Precision Health: Exploring opportunities and challenges to predict, prevent, diagnose and treat disease more precisely in Aotearoa New Zealand: Breast Cancer Aotearoa Coalition second response

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Executive Summary

The Breast Cancer Aotearoa Coalition (BCAC) represents over 30 breast cancer charities and groups across Aotearoa, as well as individual members. Our purposes are to support, inform and represent those diagnosed with breast cancer in Aotearoa from an evidence basis.

We agree that precision health and integral components including tools and technologies, require urgent focus to enable innovation in the near and longer term. Bringing focus to the various elements of precision health will lead to ongoing development and improvements across our health system, including through ongoing research and clinical trials with real world implementation, aspiration and good policy helping to translate research findings into benefits for patients with efficiencies across the system.

In January 2023 BCAC provided a comprehensive response to Manatū Hauora's request for feedback regarding the first Precision Health request for submissions. [1] We welcome the opportunity to respond to the second consultation document in June 2023.

Precision health now and in the future

Urupare | Feedback

Our feedback builds on our prior response on this topic [1].

We make clear that **we want the focus of the LTIB to include AI and multiomics**.

We **want all fundamental infrastructure and data issues resolved in the first 5 years.**

O**ur preference is a move to a more inclusive multiomics approach alongside AI indicating a broader scope**. Genomics is the study of the total or part of the genetic or epigenetic sequence information of organisms and attempts to understand the structure and function of these sequences and of downstream biological products. **Omics on the other hand provides an integrated perspective to power discovery across multiple levels of biology where data sets of different omic groups are combined during analysis. The different omic strategies employed during multiomics are genome, proteome, transcriptome, epigenome, and microbiome and the analytical tools used in this analysis are broader and include biomarkers. We may begin with genomics but by year 5 we are paving the way towards broader omics.**

In this submission we:

- outline AI and multiomic approaches being developed in France
- reiterate some important points,
- provide updates as necessary,
- respond to most of your questions and
- outline our view of staging.

1.This LTIB lists the most urgent and immediate opportunities and risks based on stakeholder feedback to date. Are there any other opportunities or risks posed by implementing precision health that we should include in this LTIB?

Chosen Topic - we change the focus in year 5 and by year 10.

While we welcome the chosen topic focus of Genomics and AI (Summary page 5) we humbly suggest that alongside AI, **genomics should be replaced by multiomics or omics for a Long-Term Insights Briefing** (LTIB). **Genomics is a near to medium term focus.**

Our concerns regarding the choice of genomics and not multiomics generally are:

- Genomics does not represent a long-term vision. We acknowledge many actions are needed to get the fundamentals in place to optimise the opportunities they represent in New Zealand but we see that work as urgently needed now and over the next 5 years. Multiomics or just omics represents a better longer-term vision that incorporates genomics and has a broader and deeper scope that includes genome, proteome, transcriptome, epigenome and microbiome. France is setting an example of what this looks like. P. 3-8[2,5] (Please refer to Pasoy et al, 2023)[3] as we expand on this view in line with our earlier submission)

We are happy with the view taken regarding AI. AI has been well defined regarding its potential contribution to health and we welcome the definitions and scope you have provided.

Models from France that reinforce our view.

We will present two models from France that incorporate AI and multiomic initiatives which have recently been publicly and privately funded in France. They are at the centre of new private public partnerships ***to increase prediction and reduce disparities in health care***.

A key leader in this work is Fabrice André MD, PhD. He received his MD in Paris in 2002, and a PhD in Biotechnology from Paris University in 2005. He is a medical oncologist working at **Gustave Roussy** and taking care of patients presenting with **breast cancer**. He is a past recipient of Awards from the American Society of Clinical Oncology (ASCO) and American Association for Cancer Research (AACR). His research work is in the field of biomarkers and personalised therapies has focused on biomarker discovery, development of targeted agents and implementation of personalised medicine. His team includes 80 people working on basic science, bioinformatics, biotechnologies and clinical research. He is also leading phase I-III trials testing targeted agents in the field of breast cancer and large national trials testing implementation of high throughput technologies in the health care system. He has published more than 300 peer reviewed papers in Nature, the New England Journal of Medicine, Lancet, Nature Medicine, as main author. He is chairman of the biomarker group at UNICANCER (French cooperative group) and was a member of several scientific committees for international meetings, including SABCS, AACR, ECCO, ESMO, and IMPAKT. He has led and established ESCAT standards for biomarkers through ESMO and ASCO.

Professor André has just been elected President of the European Society for Medical Oncology (ESMO). He has been a member of the Annals of Oncology Editorial Board (2010-2013), Associate Editor since 2014 and in September 2017 became Editor-in-Chief. He demonstrates an ability to progress with courage and yet is disciplined in holding to the evidence.

Prof. André made two announcements in May 2023.

PortrALT[2]

The first announcement related to Digital or Computational Pathology (AI) for **all cancers** through a consortium PortrAlt. This French Consortium was created to develop and accelerate precision medicine through an AI enabled digital platform for all cancers, (PortrAlt | French Digital Pathology Consortium (portraitpathology.ai) [2].

This is a landmark government- endorsed programme to provide ***structure and scale*** to the digital pathology ecosystem in France to augment and improve the diagnosis of cancer in France. They propose to:

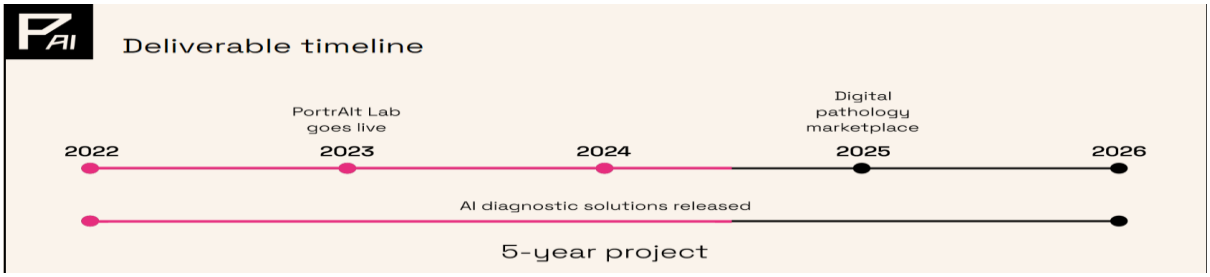
- Provide **access** to better more targeted testing and treatment for patients, no matter the location.
- **Democratise access** to care and provide more precision medicine solutions to doctors and hospitals.
- **Improve productivity and reduce inter-physician variability.**
- Support the **discovery of new therapeutic pathways** to accelerate precision medicine through AI-enabled digital pathology.

This will be done across three main areas:

- Disease diagnosis – detection of disease, tumour grading or feature counting
- Biomarker discovery – Identifying patients who may benefit from targeted therapies and those who won't.
- Outcome prediction – to characterise a patient's risk or prognosis more fully.

The backbone of this work is across 30+centres for AI diagnostics deployment through (Owkin – AI diagnostic tool development, research and market place development), Tribun Health (AI diagnostic tool development – co development of the market place), Cypath – (network of Labs to test diagnostic products and digital transformation of care), Gustav Roussy – (medical and clinical research expertise and test diagnostic products), Leon Berard - (medical and clinical research expertise and test diagnostic tools) and Unicancer – (Network of expert Centres to test diagnostic products and digital transformation of care).

This €30Million EU project is financed by the French government within the framework of France 2030 and by the European Union – next generation EU framework of the France Rebalance Plan.



In New Zealand we want to see access, democratisation, productivity and consistency so that everyone may benefit from such a networked approach through:

- automation of markers (Ki67, PDL1 etc) of which there is a growing number,
- prediction of molecular alterations (BRCA, MSI, TMB…)
- prediction of outcome/sensitivity (IO…) in selected and/or pan-cancers.

