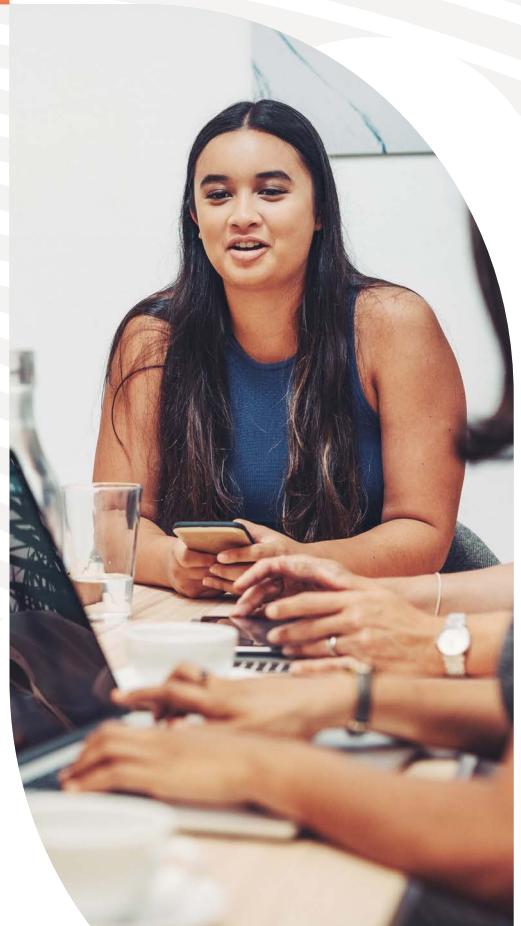
PRECISION DRIVEN HEALTH

Better Health Through Data Science

Partnership Report 2016–2023

This report summarises the activities of the Precision Driven Health partnership from 2016 to 2023.



A joint venture between:

ORION HEALTH

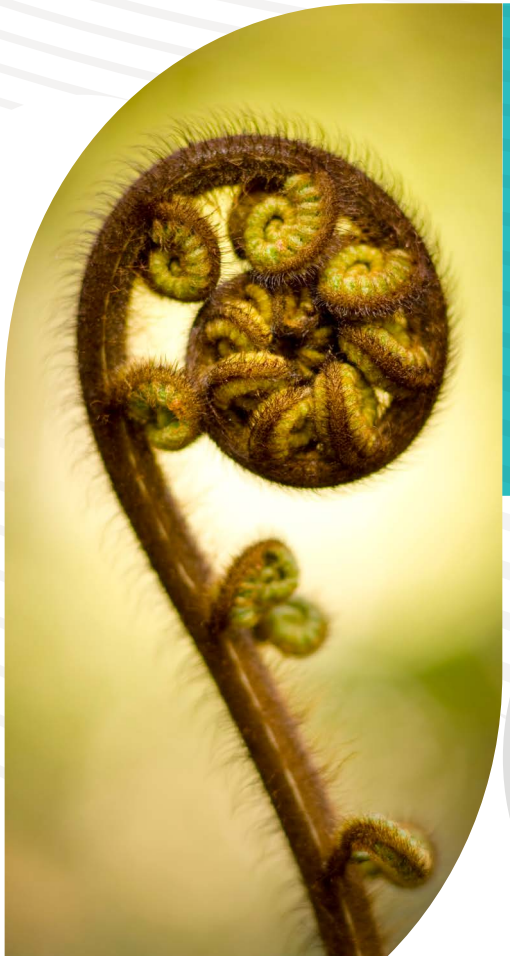
UNIVERSITY OF AUCKLAND
Waipapa Taumata Rau
NEW ZEALAND

Te Whatu Ora
Health New Zealand

MINISTRY OF BUSINESS, INNOVATION & EMPLOYMENT
HĪKINA WHAKATUTUKI

Contents

01 Precision Driven Health



Precision Driven Health (PDH) is an award-winning partnership between Aotearoa New Zealand's health information technology (IT) sector, health providers and universities, aimed at improving health outcomes through data science.

About PDH

PDH seeks to increase data science capability in New Zealand's health sector and encourage innovation in the use of health data.

Operating since 2016, PDH is an unincorporated joint venture between Orion Health, Te Whatu Ora Waitematā (previously Waitematā District Health Board) and Waipapa Taumata Rau – the University of Auckland.

PDH aims to improve the health of New Zealanders and their whānau through world-leading data science research in precision health.

The organisation fills a gap in New Zealand's landscape of health research, data science, and innovation funding by supporting commercialisable research, playing several key roles in the health data science system in New Zealand:

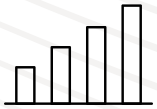
1. Investing in research activities through on-demand and contestable funding mechanisms available to researchers who are specifically targeting commercialisable research solutions
2. Supporting workforce development through scholarships at undergraduate, postgraduate, and postdoctoral fellowship levels
3. Facilitating research collaborations between commercial organisations, health sector entities, Māori health organisations, and academic institutions
4. Advising researchers and organisations on how to undertake ethical research with appropriate use of data
5. Providing sector leadership in health data science through interactions with Manatū Hauora Ministry of Health, Health Informatics New Zealand (HiNZ), The Digital Health Association (DHA) (previously NZ Health IT [NZHIT]), the AI Forum of New Zealand, and other groups.

PDH receives 37% of its funding through the Ministry of Business, Innovation and Employment (MBIE) Partnership Scheme. This funding spans from 2016 until 2023.

PDH is investing $38 million in this programme where for each activity, health partner organisations can utilise the findings, and a New Zealand entity owns the commercial rights to any resulting intellectual property (IP).

As of late 2022, PDH has helped to support over 300 researchers on more than 100 research projects involving over 45 organisations. This report outlines some of the outcomes and lessons from this research programme.

$38m
invested



100+
projects

300+
researchers

Board Chair report

Precision Driven Health (PDH) was established on the potential in our digital health technology sector, with the emergence of data science as a discipline to transform knowledge and care.

It was seen as timely to bring together the data science leadership in our universities and apply new techniques to health, where we have increasingly recognised the relevance of new data, such as genomics and social determinants, with the potential to inform and transform healthcare.

As an independent chair, I have been able to view the tripartite nature of the partnership – with founding parties providing leadership to their respective sectors. I'd like to acknowledge Orion Health, Te Whatu Ora Waitematā (formerly Waitematā DHB) and Waipapa Taumata Rau – the University of Auckland for their leadership in the commercial, health and academic sectors.

The partnership would not have formed, and later thrived, without the commitment of all three, and they all took their role as sector leads to be inclusive – as evidenced by the range of partners who have ultimately participated in the projects undertaken. PDH won at least one seminal award in each of the three sectors which highlights the contribution by our researchers and leaders.

The partnership has also contributed to the leadership of the New Zealand health system, including Juliet Rumball-Smith's clinical directorships within the Ministry of Health and Chad Paraone's elevation to Acting CE of Te Aka Whai Ora – Māori Health Authority.

PDH CEO Kevin Ross' significant contributions to the New Zealand health sector's data and digital area were recognised in 2021 when he was made a Fellow of Health Informatics New Zealand (FHiNZ), and was appointed to the Digital Council for Aotearoa.

PDH has helped build substantial new capability in health data science within commercial organisations, including Orion Health, MoleMap, Kāhu, Te Whānau o Waipareira, Groov, Atlantis Health and Vensa Health.

Two generation-defining events coincided with this programme that promised to disrupt our plans. On 16 June 2020, Heather Simpson published the Health and Disability Systems Review that led ultimately to a reform of the health system taking effect from 1 July 2022. That same period saw the COVID-19 pandemic sweep the world and bring health, and health data especially, to the public consciousness like no other events before.

With the pandemic, our clinical research staff prioritised the preparation and delivery of care. Our commercial partners also faced unprecedented uncertainty, and needed to focus people and finances on immediate needs ahead of research programmes. These abrupt changes paused or cancelled a number of key initiatives, right at a time when they were gaining momentum.

PDH, with strong support from MBIE, had to rethink plans and turn challenges – volatility and highly constrained resources – into opportunities. The focus became to demonstrate the value of good data science in our health sector, delivering on its promise at an accelerated pace through the provision of technology, capability and leadership. The leadership shown through uncertainty should not be underestimated, especially evident through COVID-19 risk modelling and national algorithm management.

Having laid a strong foundation through this partnership, we hope and expect to see New Zealand continue to invest and grow in health data science. This promises to bear fruit in both health outcomes for citizens and economic growth for the country for many years to come.

Terry Moore
Independent Chair
Precision Driven Health
November 2022

CEO report

When we first gathered the founding partners of PDH, it was clear that this would be a unique partnership.

While these partners each brought their own vision and objectives to the table, any tension this created ultimately led to greater individual and collective success.

Better Health Through Data Science highlights the range of contributions that have resulted from bringing together high-performing people and organisations, and focusing on common goals.

The PDH partnership has been incentivised by the MBIE Partnership programme, which provides co-investment to stimulate an increase in Aotearoa New Zealand's productivity. It is satisfying to reflect that in exceeding this goal, the partnership has also contributed substantially to the wellbeing of New Zealand citizens.

You will read dozens of names of individuals and organisations through this report, that represent a sample of the outstanding contributors to both the partnership itself, and more broadly New Zealand's emergence as an exemplar for good health data science. I use the word good in every sense – both of the highest quality and more importantly, driven by values.

From students to executives, public servants and private sector operators, I have observed and experienced an absolute commitment to do the right thing to enable meaningful change, and to ensure that people remain at the heart of any data initiative.

Our proudest achievements have happened without fanfare. People have discovered new careers and gone on to further study, data scientists have worked in health for the first time, and clinicians have discovered the power of data science to inform their practice. Citizens are far more informed and far more engaged with their health data, and will push the sector to modernise its approach to consent, data sharing, and the use of artificial intelligence.

All of these achievements have been possible because of a remarkable team. My core leadership team has included Chad Paraone, Fleur Armstrong, Gill Dobbie, Greg Balla, Juliet Rumball-Smith, Kelly Atkinson, Mark Capill, Michael Witbrock, Nigel Millar, and Simon Clark, whose fingerprints are on all of this mahi.

Behind us all the way has been a passionate Independent Advisory Group and a supportive Governance Board. My personal thanks go especially to chairs David Clarke, Gregor Coster and Terry Moore.

At a time when health data science is just starting to move from potential to reality, and people throughout society are recognising the positive and negative impacts of collecting, analysing and utilising personal health data for personalised health care, we have the opportunity to reform our health system, our research ecosystem, and our digital health industry.

We are hopeful for a future that embraces the collaboration model that has been created here.

Kevin Ross
Chief Executive Officer
Precision Driven Health
November 2022

Our priorities

Vision

Empowering data driven precision health

Mission

The Precision Driven Health Partnership is creating the capability to optimise the health of each individual and their whānau by combining and learning from all available data.

This will improve health outcomes for New Zealanders, increase health provider efficiency, and enable commercial success.

Principles

- Our scientific research achieves clinical and commercial domain successes, and benefits Māori
- Projects have global commercial prospects and will be supported through to realising outcomes and benefits
- We build upon current and previous successes without duplicating other New Zealand work
- We draw on mātauranga Māori and te ao Māori to inform our partnership
- Our research follows ethical principles around privacy and equity
- We grow research capability and co-development between clinical and commercial partners

Research themes

The partnership addresses four key themes to enable our mission to become a reality:

New data sources
Broaden the scope of precise, patient-centred healthcare by making new data sources available.

Predictive analysis
Utilise a variety of big data sources for predictive modelling in a healthcare setting.

Precise and timely healthcare
Utilise disparate data sources, analyses, and technologies to enable more precise and timely healthcare.

Empowering people
Leverage technology to empower all people to self-manage their health.

