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National Health Committee
Ministry of Health
By email: Omics@moh.govt.nz

Tēnā koutou

The Introduction of Fit for Purpose Omics- Based Technologies – think piece

I regret that the New Zealand Nurses Organisation (NZNO) was unable to submit the careful response to the above document that we had hoped to. The timeframe was always going to be problematic for us, especially as this is far from ‘business as usual’ and involves consideration of some profound ethical questions as well as an understanding of the technologies and their potential social and economic impact. However, I did want to convey to you briefly the result of some *preliminary discussion* amongst interested staff and members in the hope that it may still be useful, and assure the Committee that NZNO is very interested in continuing the dialogue. Nurses work at both extremes of health technologies - at the cutting edge of research and in primary health care, where access to the basic necessities of health – warm, dry housing, medicines and healthcare and information is far from universal. They are well placed to observe the effects of new technologies on individuals, communities, and the public health system.

There are two points we wish to make. Firstly, while we warmly welcome the think pieces (and congratulations on the lay version), we are not confident that a ‘public consultation’ such as this will reach beyond the mainstream of people and organisations concerned with health, science, and the business prospects of new technologies. We suspect that it is unlikely to elicit responses from a wide cross section of people and communities in our demographically diverse country, though we would be delighted if that were not the case.

It is absolutely critical that the ethical and regulatory frameworks for the development and use of these technologies are considered by people across the demographic spectrum before they are ‘released’, as they have the potential to challenge core human and social values and it will take time to get the right regulatory structures in place, that support health and equity. The lack of a well-designed, transparent platform of seeking public opinion underlines the government’s regrettable and short-sighted decision to disestablish the Bio Ethics Committee. Thought must be given to ensuring how to raise public awareness of the ethical questions posed by new technologies such as omics-based technologies, and

ensuring there are accessible and relevant opportunities for broad discussion and public scrutiny of proposals. Typically, that should encompass multimedia, multi-platform and multi lingual communications strategies to reduce structural discrimination and engage all ages, all ethnicities, and all socio-economic groups.

Secondly, we strongly challenge the inclusion of “maximising economic benefit” as a principle. It may be a desired outcome, or even a priority, but it cannot be a principle because of the potential for conflict with the other two principles – best outcomes for users and safeguarding our identity. The latter are widely recognised as public health principles and we suggest that is the appropriate framework within which to consider omics-based technologies.

The disastrous extension of market exclusivity for therapies derived from protein based living cells commonly known as biologics, in the recently signed Trans Pacific Partnership Agreement (TPPA) is an excellent example of the conflict of interest between commercial and public health principles where new technologies are concerned. With no public debate, and in defiance of scientific and economic evidence which does not support extending market protections (see the recently released Australian Productivity Commission’s draft report from the inquiry into Australia’s intellectual property arrangements which is unequivocal that “There should be no extension of the period of data protection, including that applicable to biologics¹”), access to the most effective modern therapies for a wide range of acute conditions has been made prohibitively expensive for all but the wealthiest countries, and innovation has been stifled. In this instance, the interests of multinational pharmaceutical companies have been privileged above the health of citizens and national economies. It may be too late to avoid similar path with omics-based technologies since the TPPA has established a benchmark for the numerous multilateral agreements currently being negotiated.

The tension between public health and trade objectives is reflected in World Health Organization and World Trade Organization instruments which, despite articulated principles of eg “universal extension to all peoples of the benefits of medical, psychological and related knowledge” (Constitution of the WHO) and recognition the rights of Members to adopt measures for public health and other public interest reasons (Article 8, Trade-Related Aspects of Intellectual Property Rights) have not delivered the social justice and global health anticipated. The State-centred basis of international law ignores the power of transnational corporate entities whose wealth and influence exceeds that of many sovereign states. For this reason we urge that the framework for omics-based technologies be considered in the wider context of public health law², and that it is firmly rooted in public health principles and actions that are focused on reducing health inequities, promoting distributional justice; and that are particularly focused on marginalised populations³.

I apologise again for the brevity, and tardiness, of our response to the think piece, but hope that it is useful. NZNO looks forward to further discussion as the framework is developed.

Nākū noa, nā



¹ <http://www.pc.gov.au/inquiries/current/intellectual-property/draft/intellectual-property-draft.pdf>

² Lawrence O. Gostin, 2016 *Public Health Law: Power, Duty, Restraint*. UCP: California

³ Ross EG Upshur, Solomon Benatar, Andrew D Pinto “Ethics and global Health”. Chpt 2 in Andrew D Pinto, Ross EG Upshur (ed) *An Introduction to Global Health Ethics* (Routledge, London and New York 2013, p28)

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NEW ZEALAND NURSES ORGANISATION (NZNO)

NZNO is the leading professional nursing association and union for nurses in Aotearoa New Zealand. NZNO represents over 47,000 nurses, midwives, students, kaimahi hauora and health workers on professional and employment related matters. NZNO is affiliated to the International Council of Nurses and the New Zealand Council of Trade Unions.

NZNO promotes and advocates for professional excellence in nursing by providing leadership, research and education to inspire and progress the profession of nursing. NZNO represents members on employment and industrial matters and negotiates collective employment agreements.

NZNO embraces te Tiriti o Waitangi and contributes to the improvement of the health status and outcomes of all peoples of Aotearoa New Zealand through influencing health, employment and social policy development enabling quality nursing care provision. NZNO's vision is *Freed to care, Proud to nurse*.