We accept that in New Zealand such a project may have a longer timeframe and as mentioned in our **earlier submission a funded project for HR+ breast cancer (Gavin Harris et al)[4]** is an example of an early AI initiative. It is not pan-cancer but could be built on with additional funding and resourcing and changes in **scope and scale.**

PRISM Centre[5]

The second project that Fabrice André recently announced is the establishment of **PRISM**. PRISM Centre was founded by Gustave Roussy , Universite Paris Saclay, Ecole Centrale Supelec, inserm, Unicancer. Some partners appear in to be common to both consortiums while others differ, in particular, academic institutions.

Prism Center is receiving 30-40 Million Euros to build a Precision Oncology Center.

Its **vision** is: to classify patients based on biology and not the anatomical site of a cancer.

Its **scientific strategy** is: a bottom-up approach to model cancer biology in each patient or cohort of patients for early cancer or relapse detection, & treatment optimisation.

Given the current health inequities in Aotearoa, this approach looks to address the very issues expressed as of concern in your second consultation document i.e.*, "current genomics research primarily relates to Western European and East Asian populations," (p. 16 Risks and Considerations)*

Please view this slide that identifies single omics, omics and their broad applications which go beyond genomics.

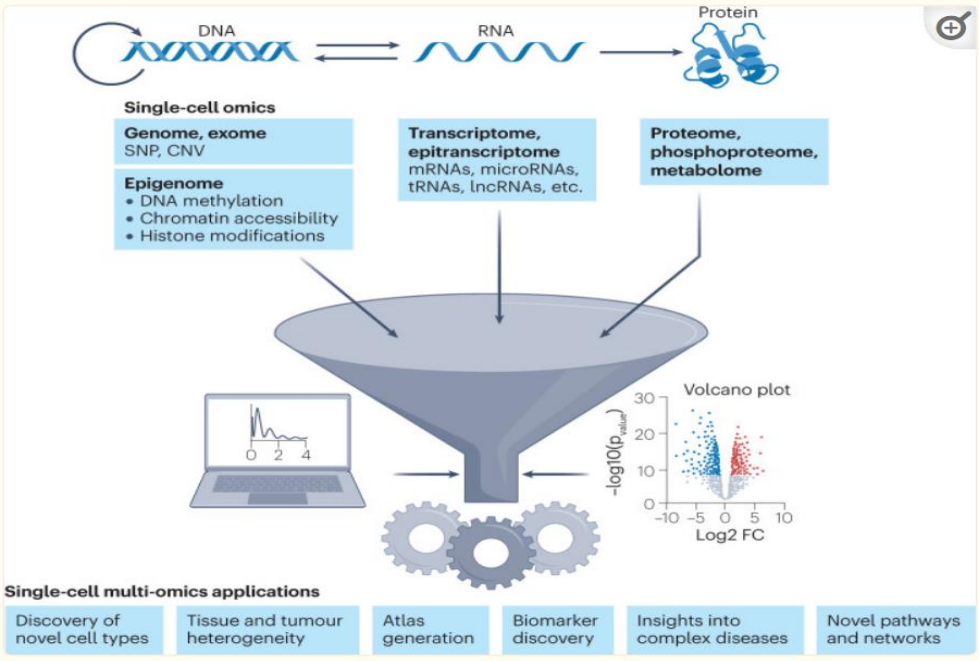


Fig. 1

From single omics to multi-omics and their broad applications.

The technological landscape and applications of single-cell omics, Alex Basoy et al, Nat Rev Mol Cell Biol. 2023 Jun 6 : 1–19. doi: 10.1038/s41580-023-00615-w. (ePub ahead of print) [3]

Improvements and advancements in the single-cell omics field will facilitate design of advanced therapeutic strategies and generate atlases to aid in our understanding of health and disease. This is a developing field and one that is open to improvement **but does include concepts not identifiable within genomics alone. Does your definition of genomics encompass some of this work?** Aotearoa has and will continue to develop strong capability in RNA science and continues to invest in that capability. New Zealand demonstrated through COVID an ability to utilise AI to quantify and understand risk. Why then are we so reluctant to have a long-term vision that incorporates a broader solution focus? **What we seem to lack is a model that we can refer to and say *"this is what we have now, this is what we need (or need to partner to capture) and this is where we aim to be in 10 years."***

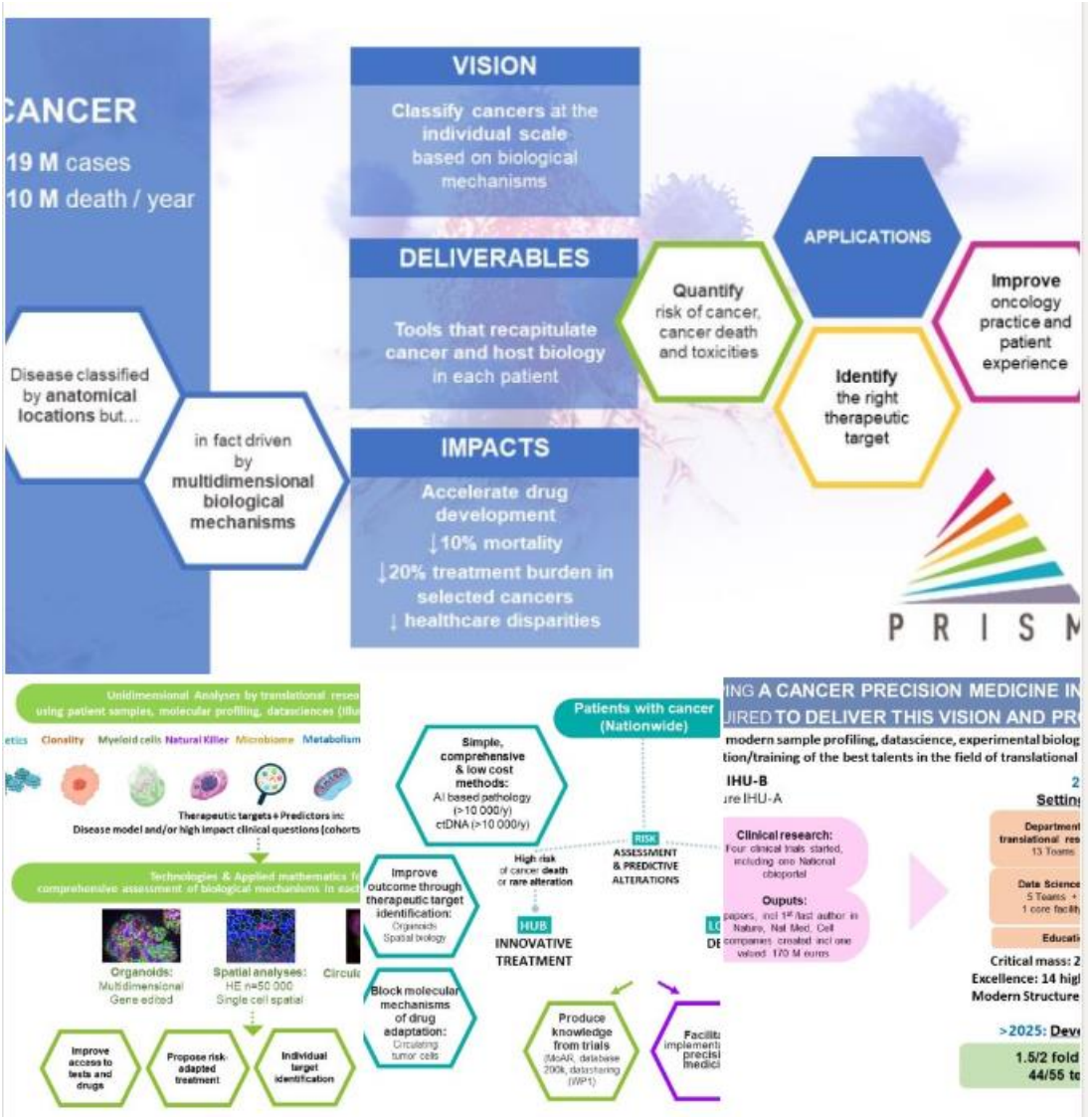
The French PRISM model (see below) incorporates:

