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Executive Summary

This report was commissioned by the Precision Driven Health (PDH) Partnership to review the state of research in areas relating to Precision Driven Health in New Zealand and internationally.

The goal of this report is to provide a basic understanding of background information for researchers, partners, and committee members of components related to Precision Driven Health. Its primary focus is collating existing reports and resources (see Appendix A).

This report draws attention to the fact that recent advanced research and development in Information and Communications Technology (ICT), specifically the ability to process and digest large-scale data (also known as Big Data), provide opportunities to improve healthcare delivery and health outcomes worldwide. Many countries have initiated government funded programs to investigate this opportunity. In the United States of America, President Barack Obama called for $215 million in fiscal year 2016 to support the Precision Medicine Initiative. The European Commission has established a vision and strategies for Personalised Medicine for its member countries and is funding relevant projects under its Horizon 2020 scheme. Specific large projects such as the 100,000 Genomes project in the United Kingdom have been initiated to sequence and store genomics data for better diagnoses and treatment of Cancer and Rare Diseases.

Currently there is a wide variety of terms used globally that roughly has the same goals as Precision Driven Health. For example, the United States of America uses Precision Medicine while the United Kingdom and European Union generally use Personalised Medicine. Canada has previously referred to this type of research as Patient-Oriented research, although recently moving towards using Personalized Medicine. These research and programs all focus on moving from a current population based one-size-fits-all approach to medicine to an evidence-based individualised approach.

Precision Driven Health is a contestable funding source that funds research activities that are applied research and experimental development. It focuses on figuring out what data is available and relevant to healthcare in New Zealand, and the integration of the data, along with the development of novel and useful smart software products that benefit the health of all New Zealanders. The criteria for funding require the projects to have potential commercial, clinical, and scientific outcomes.

The barriers of Precision Driven Health related research from the clinical and translational research side can be described by the Valleys of Death. The Valleys of Death metaphor helps explain the impediments that prevent biomedical science from realizing
its potential and the risks of failing to translate knowledge into public benefit. Barriers from the Big Data side can be described by the HACE theorem. The HACE theorem reveals three-tiered challenges to dealing with knowledge extraction from Big Data which addresses topics such as data infrastructure, privacy, and algorithmic development.

With the renewed health strategy in 2016, single electronic record in 2020, and the government investment plan in furthering scientific research, and the Precision Driven Health partnership, New Zealand is moving forward and we offer a unique potential for Big Data research in the healthcare setting.

There are a few potential suggested focus areas of Precision Driven Health:
1. There are abundant amounts of data that has been collected over the years that can be put to good use for both health delivery and research. With Precision Driven Health bringing together expertise from all disciplines and sectors, it has great potentials for expanding New Zealand’s health delivery and research capabilities with the first step of an integrated single source of data.
2. New Zealand’s unique ethnic diversity and cultural environment allows us to have novel research areas (e.g. Maori and Pacific health). These areas are unique to New Zealand and will unlikely be the research focus elsewhere in the world.
3. New Zealand’s population size allows us to be a practical testbed for innovation and a place for developing proof of concepts. There are promising topics such as: Pharmacogenomics, Haematology, individualised screening, and Melanoma

Introduction

The goal of this report is to describe the context in which the Precision Driven Health partnership sits by providing: (1) an understanding of global research efforts, (2) a sense of where Precision Driven Health currently stands nationally and internationally, and (3) directions of where Precision Driven Health should head next.

There are three sub-goals:
1. Identify the current state of knowledge in Precision Driven Health
2. Review New Zealand vs. International entities
3. Position Precision Driven Health and provide recommendations/priorities.

Scope

This report serves as a first point of reference providing a high level summary of the components related to Precision Driven Health. It should be treated as a resource for general information on the topics, providing and consolidating relevant links and useful resources (see Appendix A).
The methodology consists of a general literature review of:

- Documents released publicly of large-scale government-led international initiatives.
- Clinical and technological sciences research surveys and publications.

In addition, experts related to Precision Driven Health research are formally interviewed. This report includes their perspectives and shared knowledge.

This report also covers specifically the research in the context of New Zealand's unique environment, in particular addressing the major research funding bodies, the cultural diversity, and healthcare policy and ethics in New Zealand.

The Three Reports

At this time there are two other reports commissioned by Precision Driven Health: data availability report and clinical perspective report. Unlike this report, which aims to summarise and cover a wide breadth of related topics, the other two reports are more topic specific, aiming to provide more in-depth information on their respective topics.

The data availability report provides baseline information around the kinds of data sources that can be used for the purpose of research that enables personalized and precise healthcare. The report will seek to understand the means - privacy, security, medicolegal, data quality and interoperability - that allows us to leverage these datasets for PDH-related research.

The clinical perspective report provides a more specific survey covering relevant New Zealand based projects and insights from the clinicians' perspectives.

Context

In March 2016, the Precision Driven Health joint research partnership was announced with founding partners - Orion Health, The University of Auckland, Waitemata District Health Board, with support from the Ministry of Business, Innovation, and Employment. Precision Driven Health (PDH) brings together multiple sectors (business enterprise, government, and higher education) to achieve a better health outcome for all New Zealanders through advanced research in Information and Communications Technology (ICT) in the health sector.

Efforts to connect and utilise novel advanced research in ICT with healthcare are on the rise globally. Multiple member countries in the Organisation for Economic Co-operation and Development (OECD), including the United States of America, the United Kingdom, Canada, and countries that are part of the European Union, have already begun funding and directing healthcare research with increasing involvement of ICT.
While many international efforts have been made and these efforts are in general applicable to New Zealand, New Zealand has unique and particular challenges and environmental differences compared with other OECD member countries. New Zealand with its unique cultural and ethnic diversity and Maori and Pacific population has different health priorities and targets.