Timeline

EARLY 2015 – Idea germinated

Orion Health recognises the potential to integrate data science capability within its products. Parallel opportunity in the health sector with the emergence of technology and desire from the wider data science community for translation of research and fostering of talent

LATE 2015

MBIE & Orion Health commit to funding partnership

APR 2016

PDH partnership established, with Kevin Ross appointed to lead partnership. Board Chair David Clarke, IAG Chair Gregor Coster appointed

JUN 2016

Research Theme Leaders appointed; initial call for research proposals

OCT 2016

First projects (nzRISK, AAA screening and Stroke outcome prediction) announced by Minister Steven Joyce at launch event

NOV 2016

First PDH summer scholarship programme opens
First international presentation

EARLY 2017

Establishment of Commercial Director and Clinical Director roles

JUL 2017

PDH wins the KiwiNet MinterEllisonRuddWatts Research & Business Partnership Award

SEP 2017

First not-for-profit partner – Cure Kids

FEB 2018

Terry Moore appointed as Board Chair

JUL 2018

Establishment of Māori Health Director role, appointment of Chad Paraone

SEP 2018

First external commercial partner – Vensa Health

NOV 2018

First Māori partner – Navilluso Medical

LATE 2018

PDH-HRC Postdoctoral Fellowships established with first award to Dr Rosie Dobson

AUG 2019

Mid-term review brings international and national expertise

NOV 2019

A record number of presenters at the Digital Health Week conference event are PDH researchers

EARLY 2020

PDH researchers support the nation's COVID-19 response through data modelling

JUN 2020

Final report released on the findings of the Health and Disability System Review

AUG 2020

PDH researchers win the Visa Best Hi-Tech Solution for the Public Good Award

APR 2021

PDH researchers are part of the team winning the Prime Minister's Science Prize 2020

EARLY 2021

PDH works with MartinJenkins to propose several models for its work beyond 2023

JUL 2022

Health sector reforms change the clinical landscape of New Zealand

LATE 2022

Initial release of *Better Health Through Data Science* PDH Partnership Report

Organisations

This partnership has united more than 45 organisations, including health providers, universities and the health IT sector to create health and commercial opportunities for New Zealanders, including:

A Better Start National Science Challenge
Artificial Intelligence Forum of NZ (AI Forum)
Atlantis Health
Auckland University of Technology
Clinithink
Cure Kids
DermNet New Zealand
Digital Health Association (formerly NZHIT)
Entelect Software
Groov
(formerly Mentemia)
The Health Research Council of NZ
healthAlliance
Healthier Lives National Science Challenge
HealthStat
Hue Software
i-SENS
IBM Research
Kāhu.ai
Manatū Hauora Ministry of Health
Manawanui
Massey University
MiMar LP
Ministry for Business, Innovation and Employment
MoleMap NZ
Monash University
National Institute for Health Innovation
Navilluso Medical
New Zealand Telehealth Forum
Nicholson Consulting
NZ Analytics + Data Science Forum
oDocs Eye Care
Orion Health
Pharmaco NZ
Te Pae Hauora o Ruahine o Tararua MidCentral
(formerly MidCentral District Health Board)
Te Whānau o Waipareira
Te Whatu Ora Counties Manukau
(formerly Counties Manukau District Health Board)
Te Whatu Ora Southern
(formerly Southern District Health Board)
Te Whatu Ora Te Tai Tokerau
(formerly Northland District Health Board)
Te Whatu Ora Te Toka Tumai Auckland
(formerly Auckland District Health Board)
Te Whatu Ora Waitaha Canterbury
(formerly Canterbury District Health Board)
Te Whatu Ora Waitematā
(formerly Waitematā District Health Board)
Techwondoe
University of Canterbury
University of Otago
University of Waikato
Vensa Health
Waipapa Taumata Rau – the University of Auckland

Awards and recognition

PDH has won several national research and industry awards which are testament to the quality and impact of the research PDH is supporting. These include:

Prime Minister's Science Prize 2020

Winner, Prime Minister's Science Prize

The premier award for science that is transformational in its impact – as part of the Te Pūnaha Matatini COVID-19 response modelling team (six PDH members named).

Read more about this on page 17.

NZ Hi-Tech Awards 2020

Winner, Best Hi-Tech Solution for the Public Good Award

For the partnership's freely accessible surgical risk calculator, nzRISK. The Visa Hi-Tech Solution for the Public Good Award recognises innovation focused on improving the lives of the people it serves.

Read more about this on page 16.

KiwiNet Research Commercialisation Awards 2017

Winner, MinterEllisonRuddWatts Research & Business Partnership Award

This award recognises the deeply embedded working relationship between a research organisation and business that delivers significant commercial value for New Zealand.

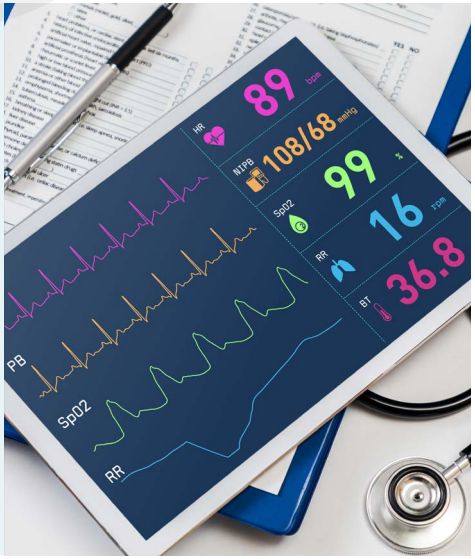
Participants in the PDH partnership were also named as finalists in the New Zealand IT Professional of the Year awards in a number of categories in 2021 and the NZ Hi-Tech Awards in 2021 and 2022.

02 Our Mahi

Precision Driven Health supports research collaborations in health data science.

We have supported activities, including:

- Projects and programmes initiated by the research community, our partners, or other organisations
- Scholarship and fellowships which allow students and postdoctoral researchers to explore precision health research through the partnership
- Events to bring together the health data science community
- Publication of research, opinions and guidelines



Our research programme delivers results across a number of areas:

Health impact
An ability to make a difference to the healthcare of individuals, whānau or populations.

Māori advancement
The potential to improve the health outcomes and capabilities of Māori.

Scientific progress
Robustly moving the boundaries of knowledge and possibility.

Commercial potential
Leading to commercialisable tools and discoveries, and for which we can see a path to sustained commercial return to our partners.

Benefit to New Zealand
Contribution to the New Zealand economy and health system.

This partnership report details successes that PDH has facilitated since it was formed in 2016, covering:

OUR VISION FOR PRECISION HEALTHCARE

Precision healthcare is about delivering the right care, to the right person, at the right time through data science – but how has it been applied in New Zealand, and what is the PDH partnership hoping to achieve by pursuing it?

TECHNICAL ADVANCEMENTS

The PDH partnership has helped develop data science knowledge and techniques which are tuned to New Zealand's unique characteristics. What are these techniques, why are they important, and how will they be built on?

DEVELOPING CAPABILITY

How has the PDH partnership helped develop the capability of partners and academics, and grown New Zealand's health data science capability?

ENGAGING APPROACHES

How has the PDH partnership supported holistic, ethical research that will have a meaningful impact and deliver an equitable, wider social good?

PUTTING RESEARCH INTO PRACTICE

What has the PDH partnership learned that helps translate research ideas into real-world use, and what tools has it developed?

OUR VISION FOR PRECISION HEALTHCARE

What is precision healthcare?

Put simply, precision healthcare is about delivering the right care, to the right person, at the right time.

Kevin Ross, PDH CEO, says precision health is leading the healthcare sector towards "the ability to take into account every piece of data known about someone, in order to give them exactly what they need."

"There's a nirvana that precision health is aiming for; a patient comes to you; you've got access to all of the data about them; and you use that to both specifically give them the advice that they need, and not waste time and resources on things that will clearly not work for them. The 'precision' piece is about being quite specific."

This is in contrast to the population health approach – which is aimed at improving the health of an entire population, based on knowledge about what generally works for most people.

The PDH partnership has developed precision health models, tools and algorithms focused on improving screening, triaging patients and surgery, in an attempt to bring greater precision into treatment.

Screening

Under the population health approach, screening tests are often carried out on people who don't have any symptoms but are perceived to be at risk of a particular disease.

Traditionally, screening isn't tailored to a person's specific risk factors – it's a 'one size fits all' approach, where all patients in an age group or demographic are treated the same way.

The PDH partnership has facilitated a number of developments in screening, including for abdominal aortic aneurysms (AAA), common eye diseases and skin cancers.

AAAs are caused by a weakness in the wall of the main artery leaving the heart and generally occurs in people over 65. While other countries, such as the UK, screen their entire population at a certain age, New Zealand does not have a standard screening programme as it is not seen as cost-effective.

Māori are nearly three times more likely to have an AAA than non-Māori. An innovative data analysis project supported by PDH helped identify and save patients with AAA, demonstrating the potential of using data and machine learning to prioritise screening for those most at risk.

Applying screening in a more personalised way using available data will increase the chance of identifying AAA early, helping to better prioritise screening resources and save lives for those most at risk.

Triaging

A number of PDH research projects have also aimed to improve the triaging process, providing patients with better access to specialists for those that need it most urgently.

Triaging focuses on people who have already presented to their doctor with some form of concern or risk. With limited resources and specialists available, making sure the right people are being seen in the right order, and enabling specialists to spend their time with patients rather than reading about them, is important.

This was the focus of PDH's project to develop a Deep Learning Platform for GP

Referral Triage, which aimed to address inequities in cardiovascular care by improving the triage process.

The triage process may see some patients with lower need being accepted for a hospital clinic appointment, moving those more in need further down the queue.

Little research had been done to improve the triaging process in New Zealand using deep and machine learning techniques. This is partly due to the challenging nature of working with electronic GP referrals in New Zealand, which contain both structured and unstructured (free text) data.

To help address this, PDH put deep learning to use to analyse the process of triaging GP referrals to cardiologists – a time-consuming task for doctors in New Zealand, who may commonly spend more than 10 hours per week on triaging referrals to various risk categories or 'direct to investigation' tests.

As with screening, this project is helping to target care towards people who have higher risks. You can read more about it on pages 26–27.

Another PDH-supported project centred on triaging developed an emergency department triage model to help address ED overcrowding by optimising existing resources, which you can read more about on page 17.

Surgery

The next step in a patients' potential journey following screening and triage is surgery. Surgery requires significant resources which are in high demand, including surgeons and theatres. Combined with a backlog in surgeries, there is a need to prioritise the order of who has surgery when.

Dr Michael O'Sullivan Senior Lecturer, Engineering Science, University of Auckland says: "Fundamentally, you're wanting to balance the priority level for surgery and the utilisation of key resources with the consequences of over-utilised surgical sessions.

"You don't want patients waiting too long for surgery or surgical teams being under-utilised, but last minute cancellations and surgical teams working overtime aren't good outcomes either. These adverse events can be disruptive and disheartening for patients, cost money and surgeons working too long is not good for anyone."

To help address this, a PDH-supported project conducted by Dr Thomas Adams has developed software that schedules elective surgical sessions quickly, and in a way that reduces the chances of the sessions running overtime. You can read more about Thomas' experience on pages 24–25.

Kevin Ross says PDH's work on screening, triaging and surgery projects advances the aim of precision health, "to make sure people are getting the care they need, that's specific to them, as efficiently as possible."

"From the point of view of a patient, you want to make sure you're getting advice that's personal to you. It's the same thing for a clinician; you want access to the latest information and give the best advice."

"The system obviously wants to be efficient at getting the right care to the right people at the right time. Because overall, that gives good health outcomes at a better cost.

"We've started this journey, and we've made good progress – which you will read about in this report. But we're only scratching the surface of the potential of precision health – there's a lot more to be done."

"You don't want patients waiting too long for surgery or surgical teams being under-utilised, but last minute cancellations and surgical teams working overtime aren't good outcomes either. These adverse events can be disruptive and disheartening for patients, cost money and surgeons working too long is not good for anyone."