- An emphasis on **analytics** to identify **therapeutic targets and predictors**, **disease models** (which could be by cohort rather than at an individual level) and the need to further investigate high impact ethical questions.
- **Risk adapted treatment utilising tools like organoids, patients explant models, spatial analytics for individual or cohort target identification**. (Nolan et al 2023) [6]
- To better understand cancers nationally by identifying those **who need greater focus, addressing the gaps in national populations, blocking molecular mechanisms, producing knowledge from trials to**
- Better **quantify cancer risk**, **identify the correct targets and improve oncology practice and patient outcomes.**

For example, as mentioned in our earlier submission [1] this is research happening now in New Zealand. By using technologies such as organoids or patient tumour explants, a patient's tumour can quickly (within 1-2 hours post-surgery) be grown on gelatin-coated sponges to provide a rapid evaluation of patient's drug response. They remain viable, with an intact tumour architecture and tumour microenvironment such as immune cell infiltration, for up to a week. The value of developing patient explant models for New Zealand is **that it is affordable technology and it may enable stratification of patients in terms of their response**. This is an example of a low-cost, rapid platform to guide therapy selection. It could also support the preclinical evaluation of **novel therapeutics on NZ patient tissue including Māori and Pacific patients**. The long-term goal is that it will support implementation of personalised medicine in NZ. This work is being done alongside advanced genetic methods to understand how patients respond to specific drugs to identify specific novel genes or biomarkers to predict response.

- Once again specific biomarkers for our population may enable a window study for example for our Māori or Pacific populations to guide treatment or through a clinical trial.
- Being more precise in how we treat patients will lead to improved patient outcomes, equity of outcome and optimise quality of life for patients - patients will spend less time taking therapies which will not benefit and we would also hope it would lead to funding of more precise therapies.

This PRISM Centre model as depicted below is our preferred target for Aotearoa as it looks beyond genomics and incorporates biomarkers and issues of biology such as where the cancer sits spatially and the biology of the individual or whānau (aspects of omics).



We are not suggesting that Aotearoa should duplicate every element of the PRISM model, but we do ask that a model with broader scope than genomics alone be considered for the LTIB.

Currently, New Zealand patients have more limited access to new therapies than those in equivalent OECD countries but use of **a model such as PRISM will identify who a therapy will work for and should release funding for a greater number of targeted therapies. For Precision Health, access to therapies is a key requirement of the model along with development of new therapies that may be better suited to our population.**

Despite current barriers to provision of targeted therapies to patients for whom they will work, we need a vision and a clear model that will provide a pathway forward. **There are opportunities for New Zealand should we have the ambition to pursue them, and we believe we have no choice if we are serious about achieving equity.**

Benefit will be gained from uptake of recent advances in diverse high-throughput omics technologies (e.g., next-generation sequencing or mass spectrometry). Scientists have started to integrate these complementary technologies, to investigate the roles and actions of different complete sets of molecules (e.g., genomics, proteomics, transcriptomics, epigenetics, multiomics etc), as well as

various post-translational modifications (e.g., methylation, phosphorylation, glycosylation, etc.) in pharmacology. For immunotherapy prognostic assays to have true utility they need to be a marked improvement over the status quo, which includes a range of biomarkers for example PD-L1, MMR, MSI, and TMB to predict if a patient will respond to immunotherapy. [1]

Is using transcriptomics, proteomics, multiomics different from using tests that have been used in the clinic for years? **We can only imagine that with significant investment happening in the omics field now and over the next 10 years there will be significant advancement and so we suggest for our population we need to adopt this approach now and as we move into the future. We have seen with genomic assays and risk stratification tools, that if these multiomic assays are not validated on our population (through trials and research) we will again have equity concerns.** [1]

Research in this area can reveal disease pathways and facilitate biomarker discovery and drug development. These broader analyses promise new and better treatment strategies and paradigms for patients in the coming years, particularly for those in our population (Māori, Pacific, older and younger populations) whose response to therapies may not have been validated through clinical trials.

Risks and Opportunities

Risk: Precision Health definition

We accept Manatū Hauora's definition of precision health in the consultation, but challenge how we can expect to separate precision medicine from precision health and why we would do so when in your words (p.6 May 2023 Consultation document) "*genomics and precision medicine to increase our understanding of how genetic factors contribute to wellbeing and risk of disease, and more effectively target care to individuals and population's"* suggests inclusivity.

The ideal strategy for controlling and reducing the social impact of disease is effective prevention. Individuals who are genetically predisposed to developing breast cancer can lower their risk through established preventative strategies, such as a mastectomy along with other preventative therapy which currently have undesirable side-effects such as impacts on fertility and triggering of menopause. Mastectomies may also have considerable short- and long-term impacts that reduce quality of life for some patients, especially for young women. To date, there are no risk reducing medications that are as effective as surgery. Providing doctors with a non-invasive and easily accessible preventative therapy for women at high risk of developing breast cancer would have numerous benefits for the health system, patients and their whānau.

New Zealand scientists are researching:

- antisense oligonucleotide therapy which has been very successful in reversing the symptoms of degenerative disorders by altering gene splicing. The research investigates whether antisense oligonucleotides can eliminate the impact of high-risk genetic variants by modifying the process of gene splicing. This study will lay the foundation for the development of novel risk-reducing therapies to prevent cancer in genetically predisposed individuals. (Vanessa Lau et al)[7].
- Based on a recent genetic discovery, a New Zealand team is investigating whether a drug used in oral contraceptives (ethinylestradiol) (Wiggins et al)[8]can be repurposed as a novel preventative therapy for women at high-risk of breast cancer.

These transformative studies are examples of preventative precision therapy for high-risk breast cancer patients which have the purpose of fewer breast cancer diagnoses. These therapies will help

women get through their reproductive years feeling well and contributing while reducing their very high risk of cancer.

There are times when therapy is better than surgery even in the context of prevention.

Risk: A lack of ambition

We want to see many activities completed in the first 5 years with the investment to support it. Why?

If this were a short or medium Insights Briefing, we would be satisfied that your consultation document was perfectly pitched. Instead, we are concerned that there are issues and risks that are of **immediate and not long-term concern.** In our view, **these need to be very clearly separated**.

We want to see the necessary infrastructure, rules and regulations, and skilled and diverse workforce built over the next 5 years and not in 10 years' time.

Risk: Limiting equity lens

Much emphasis has been placed on equity and we accept and respect the need for that emphasis in practical healthcare delivery. Precision health is in fact required to achieve equity in health outcomes. We are hopeful the current equity focus **does not become a barrier to progress in precision health advancements in the next few years**. There is a clear understanding of what needs to be done through a more focussed emphasis on cohorts of individuals, whānau and ethnic groups. By pursuing a more precise approach and better understanding our unique population along with providing the necessary infrastructure, we look forward to better delivery of precision health to our diverse population, leading to greater health equity.

For example, a local computational pathology project recognises the need to undertake multistakeholder engagement in computational approaches to breast cancer pathological assessment for the New Zealand context. This is happening now. Hei Āhuru Mōwai and key stakeholders within Te Whatu Ora and Te Aka Whai Ora are involved along with other stakeholders. **This is not 10 years away**; **it will be done well now because it is the only way the project will succeed. What is needed now is an understanding of how to mediate through points of difference.**

Recently published results of a study led by Pacific researcher Jaye Moors (University of Otago), co-authored by Dr Megan Leask (Kai Tahu) into genetic variants in Māori and Pacific people demonstrated population-specific disease-related variants [9]. They note that Māori and Pacific people are grossly under-represented in genomics research and that such studies will provide important insights into the genetic determinants of health and disease between populations, furthering genomic justice. The researchers state that "**Comprehensive evaluations of genome-wide genetic variation in Māori and Pacific populations are long overdue and essential for improvements in health outcomes. Ultimately, population-specific analyses… will address the critical issue of inequity of minority participation in genetic research, furthering genomic justice and equity in genomics research for all population groups"**.

