Omics-based technologies in New Zealand – the opportunities and challenges

There is a growing need for New Zealand to establish guidelines and processes surrounding the use of omics-based technologies. Omics-based technologies can measure various characteristics of the cells that make up our bodies (e.g., genomics is the study of our genes, metabolomics is the study of cellular metabolism, that is, the chemical processes that occur in our cells and proteomics is the study of our proteins).

Everyone has genes and everyone should have the right level of control over their own genetic information. Genetic information is a taonga (treasure) that must be treated wisely. It is important that all New Zealanders can have a say in what we want.

What opportunities do they offer?

Omics-based technologies offer opportunities for improvements in health outcomes and cost-effective healthcare at a population level. For individuals these technologies offer opportunities for improved patient experience, health and quality of life.

The National Health Committee (NHC) is interested in how omics-based technologies can improve our health and have developed a paper discussing the opportunities New Zealand has in this field. We would like your feedback to discuss how we can work together to decide what we can make use of and where we want to put our effort and development.

What issues do they raise?

Traditionally, healthcare has targeted treating symptoms once they are observed. The new technologies offer a whole new approach to healthcare and opportunities for personalised medicine and healthcare. The potential benefits include:

- **Early discovery** - finding those patients who have a genetic problem from birth
- **Increased risk of getting diseases**
- **Fast diagnosis** - finding out which disease/disorder a patient has so the patient can get treatment sooner
- **Treatment** - finding changes in the DNA that are caused by the disease and that influence whether medication or treatment will work or will not work in those patients
- **Improve care** - healthcare workers need to be trained well so they can give the correct information to patients so patients can make informed decisions

To realise the benefits of omics, New Zealand, and the health system must be prepared for the changes. At the moment, these new technologies are being developed fast, and some are being brought to market before we have new systems, processes, equipment, staff and regulations in place. The organisations developing and wanting to use these technologies are not always well
coordinated. This raises the risks of duplication of research efforts, inefficient use of resources and funding, and lack of adequately trained front-line workers. We need to make sure that the health system is ready to respond well to the new technologies.

We also need to make sure that we introduce systems that the people of New Zealand trust. People have different views about genetic information and how it should be treated. We need to know what matters to New Zealanders so that we can design systems that work for us. This will require us to evaluate our core beliefs and explore the ethics of using these technologies, such as ownership and protection of personal information.

The changes won’t just impact frontline delivery of health-care. The new technologies will require a new range of workforce skills, which in turn will require reviewing educational priorities, developing policies, safety regulations, mathematical and statistical models for analysing all the new data, and information systems to support the use of the data and technology.

New Zealand has started well with the research and development of new omics-based technologies. But to take the next step of translating those developments into real-world clinical practice, we need to understand the issues and know what principles should guide us.

**Why is the NHC consulting New Zealanders?**

The healthcare sector has not seen this degree of change for a very long time. The whole global community is facing these same needs to develop new systems, processes, equipment and staff to cope with the new technologies.

New Zealand has the opportunity to set up these systems and processes to support the introduction and best use of these technologies. To make the most of this opportunity we need to know what New Zealanders want. We also need cross-sector involvement because these technologies impact so many different areas including the health sector, education, employment and business. A collective vision and strategy needs to be developed, requiring clinical, educational, research and development, and business communities working together to deliver on the agenda that the people of New Zealand set.

The NHC is able to draw the various sectors together to develop the new systems, processes, equipment and staff needed to support the introduction and best use of omics-based technologies. Previous work by the NHC on the opportunities and risks of various healthcare assessment tools has equipped it with the experience to launch, facilitate, coordinate and guide the collective thought processes of the various stakeholders.

**What is the NHC consulting on?**

The NHC would like to ask the following questions:

1. Is the description of the risks, issues and opportunities a good reflection of reality? Is anything missing?
2. The proposed approach is for a cross sectoral whole of system collaborative approach. Is this the best approach? What are the critical success factors necessary to make this work, who needs to be involved and how?
3. The think piece proposes the use of a common thinking tool (a principles based framework). Is this a good approach? If not, what else might be a better approach? If it is, are the proposed principles generally appropriate and/or is anything missing?

The NHC is proposing a framework, based on six principles, to guide the cross-sector thought processes toward developing the necessary framework for the sustainable introduction and use of omics-based technology.

Three outcome focused principles:

- best outcomes for users - patients and the whole population
- safeguarding our people, identity and values
- maximising economic benefit.

Three implementation focussed principles:

- collaboration among all sectors that will share the risks and gains from the introduction of omics-based technologies, both nationally and internationally
- integrated introduction and use of omics-based technologies across the health, science, education and business sectors to deliver fit-for-purpose technologies
- developing essential core infrastructure to ensure the best use of capital investment.

In the New Zealand context it is important that the framework we develop meets the terms of the Treaty of Waitangi. Community consultation will be an integral part of the development process. Various pieces of national and international Human Rights legislation that New Zealand is signatory to will need to be complied with.

An open, transparent approach is needed. The NHC works within an Accountability for Reasonableness framework which involves a consultation process to give all stakeholders and affected parties the opportunity to review the work the NHC delivers. To develop the new framework the NHC is proposing a “looping” process of engaging as widely as practicable with multiple stakeholders, enabling them to provide input in to the proposed framework. The collective insights and knowledge gained from the consultation process will be repeatedly fed back to the contributors to be further refined and corrected until it is ready to be broadly accepted across the various spheres of interest.

The NHC will facilitate this consultation process through “workshopping” with various stakeholders from all the relevant sectors (clinical/healthcare; academic/training; research and development; business/investment; regulatory; workforce/health and safety and so on). The outcomes from workshops and the public consultation will ensure that all issues, opportunities and actions are recognised. The key stakeholders will need to agree on the next steps to take and the outcomes will be provided as advice to the relevant Ministers.

No one organisation in New Zealand has the responsibility or capacity and capability to introduce fit for purpose omics-based technologies. Their introduction and use requires collective input, collaboration and resources. The proposed NHC thinking strategy is intended to start focussed discussions, and is offered as a useful framework to support the development of urgently needed infrastructure for the introduction and use of omics-based technologies.
By going out for public consultation we ask people (patients, the public, doctors, nurses, researchers, health managers etc.) to read the document and think about those things that are important for them, for their whanau, for their community and for the country. We need to hear from a broad range of people to make sure the NHC is considering all the important factors, big or small.

We would like to receive feedback by 5 pm Wednesday 27th April. This can be sent electronically to Omics@nhc.govt.nz or as hard copy to:

Omics Consultation
National Health Committee
PO Box 5013
Wellington 6145

Please feel free to contact us directly on Omics@nhc.govt.nz if you have any questions

We understand that this think piece is technical and the topic is complex. It will be a challenge for people to understand it, but here are some links to websites and youtube videos with good explanations about DNA, genes and omics.

Websites:
http://www.geneticseducation.nhs.uk
http://learn.genetics.utah.edu/
https://unlockinglifescode.org/
https://www.theguardian.com/science/2013/jun/08/genome-sequenced

Youtube videos:
Genomics - https://www.youtube.com/watch?v=mmsgLCjg0Y1k
Genomics in healthcare - https://www.youtube.com/watch?v=KjQqrK3tge8