The fundamental enabler of these research efforts is the growing ICT research into the collection, integration, storage, and processing of large-scale heterogeneous data.

**Definition of Precision Driven Health**

It is important to define Precision Driven Health and the relationships between Precision Driven Health with other global initiatives with similar objectives and target outcomes.

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<tr>
<th>Country / Region</th>
<th>Primary Term(s) Used</th>
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<tr>
<td>United States of America</td>
<td>Precision Medicine</td>
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<td>European Union</td>
<td>Personalised Medicine</td>
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<td>United Kingdom</td>
<td>Personalised Medicine (Personalised Health and Care)</td>
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<tr>
<td>Canada</td>
<td>Personalized Medicine (Patient-Oriented Research)</td>
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<td>New Zealand</td>
<td>Precision Driven Health</td>
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Currently there is no single definition used globally to specify a healthcare initiative or strategy aimed at using advances in ICT and data analysis research to provide improved medicine and healthcare. The European Commission in their Horizon 2020 program has defined personalised medicine as: “[...personalised medicine] refers to a medical model using characterisation of individuals' phenotypes and genotypes (e.g. molecular profiling, medical imaging, lifestyle data) for tailoring the right therapeutic strategy for the right person at the right time, and/or to determine the predisposition to disease and/or to deliver timely and targeted prevention.”

A range of terminology and definitions exist, such as P4 medicine (Predictive, Preventative, Personalised, and Participatory), which cover similar areas of concern. Other terminologies used globally are shown in Table 1. In general the focus is on using modern ICT to leverage and maximise health and medical outcomes.

These efforts are the result of a general movement from a population based one-size-fits-all approach to medicine and healthcare to an evidence-based individualised
approach to medicine and healthcare. Traditionally, disease treatment and prevention has been a reactive approach on a population level where a single solution is used to treat or prevent one disease for the entire population. Evidence-based and individualised practice is an approach that maximises effectiveness by taking into account individual variability in genes, environment, and lifestyle. With the vast advancement in science, including in ICT research into capabilities to deal with big data, targeted medicine and healthcare is now promising with early successes in fields such as oncology where different types of cancer can be identified and treated based on certain expression of genomes.

While countries mobilise to explore the positive outcomes of Big Data analyses in healthcare by bringing together experts across sectors and disciplines, there is an apparent lack of a common language and understanding of terms and procedures between the involved parties. There are two noticeable issues:

1) There currently is no one single definition for this idea that broadly connects the research into Big Data analytics with health outcomes and healthcare systems delivery. This is evidenced by the fact that some countries use the term Precision Medicine (predominantly the United States) while European Union and the United Kingdom use Personalised Medicine. In addition, terms like Precision Health and Personalised Health are often used as well. These terms are sometimes used interchangeably to represent the same idea – research that leverages Big Data technologies to provide better healthcare.

2) There is currently a single definition used by people that in reality represents a wide range of ideas. This common misunderstanding across experts in different sectors is the understanding of what research activity entails. The term research is used commonly across sectors and disciplines but each person with their uniquely different background has a different expectation of research focuses, procedures, and outcomes.

Below we clarify the underlying meaning of some common terminology that is used globally when referring to personalized healthcare and distinguish their differences below. In a later section we clarify the term research and define different research activities using the Frascati Manual.

**Personalised vs. Precision**

Personalised medicine/health is viewed by clinicians as something that has been going on for a long time - clinicians have been doing it for a while from your local doctors’ involvement in every family member’s birth, growth, and death. A clinician would tend to view using ICT/Big Data Analytic capabilities as a potential way to improve the outcomes and delivery of personalised health.

Precision medicine/health, from a data scientists’ perspective, may imply a stronger focus
on the ICT side to improve the quality of health information and getting more precise scientific results, which when utilised correctly would improve clinical and health outcomes.

While the two definitions and views initially seem to have different focuses, the fact is that the current states of these research initiatives have a common goal – to improve overall health outcomes of people.

**Medicine vs. Health**

Medicine is the practice of diagnosis, treatment, and prevention of diseases. Health covers a broader aspect of medicine by also considering other socio-economic factors such as the environment, education, workplace, economy, and family of an individual. Health goes beyond medicine, which is physical health from the clinical perspective.

**Precision Driven Health is…**

With all the globally used terminology and their differences in mind, Precision Driven Health can be defined as leveraging our digital capability to collect, store, and process large-scale data to understand health needs and improve individualised personal health outcomes.

More specifically, the **PDH partnership focuses on figuring out what data is available and relevant to healthcare in New Zealand, and the integration of the data, along with the development of novel and useful smart software products that benefit the health of all New Zealanders.** This is achieved by bringing clinicians, academics, data scientists, and commercial entities together to work on projects that benefit everyone and New Zealand as a whole.

PDH is currently a contestable funding source with a total of 38 million over 7 years. PDH is currently considered to be funding research activity classified in the Frascati Manual as applied research and experimental development. PDH has a heavy focus on the relevance of its funded projects to include both the areas of health sciences and engineering and technology. The criteria for funding require the projects to have potential commercial, clinical, and scientific outcomes.

**Potential Areas that will benefit from Precision Driven Health**

- Health monitoring and diagnosis
- Medical treatment and patient care
- Pharmaceutical research and development
- Clinic performance optimisation
Patient understanding and involvement

Definition of Types of Research

It is important for the PDH partnership which brings together people from multiple sectors, each with different unique skills and knowledge, to have the same definition of what research activity entails. Based on the Frascati Manual used by OECD countries, 3 main types of research activity are defined: Basic research, Applied research, and Experimental development. Basic research is broken down further into pure basic research and targeted basic research.