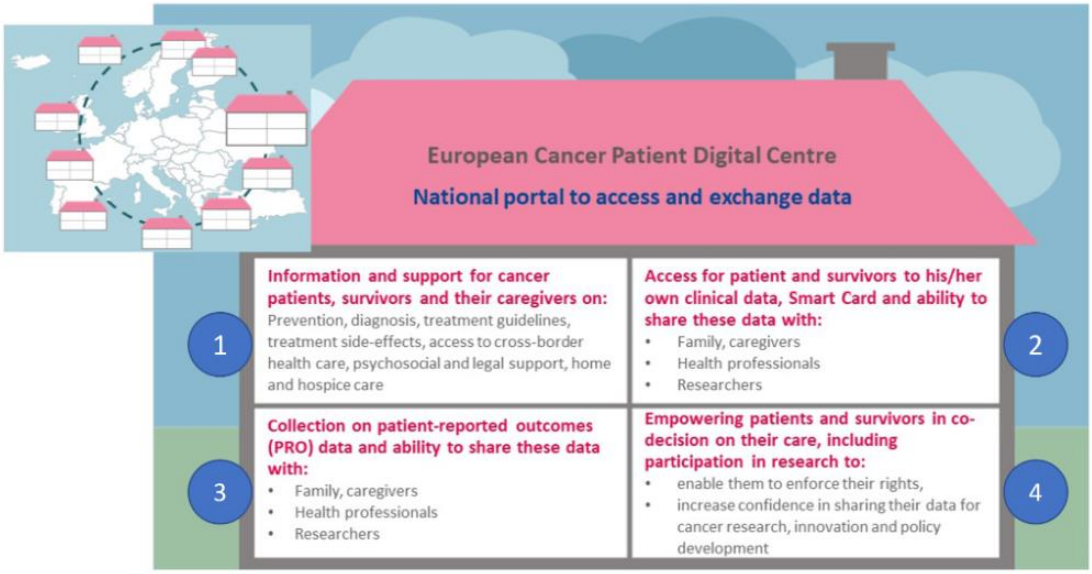
Opportunity: Informed consent

We agree there will be a rethinking of how individuals and whanau give informed consent.

Whether Māori, Pacific or of other descent, people should have the opportunity to understand how their health data may benefit themselves or others. The European Cancer Patient Data Centre (ECPD)[10]. The ECPDC needs to deliver what all key stakeholders want. We shared this groups survey with a small group of Māori consumers who were satisfied with its approach.

What will the European Cancer Patient Digital Centre be? The European Cancer Patient Digital Centre (ECPDC) is envisioned by the EU Mission on Cancer Board as a patient-focussed one-stop agency that empowers patients to self-control and share access to their own health data, as well as receive various kinds of information and support. The information platform of the ECPDC shall address relevant aspects along the patient journey, i.e., prevention, diagnosis, treatment, rehabilitation, follow-up care, re-entry into the working life, forwarding to social and legal advice etc. The study will propose a design for implementing the main functions of ECPDC:

1. Access to **general and tailored information on treatment and care** (room 1)
2. **Access of patients and survivors to their own clinical data** (room 2)
3. Possibility of **collecting and sharing patients and survivors' self-generated health data** such as PROs and PREs (room 3)
4. **Empowerment of patients and survivors** to manage their data and to co-decide on their treatment (room 4)



What is this study about?
Charité won the eTender by the European Commission for the "Study on Operational concept for a European Cancer Patient Digital Center (ECPDC)" which is conducted at the Berlin Institute of Health (BIH) at Charité in Berlin. This study will assess:

- to what extent existing and planned infrastructure can provide functionalities and contribute to ECPDC and
- what additional solutions are needed.

Who is asked and why?

They have identified different stakeholder groups such as infrastructure platforms / initiatives, patient organizations and caregivers that should express their opinion on the design of the ECPDC. Tailored surveys are conducted to collect first-hand information from these stakeholder groups.

What are the goals of the questionnaires?

- In each stakeholder group the survey pursues different goals:
  Patient Organisations:

They are interested in the patients' needs that a patient focussed ECPDC should address along the patient journey.

- **Infrastructure platforms and initiatives:**
  The overarching objective in this stakeholder group is to evaluate how the ECPDC can be built on existing and planned infrastructures. They first assess the potential and willingness of existing and planned infrastructures and platforms to contribute to the ECPDC. Based on these results they will then identify the areas in which required solutions already exist and which additional components are needed to ensure the intended functionalities.
- **Caregivers:**
  They want to collect the major pain points that a patient focused ECPDC could address to also benefit healthcare professionals.

John Fountain and CanShare through their cloud-based technology may have already conceived of how this will be managed. We share it in the hope it will assist in facilitating informed consent. The survey can be found here: Questionnaire | page 1 (charite.de) ecpdc@charite.de, Berlin Institut of Health at Charité / Center of Digital Health Charité - Universitätsmedizin Berlin. [10]

Risk: Perceived lack of consumer involvement

Consultation with Māori and Pacific has been given an appropriate emphasis and yet the **need to involve and prepare a consumer population is infrequently mentioned and does not appear to be valued in a way we would expect**. The LTIB will lead to a focus on how patients, individuals and whānau will stay healthy, well and be able to live their lives and yet we feel the paper is very light in this regard. For example, on p.27 reference is made to research science, innovation and matuaranga Māori. **Has consideration been given to partnering with consumers?** Consumers will expect to be involved in **shaping the future of precision health in New Zealand** to ensure it meets our expectations including precision in prevention, detection, diagnosis and treatment to reduce the burden of disease so that we have a **quality of life** not shared by all today. **Ideally, we want easier access, availability of detection and diagnostic techniques along with greater availability of treatments. We want those at higher risk to get more intensive treatment and those at lower risk to have the opportunity of de-escalation to improve their quality of life. We want to access precision health on a timely basis to reduce the risk of our being diagnosed too late with advanced disease and the costs to ourselves and the system of the associated treatment and care.**

Risk: Lack of capacity

We, desperately need to build capacity into the workforce to enable change.

Why? **To enable on-the-job activity that will lead to learning and from there development of Precision Health**. **Not all learning takes place away from the workplace** sometimes time is all that is required for a clinician to gain confidence to converse with a patient to reach a mutually agreed way forward for example whether targeted treatments are available for a specific mutation or biomarker and whether that treatment is available. Good communication between clinician and patient needs quality time. We as consumers interact with the current workforce, we find that the capacity is just not there in many areas to facilitate new ways of working. For several precision health activities, there will be business cases, pilots, roll out and training. There needs to be capacity to enable such activity.

We need to empower capable clinicians lead change.

