CURIOUS MINDS
HE HIHIRI I TE MAHARA

INSPIRING A NATION OF CURIOUS MINDS

Get involved with science and technology

Power and justice in citizen science

MINISTRY OF BUSINESS, INNOVATION & EMPLOYMENT
HĪKINA WHAKATUTUKI

MINISTRY OF EDUCATION
TE TĀHUHU O TE MĀTAURANGA

Office of the Prime Minister's
Chief Science Advisor

New Zealand Government

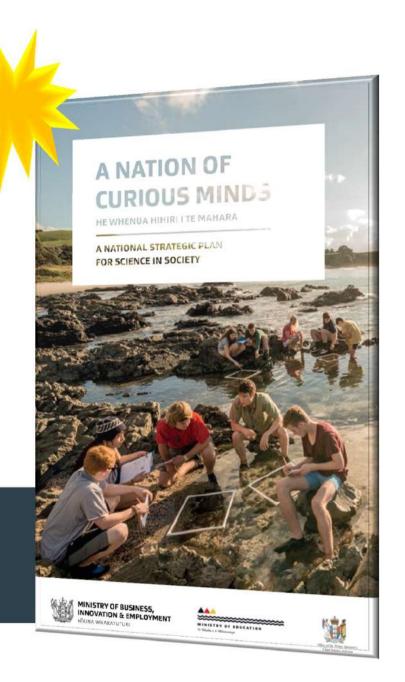# Ice Doctor

Queen of Curiosity

The National Strategic Plan for Science in Society, entitled "A Nation of Curious Minds" (2014)

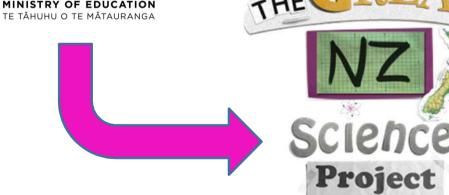https://www.curiousminds.nz/assets/science-in-society-plan-PDF.pdf
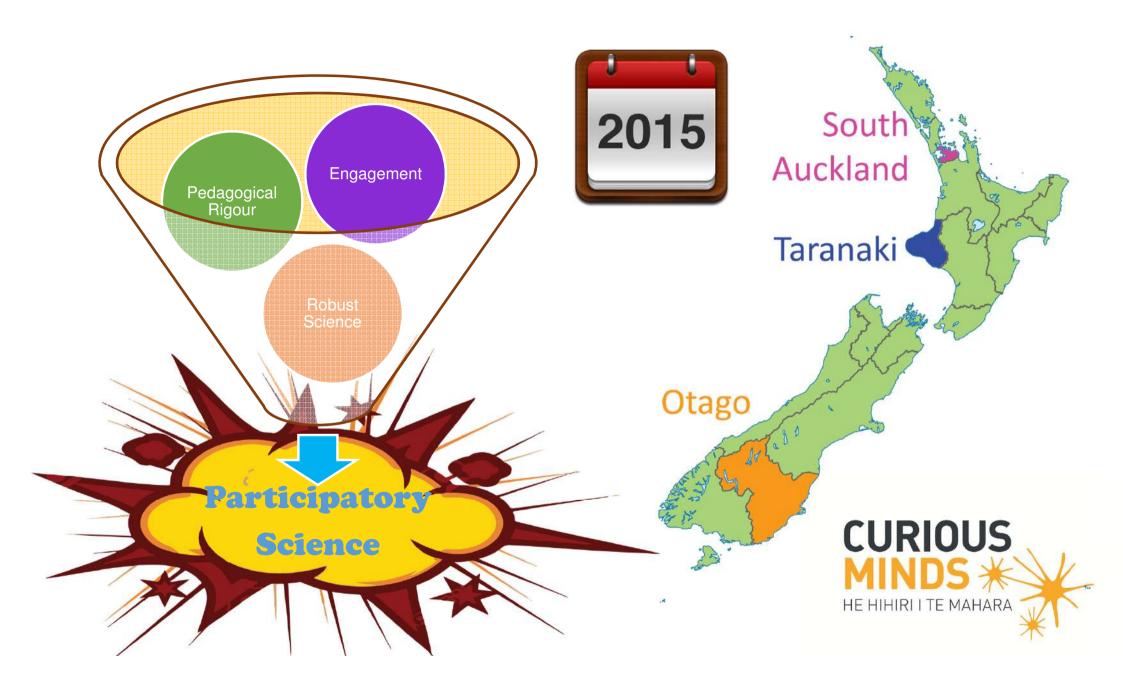
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OBJECTIVE