- **Basic research** is experimental or theoretical work undertaken primarily to acquire new knowledge of the underlying foundations of phenomena and observable facts, without any particular application or use in view.
- **Pure basic research** is carried out for the advancement of knowledge, without seeking long-term economic or social benefits or making any effort to apply the results to practical problems or to transfer the results to sectors responsible for their application.
- **Targeted (or oriented) basic research** is basic research carried out with the expectation that it will produce a broad base of knowledge likely to form the basis of the solution to recognised or expected current or future problems or possibilities.
- **Applied research** is original investigation undertaken in order to acquire new knowledge. It is, however, directed primarily towards a specific, practical aim or objective.
- **Experimental development** is systematic work, drawing on knowledge gained from research and practical experience and producing additional knowledge, which is directed to producing new products or processes or to improving existing products or processes.

In general, it can be roughly said that the higher education sector (i.e. Universities) conducts mostly basic research and applied research. The business enterprise sector conducts mostly experimental development and some applied research. The government sector is generally involved in all three types of research through directly funding these research activities.

Comparison to Other New Zealand Funding Sources

There are 3 types of funding allocations in New Zealand:

- **Contestable**
- **Negotiated or on-demand**
- **Institutional**
PDH is currently a contestable funding source with a total of 38 million over 7 years. PDH is currently considered to be funding research activity classified under the Frascati Manual as applied research and experimental development. PDH has a heavy focus on the relevance of its funded projects to include both the areas of health and engineering and technology.

Other directly relevant funding sources in New Zealand that are either fully contestable or partially contestable are: Marsden Fund, Health Research Council (HRC), MBIE Contestable, National Science Challenges (NSC), and Business R&D Project Grants.

These funding sources can be further categorised by the entity that leads the research activity into three categories:

- **Investigator-led science** is undertaken to acquire knowledge but the direction of research is led and set by researchers.
- **Mission-led science** is undertaken towards a particular policy aim or goal.
- **Industry-led research** is typically applied research either conducted within firms or in partnership with public research organisations.

**Marsden Fund**

The Marsden Fund has a funding pool of 53.6 million (annually). It is established by the New Zealand government in 1994 to fund excellent, investigator-led fundamental basic research that advances and expands the knowledge base. Research is not subject to government's socio-economic priorities. The Marsden Fund is administered by the Royal Society of New Zealand.
Health Research Council
The HRC has a funding pool of 77.2 million (annually) and is focused specifically on health and quality of life related research activity. The HRC funds mainly applied research.

Ministry of Business, Innovation and Employment Contestable
The MBIE Contestable has a funding pool of 190 million (annually). It is mission-led science that uses competition to fund excellent research with the potential to deliver long term, transformative impact for New Zealand. The MBIE Contestable funds mainly applied research.

National Science Challenges
The National Science Challenge has a funding pool of 132.3 million (annually). It is mission-led science that uses a collaborative mechanism to fund research that addresses complex, long term, national-scale issues for New Zealand. The NSC funds mainly applied research and some basic research.

Business Research and Development Project Grants
Business R&D Project Grants has a pool of 45 million and assists firms to develop the skills, expertise and connections to successfully develop ideas and take them to market. The New Zealand government supports research activity in this sector mainly through Callaghan Innovation. This is industry-led science and funds mostly experimental development research.

Healthcare Systems: New Zealand vs. the World
To provide a more comprehensive perspective of the precision driven health initiatives internationally versus those in New Zealand, we first need to consider the differences and similarities between the New Zealand healthcare system and other countries in the world.

New Zealand Healthcare System: A Quick Summary
The New Zealand healthcare system is considered as a one-payer single source public funded health system through general taxation managed by the Ministry of Health. There are 20 District Health Boards (DHBs) that are responsible for the delivery of health in their districts, which receive government funding based on the population of their district.

Public hospitals managed by the DHBs provide health services to New Zealand residents free of charge. Primary health care is subsidised by the government through a registered
GP systems with co-payments.

Other important components of the New Zealand healthcare system include:

- **Accident Compensation Corporation (ACC)** – New Zealand crown entity that provides no-fault personal accidental injury cover for all New Zealand residents and visitors to New Zealand.

- **Pharmac** – New Zealand crown entity that manages and subsidises pharmaceuticals in New Zealand. Pharmac is responsible for controlling New Zealand’s expenditure on pharmaceuticals and maintaining New Zealand’s low pharmaceutical prices.

- **St. John and Wellington Free Ambulance** – Charity funded ambulance services in New Zealand. St. John covers all of New Zealand except the general Wellington area where Wellington Free Ambulance operates.

- **Private Insurance** – Coverage varies but generally covers additional co-payments and other additional medical costs. New Zealand’s largest non-public healthcare organisation is Southern Cross, which operates on a not-for-profit principle.

**Notable Comparisons Internationally**

- **Canada** does not have a system like Pharmac. There is no centralised agency or entity directly responsible for managing pharmaceutical prices. The other aspects of the Canadian healthcare system are relatively similar to that of New Zealand with their funding source from general taxation and each state having strong influence over healthcare and funding of healthcare like New Zealand’s DHB structure.

- **Australia** healthcare is operated under the Medicare scheme. Medicare is directly funded through a percentage of taxation – the medicare levy. This is unlike Canada and New Zealand where the fund comes from the general taxation pool and monies are distributed afterwards. Australia encourages private health insurance through an additional Medicare levy surcharge if residents are above a certain income tax bracket.

- **United States of America** healthcare is run mainly through the private sector with healthcare services driven more by commercial approaches. Their primary health funding source is a multiple-payer system through private insurance.

