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Public Trust in Science and Research

responsibility and ethics

Abstract

Innovation in science and research technology often raises questions of acceptability, ethics and governance processes. This article explores research assessment and ethics frameworks based on values, responsibility, relationships, trust and distributed power, which could give guidance to decision making around research and development investments in scientific institutes. Governance using a responsibility lens alongside risk mitigation, based on explicit ethical and moral values, allows critical evaluation of research programmes which seek to address inequities in society. Funding for formal research assessment structures that bring diverse perspectives together within institutions would facilitate ongoing dialogue with Māori and local communities and strengthen decision making. The example of the current and future development of waste water-based epidemiology technologies is used to show how a responsible research approach could be applied.

Keywords social licence, governance, democracy, new technology, responsible research, te Tiriti o Waitangi

Ethics and governance of emerging technologies

Innovation in science and research technology often raises questions of acceptability, ethics and governance processes. Examples include biotechnologies (Cook et al., 2004), joined-up data sets such as the Integrated Data Infrastructure (Kukutai and Cormack, 2019), and population health surveillance tools such as those developed for Covid-19 contact tracing (Dare, 2020). Acceptability of new technology, related to perspectives of potential benefits and harms, can become a political issue, as was seen in the 2000s when the Labour-led government established the Royal Commission on Genetic Modification. Less overtly political responses may act through public agencies, such as the National Ethics Advisory Committee,¹ or working groups such as the Data Ethics Advisory Group convened by the government chief data steward.² The work of these bodies ranges from widespread engagement with communities through to consultation with small reference groups, each type of response carrying implicit claims of legitimate expertise and

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appropriate control of decision making (Fischer, 2009).

Within Aotearoa New Zealand there is currently a lot of interest in ethical research processes. For example, in recent years the Royal Society Te Apārangi has been working on guidelines for supporting good research practice, including public engagement guidelines, an updated code of professional standards and ethics, and a research charter (Royal Society Te Apārangi, 2016, 2018, 2019). These provide broad frameworks for thinking about what processes a responsible research organisation should consider, and reflect international developments in this space (International Science Council, n.d.). Another example is the Health Research Council's Māori health advancement guidelines, where the first domain for consideration is the relationships between the research team and Māori, so that the research can be aligned with what is meaningful for Māori. In this article we consider existing frameworks that may guide 'responsible' research practices, specifically for the purpose of guiding investment decisions in new and emerging technology and disciplines.

The concept of a 'social licence to operate' is a common way of thinking about ethics and engagement with communities (Edwards and Trafford, 2016). It originated in the context of extractive industries such as mining and forestry, and is now widely applied in Aotearoa New Zealand in a variety of contexts, including data sovereignty, primary industries and developing scientific technologies (Data Futures Partnership, 2017; Jenkins, 2018; Ministry for Primary Industries, Quigley and Baines, 2014). There are numerous critiques of social licence as a concept when addressing future uncertainties associated with emerging technology development, or working with te Tiriti o Waitangi-based partnerships (Jenkins, 2018; Moffat et al., 2016; Owen and Kemp, 2012; Ruckstuhl, Thompson-Fawcett and Rae, 2014; Te Mana Raraunga, 2017). While social licence is likely to have merit with specific proposals (for example, developing a tissue biobank), we sought to identify frameworks that would support decisions regarding emerging areas. By emerging we refer to either developing technologies or developing

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issues that may benefit from different applications of existing science capability.

In exploring responsible research, this article first considers the concept of responsible research and innovation (RRI), which has been prominent in European research policy and funding for the past two decades. The Māori research ethics framework *Te Ara Tika* is then considered. The third framework comes from the International Association for Public Participation and related literature that emphasises 'upstream' community engagement. All three frameworks are based on the idea that ethical engagement with communities is most effective when it is started early and develops into an ongoing relationship, and that research agendas should be shaped by such engagement. The frameworks are then applied to waste water-based epidemiology, as an example of an emerging scientific technology. The final section suggests policy implications for a responsible approach to scientific research and development in Aotearoa New Zealand.