When change occurs, people across the system are involved. In many areas change does not need to be top down but instead will rely on people who see and understand an opportunity and can lead

the change in their everyday role. An example is the roll out of genomic testing for ovarian cancer patients. This roll out is in its second year and is saving lives. Michelle Wilson, a Medical Oncologist specialising in gynaecological malignancies, sarcomas, and translational research, returned to New Zealand from Canada with a FRACP specialist qualification in 2013 after completing her training in Auckland. Following this she spent two years undertaking research at the world-renowned Princess Margaret Cancer Centre in Toronto, Canada. During her time in Canada, Michelle worked with their Drug Development Team with a focus on gynaecological cancers, sarcoma and translating new treatments to better outcomes. Since her return in 2015, Michelle has been treating women with gynaecological cancers at Auckland Hospital. Michelle is also the Service Clinical Director for Cancer and Blood Research. Her research focus is geared towards early phase ***translational studies***, the ***relevance of genetic testing in oncology*** and clinical trials design. She was awarded a post graduate Doctor of Medicine from the University of Auckland for her work on the challenges facing clinical trial design in oncology. She is also the New Zealand Board representative on the Australia New Zealand Gynae-Oncology Group (ANZGOG), an active member of their Research Advisory Committee and Deputy Chair of their Ovarian Tumour Working Group. She is actively involved with the international Gynaecologic Cancer Intergroup (GCIG) and locally with the New Zealand Gynaecological Cancer Group (NZGCG). She is principal investigator of numerous gynaecological cancer clinical trials from Phase I to III. She has published in major peer-reviewed journals. Michelle recognised the need to mainstream genomic testing in the ovarian cancer pathway about 2 years ago. She helped to pull a business case together, established a pilot for genomic testing in the ovarian cancer pathway. Concurrently olaparib has been funded by Pharmac for gBRCA patients. Astra Zeneca funds genomic testing for this pathway.

The breast cancer community is at the early stages of endeavouring to instigate something similar, working closely with the Genetic Health Service of New Zealand (GHSNZ). GHSNZ is very aware that they do not have capacity to continue to support clinicians on a centralised basis and at the same time clinicians say they do not have time to address these issues either. GHSNZ recognise how vital mainstreaming is to health outcomes. The aim of mainstreaming is to make cancer gene testing part of routine cancer patient care, by integrating testing into the cancer patient pathway. By integrating testing into cancer care considerable time can be saved and which enables clinicians to provide information about the cause of a cancer and can aid decisions about the best treatments to use. GHSNZ can also help healthy relatives of cancer patients find out more about their cancer risks and gives them a window of opportunity to decrease their risk.

There are several clinicians who manage breast and ovarian cancers and so capability and interest has already been developed to some degree.

We are also aware that the Prostate and Pancreatic groups may also be interested in this approach. Targeted therapies such as olaparib are specific to high-risk patients and there is good evidence regarding their efficacy.

What is missing is the legislative framework to protect patients deemed to have a genetic risk from genetic discrimination by insurance companies. Funding is needed for these tests, along with clear and consistent protocols.

We accept there are significant opportunities to improve wellbeing e.g., through risk assessment and early detection by increasing the precision with which we assess risk, detect and diagnose which may incorporate AI and genomics and we welcome that focus in the near term.

A clear pathway, even in simple form, is important as one of the biggest risks we **perceive is that if tasks look too big, they become impossible to implement and those in the system are at risk of**

being immobilised. Implementation tasks could be broken down into 3, 5-year tranches, leading into and going beyond the 10-year time frame.

Risk: The suggested staging will put us further behind the rest of the world

We need clearer guidance regarding what needs to happen.

a. NOW (next 5 years)
b. In the near term (5- 10 years) and
c. Beyond the 10-year horizon

We do see value in the Manatū Hauora definition of fundamentals stage 1. These fundamentals need to be put in place in the next 5 years as do regulatory frameworks currently regarded as stage 2.

In the next 5-10 years we want to see increasing certainty regarding precision health and not uncertainty.

10 years and beyond we agree there would be growth and development. We will highlight what this might look like in p.21.

Risk: Inadequate funding

We suggest funding be made available in 5-year tranches. Funding for genomic testing and mainstreaming of genomic testing is needed today. Our standard **of care guidelines based on ESMO's Guidelines recommend the use of genomics in New Zealand for metastatic patients today**. In addition, there are also **recommendations for some at risk early breast cancer patients.** In the absence of ease of access and funding, patients who can afford to are being referred to **Fertility Associates for genomic testing** and **some surgeons are referring others to Invitae because it is cost efficient. We need progress on genomics now and not in 10 years' time.** What is missing is funding for genomic tools and the various molecular biomarker assays in early and metastatic disease. These tests are aligned with modern cancer treatments. The real benefit of these tools and assays is that they allow more precise targeting of treatments and avoidance of treatment for those who will not benefit. The Consultation paper indicates is currently not widely used. We believe this is partly driven by a lack of funding and capacity.

2.We have created a list of essential changes that will be needed to mitigate the risks and realise the opportunities of precision health. Are there other changes we should consider?

We believe we answered this question in our earlier submission in January 23 [1] and in our response to question 1 above. The issues we have highlighted include: A need for greater ambition in our focus, a need to recognise that precision health is an answer to our equity issues if managed well, informed consent is critical to our ability to move forward, greater recognition and inclusion of consumers and patients in this process. A lack of capacity and inadequate funding of our existing system is hampering capable leaders from leading change. We want to see greater aspiration and the necessary funding to achieve positive change and greater implementation of precision health in the next five years.

3. What are the most pressing data infrastructure issues that will need to be addressed to enable the safe introduction of emerging precision health technologies?

We will leave others to answer this but again **we want to see these fundamental issues resolved within the next 5 years.**

4. What are some steps we could take to enable Māori data sovereignty and ensure robust data governance, including Pacific people's autonomy over their data?

We will leave others to respond to this question but hope that the **Rakeiora** [10] project outcomes will provide **guidance** so that they may be implemented, as this issue is one of the **barriers** to progressing precision health.

5. Feedback suggests that existing consent processes are often inconsistent, inaccessible, and not always culturally appropriate, particularly for Māori, Pacific peoples, and those with language barriers. What would culturally appropriate consent look like in the context of precision health?

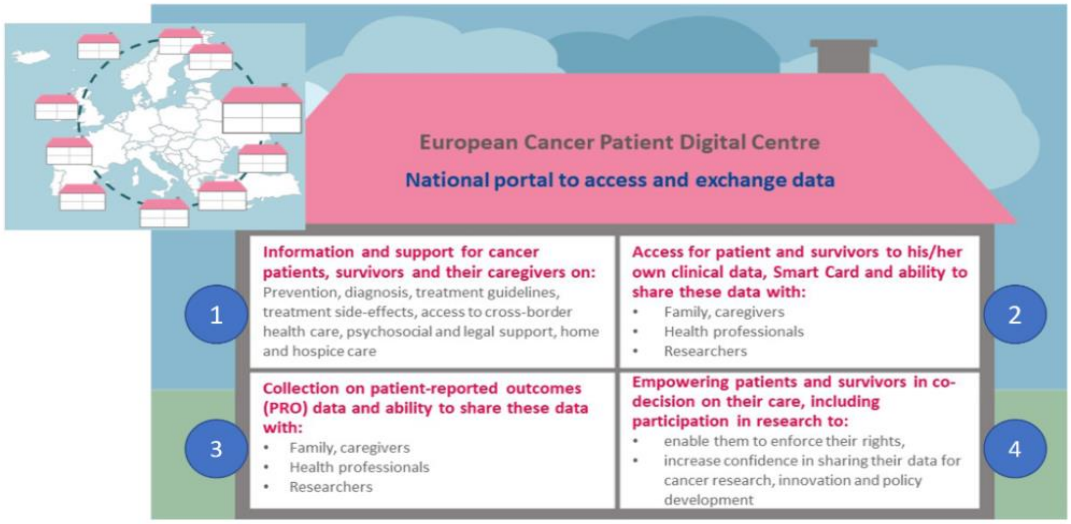
The response to this question also appears on p.11 of this submission. We agree there will be a rethinking of how individuals and whānau give informed consent.

Patients, whether Māori, Pacific or of other descent should have an opportunity to understand what the ways their health data may be used to benefit themselves, whānau or others. The European Cancer Patient Data Centre (ECPD) aims to empower patients to control use of their data throughout their health journey. There is a survey out currently that has received positive feedback from a small number of Māori consumers.