- **Taiwan** has a compulsory government managed universal health insurance. In addition to compulsory insurance fees, it also receives additional funding from government through general taxation. The Taiwanese healthcare system is a highly centralized public health system and healthcare structure with minimal private sector involvement. Since the inception of the universal health insurance in 1995, a large amount of health data has been collected.

- **European Union** has large variations across member countries.

- **United Kingdom’s** healthcare system is claimed by many to be broadly similar to New Zealand, with different publicly funded healthcare systems across regions of the United Kingdom.
Clinical and Big Data Research: Barriers and Challenges

PDH brings together clinical and ICT big data research to improve health outcomes. It is important to discuss the main challenges and barriers in both clinical research and ICT big data research.

Clinical and Translational Research Challenges: The Valleys of Death

Translating the knowledge from biomedical science into clinical applications that help patients has been compared to crossing a valley of death because of the many issues that separate the bench from the bedside and threaten to stall progress. The valley metaphor helps explain the impediments that prevent biomedical science from realising its potential and the risks of failing to translate knowledge into public benefit. The impediments range from lack of technological innovation, to particular obstacles such as a lack of access to well characterised biological materials in biobanks, or insufficient training in translational science for the next generation of investigators. The principal risks of failing to translate this science are the perceived delays in providing diagnostics and clinical care to patients.

1 http://www.clintransmed.com/content/2/1/14
Getting from one side to the other involves navigating through a diverse collection of organisations and institutional players - government, business enterprise. Particular challenges include ambiguous regulation, unnecessary bureaucracy, lack of commercial incentives to innovate, and few opportunities to revise legislation or to change habits or practices in the light of new knowledge.

**Big Data Research Challenges: HACE Theorem**

The characteristics of the recent great ICT advancement - Big Data - can be summarised by the HACE theorem. The HACE theorem states: Big Data starts with large-volume, heterogeneous, autonomous sources with distributed and decentralized control, and seeks to explore Complex and Evolving relationships among data.

The HACE theorem describes the fundamental characteristics of Big Data. An analogy to this challenge is the blind men and the elephant. The giant elephant represents the large volume of the data we now possess. Each of the blind men wishes to draw a conclusion of the giant elephant but is limited by their exposure to a smaller part of the elephant.
The blind man touching the tail of the elephant will think the elephant is like a rope, while the blind man touching the ears of the elephant will think the elephant is like a giant fan. In this analogy each of the blind men represents a localised view (similar to what we have today in the healthcare structure) where individuals see only a subset of the overall large amount of data. This localised and dispersed approach to the large amount of data often leads to biased results and outcomes.

In addition to the large volume issue, is the fact that the giant amount of data we have are dynamic and changes very quickly as more and more data are collected. Not only were the blind men trying to look at the large elephant based on their limited localized view, the elephant now changes shape as time goes by.

Exploring Big Data is then equivalent to aggregating heterogeneous information from different sources (the blind men) to derive a better overall description of the data we now possess (the elephant).

New Zealand currently has heterogeneous data and information stored separately at different locations and in different formats but are (pseudo)-linked using the NHI and HPI. Applying the HACE theorem to New Zealand's healthcare data demonstrates a fitting model for regarding New Zealand's healthcare data landscape as a Big Data problem. To derive a better overall description of the data we now possess (the overall collective of New Zealand's healthcare data), we need to aggregate the heterogeneous information from the different sources (the current individually stored datasets across

[16]
The key to constructing a successful modern intelligent system that is capable of extracting knowledge from Big Data, is to scale up to the exceptionally large volume of data and provide solutions for the characteristics featured in the HACE theorem. There three-tiers to the challenge of dealing with knowledge extraction from Big Data:

- Tier I: Considerations of mining platform and infrastructure
- Tier II: Data privacy
- Tier III: Big Data mining algorithms

**Tier I**

Unlike the processing and mining of a smaller chunk of data samples that can typically be performed on a single machine, Big Data processing requires considerations of a platform that has the processing power beyond single machines. A typical framework for processing Big Data will rely on cluster computers with a high performance computing platform, where a data mining task is deployed by running some parallel programming tools such as MapReduce. An example of a supercomputer with that mining capability is Titan deployed at Oak Ridge National Laboratory in Tennessee, USA, containing 18,688 nodes each with a 16-core CPU.

While separated healthcare data can be individually processed, when combined they require a proper platform and infrastructure to allow for both storage and processing.

**Tier II**

Sharing and integration of heterogeneous data from autonomous sources is an important task in dealing with Big Data. A subsequent challenge is concerns around data privacy. In the healthcare domain, protecting the privacy of individuals' healthcare information is particularly important. At certain levels the protection of data privacy hinders the integration of certain datasets into one pool of data.

Much research has circled around anonymising key identifying information to allow for the integration of data while preserving the data privacy of the individuals involved. Nevertheless, challenges around data access and integration are still an ongoing problem and a current barrier to a fully integrated platform for both storage and access of healthcare data and significant clinical decision systems in New Zealand.

**Tier III**

A vast number of new algorithms have been researched and developed to enable valuable knowledge to be extracted from Big Data. The first advance in the mining algorithms is moving from the traditional offline and multiple pass (reading the data more than once) approaches to online and single pass approaches. The traditional algorithms assume the
entire dataset can be read into memory and thus is designed to read data more than once to ensure the accuracy of the produced model. Nowadays data arrives both at a faster pace and a larger volume. This renders traditional multiple pass algorithms unusable. Modern mining algorithms adopt the single pass approach where each data instance is read only once to build a representative model of the overall data. An example of a famous adaptation of the traditional classification algorithm is the Very Fast Decision Tree (VFDT) which is a one pass online classification algorithm specifically used for large scale Big Data.