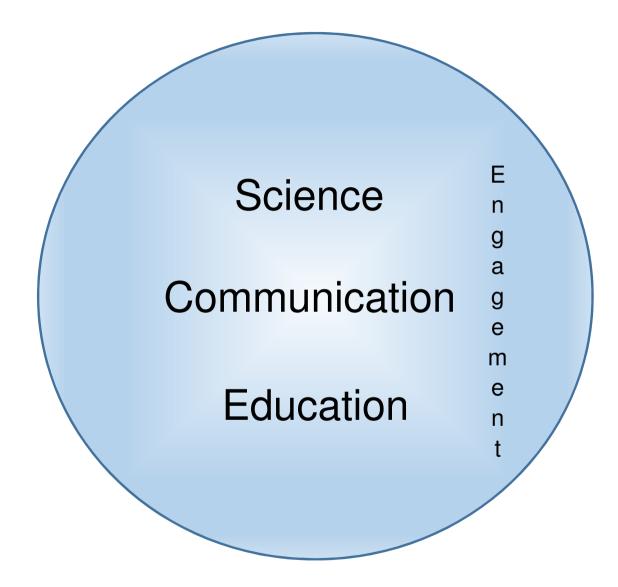**ENCOURAGE AND ENABLE BETTER ENGAGMENT WITH SCIENCE AND TECHNOLOGY IN ALL SECTORS OF NEW ZEALAND**

NEW ACTIONS

ENHANCING THE ROLE OF EDUCATION	PUBLIC ENGAGING WITH SCIENCE AND TECHNOLOGY	SCIENCE SECTOR ENGAGING WITH THE PUBLIC
• Science Skills in Education initiative • Teachers in Industry project • Review positioning and content of digital technology within the New Zealand Curriculum/ Te Marautanga o Aotearoa • Increase the science and technology content in initial teacher education	• New contestable fund for science and technology outreach and initiatives for harder-to-reach audiences • Better connect business/ educators/learners/local government with the science sector • Increase girls' participation in science/ICT study and careers • Better connect museums/ zoos/science centres with the science community • Parents and whānau to be more engaged with science	• Implement a participatory science platform • The Royal Society of New Zealand to develop a code of practice for public engagement for scientists • Public engagement in implementing the National Science Challenges • Access to public engagement training for researchers • Increase the profile of researchers in pūtaiao/ mātauranga Māori

SUPPORTING ACTIONS

PARTICIPATORY SCIENCE PLATFORM

Pedagogical Rigour

Engagement

Robust Science

Participatory Science

2015

South Auckland

Taranaki

Otago

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Craig Grant, Otago PSP

"I think the fact that PSP projects are inherently community driven / bought into, mitigates against many of these (data) concerns (if the community wasn't happy with terms of data collection, storage and use, the project simply wouldn't happen...as least via PSP support)."

"Moreover, PSP participation is on an opt-in basis (no coercion/incentives to participate) and the data used is nearly always in aggregate form and hence anonymous (unless of course say an individual elects to presents his/her own data/case study)."

Lighting the Way for VIPs

Photo: teaching students to do a lighting assessment

http://www.marybutler.org/research-2/visual-impairment/the-lighting-project/
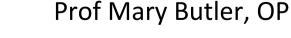
Lighting the Way for VIPs

"Data ownership was not an issue with the Lighting Project, and I would agree with Craig that this was largely because the participants bought into the project completely.