What will the European Cancer Patient Digital Centre be? The European Cancer Patient Digital Centre (ECPDC) [11] is envisioned by the EU Mission on Cancer Board as a patient-focussed one-stop agency that empowers patients to self-control and share access to their own health data, as well as receive various kinds of information and support. The information platform of the ECPDC will address relevant aspects along the patient journey, i.e., prevention, diagnosis, treatment, rehabilitation, follow-up care, re-entry into the working life, forwarding to social and legal advice etc. The study proposes a design for implementing the main functions of ECPDC:

1. Access to **general and tailored information on treatment and care** (room 1)
2. **Access of patients and survivors to their own clinical data** (room 2)
3. Possibility of **collecting and sharing patients and survivors' self-generated health data** such as PROs and PREs (room 3)

4. **Empowerment of patients and survivors** to manage their data and to co-decide on their treatment (room 4)



What is this study about?
Charité won the eTender by the European Commission for the "Study on Operational concept for a European Cancer Patient Digital Center (ECPDC)" which is conducted at the Berlin Institute of Health (BIH) at Charité in Berlin. This study will assess:

- to what extent existing and planned infrastructure can provide functionalities and contribute to ECPDC and
- what additional solutions are needed.

Who is asked and why?

They have identified different stakeholder groups such as infrastructure platforms / initiatives, patient organizations and caregivers that should express their opinion on the design of the ECPDC. Tailored surveys are conducted to collect first-hand information from these stakeholder groups.

What are the goals of the questionnaires?

- In each stakeholder group the survey pursues different goals:
  Patient Organisations:
  They are interested in the patients' needs that a patient focussed ECPDC should address along the patient journey.
- **Infrastructure platforms and initiatives:**
  The overarching objective in this stakeholder group is to evaluate how the ECPDC can be built on existing and planned infrastructures. They first assess the potential and willingness of existing and planned infrastructures and platforms to contribute to the ECPDC. Based on these results they will then identify the areas in which required solutions already exist and which additional components are needed to ensure the intended functionalities.
- **Caregivers:**
  They want to collect the major pain points that a patient focused ECPDC could address to also benefit healthcare professionals.

John Fountain and CanShare through their cloud-based technology may have already conceived of how this will be managed. We share it in our submission in the hope it will assist. The survey can

be found here: Questionnaire | page 1 (charite.de) ecpdc@charite.de, Berlin Institut of Health at Charité / Center of Digital Health Charité - Universitätsmedizin Berlin [11].

6. Which areas of our regulatory and legislative settings will require further attention to enable us to harness innovations in precision health technologies while ensuring safety risks are sufficiently mitigated?

The barriers to be overcome to enable a move to Precision Health including Precision Medicine include **policy leadership to facilitate an approach to prevent genomic discrimination** and to better enable gene editing. New Zealand sits separately from other OECD countries in this regard. [1]

On P.26 of the May 23 consultation document, it is indicated that Australia has a voluntary moratorium on genetic discrimination. This is correct but there is a desire to move to a more permanent legislative response in Australia.

A new survey has recently revealed our health professionals want government regulations to protect New Zealanders from genetic discrimination by insurance companies .[12] They discussed their experiences and those of their patients in relation to the use of genetic test results in insurance. Around half said they had been informed by their patients of insurance companies using genetic test results to deny coverage or increase premiums. There are currently no legal protections against genetic discrimination in health or life insurance in Aotearoa New Zealand, while some protections exist in Australia. Dr Jane Tiller, Ethical Legal & Social Adviser in Public Health Genomics, Monash University, Australia, comments: “Many countries have prohibited or restricted the use of genetic test results in insurance underwriting. Here in Australia, we have some protections against genetic discrimination in insurance. Those protections need bolstering further (she has separately indicated legislation is preferred) to keep up with international progress, but in New Zealand, there are no protections at all. “Although the self-regulated, the partial moratorium introduced by industry in Australia is seen as better than nothing. New Zealand health professionals believe it’s not ideal. They are concerned about industry self-regulation in this area and believe that government regulation through **national legislation is required to protect consumers against genetic discrimination** in Aotearoa.”[12]

7. How could we design regulations that will be fit for purpose for technologies that may not exist yet? What should our guiding principles be and who needs to be involved in deciding those principles?

Legislation should open the way for early innovation that will benefit patients. Regulations should be designed to address risks and consider benefits of technologies in terms of how they will be applied and the outcomes they can generate, and not be based simply on the technology itself. The regulations should not be overly prescriptive or based solely on the type of technology but should address any risks associated with the application of a technology and the outcomes from that.

An example of a legislative barrier to the beneficial use of modern technologies is the HSNO Act, which has a restricted and dated definition of genetic modification and directs decision-makers to

consider only the nature of the technology itself and not its application for specific purposes. This has limited the ability of NZ researchers to research and develop useful applications of gene-based technologies for Aotearoa NZ.

8. Where should we look to strengthen our international relationships to ensure Aotearoa New Zealand keeps up with international advancements? Are there areas of precision health where Aotearoa New Zealand could lead on a global level?

Risk assessment

Professor Antois Antoniou, Cambridge University UK. With one of the most advanced Cancer Risk Assessment tools which is free and is frequently used in New Zealand but not in its complete form. Used fully this tool flattens the curve and reveals those truly at high and low risk for better stratification in need of surveillance and intervention. https://www.phpc.cam.ac.uk/people/centre-for-cancer-genetic-epidemiology-people/ccge-senior-academic-staff/dr-antonis-antoniou/ [13]

Computational radiology

A **New Zealand** company, Volpara Health, is leading on a global level in Computational Radiology through the use of Volpara software that analyses mammogrphs and reports breast density, a risk factor for breast cancer and breast feature that can mask tumours. Volpara Health was recently selected as a founding member of **CancerX** [14], a public-private partnership aimed at revolutionizing cancer innovation in the United States. As a global leader in cancer detection software, Volpara joins other leaders in advancing patient care, communication, and policy in the fight against this devastating disease. **Cancer Moonshot** [15] and Cancer X brings together diverse stakeholders with a singular focus on advancing innovative solutions for cancer prevention, treatment, and cure. It suggests the expression “no one is a prophet in their own land.” https://www.volparahealth.com/ [16].

BCAC looks forward to the adoption by BreastScreen of this technology that is currently used in 40 countries.

Denmark

Mads Neilson Professor Image Analysis, Computational Modelling and Geometry, University Copenhagen, Denmark [17].

Sweden

Determining Future Risk, Stratification and modality selection: Per Hall, Department of Medical Epidemiology and Biostatistics, Karolinska Institutet, Sweden. Individualised prevention and screening of breast cancer: the KARMA experience [18].

Breast density

US/Global

This team in the US can provide detail of what is happening in the US, Canada and Ireland. https://densebreast-info.org/ Jo Ann Pushkin key contact. [19]. A European organisation works alongside this group. Canadian contact Dr Wendi Berg https://youtu.be/335FWnkLy9s [20].

European

Prof. Christiane Kuhl Radiologists must be more active in providing objective and understandable information to women about the diagnostic and prognostic implications of dense breasts, and the value of using other screening methods. March 14, 2023. https://www.myesr.org/article/23 [21].

Blood Test Guardant Health (US)
First blood-only liquid biopsy test for monitoring molecular response to immune checkpoint inhibitors now covered for US Medicare patients with metastatic or inoperable solid tumours. https://investors.guardanthealth.com/press-releases/press-releases/2023/Guardant-Health-Receives-Medicare-Coverage-for-Guardant360-Response-to-Monitor-Cancer-Patient-Response-to-Immunotherapy/default.aspx [22].