Other important areas of development include mining from sparse, uncertain, incomplete, complex and dynamic data.
100,000 Genomes Project
- £800 million in total

Precision Medicine Initiative
- $215 million in fiscal year 2016

Combined Horizon 2020 & Other Funding
- €100+ million annually

Zero Childhood Cancer
- $50 million over 5 years

Precision Driven Health
- $38 million over 7 years
State of Knowledge

Large International Research Entities and Projects

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<tr>
<th>Country / Region</th>
<th>Entities / Projects</th>
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<td>United States of America</td>
<td>Precision Medicine Initiative</td>
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<td>United Kingdom</td>
<td>Personalised Health and Care</td>
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<td>100,000 Genomes Project</td>
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<td>International Consortium for Personalised Medicine</td>
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<td>Innovative Medicines Initiative</td>
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<td>Australia</td>
<td>Zero Childhood Cancer</td>
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International Context

Multiple member countries of the Organisation for Economic Co-operation and Development (OECD), including the United States of America, the United Kingdom, Canada, and countries part of the European Union, have already began investigating and funding research in this new exciting area. This new research area is characterised by a fusion of clinical research and ICT research that requires bringing together experts from both disciplines.

A review of the literature and interviews of the experts showed that we are still in the establishment phase of this new area of research and the first noticeable barrier is the lack of common language and definitions. While there are programs and initiatives established by OECD member countries, the terminology used and the understanding of the terminology is vastly different. Adjectives like precision and personalised are sometimes used interchangeably to describe the same idea: tailored to an individual rather than to the population. Another example is medicine and health.

Most international projects are still in the early stages and/or just beginning to start. Actual outcomes are currently still unknown. Most countries begin with reinforcing data collection and building a large database of patient information for genomics analysis and research (as is the case for the US PMI Cohort program, 100,000 Genomes Project and Zero Childhood Cancer).

Currently genomics has shown effectiveness and promises of usage mainly in Oncology. Major countries have begun funding or focusing funding on ICT data driven healthcare. Different programs have different emphasis. Some focus more on medicine and coming
up with clinical results while others focus on public and personal involvement in healthcare. The United States appears more clinically driven while the United Kingdom and European Union appear more driven towards involving patients to understand their own health, manage their own health through ICT.

**Commercial Entities and Research**

Most top IT companies in the world have health related software products. These companies include, but are not limited to, Google, IBM, Microsoft, SAP, Oracle, and Hewlett-Packard.

These software products in general provide the infrastructure for handling and facilitating health delivery data and process. In general they provide support for storage of data and interfaces for ease of access and visualisation tools by clinicians, nurses, and administrators. Some also offer (to a limited degree) clinical decision support systems which use more advanced machine learning techniques to provide a better health delivery service. The actual capabilities of these support systems vary across products and companies.

Google DeepMind Health and IBM Watson Health are the front-runners of machine learning research in the commercial sector. In addition to providing the infrastructure and software products, Google and IBM also have active projects in machine learning research in the Health setting which explores targeted diseases and areas. Google DeepMind Health has projects targeting eye diseases and head and neck diseases through using machine learning to analyses results of medical scans. IBM Watson Health targets areas like genomics, oncology, and imaging and using their Watson research.

**What is happening in New Zealand?**

- Renewed Health Strategy 2016
- Mobile Device Prevalence
- Electronic Medical Record Adoption Model (EMRAM) Assessment
- Single Electronic Health Record in the year 2020
- Strategic Science Investment Fund
- Precision Driven Health

**The New Zealand Context**

While there are global efforts similar to Precision Driven Health initiated in other countries, New Zealand in its environment has unique differences to other countries. New Zealand is a country with high cultural and ethnic diversity consisting of populations
identifying themselves as approximately 74% European, 15% Maori, 12% Asian, and 7% Pacific. The diversity combined together with the relatively smaller total population size makes New Zealand a unique place for healthcare research.

The New Zealand healthcare system is a single-payer universal health system funded from general taxation. The Ministry of Health sets the direction for general health governance and the 20 district health boards (DHBs) are responsible for providing or funding the provision of health services in their district. New Zealand has a well-established Health Information Privacy Code 1994 forming the basis for the usage, storage, and governance of health information through National Health Index (NHI) number and Health Provider Index (HPI). Through NHI and HPI, New Zealand has been able to collect and store a large number of data that forms a pseudo-connected data network of health information. Although medical/health records are connected through NHI and HPI, they are not all accessible at the click of a mouse in real-time. This is due to the lack of a single Electronic Health Records (EHR) system and also the federated IT governance and autonomy of the DHBs. This results in the deployment of smaller scale IT solutions and projects with varying success. A wide diversity of different systems used across different DHBs also leads to an increased complexity of the overall system on a national scale.

**New Zealand Health Strategy 2016**

In the 2016 New Zealand Health Strategy, the Ministry of Health identified 5 strategic themes for the next 10 years. One of which is the theme of Smart System. The ministry recognises the immense opportunity and potential for ICT smart systems to assist and improve health outcomes through research such as teleHealth and mHealth. Part of the theme includes the vision to improve data sharing throughout the health system.

