advisory committee must—

(a) notify the persons who wish to make oral submissions of the time and place of any meeting to be held under subsection (1); and

(b) publish a notice on the Internet and in any other publication the committee thinks appropriate that states the time, place, and purpose of any such meeting and that it will be held in public.

(3) A meeting held under subsection (1) must be held in public.

41 Requirement to consult

(1) Before the advisory committee gives advice to the Minister or issues guidelines to the ethics committee, it must consult on the proposed advice or guidelines with—

(a) any members of the public that the committee considers appropriate:

(b) appropriate government departments and agencies:

(c) any other person or group that the committee considers appropriate.

(2) Before the advisory committee issues guidelines to the ethics committee, it must consult on the proposed guidelines with the Minister.

Appendix 2

Decision making framework under the HART Act