Dr Michael O'Sullivan
Senior Lecturer, Engineering Science, Waipapa Taumata Rau, the University of Auckland

TECHNICAL ADVANCEMENTS

Reflecting Aotearoa's unique population

Tuning models

Healthcare is increasingly informed by data, but often data used in research to drive medical practice is based on overseas populations. That means the majority of data-driven innovations are unproven for local conditions, and could struggle to deliver benefits to New Zealanders.

Tools are also often finely tuned to European and American populations, which makes them more likely to work for Pākehā New Zealanders, therefore potentially increasing inequities.

Risk calculators and models can help patients and clinicians assess risks related to health outcomes, or a potential course of treatment. For risk to be accurately predicted, the data used to create these calculators and models needs to reflect the local population and context.

New Zealand clinicians and decision makers have previously relied on risk assessment tools that weren't locally tailored. Research by PDH in an Algorithm Scan project reviewed use of algorithms and risk calculators in Aotearoa New Zealand, finding that many of the tools in use have not been locally validated or are viewed as unreliable.

Other PDH research projects have taken steps towards addressing this, tuning models to New Zealand's population and context, to help more accurately assess risk. Read more about the Algorithm Scan on page 36.

nzRISK – surgical outcomes

New Zealand clinicians have previously had to rely on risk assessment tools that are based on a small number of patients' data from either the UK or USA, and many of which have been in place for up to 30 years. These tools weren't tailored to New Zealand, and tended to underestimate the risks for our Māori and Pacific populations especially, who experience a higher risk of death or extended hospitalisation following surgery.

To achieve better health outcomes for Māori and New Zealand's other high-risk populations, Dr Doug Campbell of the Department of Anaesthesia at Auckland City Hospital set out to develop a surgical risk calculator in 2017 through the PDH partnership, working with Orion Health researcher and University of Auckland student Luke Boyle.

The result was nzRISK, an easy-to-use online risk calculator that allows for a more informed decision-making process. Patients and clinicians can use nzRISK to enter risk factors including age, gender, ethnicity and the procedure they're having to get a 30 day, one- and two-year estimate of mortality.

nzRISK has been created using data from over 270,000 New Zealand patients undergoing non-cardiac surgery. This local data gives New Zealanders the information they need to inform their

decision making. This has included working alongside Taia Te Hauora, a University of Auckland, Waipapa Taumata Rau Māori research advisory group, to ensure a Māori health lens is applied. Learn more by visiting nzrisk.com.

The calculator is being used by New Zealand clinicians, and was recognised at the NZ Hi-Tech Awards in 2020 where it won the Best Hi-Tech Solution for the Public Good Award.

COVID-19 modelling

The COVID-19 pandemic called on many of New Zealand's brightest minds to help address one of the greatest health challenges our country has ever seen.

Amongst those who answered the call was Te Pūnaha Matatini, a Centre of Research Excellence funded by the Tertiary Education Commission and hosted by the Waipapa Taumata Rau, the University of Auckland.

The Te Pūnaha Matatini COVID-19 modelling team brought together researchers and experts from across academia, Crown Research Institutes and industry, and included Orion Health and PDH data scientists Pieta Brown, Dr Ning Hua and Dr Kevin Ross, as well as PDH advisors Dr Michael O'Sullivan, Professor Shaun Hendy and Andrew Sporle.

The team was recognised for their tireless work in developing mathematical models, analysing data and communicating the results to inform the New Zealand Government's response to the global pandemic. The results of this work were translated for Government policymakers and front-line operators.

This included using Te Pokapū Hātepe o Aotearoa, the New Zealand Algorithm Hub, which was created through PDH to deploy and operationalise COVID-19 models in New Zealand. This Orion Health technology provided a platform to share the latest findings from research and practice for operational use, with the modelling helping the Government in its decision making on lockdowns. Read more about this research on page 35.

These public health interventions have had an immense impact on New Zealanders' lives, preventing a considerable number of deaths if the virus had been allowed to spread.

Prime Minister Jacinda Ardern recognised the significant work of this group too, awarding Te Pūnaha Matatini the prestigious 2020 Prime Minister's Science Prize for their contribution to Aotearoa New Zealand's globally-lauded COVID-19 response.

Readmission risk and ED triage model

Patients being readmitted to hospital in avoidable situations, and overcrowding in emergency departments (ED), impact the quality of healthcare worldwide, and contribute to high costs. PDH-funded projects are helping contend with these issues in New Zealand, developing local models where overseas models were previously relied on.

Electronic health records (EHR) provide an opportunity to apply predictive modelling to identify patients with high risk of hospital readmission, and apply effective interventions to mitigate that risk for New Zealand patients.

A PDH project aimed to deliver this by creating two machine learning-based predictive models – for the post-discharge risk of readmission and the post-admission risk prediction – using data from Te Whanau Ora Waitematā.

It's evident that these models, trained using local data, perform better in New Zealand in comparison to international tools and risk scores for readmission, such as LACE from Canada and PARR from the UK.

To help address emergency department overcrowding, which has well-established consequences for patients (poor outcomes), staff (stress) and the healthcare system (long length of stay), optimising existing resources is important.

A PDH-supported study is aiming to help achieve this by developing a decision support system using routinely collected data. This system has the potential to reduce length of stay and lower hospital admission rates, by accurately identifying high-risk patients who present at an ED, and prioritising care for them.

If this can be achieved, this decision support system can be widely used by ED triage assessors in the near future, with the potential to improve the quality of acute care and better utilisation of clinical resources.

TECHNICAL ADVANCEMENTS

Seeing the real picture

Images play an important role in medical diagnostics, and machines are increasingly capable of matching human accuracy in detecting abnormalities.

Image processing

Using automated technology to analyse images – otherwise known as image processing – has the potential to change the way clinicians work, with PDH partnering with New Zealand organisations to help realise this opportunity.

Image processing in healthcare has centred on developing algorithms and software that can analyse medical images of patients – for example, from Computed Tomography (CT) or Magnetic Resonance Imaging (MRI). A number of New Zealand companies are making good progress in this potentially game-changing field.

Two such companies are Kāhu, an Auckland-based company developing artificial intelligence (AI) technology for detecting skin cancers; and oDocs Eye Care, a Dunedin-based company which has produced products and software platforms that are disrupting the inequities in eye care globally.

Kāhu

Kāhu aims to develop image processing technology that makes healthcare more accessible, with PDH supporting its work developing artificial intelligence (AI) technology for detecting skin cancers.

Skin cancer is one of the more common forms of cancer worldwide. It's particularly prevalent in New Zealand, though, which has the highest rate in the world with nearly 400 New Zealanders dying each year from skin cancer. Studies indicate that early detection could have greatly improved the chance of survival in the majority of cases.

Kāhu – which is a sister company of MoleMap, a network of skin cancer clinics across Australia and New Zealand – is aiming to play its part in early detection. GP clinics will be able to offer patients early, low-cost access to skin lesion checks through an artificial intelligence clinical decision support tool that gives clinicians more information about skin lesions.

Kāhu is partnering with PDH to build tools based on MoleMap's research on skin lesions. This research project will enhance Kāhu's AI algorithm, which leverages MoleMap's world-leading database of high-quality dermatological images. The AI differentiates cancerous skin lesions from benign lesions, and prioritises lesions which need to be reviewed by a dermatologist.

A key focus of this work is about the new application of data science techniques to advance Māori health outcomes. You can read more about this on page 29.

oDocs Eye Care

Early treatment is vital in preventing some common eye diseases from causing permanent vision loss or blindness. oDocs Eye Care is aiming to play its part to end preventable blindness by making eye care more accessible and affordable.

Since launching in 2014, oDocs Eye Care's achievements include fighting blindness with $20 and a smartphone through creating the world's first open-source smartphone retinal imaging adapter.

More recently, the company has introduced the CureMyopia programme, which aims to reduce progression of myopia (otherwise known as short-sightedness, the most common refractive error).

Humans perceive up to 80 percent of all impressions by means of our sight, making it one of our most important senses.

Across the world however, visual impairment is widespread. It's estimated that a person goes blind every five seconds, while 2.2 billion people are visually impaired and forty-two percent have an uncorrected refractive error.

A refractive error is a very common eye disorder which occurs which can cause blurred vision. Severe cases can cause visual impairment.

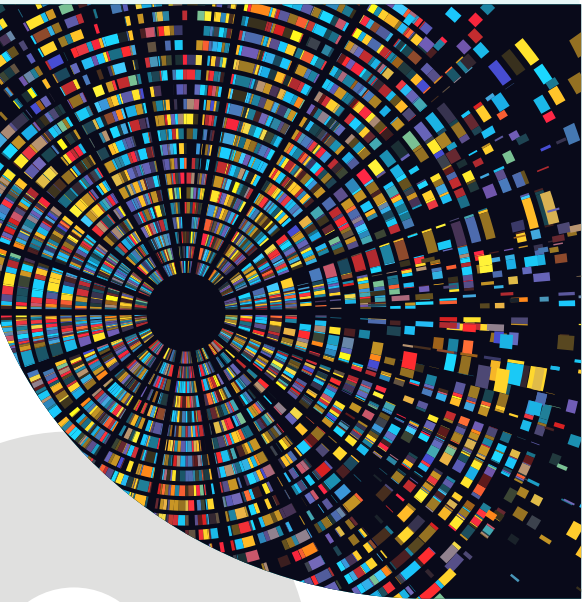
In New Zealand alone, 180,000 people have severe to moderate functional vision loss, while the total cost of vision loss in New Zealand according to Blind Low Vision NZ was $3.74 billion in 2021 – an increase of 33.6% since 2009. Māori and Pasifika are also more likely to suffer visual impairment.

PDH partnered in oDocs Eye Care's CureMyopia research programme, focusing on machine learning to look at refractive error detection using smartphones. oDocs Eye Care leads this programme which also includes activities at the University of Otago and the Choithram International Foundation in India.

oDocs Eye Care is capturing red reflex images taken as part of a non-invasive test used to estimate refractive error, and developing an AI-based system to see if myopic progression can be detected using these images. This technology could be used to reach those in rural areas, as well as developing countries who don't have ready access to specialised equipment.

With support from PDH, oDocs Eye Care is aiming to bring care directly to patients so they don't have to travel to see an optometrist with specialised equipment to receive these tests. This innovation provides vital support in Aotearoa New Zealand, and abroad, to address vision issues early and inexpensively.

TECHNICAL ADVANCEMENTS



Searching for meaning in free text

Applications of Natural Language Processing research

Some of the most important and insightful information about patients is found in 'free text' notes exchanged within the health sector. A referral letter, a note to the laboratory, or a discharge summary, for example, will often highlight unique or pertinent facts about a patient.

However, using technology to interpret this text, and extract insights from this information, isn't straight forward.

Health data exists in many forms, ranging from structured data – a patient's age, weight or height, or numerical values from device or medical test results – to unstructured data, including images, videos, and free-form text fields and clinical notes.

Unstructured data (free text) represents up to 80% of all healthcare data. While it is relatively straightforward to analyse structured data (which is often quantitative), for unstructured data, a different, technology-based approach is needed.

To help achieve this, PDH has supported a number of research projects in a fast-developing area known as Natural Language Processing (NLP) – a form of machine learning that allows text such as that found in electronic health records to be processed and analysed.

Through NLP, written and spoken language is converted to a form a computer can read and understand. NLP uses artificial intelligence to analyse real-world inputs and present them in a form where clinicians can find out information they need about a patient or population, without having to undertake manual searches.

One such tool developed to tackle this is Smart Coder, developed through the PDH partnership to convert unstructured text into structured, codified content linked to standardised international medical dictionaries, so that focused clinical insights can be extracted.