Responsible research and innovation (RRI)

The concept of responsible research and innovation focuses on the responsibility that research institutions have towards society. Current research investment decisions are often based on benefits and costs (of development, but also of mitigating risks), capability, demand

and potential future revenue. An RRI approach adds a critical assessment that is based on values and responsibility, along with addressing inequities in society. RRI involves ongoing dialogue and responsive processes, and considers what could and should be done for the benefit of society, not just what should *not* be done. The concept arose in Europe in the late 1990s as a result of public rejection of biotechnologies, such as genetic modification of food and stem cell research; new concerns arose about the development of nanotechnology in the early 2000s (Pidgeon and Rogers-Hayden, 2007). RRI as a concept became widely utilised after the European Commission's *Horizon 2020* research and innovation strategy for 2014–2020 explicitly included it as a funding requirement (European Commission, 2019), similar to the way Vision Mātauranga has been integrated into the science funding system in Aotearoa New Zealand (Rauika Māngai, 2020). The concept of responsible research, over and above a duty to practise ethical behaviour, is supported by the International Science Council and the Royal Society Te Apārangi (International Science Council, n.d.; Royal Society Te Apārangi, 2018).

An influential definition of RRI is: 'Responsible innovation means taking care of the future through collective stewardship of science and innovation in the present' (Stilgoe, Owen and Macnaghten, 2013, p.1570). Stilgoe et al. suggest that RRI has four dimensions. *Anticipation* means that the research institution should make considered judgements about potential impacts of new technologies and research, and act to maximise benefits and minimise risks, as well as reduce inequities. *Reflexivity* requires the institution to build in a transparent system for reflecting on its own values and potential different framings of the research. *Inclusion* of a diversity of voices in decision making is needed for public legitimacy. Finally, *responsiveness* involves both the capacity and willingness to change the direction of the research in response to the outcomes of anticipation, reflexivity and inclusion.

RRI has been defined as a process rather than an outcome, something an organisation *does* rather than *gains*. Importantly, RRI includes the idea of questioning the societal desirability of the

proposed research or development, and not assuming that innovation processes and the resultant products are going to be wanted by society simply because they are available. René von Schomberg from the European Commission suggested that there should be agreement on what counts as ‘responsible’ research and for this he turned to the democratically agreed values in the Treaty on European Union (von Schomberg, 2013). Applying RRI to Aotearoa New Zealand requires (re) defining values for this context.

Te Ara Tika

Te Ara Tika—‘the right path’—is a framework for human research ethics based on Māori cultural values. A collaboration in 2005 between the National Ethics Advisory Committee, the Health Research Council and Ngā Pae o te Māramatanga – Māori Centre of Research Excellence produced *Te Ara Tika* (Hudson et al., 2010; Hudson et al., 2016). These Māori human research ethics guidelines are based on the principles of whakapapa, tika, manaakitanga and mana, defined in *Te Ara Tika* as connected with relationships, research design, cultural and social responsibility, and justice and equity respectively.

Whakapapa is the central principle, and in this context refers to the quality and processes of research relationships. Whakapapa relationships can be concerned with the subject matter of the research – for example, in genomic research involving DNA which is linked back to ancestors – or to digital data collected from the research, or to relationships between people involved in conducting or participating in the research. *Te Ara Tika* describes three levels of relationships between researchers and iwi and hapū, where the minimum standard is ‘consultation’, good practice is ‘engagement’, and best practice is empowering Māori to take a ‘kaitiaki’ (guardian/advocate, briefly defined) role. This continuum moves from inviting critique of the research through to partnership with Māori on issues that involve Māori communities. In the context of the public service, similar recommendations for best practice engagement with Māori have been produced by Te Arawhiti, the Office for Māori–Crown Relations (2018).