We have learned a lot about ensuring that there is a wide and deep process of consultation before the project gets going. It's all about ensuring that the relationships are real. I think that participatory research works best where there is a feeling that the research is just one part of a relationship that is genuinely concerned about the group and the individuals in the group.

In the case of my relationship with people with low vision - this involves attending a lot of meetings; offering to give talks; getting students on placement and ensuring that there are real outcomes; and then developing research projects that arise from the conversations that we have as a group."

Prof Mary Butler, OP

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Warm Not Wet

- Affordable Heating and Humidity Control for North East Valley Homes - University of Otago and Valley Community Workspace
- UO Ethics Approval
- 16 Households participated, 2 school groups
- Temperature and humidity time series collected for 3 months
- Analysis of temperature and humidity patterns
- Survey of heating and ventilation practices

Warm Not Wet

- Intermediate school class monitored 3 experimental house models to show the condensation and evaporation water cycle in homes.

- Senior school students helped develop electronic sensors

- 20 Temperature and Humidity kits designed, tested, with the help of Logan Park students and Dunedin Makerspace contributors.

- 16 distributed to houses, 4 placed in Dunedin North Intermediate School classroom.

Warm Not Wet

- Development of Home Dryness Score: emailed to households weekly.

- Not all insulated, warm houses were found to be dry, and not all cold, uninsulated houses were found to be wet.

- Moisture Content: a lot of moisture is stored in building materials and furnishings.

Ermell / Wikimedia Commons

Warm Not Wet

"We found people happy to contribute their data to the community science project. They could see that it brought benefits to the community. A non-profit was collecting the information, and we had a confidentiality agreement to keep identifying information private.

One of our data streams was temperature and humidity from each house. We at first offered aggregate data, but we found in fact that householders wanted to see their individual data compared against other households in an anonymized way, so that other participants could not be identified. All householders were quite happy for their individual temperature time-series data to be made public, as long as it was anonymised and only they knew which time-series was theirs."

Tim Bishop

Warm Not Wet

"People also appreciated how we sent them weekly analysis of their data via automated email. They received a weekly Home Dryness Report that gave them feedback as to how well their ventilation and heating strategies were working."

Tim Bishop

Healthy homes, healthy futures

- Rongomai School

- Focus on anonymising data. Shown how to take photos of mould without any identifying factors

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Getting to the heart of the matter

- Manurewa High School
- Fitness data and a diabetes learning context

Getting to the heart of the matter

Science of School Exercise

- Rongomai Primary
- Data was anonymised, but also not collected or analysed with a rigorous attention to scientific detail.

Science of school exercise

Science of school exercise

Project Reef Life

Project Reef Life

"The location of the reef that is monitored through this project was given to us by a local fisherman. The project team has always kept the exact location private out of respect for the individual who provided it.

It's important for the project team to maintain good relationships with the recreational and commercial fishers in the South Taranaki Bight. We hope that maintaining these relationships will also lead to more information sharing in the future.