Research to create Smart Coder involved a multidisciplinary team from Te Whatu Ora Waitematā, Waipapa Taumata Rau – the University of Auckland, the University of Waikato, and Orion Health. You can read more about Smart Coder on page 37.

PDH-supported research projects have leveraged Smart Coder's capability and used it in different contexts. These include Smart Search, at an individual level; Smart Patient Cohort Builder, at a population level; and Patients Like This, where population level information is applied to an individual.

Smart Search

Accessing important information about individual patients can be time consuming, but Smart Search – a search engine for EHRs – allows for real-time searching of an individual patient's record.

With patient data captured in many different ways – including clinical notes, clinic letters, discharge summaries and diagnostic reports – and clinical concepts often described inconsistently across different records, finding important information can be time consuming.

Smart Search, which has been developed by Orion Health, Te Whatu Ora Waitematā, the University of Waikato and Waipapa Taumata Rau, the University of Auckland, aims to address this, starting with the idea that clinicians should be able to look across a single patient's record, rather than having to search across multiple documents.

The benefits of Smart Search include time saving, improved productivity and ability to find information easily. Access to faster and more incisive search results may mean clinicians are less likely to order duplicate and expensive tests.

Automated clinical coding of discharge summaries could also provide hospital administrators with the ability to identify resource gaps.

Smart Search creates a structured representation of the text that's being searched. This provides the potential for Smart Search to be used to display a 'snapshot' dashboard of a patient and their conditions. Smart Search has been evaluated by clinicians on local data.

Smart Patient Cohort Builder

While Smart Search is a NLP solution for individual patients, PDH has also supported projects that provide potential NLP solutions at a group, or population, level.

Smart Patient Cohort Builder is an Orion Health-developed machine learning and NLP software tool, built on the Smart Coder technology. It uses unstructured and structured patient data to identify groups of patients that share specific clinical criteria.

It is then able to build a 'cohort' – a group of people with a shared characteristic – which can be recruited to take part in clinical trials, effectively managing what can be a very labour-intensive, manual process.

The functionality of Smart Patient Cohort Builder has received a positive response from clinicians and academic researchers alike. The tool deployment within a clinical organisation enables tests of the functionality on real-world data, and usability tests with representative users.

Patients Like This

Patients Like This is an example of a PDH-supported NLP solution that uses information from a population level to help inform an individual, comparing them to other patients who have the same disease but variations in other health factors.

While the Smart Patient Cohort Builder enables clinicians to find a group of patients who share specific characteristics, the Patients Like This project aims to support clinicians and individual patients in their decision making. This project includes a wide multidisciplinary team from Te Whatu Ora Te Toka Tumai Auckland, Orion Health, and independent clinical research advisors.

Patients Like This is centred on developing and evaluating an algorithm-based approach for determining the 'similarity' between patients, based on various user-specified attributes, captured in the patients' EHRs. This patient similarity measure can then be used for finding 'similar' patients in a population.

This project aims to create an interactive dashboard that displays a "progression of disease" trajectory of similar patients (within a certain timeframe). It will also be able to display an adjusted progression trajectory in real-time by updating different variables, such as treatment plans, lifestyle choices and medications.

DEVELOPING CAPABILITY

Fostering data science in Aotearoa

Developing capability with partners

PDH fills a number of key roles in New Zealand's burgeoning health data science system, but one of its most important functions is developing local data science capability within New Zealand technology companies.

Through its research programme, PDH has encouraged investment in data science, and served as a 'connector' between commercial organisations, health sector entities, Māori health organisations, and academics.

PDH has also helped facilitate partnerships between a wide range of organisations, bringing together academics, data scientists, software engineers and clinicians to work on multidisciplinary research projects.

Through this approach, PDH has enabled research to be conducted with groups who don't often collaborate, and widened research networks for clinicians, academics and entrepreneurs.

Encouraging investment in data science

One of PDH's most important areas of influence has been supporting New Zealand companies to invest in capability in data science research and development (R&D). This has been enabled through the MBIE Partnership programme, which provided proportional matching funds for R&D investment.

PDH has helped many New Zealand companies develop their data science capability, including Orion Health, Groov, Atlantis Health, Te Whānau o Waipareira, MoleMap and its subsidiary/spin-off Kāhu, Vensa Health, and oDocs Eye Care.

Groov (formerly known as Mentemia), which has created a platform that helps workplaces embed wellbeing with their organisations, is one example of an organisation which has developed its data science capability since working with PDH.

According to Groov, working on a project with PDH helped formally establish its data practice, and prompted the recruitment of a dedicated data engineer. Working alongside experienced data scientists has helped upskill Groov staff in data science, and given the company more confidence to execute data science projects in the future.

Tertiary links

PDH has also linked many of its partners with universities, pairing them with academics and students to help them realise how data science can help their organisations solve problems and capitalise on a range of opportunities.

An example of this in action can be seen with Atlantis Health, a New Zealand-founded company that has a global presence.

Atlantis Health – which develops and delivers behavior change solutions for healthcare and life sciences organisations around the world – worked with PDH to identify and place a data science student from Auckland University of Technology (AUT) within the organisation.

After seeing the value that the student's skill set provided, Atlantis Health subsequently created a role for the student to join them as a permanent data scientist.

Connecting data scientists

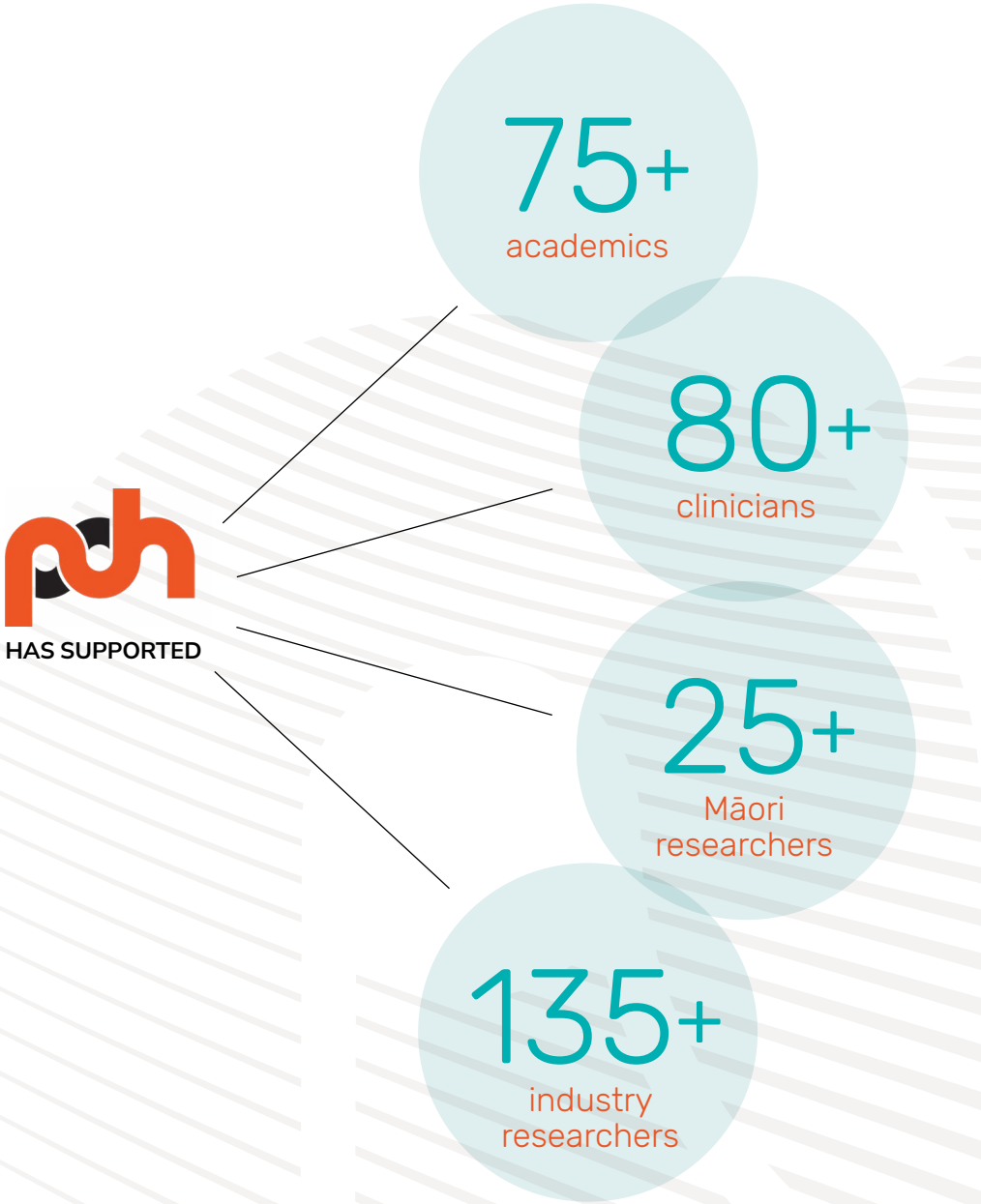
PDH has provided a network for data scientists across New Zealand to connect with and learn from their peers, putting researchers with similar interests in contact through initiatives like PDH 'Research Days'.

Research Day events bring together researchers working on PDH projects to present and discuss their research. Researchers can also seek advice and meet with the PDH leadership team and peers who may be working in similar areas during these days, which are held up to twice a year. Guest speakers are also invited to present on relevant data topics, such as ethics and data management.

PDH also raises the profile of health data science through its research and public outreach events. These include contributing to conferences and events with both HiNZ and Digital Health Association (DHA); and several public events including hosting a Data Science in Healthcare webinar series in collaboration with Orion Health, and contributing to New Zealand Data Science and Analytics Forum events.

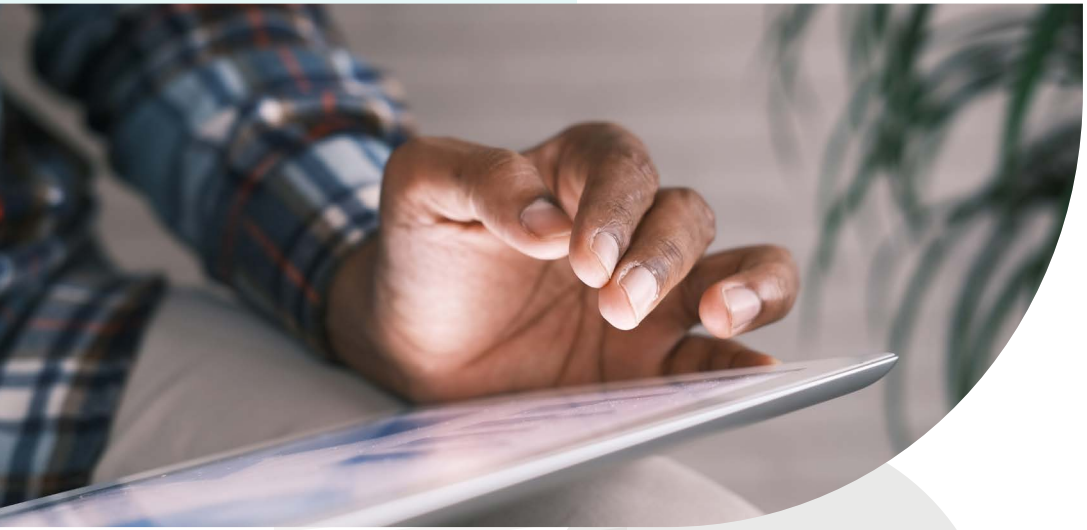
Other areas where PDH has played an important role include providing expert advice and peer review, with notable contributions including advice and feedback to the Health Reforms, Te Ara Paerangi Future Pathways Green Paper, Hira programme, and a revision of the National Ethical Standards for Health and Disability Research and Quality Improvement.

PDH has also supported researchers and organisations to undertake ethical research, and provided sector leadership in health data science through interactions with groups including Manatū Hauora Ministry of Health, Health Informatics New Zealand (HiNZ), DHA and AI Forum.



DEVELOPING CAPABILITY

Beyond studies



Developing capability in students

Summer provides a chance for many students to step away from the classroom – but for Thomas Adams, it was a summer internship focused on data that set him on his current path to being a data scientist.

Many health organisations in New Zealand are awash with data, but collecting and extracting meaning from this data – which can help organisations solve some of their toughest problems – requires skilled data scientists.

Data science isn't something that can be learned overnight, though. As the demand for data science increases, it's important that New Zealand's aspiring data scientists and researchers, like Thomas, are supported to develop their capability.

PDH plays an important role in fostering talent and supporting the next generation of data scientists, providing students with the opportunity to work on health data science projects where they are partnered up with experienced data scientists.

PDH has supported a range of student research projects and opportunities. These range from summer internships and masters and PhD scholarships, through to postdoctoral fellowships in conjunction with the Health Research Council (HRC).

These fellowships support emerging scientists – who have outstanding potential to develop into highly skilled independent researcher-innovators – to explore more effective and personalised healthcare for New Zealanders, leading to improved health outcomes and discoveries with a clear pathway to commercialisation.

Since 2016, PDH has facilitated 46 summer scholarships and internships, providing funding and organising placements for up to 10 opportunities each year for students studying a range of subjects, including computer and data science, engineering and medicine.

This involves interns being placed with partner organisations which have discrete health data science projects to give students exposure to different projects, and the chance to increase their experience and learn from a supervisor. Student placements have been made with Vensa Health, oDocs Eye Care, Atlantis Health and Orion Health as well as major New Zealand universities.

PDH also provides masters and PhD scholarships, and has provided funding for seven students to pursue their own research topic related to PDH themes and data science.

Thomas is a good example of someone who's benefitted from PDH's focus on developing research capability. After completing a Bachelor of Engineering specialising in engineering science, and focused on decision-making optimisation, Thomas commenced his PhD focused on rostering and scheduling within hospitals.

It was a chance conversation with Thomas' PhD supervisor that led to him applying for the summer internship through PDH, which provided an opportunity for him to continue his research on rostering and scheduling.

"I worked with Te Whatu Ora Counties Manukau initially looking at scheduling surgeries, seeing if we can fit more people in, or schedule it in a way that's more efficient, which was really interesting," says Thomas.

"I was specifically looking at rostering and scheduling within hospitals. You can define these things mathematically and build rosters that are fair, in terms of the shifts that they work, or the patients that they see."

After completing his PhD in 2020, Thomas subsequently applied for a PDH-HRC Postdoctoral Fellowship to continue his research.

The aim of Thomas' work is to develop software that schedules elective surgical sessions quickly, and in a way that reduces the chances of the sessions running overtime. The software will use novel machine learning techniques that incorporate historical surgery data to estimate the probability that sessions run overtime.

Further research into improved prediction of surgery durations, for use in scheduling sessions, that utilises individual patient data has also been performed.

As well as providing funding, Thomas says PDH played an important role in connecting him with the people he needed to progress his research.

"PDH put me in touch with the people in Te Whatu Ora Counties Manukau in the first place, and they've been able to put me in touch with people at Auckland Hospital and Te Whatu Ora Waitematā. Having access to the people I needed to talk to was very important, and PDH helped me connect with them."

"I wouldn't have been able to do a postdoc without funding from HRC and PDH; it's really allowed me to do research, and dig deeper into how we can make improvements to the way things are done."

Dr Thomas Adams

Thomas says the summer internship and Postdoctoral Fellowship programmes have been "huge" in developing his capability. "I'm really grateful for the opportunities. The summer intern scholarship was my first introduction into the surgery schedule area; it was very interesting and quite a change."

"I wouldn't have been able to do a postdoc without funding from HRC and PDH; it's really allowed me to do research, and dig deeper into how we can make improvements to the way things are done."

PDH HAS SUPPORTED

65+

students

ENGAGING APPROACHES

Creating equitable solutions

Pursuing equity in healthcare

Health equity will be achieved, according to the World Health Organisation (WHO), "when everyone can attain their full potential for health and well-being." But in New Zealand, it's widely acknowledged that there's more work to be done to achieve health equity for Māori and for all New Zealanders.

Examples of inequity include Māori life expectancy being considerably lower than that of non-Māori, with overall mortality rates being higher for Māori than for non-Māori in nearly all age groups.

While Manatū Hauora Ministry of Health notes there has been some progress towards health equity (for example, immunisation rates for Māori children), collaboration across sectors is required to make progress towards the goal of health equity, with the newly formed Te Aka Whai Ora – Māori Health Authority playing a key role.

In New Zealand, there is a realisation that equity must be front and centre when developing new technologies and techniques.

Andrew Sporle, PDH Independent Advisory Group member, says: "History shows that in many cases, any advancement typically works more for the people who are already better off than those who are worse off.

"What you often see with technological developments is the average improves, but the gap widens between those who have the best outcomes and those who have worse outcomes."

The PDH partnership is focused on creating equitable solutions through its work. Health data research requires deliberate engagement with populations with poorer health outcomes, and PDH has focused its sights on projects and developing capability that takes into account current and historical bias.

Countering bias – Triaging GP referrals to cardiologists

Heart disease is the leading cause of preventable mortality in New Zealand, and disproportionately affects certain groups including Māori and Pasifika.

In order to prevent serious illness early medical intervention is essential, but this is dependent on patients having access to medical care. This is not always the case

for Māori, whom data shows have lower access to health care than non-Māori.

There is, however, an opportunity to use data and machine learning techniques to address this, and take affirmative action to work towards equity.

Investigating inequities has been part of a PDH-supported research project undertaken by Orion Health, with support from Te Whānau o Waipareira advisors, which developed a deep learning tool to help improve the triage process from GP referrals, to improve health outcomes for patients through efficient and timely processing of their referrals.

A key objective of this project was to identify potential bias in the existing triage dataset, and provide a machine learning solution that mitigates implicit bias, reducing the issue of access by moving patients most in need up the queue.

Haze White, a Māori health advisor who has played a key role in this project, says: "For data science to be effective the data it uses needs to accurately represent the problem at hand. For example, the people who could really benefit might not be those who go to GPs, or alternatively, go straight to the hospital."

"When we spoke to GPs and some of the specialists, ethnicity was not formally used as a variable to triage a patient's priority. That can be something that the GP referrals triage tool does."

Capability development

Developing the capability of Māori data scientists is also an important part of achieving health equity.

As Andrew Sporle says: "Public precision driven health [can help address inequity], and it needs to involve the people who have provided the data, or from whom the data is about. They'll know what's missing, both in terms of the content of the data, and the stories that it can or can't tell."

PDH-supported projects have also helped Māori health organisations gain greater exposure to data science. Alana Harris of Te Whānau o Waipareira has been introduced to data science through working on its 'Best Practice Pathways to Achieve Priority Outcomes for Whānau' project, supported by PDH.

"As Māori, we talk; we're oral, we tell stories – hence why this marriage with PDH and data science worked perfectly because now our data scientists can unpack words, including Te Reo Māori, to see patterns, relationships and trends," says Alana.

"We attempt to analyse this data by transforming it into something quantitative, so that together with the qualitative data it tells a more accurate story."

"I am totally sold on data science and how it's going to achieve better insights on the data that we have... We've actually been approved to build out our data science team here at Waipareira, which is really cool."

"History shows that in many cases, any advancement typically works more for the people who are already better off than those who are worse off.

What you often see with technological developments is the average improves, but the gap widens between those who have the best outcomes and those who have worse outcomes."

Andrew Sporle
PDH Independent Advisory Group member

ENGAGING APPROACHES

Mahi tahi

Co-designing with Māori

Partnering with Māori has been an increasing focus for PDH, recognising both its role as a Te Tiriti o Waitangi (Treaty of Waitangi) partner, and the inequities that Māori have experienced through Aotearoa New Zealand's health and disability models of care.

Chad Paraone, PDH's Māori Health Director, says: "There are clear inequities in Māori health outcomes, and we want to make sure that through our work, these gaps get smaller and eventually disappear. How do you do that? Just like in any research, if you want to make sure that this works for a particular group, you have to involve that group. As the saying goes – 'Nothing about us, without us.'"

PDH has demonstrated an emerging strength in the way it has developed relationships with Māori health providers. It has partnered with Māori health organisations to co-design projects together, particularly where the end product will be used by Māori.

Best practice pathways to achieve priority outcomes for whānau

Māori have a higher incidence of health needs that haven't been met by existing programmes. One of the critical barriers preventing progress in this area has been the failure to engage with whānau in a Māori setting that respects concepts of mana, rangatiratanga, and the tapu nature of certain information and interactions.

One area where PDH has sought to address this is through supporting West Auckland-based Te Whānau o Waipareira and its subsidiary, Whānau Tahi, to undertake the Best Practice Pathways to Achieve Priority Outcomes for Whānau project, researching an appropriate artificial intelligence (AI) solution.

The resulting AI prediction model that eventuates from this research will be developed to predict priority outcomes for new and existing whānau, and the best courses of action to achieve these, based on past experiences of whānau.

The research is being conducted by Māori, for Māori, and aims to contribute to Māori health gains.

Self-care at home in Te Hiku

Consumers have many digital tools available today that can support aspects of their healthcare, but there is no easy way to evaluate, select and engage with the ones that would be most beneficial to them.

As a result, PDH supported a co-designed research project to better understand the dynamics of patient engagement and interactions with existing and new technologies and tools to support self-care at home in the predominantly Māori-populated, rural Te Tai Tokerau (Far North) region.

The research was a collaboration between Te Hiku Hauora (the Far North's most comprehensive health service provider), Te Whatu Ora – Waitematā (formerly Waitematā DHB), and Orion Health.

The findings will be used to develop and evaluate an integrated solution to enable access to comprehensive, patient-centred, self-management applications to manage their own health and well-being needs.

The solution, which will be trialled in 2023, will utilise Orion Health's Digital Front Door. This solution will provide individuals with access to a wide range of health services, education, and information, and integrate personal health device data to better inform the decision-making for Te Hiku Hauora's patients and support services.

Manawanui

Little data has been collected and analysed in New Zealand to show how disabled people use and access disability services, and the associated outcomes. In fact, many individuals and minority groups with disabilities can pass through the health system unnoticed.

To facilitate improved understanding of New Zealanders who receive Individualised Funding for disability services throughout Aotearoa, PDH supported Manawanui – the leading facilitator and largest individualised funding host provider in Aotearoa – and Nicholson Consulting to undertake research, including a segmentation analysis for Manawanui.

This research partnership – which aimed to assist Manawanui in its mission to empower people through improved services – has featured strong contributions from people with lived experience of disabilities, including Dr Huhana Hickey, a Māori human rights and disability lawyer who lives with multiple sclerosis.

Dr Hickey advised Manawanui on the research project, bringing her lived experience to contribute to understanding how services can better empower disabled people.

Kāhu and Te Hau Ora O Ngāpuhi

While Māori do not have a high incidence of melanoma, there is a high mortality rate for those who have melanoma. Earlier and easier melanoma detection could help decrease this mortality risk and save lives.

Kāhu is working in conjunction with MoleMap to identify partnerships with specific Māori communities to ensure technologies of the future increase health equity for all. This includes partnering with Te Hau Ora O Ngāpuhi to offer free skin checks in Kaikohe, Northland in 2022.

Tia Ashby (Ngāpuhi, Te Rarawa, Te Ati Awa), Interim CEO of Te Hau Ora O Ngāpuhi says her organisation loved the MoleMap and Kāhu technology which was easy to use.

"They liked how there was a follow up for whānau immediately. They didn't have to offer transport to a, b and c to help complete their journey...That's even more equitable, because it's removing barriers to care." You can read more about Kāhu's work on pages 18.