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Related to the ethical guidelines outlined in *Te Ara Tika* is the concept of Māori data sovereignty. Te Mana Raraunga, the Māori Data Sovereignty Network, advocates for Māori data to be subject to Māori governance (Te Mana Raraunga, 2017). Māori data sovereignty implies co-governance of data, according to the principles of te Tiriti o Waitangi and the United Nations Declaration on the Rights of Indigenous Peoples. According to *Te Ara Tika*, therefore, a responsible approach to scientific research and development in Aotearoa New Zealand requires a focus on relationships and co-governance with Māori. This is in addition to engagement with the broader community, where the quality of relationships also has importance.

Upstream community engagement

Community engagement is an important part of ensuring that public good research is ethical, perceived to be beneficial and therefore welcomed. The timing and extent of engagement is critical to its effectiveness. This was shown clearly with the resistance to biotechnologies in Europe in the 1990s, when engagement with the community only occurred after there had been significant investment and development of the science. The

political fallout from this influenced the development of the RRI concept (Pidgeon and Rogers-Hayden, 2007). The approach of engaging with communities after technology development, rather than at an earlier stage, is linked with a deficit view of community concerns. The deficit view suggests that communities object to technology mainly because of a lack of understanding, and that this can be overcome with careful communication of the technology’s benefits. Such a view glosses over the idea that the community might have different perspectives on what constitutes ‘benefits’; nor does it involve reciprocal dialogue, where the community views are listened to and acted upon (Becker et al., 2017).

An international framework for guiding community engagement is the Spectrum of Public Participation, highlighting increasing impact on decision making as public participation moves through a continuum of inform–consult–involve–collaborate–empower (International Association for Public Participation, 2018). There are clear alignments here with *Te Ara Tika*, which proposes a continuum of Māori engagement moving through consult–engage–kaitiaki (Hudson et al., 2010), the Health Research Council emphasis on developing ongoing, mutually beneficial relationships between researchers and Māori (Health Research Council, 2019), and the Royal Society Te Apārangi’s public engagement guidelines based on a principle of an engaged and informed society (Royal Society Te Apārangi, 2016). Community engagement at the beginning of the continuum (inform) represents ‘downstream’ community engagement, and the other end (empower) is ‘upstream’ community engagement. Upstream engagement is useful in the context of developing potentially controversial technologies, as an emphasis on authentic and reciprocal dialogue enables public voices to be heard at a stage where they can influence the research agenda (Becker et al., 2017).

Connecting themes

These three frameworks are from different countries and different research fields and target different levels of influence. Yet common themes can be discerned

for guiding an ethical and responsible approach within the context of innovation in science and technology in Aotearoa New Zealand. First, the frameworks are based on explicit normative values, whether coming from a cultural world view or from democratically derived agreement. Then there is a broad view of research ethics which encompasses not only risk management, but a responsibility to work in the interests of the community. These three approaches are based on the establishment of trusting relationships and involve sharing of power and influence on decision making. Finally, these conversations are extended beyond the research institute to the wider public, encouraging deliberative processes for setting the agenda for publicly funded research.

Values

Both RRI and *Te Ara Tika* are explicit that research ethics should be underpinned by a set of values. Values can provide direction as to what is important when evaluating research programmes and making investment decisions. There are many values that can be chosen, some complementary and others conflicting. The question of 'which values' is important. For RRI in a European context, von Schomberg (2013) recommended basing decisions on the values of the Treaty on European Union. In our local context, other values can be called upon. The fundamental purpose of *Te Ara Tika*, for example, is to provide an ethical framework based on generalised Māori cultural values. Arguably, in Aotearoa New Zealand high-level guiding values are contained in te Tiriti o Waitangi and the New Zealand bill of rights. These highlight values of equality, freedom, recognition of the rights of indigenous peoples, protection from discrimination, and fair treatment by the government and others. These values already underpin ethical approaches in use, such as the national ethical standards which integrate the principles of *Te Ara Tika* and bioethics (National Ethics Advisory Committee, 2019). The bioethics principle of justice is similarly underpinned by equality, fair treatment and protection from discrimination, and the principle of respect for people (autonomy, informed

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consent) can be seen to rest on the values of freedom and human rights. For an organisation to implement a responsible research approach, it must first be explicit about the values that are used as criteria for decision making. Such an explicit statement of values will be important for developing relationships with diverse publics, which underpin an RRI process.