Data taken from the reef is shared with the public in a number of ways without the GPS location included. When uploading observations to iNaturalist the location is obscured."
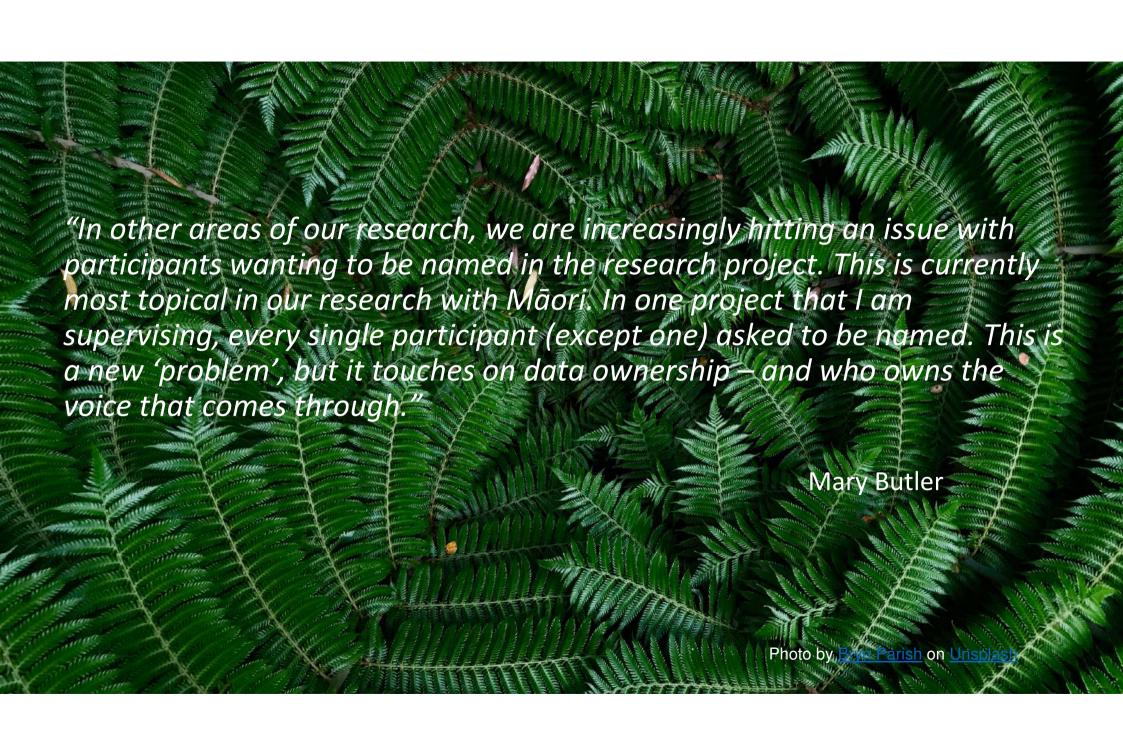
Josh Richardson

PSP

- empowers and builds communities

- fosters networks

- creates space for other knowledge sources, e.g. Mātauranga Māori

"In other areas of our research, we are increasingly hitting an issue with participants wanting to be named in the research project. This is currently most topical in our research with Māori. In one project that I am supervising, every single participant (except one) asked to be named. This is a new 'problem', but it touches on data ownership – and who owns the voice that comes through."

Mary Butler

Anonymity or not

"Several participants asserted the significance of immortalizing their deceased loved ones in the pages of my thesis, retaining ownership over their words and maintaining a public attachment to their personal identity."

- memorialisation and memory making

- openness on death and dying

- relating to the results and write-up

- self identity and ownership of words

Scarth, B. J. (2016) 'Bereaved participants' reasons for wanting their real names used in thanatology research', *Research Ethics*, 12(2), pp. 80–96. doi: 10.1177/1747016115599569.

Anonymity and indigenous peoples

"naming or anonymising participants is particularly pertinent in research with indigenous peoples because of the problematic history of research speaking about the indigenous other."

"Main concerns revolve around respect for their indigenous rights, control over research processes and reciprocity within research relationships to ensure that equitable benefits are realised within indigenous groups (Hudson & Russell, 2009)*"*

Ashdown J. et al. (2018) The Ethics of Allowing Participants to Be Named in Critical Research with Indigenous Peoples in Colonised Settings: Examples from Health Research with Māori. In: Macleod C., Marx J., Mnyaka P., Treharne G. (eds) The Palgrave Handbook of Ethics in Critical Research. Palgrave Macmillan.

Anonymity and indigenous peoples

"discussion of the considerations around naming or anonymising participants adds to critical debate on the best ways of achieving greater autonomy for communities involved in research that is about, with, and truly for them."

Ashdown J. et al. (2018) The Ethics of Allowing Participants to Be Named in Critical Research with Indigenous Peoples in Colonised Settings: Examples from Health Research with Māori. In: Macleod C., Marx J., Mnyaka P., Treharne G. (eds) The Palgrave Handbook of Ethics in Critical Research. Palgrave Macmillan.

https://link.springer.com/chapter/10.1007/978-3-319-74721-7_18

Tell Us

"Tell us!" is sponsored by the Ludwig Boltzmann Gesellschaft (LBG) and the Ludwig Boltzmann Institute for Experimental and Clinical Traumatology (LBI Trauma).

WHAT QUESTIONS ABOUT ACCIDENTAL INJURIES DOES RESEARCH NEED TO ADDRESS?

SCIENTIFIC KNOWLEDGE

EXPERIENTIAL KNOWLEDGE

RESEARCH

CLINICAL ROUTINE

EXPERIENCE
SKILLS
EXPERTISE
PROBLEM SOLVING

• https://tell-us.online/

Tell Us

WHAT HAPPENS TO MY PERSONAL DATA?

We take privacy very seriously. The data contained in your profile and your contributions will be treated in accordance with the new EU General Data Protection Regulation (GDPR). Other participants in the project will not be able to view your data at any time. Your personal data will not be disclosed to third parties. Upon request, we can delete your data.

HOW DOES "TELL US!" BENEFIT THE GENERAL POPULATION?

We want to incorporate knowledge based on your experience into research, to generate new points of departure for research projects that will be of particular benefit to society. This will make it possible to improve the diagnosis and treatment of accidental injuries in the future.

- https://tell-us.online/

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Tell Us

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▼ **HOW DO I BENEFIT FROM THIS PERSONALLY?**

"Tell us!" gives you an opportunity to draw upon your clinical experience in the field of accidental injury as an expert, or your own experience as a patient or relative, and contribute this to research. Your contribution helps researchers ask the right questions, thus improving our medical system in the long term.

▼ **WHAT HAPPENS TO THE RESEARCH QUESTIONS I SUBMIT?**

After the end of the submission phase, your research questions will be anonymously evaluated by the "crowd," on the one hand, and by experts in the field of traumatology on the other. This is how we arrive at a joint assessment of the research questions. The research questions will also be provided anonymously to researchers from the field of traumatology. You have an opportunity to be notified if your question is selected.

- https://tell-us.online/

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Science and technology is central to many global problems we face

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Science literacy & participatory approaches are fundamentally important to our future

Science isn't objective

"We dodge moral responsibility by appealing to the intrinsic morality of advancing knowledge, pretending that science is objective, separating what we discover from how it is used, partitioning science from other ways of knowing (and often holding it above other ways of knowing), and gatekeeping who can be part of science and who gets to ask scientific questions."

Pay attention to the applications and impacts of our work, especially negative ones.

Accept and embrace the imperfect nature of science.

Welcome diverse people, voices, perspectives, epistemologies.

Acknowledge our values and act on shared values.

https://ethicsandequitycenter.org/making-science-moral/

Raj Pandya, Director, Thriving Earth Exchange

"*Community science necessarily grapples with ethical and moral questions about who uses science and to what ends.*

By respectfully partnering with diverse communities, we access a broader range of values, ask questions that haven't been asked before, and avoid the inadvertent use of science to enhance inequity.

Most importantly, by designing science with communities, community science allows us to grapple with moral issues, consider values, and weigh options in a much larger and more inclusive context"

Raj Pandya, Director, Thriving Earth Exchange

A voyage of discovery & collaboration

Summary

- Participatory approaches where possible

- Open access data in general

- Cultural sensitivities around data access and anonymization

- Research should do good (beneficence)

- What knowledge will the community gain from this study? To whom is the researcher accountable?'

www.curiousminds.nz