PDH HAS SUPPORTED

25+

Māori researchers

ENGAGING APPROACHES

How we feel about our data being used

Social license in health data use

As patient health records transfer from paper-based to digital systems, an exponentially growing volume of data is being generated. The possibilities to use this data for research and medical practice are increasing quickly, too.

But how do patients feel about their data being used? And do clinicians and researchers have the 'social licence' – in other words, the community acceptance - to use this? When people trust that their data will be used as they've agreed, and accept that enough value will be created, are they likely to be more comfortable with its use?

The thoughts of patients in Aotearoa New Zealand on having their health information used for purposes beyond their own immediate care has been a relatively uncharted area, until Dr Rosie Dobson turned her attention to this topic in 2020.

Rosie undertook this work through a PDH and Health Research Council (HRC) Postdoctoral Fellowship, carrying out research on patient perceptions of how their data contained in electronic health records (EHRs) may be used.

Since 2016, PDH and HRC have offered a small number of these prestigious Postdoctoral Fellowships to support innovative research into the emerging area of precision health and to help foster the health research workforce in New Zealand.

Rosie, a Psychologist and Senior Research Fellow at the National Institute for Health Innovation (NIHI) at Waipapa Taumata Rau, the University of Auckland, says: "Data is extremely powerful, and we have a very good [health] data set here in New Zealand... The opportunities for secondary use of health information are growing by the day."

"As a result, we wanted to understand whether New Zealand is handling consent for using patient data in a patient-informed way, and how we can make sure we do that going forward."

Rosie's Postdoctoral Fellowship work commenced in 2020 with a survey of patients at Waitematā DHB (now Te Whatu Ora Waitematā). "Our aim was to find out the overarching levels of comfort of patients with what was happening with their data," says Rosie, "and identify what the concerns were around the use of data."

This survey was completed by almost 1400 current users of hospital and clinic

services in Te Whatu Ora Waitematā. While health data is amassing quickly, Rosie indicates that the survey results showed many patients "don't have great awareness of what goes on with their data, because it's not something that is very well communicated."

The survey found that most people were comfortable with the health service using their de-identified health information beyond their care if it benefited others. Further, it showed that Māori participants were more comfortable with their data being combined with the health information of others, in contrast to previous research.

This is a potentially important finding that can inform national developments around Māori data sovereignty.

After analysing the survey results, Rosie conducted follow-up in-depth interviews in 2021 and 2022 with patients who had different experiences of the health system to further explore the key issues identified in the survey.

These interviews covered a range of scenarios, from the use of health information for artificial intelligence and machine learning, to using de-identified health information to create New Zealand-specific calculators, to the use of health information for public health purposes – for example, COVID-19 surveillance.

Rosie says the use of data for COVID-19 pandemic public health surveillance demonstrates how nuanced consent to use data is.

"Sharing health information with other health organisations, and then with the media and public, is using the data for secondary purposes," says Rosie. "It's not about treating your COVID; it's actually being used to prevent the spread of a disease in the public."

"The interviewees discussed that they didn't think the handling of health data related to COVID-19 was always ideal but participants understood that the pandemic was a global crisis; and they knew that the risks of not using information in this way were greater."

Rosie says the research identified the need for "better communication and transparency about what the data is being used for, and that patients should be able to access all their own health information... [which is still a] very complicated process."

Other findings from the research included that health information should not be shared outside the health sector or for commercial uses or financial gain; that information must be stored securely; and that individual privacy and confidentiality needed to be prioritised, and only de-identified data shared beyond immediate care.

"People want their health organisation to continue to look at using data in innovative ways, but they want to be able to trust the health service to protect their data and respect it."

Dr Rosie Dobson

According to Rosie's research findings, most participants were comfortable with their health information being used by the health service for secondary purposes without additional consent, as long as some key considerations were met.

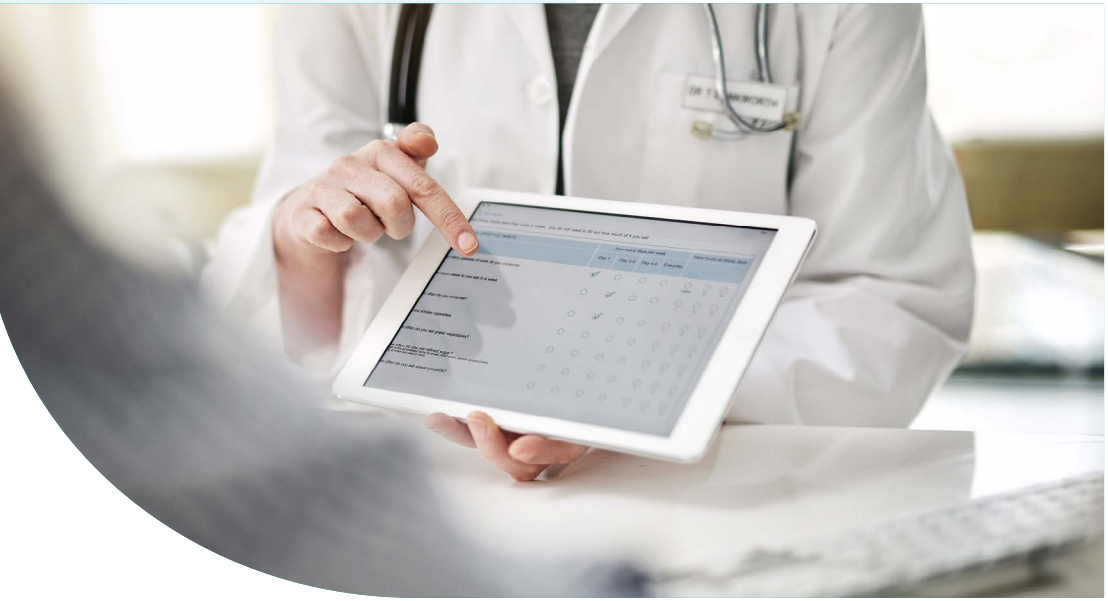
These included the correct approvals being obtained in advance; the privacy and security of the individual data and dataset being maintained; the health information remaining in the health service; and the intention of the use of the health information being to benefit others.

Rosie says her research showed that while there is work to do in what is a constantly evolving area, there was a real desire from those who participated in the research to help others – "and people are very aware that health data is a way that they can easily contribute to the greater good."

"People want their health organisation to continue to look at using data in innovative ways, but they want to be able to trust the health service to protect their data and respect it. They want to feel that... their data is respected as a taonga, and that they as a person are respected, and their consent is respected."

ENGAGING APPROACHES

Ethical data science



Advancing ethics in health data science

Ethics and healthcare have a long and interconnected history which dates back to the Hippocratic Oath. This is regarded as the earliest expression of medical ethics in the Western world, and outlines principles such as medical confidentiality and non-maleficence that continue to shape medical practice today.

But the application of ethics in health must continue to evolve to keep pace with changing times, and the technology that is helping propel new healthcare research forward.

The potential for good to come from algorithms and models developed through the PDH partnership is huge. Benefits could include reduced waiting times, bias or costs, as well as improved accuracy, quality, and consistency.

As health data science continues its rapid rate of progress though, people and organisations crossing into the world of health need to be mindful of ethical standards required of research projects in this area, and trained in what ethical questions to think about.

A software developer or data scientist who has transferred their skills from fields such as marketing and finance, has often not had to contend with the ethical oversight that traditional health research is bound by.

When they start creating a health algorithm, there are ethical questions they need to consider if the output of their system is affecting someone's care.

Ethics is about the identification, study, and resolution or mitigation of conflicts among competing values or goals. The core ethical question is, therefore, "what should we do, all things considered?"

Traditional healthcare research has well-defined ethical processes. But machine learning, by its nature, is often effectively 'real-time' research, where typical ethical reviews cannot take place. For example, an algorithm might produce different results for the same input data on different days, because it is learning and adapting to new data.

This is in contrast to most pharmaceutical products and medical devices, which typically produce reproducible results. Ethical review processes now need to somehow account for new processes therefore, in a way they haven't had to before.

Health data science ethics in New Zealand

In order for projects to be delivered well, with minimal unintended consequences, it's important that robust ethical processes which meet the needs of modern times and practices are incorporated into machine learning design and practice.

In New Zealand, health research is subject to an ethical review through a process overseen by Manatū Hauora Ministry of Health, and administered through the Health and Disability Ethics Committees (HDEC).

The HDECs check that proposed health and disability research meets or exceeds the established ethical standards, as determined by the National Ethics Advisory Committee (NEAC).

This ethics guidance was originally written for studies involving interventions such as medicines or medical devices, where a new drug or product is tested, and effects observed.

While health data science shares some similarities with these more traditional previous practices in health, there is often less of a physical, interventional product that's produced. Rather, the focus is more about looking at a body of evidence, analysing it, and creating a tool – for example, to carry out precision screening or triaging – that helps improve healthcare.

Clinical trials for new medicines or devices typically receive consent directly from patients who agree to be involved in them. In data science research, which uses de-identified data to conduct assessments, there are ethical questions around consent and the re-use of data which was not originally collected for this purpose.

PDH's projects have challenged researchers from commercial organisations who are part of the partnership to work through the HDEC processes and with the NEAC guidelines relating to clinical research data.

In particular, these projects have often wanted to make use of de-identified data originally collected for other purposes.

From a researcher and sponsor perspective, ethics approval processes can slow research down as there are distinctive stages between securing funding; then seeking ethical approval to conduct the research from HDEC; and finally, asking for access to the appropriate data. This is a long process.

The application of ethics in health must continue to evolve to keep pace with changing times, and the technology that is helping propel new healthcare research forward.

There has been positive work in this area, though: through engagement between PDH-associated organisations and HDEC, there is greater understanding about how research with data differs from physical interventions, and has a different level of risk associated with it. This has been reflected in the NEAC guidelines, which have been adapted to include information about data use and reuse, and informed consent.

There are examples of research projects that have battled to get permission to follow their plans to conduct robust scientific research. The continued development of ethical guidelines that support and guide researchers in their development and use of algorithms will be key to resolving this tension.

This is an area that will continue to evolve as more organisations conduct research using health data, and PDH will continue to advocate for ethical guidelines that are fit for purpose, allowing data science to deliver to its full potential.

PUTTING RESEARCH INTO PRACTISE

Building blocks for the future

Enabling technology

As outlined throughout this report, PDH has facilitated a thriving health IT sector in New Zealand, investing $38 million in research between 2016–2023 and supporting partners to develop innovative tools that enable people to live longer and healthier lives.

Over the lifetime of the partnership, PDH has played an integral role in industry-wide research projects where findings can be applied in the wider health system in New Zealand.

Ranging from a tool to de-identify health data to a platform for health algorithms and models, there are many examples of PDH-supported homegrown technology, which have been developed using local research. These technologies have the potential to accelerate and scale up the practice and progress of precision health.

De-identifier

In Aotearoa New Zealand, organisations have clear obligations when collecting, storing, using and disclosing personal data. Data is also essential for making decisions that lead to the best outcomes for patients and whānau.

How can data be best used, while protecting the identity of the person who it relates to? That's where 'de-identified' data – or data where a person's identity is no longer apparent or cannot be reasonably ascertained – is critical.

PDH has supported research projects that have developed a tool to automate the de-identification of data within electronic health records, and sought to understand the implications of de-identification on use of the resulting data.

The de-identification framework guides users through the entire process, taking 'raw' data and making regulation-compliant, de-identified data, balancing between utility and privacy to provide data that can be utilised to impact outcomes for patients.

Manatū Hauora Ministry of Health has trialled the De-identifier tool, which can be deployed for a range of potential uses including data release for research, media enquiries and population reporting.

Te Pokapū Hātepe o Aotearoa, the New Zealand Algorithm Hub

PDH, in collaboration with Orion Health, initially identified the gap in the market for a resource that made algorithms and models more accessible for New Zealand prior to the COVID-19 pandemic.