Responsibility versus risk

Mitigating risks is a major focus of current ethical approaches. Risk management necessarily starts from a deficit viewpoint, identifying those things that should be avoided. This is essential in a robust assessment of research programmes and making investment decisions; however, a 'responsible' approach would take the assessment further. If societal values such as equity and the principles of te Tiriti o Waitangi underpin research decision making, then publicly funded scientific development should not only provide

positive public benefits, but should also reduce existing inequities. This positive framing exists in *Te Ara Tika*, where good research is that which focuses on Māori goals and aspirations, as defined by Māori themselves. Similarly, upstream community engagement enables the research agenda to be set in consultation with the community to reflect their goals and aspirations. With limited resources for research, institutions have a responsibility to ensure that research programmes address the issues of most importance for the community, defined in partnership with the community. This requires actively seeking the voice of those groups who are most affected by inequities, in some cases moving beyond groups who are already organised and resourced for engagement. Taking responsibility means proactive outreach and establishing meaningful relationships (Hepi et al., 2016; Royal Society Te Apārangi, 2016).

Relationships and trust

A common theme in these frameworks or approaches is that trust is the basis for all positive community engagement. Trust is built up over time, in the context of an ongoing relationship where there is fairness, transparency, communication and reciprocity (Becker et al., 2017; Dare, Schirmer and Vanclay, 2014; Hepi et al., 2007). Importantly, the community needs to have trust in the intentions of the research institution, which again relates to being explicit about the underpinning values of the organisation. Community trust in an institution implies a reciprocal responsibility from the organisation to act in alignment with that trust. In developing relationships to support research organisation decisions, there must be explicit consideration of how these external perspectives interact with layers of governance in an organisation.

The three approaches discussed consider community engagement and research ethics as relationship-based processes. Trusting relationships are the *mechanism* for positive community input into research agendas, not a by-product. The bioethical framework commonly used in health research gives guidelines for conditions that should be met for research to be considered ethical. This checklist is

necessary but not sufficient for research to be considered responsible. *Te Ara Tika*, for example, stresses the need for ethics approval to be evaluated against the demonstrated research relationships. Such trusting relationships require time to establish, active effort to maintain, and funding to allow these things to happen.

Distributed power

A common thread that connects RRI, *Te Ara Tika* and upstream community engagement is that best practice is seen as a genuine partnership with the community, where power is distributed among the partners. RRI argues for inclusivity and responsiveness, *Te Ara Tika* understands that the ideal is for Māori to be empowered as kaitiaki in a full expression of te Tiriti o Waitangi partnership, and the furthest point on the spectrum of public participation places final decision making in the hands of the public. A responsible research approach insists that hearing the views and concerns of the community is only the first step in the relationship process, and that the next step is a responsiveness and willingness to allow those views to shape the research (Hepi et al., 2007).

Distributed power is relevant not only for the research process but also for research data. This is of particular concern for developing scientific technologies, which increasingly can store digital data for use with future applications. Gaining consent for these new purposes is usually logistically difficult or impossible, and therefore the governors of the data asset have an important ethical role. A responsible research approach suggests that the research institution should pay as much attention to ethical procedures and decision making with data as with the original research. For data related to Māori, an RRI approach based on the principles of te Tiriti o Waitangi and the value of recognising indigenous rights and data sovereignty would imply that a formal co-governance structure is necessary to meet the institution's public responsibilities.