**High Mobile Device Use and Prevalence**

There is a sharp increase in the penetration of mobile devices like smartphones into the New Zealand population over the past 4 years. In the year 2015, the proportion of New Zealander's having smartphone ownership/access is 70 percent. This is a significant increase from only 48 percent in 2013. Smartphones are also now the most frequently used mobile communications device with 91 percent of users using their smartphones everyday. In comparison, only 41 percent use feature phones, 53 percent use laptops, 53 percent use PC, and 52 percent use tablets on a daily basis, respectively. This trend of prevalent use of smartphones and mobile technology amongst the New Zealand population allows for opportunities in mHealth focusing on the use of mobile devices for each individual to self-manage their health.
Electronic Medical Record Adoption Model (EMRAM) Assessment

The core Electronic Medical Records capabilities of New Zealand’s hospitals across DHBs are evaluated by the Electronic Medical Record Adoption Model (EMRAM) assessment\(^2\) commissioned by the Ministry of Health in 2016. The model consists of 7 stages and a previous stage must be fully accomplished before the service can move to the next stage. Evidence from digitally enabled hospital services overseas has shown a strong correlation in improved productivity and quality as hospitals move up the EMRAM scale to Stage 7. The results of the assessment show that most DHB hospitals have capabilities between stage 2 and stage 3 under the EMRAM.

The EMRAM Explained

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<thead>
<tr>
<th>Stage</th>
<th>Short Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 7</td>
<td>Hospital wide - Complete EMR, CCD transactions to share data, Data warehousing; Data continuity with ED, ambulatory, OP</td>
</tr>
<tr>
<td>Stage 6</td>
<td>**ONE INPATIENT UNIT - Physician documentation (structured templates), full CDSS (variance &amp; compliance), closed loop medication administration</td>
</tr>
<tr>
<td>Stage 5</td>
<td>Full complement of R-PACS displaces all film-based images</td>
</tr>
<tr>
<td>Stage 4</td>
<td>*ONE INPATIENT UNIT - CPOE, Clinical Decision Support (clinical protocols)</td>
</tr>
<tr>
<td>Stage 3</td>
<td>**ONE INPATIENT UNIT - Nursing/clinical documentation (flow sheets), CDSS (error checking), PACS available outside Radiology</td>
</tr>
<tr>
<td>Stage 2</td>
<td>Clinical Data Repository (CDR), Controlled Medical Vocabulary; CDS, may have Document Imaging, HIS capable</td>
</tr>
<tr>
<td>Stage 1</td>
<td>Ancillaries – Lab, Radiology, Pharmacy – All Installed</td>
</tr>
<tr>
<td>Stage 0</td>
<td>All Three Ancillaries (LIS, RIS, PMS) Not Installed</td>
</tr>
</tbody>
</table>

EMR Adoption Model Scores for the District Health Boards

[Graph showing EMRAM scores for different DHBs]

Source: HIMSS Analytics® Database

Single Electronic Health Record in the year 2020

The Ministry of Health has begun the process to establish a single EHR by the year 2020, which will improve New Zealand’s health IT capabilities. A single connected source of all separated data can be extremely valuable for research purposes and will fully utilise New Zealand's existing data advantage. A single storage and access system as part of the single EHR will integrate all health data into one single platform and an integrated data storage is the first step towards developing, through research, additional intelligent systems in the advanced EHR platform like clinical decision support systems.

New Zealand's DHBs have control over their allocated budget spending, including health IT spending. In the National Health IT Plan, the National Health IT Board estimates that 40-70% of the DHBs IT investment is spent on infrastructure and maintaining existing systems, which means goals such as IT product innovation for better health delivery is receiving insufficient funding limiting any innovation and progress. The New Zealand target for IT investment in healthcare is set at 4% of operating expense, but DHBs barely achieve 2% across the country.

Outside health IT and on the overall ICT industry in general, IT research and innovation expenditure from the government have also been comparatively lower when compared to other industries. The government contributes only 6-7% of the total research expenditure in ICT - total of 305 million while the business sector contributes 80% of the 305 million.

Strategic Science Investment Fund

As part of the National Statement of Science Investment 2015-2025, the Ministry of Business, Innovation, and Employment (MBIE) indicated that the New Zealand ICT industry's contribution to New Zealand's GDP is rapidly growing and is a thriving sector. The government has also announced a new plan for a Strategic Science Investment Fund 2017-2024 which will re-focus research investments. A part of the plan involves new funding opportunities in advanced genomics research and analysis and computation of big data. These actions of government confirm the growing opportunities in both health IT and ICT to conduct innovative research that delivers better outcomes for New Zealand.

Other unique opportunities in New Zealand include unique research areas specific to Maori and Pacific health. There are cultural and genetic differences that leads to different onset of diseases in the different ethnicity groups in New Zealand that other countries do not have. Diseases like Melanoma are also more prominent in New Zealand as opposed to other countries in the world due to our environment and our geographic location.
SWOT Analysis

Strength
- Established NHI / HPI
- Single Payer Universal Public Health System
- Ethnically Diverse
- We have been collecting data for a long time

Weaknesses
- Federated Governance (DHBs)
- Underfunded health IT and ICT sector
- Health IT Capabilities lagging behind other OECD countries.

Opportunities
- Government Strategies recognises and addresses weaknesses
- A good test bed (due to population size and ethnic diversity)
- Maori and Pacific population specific research

Threats
- Economic stability reliant on foreign investments
- Growing competition and lower profitability

Data Science Research Groups in New Zealand

The University of Auckland
- Software Engineering Research Group
- Intelligent Systems and Informatics
- Operations Research Union Analytics (ORUA)

The University of Waikato
- Machine Learning Group
- Information Systems and Databases Group

Victoria University of Wellington
- Evolutionary Computation Research Group

Massey University
- Data Science Lab

AUT University
- Data Science Research Group
Maori Health

The Ministry of Health of New Zealand acknowledges that Maori communities should be able to define and provide for their own priorities for health and be encouraged to develop the capacity for delivery of services to Maori communities. With this, all research efforts (specifically the health sector for the context of this report) in New Zealand relating to Maori and its subjects should consider the Treaty of Waitangi principles of partnership, participation and protection.