When the pandemic emerged in early 2020, data scientists became involved with supporting key government and healthcare decision-making efforts in scenario modelling and risk prediction.

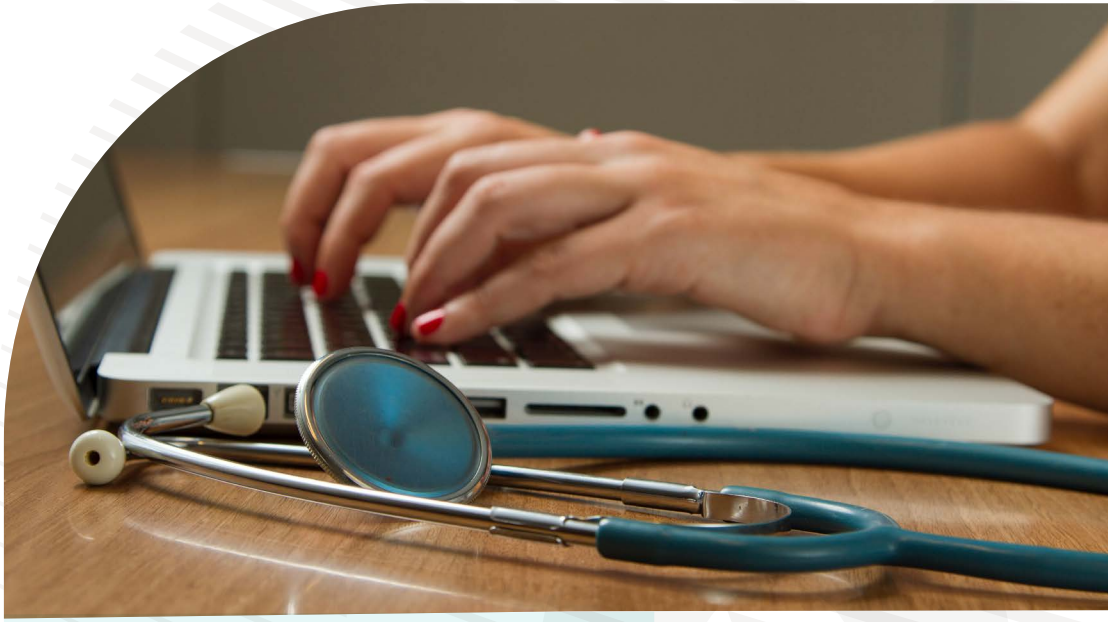
New models were emerging quickly, and there was confusion over what to trust, and which scenarios to evaluate. Service providers across New Zealand needed access to trustworthy technology and validated models.

With this in mind, Orion Health implemented Te Pokapū Hātepe o Aotearoa, the New Zealand Algorithm Hub (the Hub), with support from the Ministry for Business, Innovation and Employment's COVID-19 Innovation Acceleration Fund.

The Hub provides the infrastructure, tooling, and resources necessary to support operational modelling and timely information dissemination to the government and healthcare organisations, and professionals.

It provides access to models, algorithms, and risk calculators for healthcare providers and organisations. As new algorithms and models are developed, these can be quickly and safely deployed and made available on the Hub for maximum impact.

The New Zealand health sector uses the Hub as a central, shared knowledge base of validated algorithms and models. Ultimately, the Hub is for the citizens of New Zealand, to help ensure equitable



The Hub is for the citizens of New Zealand, to help ensure equitable access to healthcare and support safe and effective health decision-making.

access to healthcare and support safe and effective health decision-making from the latest findings from research. You can read more about the Hub governance on pages 40–41.

To complement the Hub, PDH also supported an Algorithm Scan describing the New Zealand healthcare algorithm landscape, focused on predictive algorithms for decision support. The study included in-depth interviews with 35 health sector representatives, a literature review and an online survey. You can read more in the report 'The future of healthcare algorithms in Aotearoa New Zealand – Algorithm Scan'. Refer to Reports and guides on page 45.

Dynamic consent

Healthcare-related data about patients' genetic makeup, lifestyle choices and social profile is being generated constantly. But managing consent for how this data can be used for research and treatment requires innovative solutions.

One such solution is a system that allows 'dynamic consent', enabling patients to freely approve – or withdraw – their consent for the use of their health data, and always remain informed about why and how their data is being used.

Work on a patient-centric dynamic consent management solution that empowers individuals to control, guard and manage their own information has been conducted by Orion Health, Waipapa Taumata Rau, the University of Auckland, and Te Whatu Ora Waitematā, supported by PDH.

This project aims to define and build a dynamic consent framework and digital interface that can accommodate consent, privacy and permissions.

It's hoped that this will support informed, ongoing capture of consent from patients, preserving their rights while potentially increasing the availability of data to provide the most effective care and support clinical and service improvement research.

Towards telehealth

As the COVID-19 pandemic took hold in New Zealand, telehealth increased in popularity, providing a healthcare lifeline during a time of restricted access. As lockdowns eased however, telehealth use was soon back to its comparatively low pre-COVID level.

To learn more about the potential reasons for this, a PDH-supported research project is being undertaken by Massey University, the NZ Telehealth Forum and Vensa Health.

This project sought to uncover evidence as to why telehealth has not become a standard part of healthcare delivery in New Zealand, in three phases using co-design with an underserved population of rural patients.

By considering rural patients first in the design process, it's hoped that better results will be delivered for this group, alongside other underserved populations, rather than creating a solution best suited to the majority of the population.

The findings also have the potential to apply to other populations underserved by more traditional 'in person' models of health care, such as New Zealand's Māori population.

Missing data imputation

Most patients are likely to have gaps in their medical records. These gaps can present problems for medical professionals and health service providers; if the data isn't handled correctly it can result in negative outcomes such as bias or ultimately invalid conclusions.

The process of replacing missing data with substituted values – otherwise known as data imputation – can help address this issue though, and was the focus of a PDH-funded research project undertaken by Orion Health and Waipapa Taumata Rau, the University of Auckland.

This research found that while single-data imputation methods suffer from the problem of 'making up data', multiple imputation works by creating a representative sample of plausible values that the missing data could have had, and then averaging the analysis over that sample.

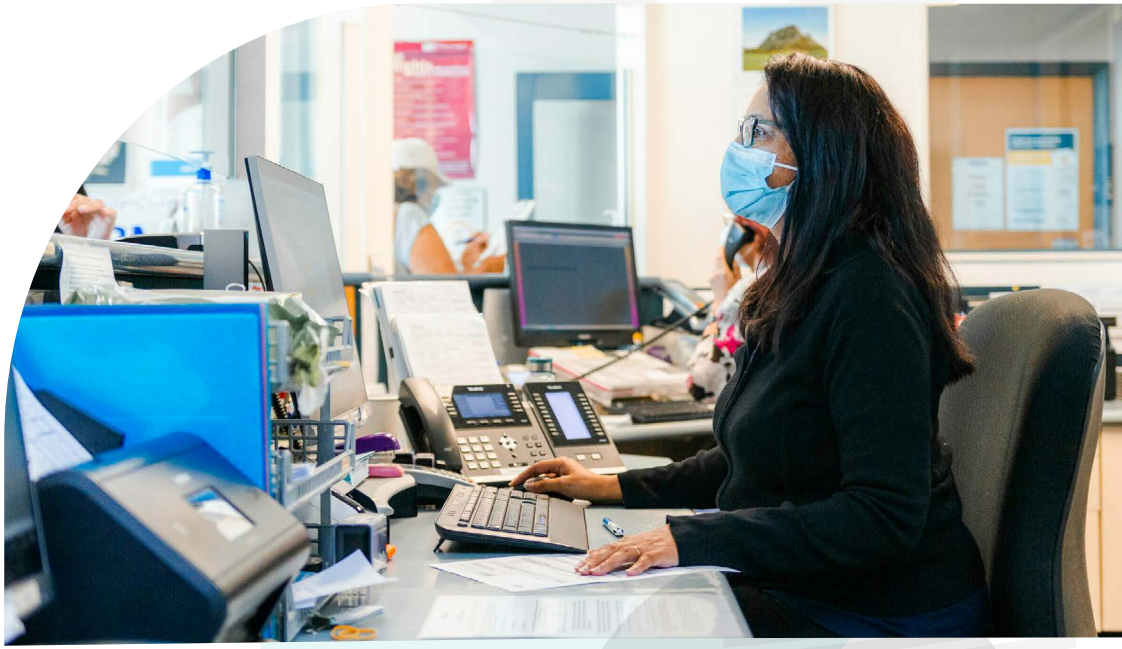
Multiple imputation is a valuable technique for reducing bias when training predictive models in health data with missing values, and for increasing applicability when deploying models based on data with missing values.

This is particularly useful to fill gaps in data used in machine learning models, helping to address bias towards those members of the public who are less engaged with the health system, or less digitally engaged, and therefore have incomplete health records.

Smart Coder

Free text fields in electronic health records (EHRs) give clinicians the opportunity to provide complete descriptions of interactions with patients, providing more flexibility than a structured field. Smart Coder has been developed through PDH research to identify and code terms within free text that have clinical significance.

With New Zealand health records containing significant amounts of uncoded, free text data, Smart Coder has the potential to be valuable, both for the New Zealand health system and throughout the world.



Smart Coder's capability is being leveraged in other research projects, including the potential to be used to identify people who are eligible to take part in clinical trials. Read more about the application of Smart Coder on page 20.

PUTTING RESEARCH INTO PRACTISE

Making models make sense

The importance of interpretability

For all the good work that goes into developing health algorithms and models globally, many do not see the light of day. New Zealand is not immune to this: like other countries, many of our data science pilot and research projects don't find their way into general use.

This is no reflection on the quality of the work produced. New Zealand's health data science community has great ideas which are shown to have benefits.

It remains a challenge though for many organisations – which have spent significant time, effort and money on research – to move their work off the shelf and into regular use.

An area of focus for PDH during the life of the partnership has been to identify and, where possible, address the barriers that stop ideas being implemented and used by their intended audiences.

Through this effort, a number of PDH projects have successfully navigated the path to regular use. This has been assisted by a deliberate focus from PDH on identifying and supporting tools that have a wide range of potential use, and can be easily interpreted by or explained to their intended audiences.

Encouraging greater understanding

An important part of getting models and algorithms into regular use is making sure they're interpretable – or, in other words, the people who use the models and algorithms are able to understand the reasoning behind the predictions and decisions they make.

Pieta Brown, PDH researcher and Product Director – Intelligence, Orion Health says: "It's important to put models and algorithms out there in a way that makes them relatively easy for people with a range of different needs to use and trust – explaining the 'why' of how it reached its finding."

Another example of a model created through the PDH partnership that is in regular use is nzRISK, a surgical outcomes tool that is the preferred model in New Zealand, read more about nzRISK on page 16.

As well as expressing risk outcomes through mortality rate, nzRISK also

includes ‘days alive out of hospital’ as a comparison, with visualisations on the website expressing this information in a range of ways.

Pieta explains: “We had to dive in and actually build the content, engaging with clinicians, who are experts in that area, as well as data scientists, who could develop models to calculate and present risk.”

“There are multiple ways of interacting with the nzRISK findings, however, to improve usability by clinicians, patients and whānau, developers had to accommodate different considerations when presenting the information back to these users.”

The GP Referrals Triage project (which you can read more about on page 26) and COVID-19 modelling project (refer page 17) further reinforce that the key to implementing algorithms and models is enabling them to reveal a relevant story that demonstrates value to users.

“The GP Referrals Triage project included a simulation that really helped users to understand what the impact of their decisions might be,” says Pieta. “It shows how many people who should be considered urgent, might get missed, or how many who would have been waiting could actually get prioritised to be seen sooner.”

“COVID-19 modelling allowed for standardised reporting and communication of information that could be used during the daily 1pm COVID-19 media stand ups,” Pieta continues. “The model was tuned to the sorts of questions that were being asked.”