Blood tests

Blood test Biomarker (New Zealand) Dr Annette Lasham University of Auckland
In their study group, the predictive ability of the test for recurrence or death from breast cancer nine to ten years after surgery was 88% -98% accurate, a better predictor of outcome than the Nottingham Prognostic Index on NZ patients. They see this information guiding treatment decisions or suggesting closer surveillance of patients following surgery for breast cancer. [23]

International pan cancer test Blood Test Grail - **https://grail.com/** [24].

Computational pathology (AI) and multiomics

France
PortALT and **PRISM** [2,5]. We have focussed on France as a country that has developed a well-funded (Government and Private) model through strong partnerships and clear timelines. One of the key players Fabrice André, Gustav Roussey is known to us through our attendance at online conferences over many years. They have a focus on democratisation and health equity and their focus incorporates Computational Pathology and Omics.

New Zealand
Dr Gavin Harris Te Whatu Ora Health New Zealand, Waitaha Canterbury
https://www.breastcancercure.org.nz/research-projects/2022/gh-x7nm3 [4].

9. Where should we focus more investment and funding to realise our vision of pae ora in emerging precision health technologies and why?

1. We want to see our screening services in particular our breast cancer service better funded to improve detection. We want more cancers detected at an earlier stage and fewer at later stage.

- The resource on the ground and the facilities are a barrier.
- There is evidence that extending the screening age will improve outcomes and reduce advanced disease and morbidity.
- Māori and Pacific and other communities e.g., disabled, diverse, rural and disadvantaged need more resource within the system to help make this happen.
- We want to see breast density measured and reported to reduce late-stage diagnosis and knowledge and protocols developed for how to respond to this need.
- We want education relating to lifestyle provided as an option alongside screening services as trialled by Monash University.

2. We want funding for mainstreaming of genomic testing and biomarker testing of all metastatic and high-risk patients now.

- To build our genomic knowledge (yes done according to Te Tiriti/data sovereignty)
- To build capability
- To target treatments to reduce the need for chemotherapy and radiotherapy and better target treatment improving health outcomes and improving quality of life and equity.
- We also want to see improvements in the number of treatments requiring infusion instead moving to those given by subcutaneous injection and or pill form so that patients can get on with their lives.

3. Funding must be directed to precision medicines for disease subtypes identified through genomics and biomarkers

- Precision health cannot be implemented if we do not have access to the precision medicines to treat the particular conditions identified by genomic testing and biomarkers.

10. How does health workforce education and training need to change to keep pace with developments in precision health?

By building more capacity into the system to **enable on-the-job experience and training that will lead to learning about Precision Health**. **Significant learning can occur in the workplace.** Sometimes time is all that is required for a clinician to practise new knowledge or start a new initiative.

Breast Cancer Trials, a Trans-Tasman clinical trials and research organisation, cannot get local clinicians to support them in their work. Why? It is not through lack of initiative; it is not through lack of capability or lack of motivation to get innovative treatments to their patients faster. **It is because they are so stretched**. We as consumers interact with the current workforce and find that the capacity is just not there in many areas to facilitate new ways of working. For several precision health activities, there will be business cases, pilots, roll out and training. There needs to be capacity and increased workforce to enable such activity.

We need to empower capable clinicians lead change

When change occurs, people across the system are involved. In many areas change does not need to be top down but instead will rely on people who see and understand an opportunity and can lead the change in their everyday role. An example is the roll out of genomic testing for ovarian cancer patients. This roll out is in its second year and is saving lives. Michelle Wilson, a Medical Oncologist specialising in gynaecological malignancies, sarcomas, and translational research, returned to New Zealand from Canada with a FRACP specialist qualification in 2013 after completing her training in Auckland. Following this she spent two years undertaking research at the world-renowned Princess Margaret Cancer Centre in Toronto, Canada. During her time in Canada, Michelle worked with their Drug Development Team with a focus on gynaecological cancers, sarcoma and translating new treatments to better outcomes. Since her return in 2015, Michelle has been treating women with gynaecological cancers at Auckland Hospital. Michelle is also the Service Clinical Director for Cancer and Blood Research. Her research focus is geared towards early phase ***translational studies***, the ***relevance of genetic testing in oncology*** and clinical trials design. She was awarded a post graduate Doctor of Medicine from the University of Auckland for her work on the challenges facing clinical trial design in oncology. She is also the New Zealand Board representative on the Australia New Zealand Gynae-Oncology Group (ANZGOG), an active member of their Research Advisory Committee and Deputy Chair of their Ovarian Tumour Working Group. She is actively involved with the

international Gynaecologic Cancer Intergroup (GCIG) and locally with the New Zealand Gynaecological Cancer Group (NZGCG). She is principal investigator of numerous gynaecological cancer clinical trials from Phase I to III. She has published in major peer-reviewed journals. Michelle recognised the need to mainstream genomic testing in the ovarian cancer pathway about 2 years ago. She helped to pull a business case together, established a pilot for genomic testing in the ovarian cancer pathway. Concurrently olaparib has been funded by Pharmac for gBRCA patients. Astra Zeneca funds genomic testing for this pathway.

The breast cancer community is at the early stages of endeavouring to instigate something similar, working closely with the Genetic Health Service of New Zealand (GHSNZ). GHSNZ is very aware that they do not have capacity to continue to support clinicians on a centralised basis and at the same time clinicians say they do not have time to address these issues either. GHSNZ recognise how vital mainstreaming is to health outcomes. The aim of mainstreaming is to make cancer gene testing part of routine cancer patient care, by integrating testing into the cancer patient pathway. By integrating testing into cancer care considerable time can be saved and which enables clinicians can provide information about the cause of a cancer and can aid decisions about the best treatments to use. Genetic testing can also help healthy relatives of cancer patients find out more about their cancer risks and gives them a window of opportunity to decrease their risk.

There are several clinicians who manage breast and ovarian cancers and so capability and interest has already been developed to some degree.

We are also aware that the Prostate and Pancreatic groups may also be interested in this approach. Targeted therapies such as olaparib are specific to high-risk patients and there is good evidence regarding their efficacy.

What is missing is the legislative framework to protect patients deemed to have a genetic risk from genetic discrimination by insurance companies. Funding is needed for these tests, along with clear and consistent protocols. We accept there are significant opportunities to improve wellbeing e.g., through risk assessment and early detection by increasing the precision with which we assess risk, detect and diagnose which may incorporate AI and genomics and we welcome that focus in the near term.

A clear pathway, even in simple form, is important as one of the biggest risks we perceive is that if tasks look too big, they become impossible to implement and those in the system are at risk of being immobilised. Implementation tasks could be broken down into 3, 5-year tranches, leading into and going beyond the 10-year time frame.

Breast cancer consumers want to see mainstreaming of genomic screening for high-risk patients now. The Genetic Health Service of New Zealand is helping us because they are beyond their capacity NOW. It takes up to 8 months to get a genetic test result in New Zealand. They are very aware that they do not have capacity to continue to support clinicians on a centralised basis. They recognise how vital **mainstreaming is to health outcomes. There are several clinicians who manage breast and ovarian cancers and so capability and interest has already been developed to some degree.**

We are also aware that the Prostate and Pancreatic groups may/will also be interested. Now these targeted therapies are specific to high-risk patients and there is good evidence regarding their efficacy.

What is missing is:

- **the legislative framework to protect patients deemed to have a genetic risk to provide protection from discrimination.**
- **mainstreaming of genetic assessment**
- **funding for these tests and other assays and**
- **consistent protocols.**

11. What can we do to support a more diverse workforce in both the health delivery sector (clinicians) and academia (researchers, scientists), particularly in relation to precision health?

We have observed a change in the health delivery sector, with a strong commitment to greater diversity. Keep working at it, facilitate change, be patient and watch it happen. Don't let it hold us back. While improved ethnic diversity will improve the quality and connectedness of health research and delivery, ancestry doesn't always dictate how well a person will work with a diverse population or how much benefit they can deliver to individuals and populations. Don't let this be a barrier to progress with and implementation of precision health.