- **Partnership** involves working together with Maori communities (iwi, hapu, whanau)
- **Participation** requires Maori to be involved at all levels including decision-making, planning, development, and delivery of results
- **Protection** involves ensuring the equity and safeguarding Maori cultural concepts, values, and practices

This section will introduce basic level information on conducting research in New Zealand relating to Maori and provide resources such as research guidelines and government strategies. These information and resources should be considered by all potential and existing stakeholders involved in Precision Driven Health research.

Maori Health Models

A simple model for understanding the components of the Maori's holistic approach to health is explained by Mason Durie known as the four sides of Maori health -- Te Whare Tapa Wha. The Te Whare Tapa Wha consists of:

- **Physical health:** the capacity for physical growth and development
- **Spiritual health:** the capacity for faith and wider communication
- **Family health:** the capacity to belong, to care and to share where individuals are part of wider social systems
- **Mental health:** the capacity to communicate, to think and to feel mind and body are inseparable

For many Maori, modern health services lack recognition of the spiritual health.

Strategies and Guidelines

*Maori Health Strategy*

The Maori Health Strategy - He Korowai Oranga is a high-level strategy that supports the Ministry of Health and the DHBs to improve Maori health in New Zealand. The strategy states the government's vision and planned future directions for improving Maori health through partnership, participation and protection under the Treaty of Waitangi.
Guidelines for Researchers on Health Research Involving Maori

The Guidelines for Researchers on Health Research Involving Maori is for researchers undertaking biomedical, public health or clinical research involving Maori participants or research on issues relevant to Maori health. The guidelines will inform researchers about consultation and the processes involved in initiating consultation with Maori which ensures proper research practices that will effectively contribute to Maori health.

Te Ara Tika Guidelines for Maori Research Ethics

The Te Ara Tika Guidelines for Maori Research Ethics outlines a framework for addressing Maori ethical issues in research procedures and activities. Ethics has a specific role in guiding key behaviours, processes, and methodologies used in research. These guidelines serve to inform and guide research activities with regards to Maori issues to reduce potential adverse outcomes and/or experiences for participants and their communities. This framework has four main objectives:
1. to explain key ethical concepts for Maori;
2. to support decision-making around Maori ethical issues;
3. to identify ways to address Maori ethical concerns, and
4. to clarify the guardian (kaitiaki) roles of Maori ethics committee members

He Tangata Kei Tua Biobanking Guidelines

The He Tangata Kei Tua Biobanking Guidelines is a more specific set of guidelines for Maori research ethics within the context of biobanking.

Te Mata Ira Genome Research Guidelines

Te Mata Ira Genome Research Guidelines is a more specific set of guidelines for Maori research ethics within the context of Genome research.
Ethics and Privacy

Questions of ethics, privacy, and intellectual property rights are ongoing topics of concern as part of the Big Data analytics and data integration continuum.

Ethics has a specific role in guiding key behaviours, processes, and methodologies used in research. Research activities need to be conducted in an ethical manner to prevent potential adverse outcomes and/or experiences for the participants and communities involved. Currently in the area of Precision Driven Health, the issue over ethics, data privacy and ‘who owns the integrated data and how should it be used and shared’ has major concerns.

As we collate together more data and better analyse those data to personalise healthcare through means such as genetics testing and grouping, we gain clear benefits in the form of better health outcomes. However, at the same time, there are also great socio-economic impacts of gaining such knowledge. There are also data ownership concerns over usage and sharing of genetics data (and any knowledge derived from the analyses of genetics data). For a healthcare system primarily funded by private insurance, the United States of America is showing signs of private insurance companies shaping an individual’s insurance policies and premiums based on personalised health analyses such as genetic tests. The million dollar ethics and privacy question is: Should parties like your insurance company gain access to information such as your genetics testing results? The implications of revealing such information to private companies are undoubtedly major. What would happen to your insurance policy and premium when your insurance company learns of your likelihood of a rare disease discovered through genetic testing?

Suggestions for Precision Driven Health

*Infrastructure for an Integrated Data Source*

New Zealand has a large number of collected data that is currently not connected into one source. There is sufficient evidence for the likely benefits of having an integrated data source for both clinical use and research purposes. With New Zealand’s established NHI and HPI, there are already connecting points for these distributed datasets. New Zealand also has a sufficient number of world renowned research teams that can make great research usage of the integrated data source.

With the PDH partnership bringing together expertise from all disciplines and sectors, it has great potentials for expanding New Zealand’s health systems infrastructure and research capabilities with the first step of an integrated single source of data.
1-2 Larger-scale Projects
While PDH is a major initiative in New Zealand, the funding is still limited and many experts have expressed a better likely success of setting up a centralised core group of scientists, researchers, and practitioners from all involved sectors (including government, commercial and higher education) to work on 1-2 larger-scale projects. This is opposed to having PDH fund a larger number of smaller projects that have varying results. The rationale being the wide range of topics that is possible under the PDH umbrella and it is difficult to piece together the results of a large number of small projects.

New Zealand is a great testbed and a place for developing proof of concepts. There are topics and areas that are specifically promising for PDH, such as: Pharmacogenomics, haematology, individualised screening, and melanoma.

Maori and Pacific Specific Outcomes
Unlike anywhere in the world, New Zealand has a large number of Maori and Pacific populations that are prone to specific types of diseases and have different reactions towards treatments. This area is unique to New Zealand and will not be investigated anywhere else in the world except in New Zealand.