“Te Pūnaha Matatini had a team of leading academics doing amazing work on continuous model development, and PDH was able to support with standardised processes, automation that could be run daily and scaled to thousands of scenarios, and communication of the outputs.”

According to Pieta, the key lessons PDH has learned on its journey along the path to implementing and getting tools used is “focusing on what your users really need – that means engaging with people from a place of curiosity and empathy, understanding their unique challenges and opportunities.”

“From our experience, it seems that some tools may not be used, because they’re asking the wrong question. With surgery, for example, expressing risk as a one-in-one-thousand chance of happening, might not resonate.

“But if it told me that I might spend ten days in hospital, versus the average person spending five, then that’s meaningful. The focus should be on outcomes that are meaningful to the patient and also to the clinician.”

“If more of these solutions ask the right questions and are implemented in context, that will lead to longer term, positive outcomes that are part of precision healthcare, whether that’s a better quality of care or a better cost for care, with the right people being seen in the right place at the right time.”

“If more of these solutions ask the right questions and are implemented in context, that will lead to longer term, positive outcomes that are part of precision healthcare.”

Pieta Brown

PUTTING RESEARCH INTO PRACTISE

The importance of good governance

Governance lessons learned for new models and algorithms

With a commitment to translating research to practice, and realising the benefits of this work, PDH has had to contend with the process of evaluating, approving, and implementing new models, the outputs of which subsequently impact patient care.

This has involved decisions that come under the responsibilities of governance, which is at its core about the values and risks of an organisation or process, and taking responsibility for the decisions made in this tradeoff.

Most organisations have governance boards, and in healthcare there are usually clinical and data governance groups. Often, these groups are not fully equipped to understand and oversee decisions with respect to the models and algorithms that are produced through data science research.

Algorithms are decision-making tools, which process data, and determine opportunities and risks. The opportunities are realised through the outcomes that algorithms can create for populations, but the risks – from issues with data sources to algorithm training – can undo this. Good governance is key to mitigating these risks.

Operationalising and deploying an algorithm is not the end of the road for researchers; instead, it is vital that there's consideration for how these models will be managed. This includes implementing ways of monitoring and maintaining oversight during the lifecycle of the algorithm.

Algorithm governance in the midst of a pandemic

The COVID-19 pandemic has been widely described as the biggest public health challenge of a generation. Governments and the health sector needed quick information based on quality data to predict the unknown – but the 'need for speed' did not mean that governance was able to fall by the wayside.

While COVID-related algorithms were created around the world, New Zealand took a very deliberate, evidence-based approach to managing the pandemic and utilising these algorithms.

Te Pokapū Hātepe o Aotearoa, the New Zealand Algorithm Hub, was developed to evaluate and host COVID-19 related models and algorithms, and provide a central and secure infrastructure to support the country's pandemic response. Read more about the Hub on page 35 and at algorithmhub.co.nz.

Model developers were able to submit an algorithm for evaluation and hosting on the Hub, which were subsequently reviewed by a multidisciplinary Governance Group with a wide range of experience, before being accepted and published.

Good governance

A critical aspect of the Hub was the formation of the Governance Group, to ensure that algorithms being deployed underwent cross-disciplinary scrutiny prior to being made available for quick and safe implementation.

Governance group members represented Māori, consumer, ethical, clinical, public health, privacy/legal, data science, governmental and commercial perspectives. This group reviewed more than 30 models and calculators for inclusion on the Hub, including models related to the pandemic spread and relative risk calculators.

The review process the Governance Group undertook included an initial discussion on submissions, followed by the submitter completing a long-form, documented submission on the model.

This 'Algorithm Information Request' required them to outline the model's purpose, intended use, development, deployment, Māori impact, equity and ethical considerations.

Lessons learned

Robust and wide-ranging conversations within this group, and with those applying to have their algorithms included on the Hub, highlighted a number of lessons important for good algorithm governance, including several related to ethics, Māori, localisation and intended use.

Dr Alex Kazemi, emergency medicine and intensive care physician, and a member of the governance group, says the group considered the potential benefits and risks of each submission.

"The group really considered the impacts of each algorithm submitted, looking at how it might affect different groups, and what the unintended consequences of having that algorithm available might be."

The governance group has already identified some aspects of the Hub that require further development – such as stronger feedback mechanisms for those using algorithms on the platform and developing capacity to evaluate model inputs and outputs over time.

To the group's knowledge, this is the first implementation of this type of national algorithm governance in New Zealand, building upon broad local and global discussion of guidelines in recent years. This is a step forward in ensuring good governance of algorithms in our country.

Alex says the diversity of the governance group was a real strength, with a wide range of views being immediately available.

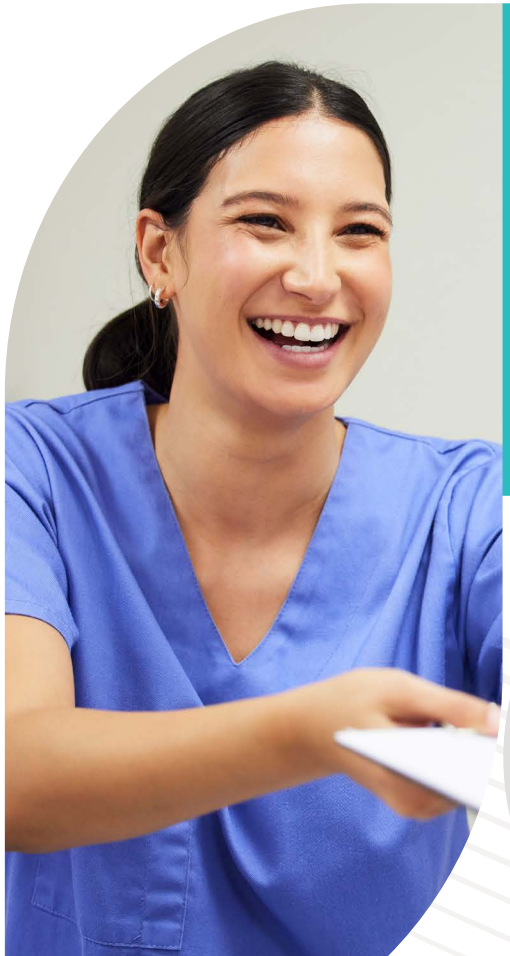
"The governance group was really motivated to deliberately put guidelines in place. This really came about because we had a governance group that had community representatives as well as clinicians, Māori, data scientists all sitting down together, trying to figure out what might happen. Having these different voices around the table was vital for good governance."

An open-access article describing these lessons was published in the Journal of the Royal Society of New Zealand; read more on page 45.

"The group really considered the impacts of each algorithm submitted, looking at how it might affect different groups, and what the unintended consequences of having that algorithm available might be."

Dr Alex Kazemi

03 Financials



PDH has supported projects, events, and activities that deliver health and commercial value to Aotearoa New Zealand.

Lifetime totals

Partnership lifetime actuals to Oct 2022
plus forecast to completion, March 2023

Funding received	$000
Commercial	21,000
Partner – Orion Health	13,148
Other	7,852
MBIE Partnership programme	14,000
Non-commercial	1,865
Partner – Waitemata DHB	1,400
Other	465
Commissioned research	714
Total	37,579

Expenditure	$000
Research projects	31,028
Scholarships and fellowships	1,474
Commissioned research	714
Operations	4,363
Leadership personnel	3,716
Other operations	647
Total	37,579

04

Outputs

For a complete list of outputs, please visit precisiondrivenhealth.com/outputs.

Selected publications

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Reports and guides

Health Data Science in Aotearoa New Zealand: A Practical Guide >>

Multiple Imputation Guide – How and Why to Use Multiple Imputation >>

Aotearoa New Zealand Health Dataset Review >>

Artificial Intelligence for Health in New Zealand report, AI Forum >>

PDH Programme evaluation and future options report, April 2022. MartinJenkins >>

The future of healthcare algorithms in Aotearoa New Zealand – Algorithm Scan >>

Te Pū Waiora

Stories reflecting Māori leadership and engagement in health data science >>

05

Our People

There have been many contributors to the PDH partnership's functions. These contributors, past and present, are listed in their capacity and affiliation at the time of their most recent involvement.

Governance Board

PDH's Governance Board sets the vision, strategy and direction of the joint venture, and maintains budget and financial authority. It provides final approval for the research activities we support, and ensures they are relevant to PDH's vision and goals. Board members are appointed by PDH joint venture partner organisations – Orion Health, University of Auckland and Te Whatu Ora Waitematā.

Dr Andrew Brant
Te Whatu Ora Waitematā

Dr Andrew Old
Te Whatu Ora Waitematā

Anne O'Hanlon
Orion Health

Belinda Allen
Healthpoint

Craig Holmes
MBIE* (Observer)

Dr Dale Bramley
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Independent Chair

David Leach
Orion Health

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Kylie Hood
MBIE* (Observer)

Sarah Thompson
Orion Health

Terry Moore
Independent Chair

*Ministry for Business, Innovation and Employment

Independent Advisory Group (IAG)

PDH's Independent Advisory Group provides a variety of perspectives on the partnership's research activities and projects, including views of consumer, industry, Māori, Pacific, clinical, and academic experts. The IAG recommends the research portfolio and projects to the board. IAG members are appointed by PDH.

Dr Allan Moffitt
ProCare Health

Andrew Sporle
Waipapa Taumata Rau, the University of Auckland

Caitlin Smart
Consumer representative

Dr Diana Siew
Waipapa Taumata Rau, the University of Auckland

Professor Gail Pacheco
Auckland University of Technology

Professor Geoffrey Holmes
University of Waikato

Professor Gregor Coster CNZM
Chair

Dr Helen Lunt
Te Whatu Ora Canterbury

Dr Helen Wihongi
Te Whatu Ora Waitematā and Te Toka Tumai Auckland

Dr Jacqueline Schmidt-Busby
Comprehensive Care PHO

Jon Herries
Manatū Hauora Ministry of Health

Dr Jonathan Gray
Te Whatu Ora Counties Manukau

Dr Judy Blakey MNZM
Health Consumer Advisor

Dr Kathryn McPherson
The Health Research Council of New Zealand

Dr Lara Hopley
Te Whatu Ora Waitematā

Lope Ginnen
Vaka Tautua

Richard Fraser
Orion Health

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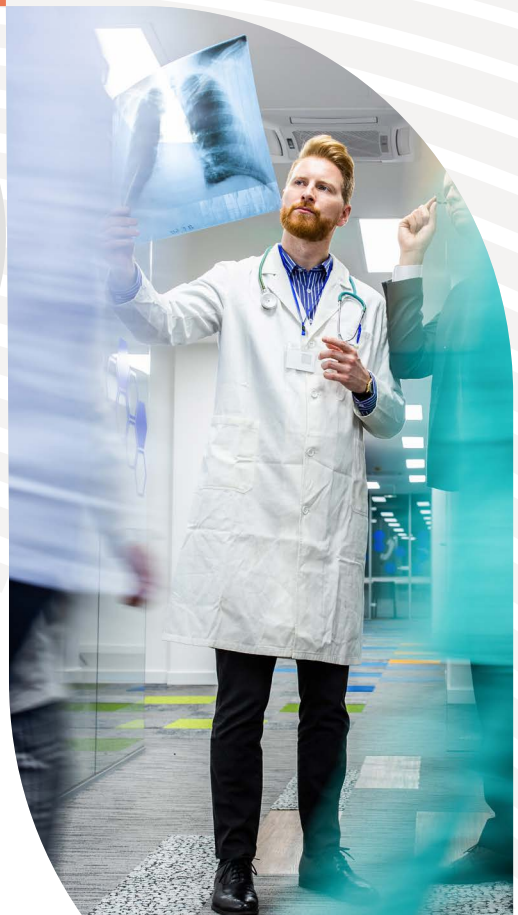

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