12. What are the primary activities that should take place at each stage to support equitable implementation of precision health technologies within Aotearoa New Zealand: to ensure services are comparable with international systems but appropriate for the New Zealand context?

We need clearer guidance regarding what needs to happen.

a. NOW (and next 5 years)
b. In the near term and (5 - 10 years)
c. Beyond the 10-year horizon

We do see value in the definition provided of fundamentals stage 1. These fundamentals need to be put in place in the **next 5 years as do regulatory frameworks currently regarded as stage 2. In the next 5-10 years we would see increasing certainty and implementation of precision health rather than uncertainty and delay.** From 10 years and beyond we agree there would continue to be growth and development. We will highlight what this might look like in the following table.

Stage 1: Up to 5 years *The Fundamentals*	*Stage 2: 5-10 years* *Growing confidence in Precision Health, focus on AI and Genomics*	*Stage 3: 10 years and beyond* *Growth and development of Precision Health incl.AI and expansion into multiomics*
Identify all relevant risk and opportunities. Complete a cost benefit analysis on the benefits available from initiating funded access to genomic medicine.	Funding, resourcing and assessment protocols are well established.	New Zealand's AI leadership and scientific and clinical expertise and partnerships continue to grow and develop with multiple benefits delivered to patients
Publish the LTI Briefing	Māori and Pacific and other communities have growing confidence in genomics.	Equity is being achieved through the acceptance and early use of these broad technologies

Gain funding and resources to cover 5-year tranches. Identify and initiate key partnerships	Regulatory, legislative and security legislation has been passed	There is a clear understanding of which patient cohorts require further research and attention and for whom new targeted therapies will be developed and implemented.
Establish mechanisms to support Te Tiriti for design and implementation of new technologies including protection of taonga and data (including data sovereignty) of benefit to all New Zealanders.	Te Tiriti is embedded in precision health pathways and our enabling environment is in place	Incidence of cancer is dropping through more effective prevention and early diagnosis for some conditions
Engage and work with key stakeholders. Māori, Pacific and other key groups including patient groups and consumers to ensure issues of concern are dealt with.	Genomics are applied across the life course and the need to take genomics to a broader multi omics environment is better understood. This is seen as key to achieving equity	Funding is made available for medicines as fewer advanced cancers are being diagnosed
Put in place the necessary security, regulatory and legislative settings. All metastatic patients receive genetic testing.	AI capability has grown and has moved from a concept to a key deliverable across a range of activities	
Develop and initiate informed consent procedures.	Research that was previously difficult to establish is now understood, facilitated and under way	
Establishing relationships to learn and identifying potential partnerships locally and globally.	Key partnerships built and they are delivering innovative beneficial outcomes for patients	
Build and grow workforce capacity to encourage leadership of precision health Initiatives. Establish national leadership models as required.	New Zealand has well developed genomic and multiomic capability, capacity and leadership	
Establish protocols for genomics and AI in New Zealand including oversight and funding for these initiatives. Funding provided for data infrastructure, workforce capacity and a nationally consistent facilitated pathway for research.	Ongoing evaluation is undertaken to identify opportunities for further progression. Greater equity is embedded. Stakeholders determine a strategy for the next 10 years.	

Conclusion

"We are all different, our genes are different (although marginally), we all develop differently, we are all built differently and our life experiences are all different" – *The Song of the Cell, Siddhartha Mukherjee.*

Precision health and precision medicine are not new concepts as we have tailored therapy to treat increasingly smaller populations. However, to date, **Aotearoa New Zealand has not consistently used the more advanced tools and technologies now available, as they have not been publicly funded**.

This needs to change. We **support the concept of public private partnerships** as these are enabling rapid development internationally**. We strongly recommend we follow move towards an AI and multiomic approach like France** and other countries internationally.

We want investment and funding focused on getting the fundamentals right in the first 5 years. New Zealand will fall far behind the rest of the world if we wait 10 years to do this. We need to enable genomic research of our indigenous populations to immediately begin to address gaps in knowledge, health service provision and health outcomes rather than waiting 10 years.

There is an opportunity for New Zealand to **lead the way** on **genomics research in the near term** for our **Māori, Pacific and Asian populations**. We are a small country with talented researchers, a committed health workforce, consumers and ethnic groups willing and able to engage and we can be aspirational and agile with sound scientific leadership. An early commitment to precision health and an enabling legislative environment for genomic health research will result in the development of Aotearoa-focused knowledge and solutions that benefit our population.

What is **missing for us is a clear model of how, for example, AI and genomics and multiomics or just omics might be used.** These technologies that include genomics, proteomics, metabolomics and bioinformatics are used to generate and analyse large sets of data to make key precision health care decisions.

Precision health informs risk stratification, prevention, detection, diagnosis and treatment decisions.

In our earlier submission we stated that "for our population to benefit from a move to precision health and precision medicine **we must remain very aware of ethnic disparity** in breast cancer prevalence and survival within NZ, with Māori and Pasifika women experiencing higher occurrence and worse outcomes with the need to address rather exacerbate this issue". **We have concern reading the consultation paper that the push for equity, while absolutely necessary, could become a barrier to a move to precision health, stalling progress for Māori and Pacific people.** This depends on how progress is achieved in striving for equity and delivering precision health. **It is not a case of having one or the other but adopting a balanced approach so that one will enable the other. Precision health is in fact the means by which equity can be achieved for our various ethnic populations.**

There are clear health system and social determinants of disparities in access to healthcare, resulting in unacceptable inequities in Aotearoa. For the benefits of precision health and oncology to be realised for all New Zealanders, and especially our Māori and Pacific populations, genomic and multiomic research is needed to better understand our unique genetic make-up**.**

Is using genomics, transcriptomics, proteomics, multiomics different from using tests that have been used in medical clinics and laboratories for many years? AI and Machine learning can help us leverage existing resources in radiology and pathology and pharmacogenomics. **We as consumers want this to happen.**

The Breast Cancer Aotearoa Coalition wants and encourages New Zealand to move towards genomic testing now and over the next 5 years, as this is already the global standard of care. By doing so we will realise that this is a preventative precision health strategy that will positively improve health outcomes for our population. Countries such as the UK and Australia understand the value provided by genomic testing as well as the research it drives and therapies it produces. These countries are assertive in its use as well as providing the guidance and support required.

There is a need for patient consumer and community input, education and socialisation regarding these issues so that people may understand the positive outcomes to be gained from genomic testing and precision health. **We perceived that consumers were poorly recognised in the Consultation paper.**

There is steady de-escalation and greater precision occurring in surgery, systemic treatment and radiotherapy, but this progress must be guided by a deeper understanding of the disease and its prognosis in individual patients.

Increased use of artificial intelligence, big data, and digital transformation in breast cancer management will enable us to better tailor treatment to each individual patient while delivering efficiency and productivity improvement. Stratifying patients based on biomarkers in their breast cancers is one approach. **Te Rehita Mate Utaetae Breast Cancer Foundation National Register could provide a means to model such improvements, especially now that data is gathered nationally**.

Progress will best be made by working with models relevant to our unique population. This will facilitate a confident transition from a dedicated Population Health approach to one that increasingly incorporates Precision Health.

This will be made possible by addressing barriers enabling progress at legislative, policy, leadership, cultural/ diversity, operational, technology and infrastructure levels and investing in research and trials as well as medicines, technologies and implementation.

These actions will be dependent on putting in place budgets, systems and tools that will enable us to build capability and capacity to transform, over time, to optimise quality of life and health outcomes for our population.

Over recent years we have been slow to innovate in New Zealand. We need to acknowledge that there are negative consequences of not acting in a timely way and that this will continue unless we adopt a precision health and precision medicine approach beginning now and over the next 10 years.

As consumers we want clinicians, researchers, scientists and policy makers alongside us with equal ambition to make such improvements.

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