Assessment of Socio-Economic Implications of Research
While research and development surrounding PDH is promising, there are great implications of socio-economic impacts to the lives of the people involved. There are major questions regarding ethics, data privacy and ownership and the implications of these issues and decisions should be properly assessed and addressed.
Conclusion

This review identified the current state of knowledge in Precision Driven Health. The purpose of this report is to serve as the first point of reference for all involved stakeholders. This report covers a high level summary of the components related to Precision Driven Health and its primary focus is collating existing reports and resources.

In summary, New Zealand overall has various strengths such as a well-established NHI and HPI system which forms a good basis for Big Data research in the healthcare setting. There are abundant amounts of data that have been collected over the years that can be put to good use for both health delivery and research. Our unique ethnic diversity and cultural environment provide unique priorities (e.g. Maori and Pacific health and Melanoma) and our population size allows us to be a practical testbed for innovation.

Currently New Zealand is behind the rest of the world in our health IT capabilities. This is partly due to the federated governance of our healthcare system in the form of DHBs, which also create a wide variation of IT systems deployed. The health IT innovations and ICT sector in general are underfunded, which is the main cause for our low innovative technological competitiveness and capabilities compared other OECD countries.

However, the government is recognising the potential opportunities for investing in smart systems and ICT research. The potential for increased funding and a focused direction on improving our competitiveness and capabilities brings New Zealand and PDH the opportunity to progress faster and achieve the desired outcomes.

In the future, PDH should consider working towards bringing together the separated datasets across New Zealand into one integrated data source. This data source should be shared across the partnering sectors for research into better smart systems and improved health delivery and outcomes for New Zealand. Detailed assessments for the socio-economic implications and impacts of its research should be conducted. In addition, questions regarding data privacy and ownership will be ongoing and require careful consideration.
Appendix A: Resources

Reference Websites

Accident Compensation Corporation: http://www.acc.co.nz/
Centre for Brain Research:
Dunedin Study: http://dunedinstudy.otago.ac.nz/
Google DeepMind Health: https://deepmind.com/applied/deepmind-health/
IBM Watson Health: https://www.ibm.com/watson/health/
Innovative Medicines Initiative: https://www.imi.europa.eu/
Microsoft Health: https://enterprise.microsoft.com/en-us/industries/health/
NETwork! Group: http://www.network.ac.nz/
New Zealand EMRAM Assessment:
New Zealand Health IT Board: http://healthitboard.health.govt.nz/
New Zealand Institute for Rare Disease Research: http://www.nzirdr.org.nz/
New Zealand Ministry of Health: http://www.health.govt.nz/
New Zealand Pharmac: https://www.pharmac.govt.nz/
OpenFDA: https://open.fda.gov/
Oracle Healthcare:
https://www.oracle.com/industries/health-sciences/healthcare/solutions.html
Precision Driven Health: http://www.precisiondrivenhealth.com/
ProCan: http://www.cmri.org.au/ProCan
Project Masiluleke:
Seven Bridges: https://www.sbgenomics.com/biotech-pharmaceutical/
Southern Cross Insurance: https://www.southerncross.co.nz/
Taiwan National Health Insurance Administration:
Verily: https://verily.com/
Relevant Conferences and Journal

**Data Science Area:**
- Machine Learning
- Data Warehousing and Knowledge Discovery
- Transactions on Knowledge and Data Engineering
- SIGKDD Explorations
- Transactions on Knowledge Discovery from Data
- Transactions on Knowledge and Data Engineering
- AAAI Conference
- International Conference on Data Mining
- European Conference on Machine Learning / Principles and practices of Knowledge Discovery in Databases
- Knowledge Discovery in Databases
- Critical Care
- INFORMS Journals
- INFORMS Healthcare
- Winter Simulation: Health care Applications

**Health Area:**
- JMIR
- Telehealth & telemedicine
- Translational medicine
- Medicine 2.0
- Standford Medicine X
- Digital Health

**Large Initiative/Program Reports**

The Precision Medicine Initiative Cohort Program Group Report:

Genomics England and the 100,000 Genomes Project:
[https://www.genomicsengland.co.uk/?wpdmdl=5203](https://www.genomicsengland.co.uk/?wpdmdl=5203)


Personalised Health and Care 2020:
mHealth New Horizons for Health through Mobile Technologies:
http://www.who.int/goe/publications/goe_mhealth_web.pdf
Use of '-omics' Technologies in the Development of Personalised Medicine:
Improving Outcomes through Personalised Medicine:
Healthcare and Life Sciences Predictions 2020:

New Zealand Related Reports

New Zealand Health Strategy 2016:
National Health IT Plan:
National Statement of Science Investment:
Strategic Science Investment Fund Investment Plan:
A Report on a Survey of New Zealander’s Use of Smartphones and other Mobile Communication Devices 2015:
Independent Review of New Zealand’s Electronic Health Records and Strategy:

Maori Interest Reports

Guidelines for Researchers on Health Research Involving Maori:
He Korowai Oranga: Maori Health Strategy:
Te Ara Tika Guidelines for Maori Research Ethics: A Framework for Researchers and
Ethics Committee Members:

He Tangata Kei Tua Guidelines for Biobanking with Maori (not available publicly yet? – published OCT 2016):

Te Mata Ira Guidelines for Genomic Research with Maori (not available publicly yet? - published OCT 2016):
https://www.dropbox.com/s/3cr9impojwncc8/Te%20Ara%20Tika%20Guidelines%20for%20Maori%20Research%20Ethics.pdf?dl=0

Relevant Research Publications

Going Digital: A Survey on Digitalization and Large-Scale Data Analytics in Healthcare:

Mapping the Translational Science Policy 'Valley of Death':
http://www.clintransmed.com/content/2/1/14

Data Mining with Big Data:

Manuals and Policies

Frascati Manual 2015:

Health Information Privacy Code 1994: