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Hack Aotearoa

Summary

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Ethics and ownership: Hack Aotearoa 2020

by Jamie Small

The ownership of data, and the ethics of how they are collected and used emerged as strong themes from the Hack Aotearoa 2020 conference.

The conference and datathon, held over three days in January, brought together 190 data scientists, health professionals and others to discuss, learn and practice health-related data science.

Several keynote speakers focused on how data collection, AI and their use in healthcare impact Māori and other minority groups.

Māori are not a homogenous population, and different iwi (tribes), hapū (sub-tribal groups) and individuals have different approaches to their data, says leading Māori data and information specialist Kirikowhai Mikaere.

She says there is a lack of relevant data to indigenous people in New Zealand and around the world.

“We have tribal groups wanting to access and have possession of data for their own development,” Kirikowhai says.

“Māori data should be subject to Māori governance.”

Māori data scientist Caleb Moses wants Māori – rather than university, government and private organisations – to own their own data.

He says that rule should apply to all people and groups.

“The subject of the data should have control over it ultimately, not just where it is being stored.”

Doctor Leo Anthony Celi, clinical research director and principal research scientist at the Massachusetts Institute of Technology Laboratory for Computational Physiology, highlighted the potential of data science in health while warning of how organisations could abuse it.

He cautioned against using data without knowing enough about the people they were gathered from and how the data were gathered.

Many datasets, Dr Celi says, do not have enough women and people of colour in them, meaning the findings may not help those people, or could be harmful to them.

“How do we take care of these people when they are under-represented in the studies from which evidence comes?”

Dr Celi also spoke about companies and organisations that use data for the sole purpose of making money.

He is calling for more regulation on the use of health-related and other sensitive data, saying the industry cannot be trusted to regulate itself.

Dr Matthew Strother – an oncologist, clinical pharmacologist, clinical senior lecturer at University of Otago in Christchurch, and PhD candidate in evaluating machine learning governance in healthcare – says ethics in the field of data science is “undeveloped”.

“Data science has largely evolved in the business arena and, arguably, business ethics have been the dominant paradigm.”

He says there is no quick solution to the problem, but hopes the field will adopt a culture of ethics similar to that which is embedded in medical research.

Dame Diane Robertson is writing data governance guidelines for boards of trustees in New Zealand.

She says almost no organisations have data governance policies, which is a risk to the people the data are collected from and also to trustees.

“The buck stops with the Board, and the opportunity starts with the Board,” Dame Diane says.

“If you don't know what data you've got, you've got real problems. And most organisations have no idea.”

As the conference concluded, groups of attendees including data scientists, doctors and others prepared to compete in the Hack Aotearoa 2020 Datathon, this first of its kind in New Zealand.

Datathon organisers gave 18 teams access to anonymised critical care datasets from the US and computing tools for creating and running machine learning algorithms.

One team, “Mōwai.py”, explored the accuracy of a model to predict probability of death (mortality) in intensive care across patient subgroups.

The group's analysis demonstrated that prediction models did not perform equally across groups with different ages, ethnicities and gender.

Mōwai.py concluded that more research is needed to identify what could be done to address this issue of algorithmic bias.

Conference convenor Dr Mataroria Lyndon says Hack Aotearoa's second year brought together thought leaders from the fields of healthcare and data science.

“There were a lot of thought-provoking discussions about how data science can help with healthcare – both the opportunities and the challenges”.

“Everyone who attended learned together and got to apply data science concepts to solve critical care problems. The fields of healthcare and data science will be advanced because of it.”

If you work in health or data science, or are interested in either field, follow Hack Aotearoa on [Facebook](#) and [Twitter](#) to be the first to hear when [Hack Aotearoa 2021](#) opens for registration later this year.