Waste water-based epidemiology

This article arose from a study of the ethics and public acceptance of waste water-based epidemiology as an emerging science and

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set of technologies. This is a field which has been developing rapidly since the mid-2000s and involves taking samples of waste water entering a treatment plant and chemically analysing them for biomarkers. A biomarker is a substance that has been excreted by a human body, as opposed to a substance that enters the waste water from the environment (or, say, the laundry). To date, waste water-based epidemiology has been used primarily for providing quantified estimates of illicit drugs consumed in a given area. These estimates show a population-level picture of drug use in a non-invasive way, not reliant on the self-reporting of traditional drug-use surveys. Other uses are being investigated, such as detecting the Covid-19 virus for surveillance purposes (Institute of Environmental Science and Research, 2020), and examining consumption of nicotine and caffeine or exposure to environmental pollutants (for reviews, see Choi et al., 2018; Farkas et al., 2020).

To identify different perspectives on waste water-based epidemiology, interviews

have been conducted with stakeholders involved in it in some way, or with ethics or data usage. Detailed findings are being written for publications elsewhere. For the purposes of this article, the findings demonstrate how boundaries of acceptability for stakeholders were intimately connected to the motivations of research, intended purposes and potential beneficiaries. For example, public health uses of waste water-based epidemiology were seen as less problematic than law enforcement purposes. Also, when data is shared to support community decision making and action, it was viewed as less problematic than 'taking' local data for central government decision making without community voice.

Given that perceptions of acceptability were tied up with motivations, purposes and beneficiaries, as waste water-based epidemiology technology and applications develop we can expect the boundaries of acceptability to shift, and that there will be diversity of perspectives on either side of these boundaries. It would be difficult to develop a new research project to assess each generation of the technology and associated uses. Instead, in line with principles underpinning *Te Ara Tika*, upstream community engagement and RRI, ongoing relationships with diverse stakeholders would allow for regular testing of perspectives of new technology and applications. Indeed, in our research on waste water-based epidemiology, stakeholders expected that a 'responsible' research organisation would have such relationships and mechanisms for engagement in place. This expectation is also stated in the Royal Society Te Apārangi research charter, where it states that researchers should 'endeavour to identify and engage with stakeholders and/or affected communities' and research organisations should 'establish and maintain good governance and management practices to support and encourage responsible research practice' (Royal Society Te Apārangi, 2018, p.1).

Secondary uses and data governance concerns are also illustrated through the example of waste water-based epidemiology. Communities may find that waste water-based epidemiology data, gathered for other purposes, could be useful for their

own benefit. Aggregated data on illicit drugs, for example, is routinely published online; however, some community health, addiction and rehabilitation services may be able to use the more detailed data for delivering health services. Governance decisions around this release of data may include considering who has rights to such data, and the need to support the community services to interpret and use the scientific data in order that it can be used in a responsible fashion.

Implications for funding policy

A responsible research approach is based on creating long-lasting, trusting relationships. Multiple research projects have investigated how to create such relationships (Becker et al., 2017; Dare et al., 2014; Ministry for Primary Industries, Quigley and Baines, 2014; Pidgeon and Rogers-Hayden, 2007). To achieve this takes time, as relationships are built through shared experiences, open and transparent communication, and consistent delivery on promises. It requires a genuine commitment to reciprocity, to listening and responding. Those people who can bridge the gaps between different world views and communities are invaluable, and such capacity within research organisations should be nurtured.

Developing relationships requires guaranteed resourcing beyond the lifespan

of any one research project. When science funding is predominantly focused on projects, there is little incentive to establish and maintain structures which enable relationships to be built and community engagement to be normalised. When government agencies purchase scientific services they are, in effect, leveraging the relationships that the research organisation and communities already have. To support responsible research processes, and relationships that underpin these processes, scientific service contracts should acknowledge the shared power and the influences on how science is conducted, managed and communicated. The costs of shared governance structures, community engagement and te Tiriti o Waitangi partnerships need to be considered in funding models for contracting scientific research, testing and advice. For government agencies purchasing research, they may need to consider responsible research processes research organisations have in place when evaluating providers.

Conclusion

Making investment decisions in emerging science and technology in the context of publicly funded research can be usefully guided by approaches and frameworks that emphasise proactive responsibility and move beyond risk mitigation. Aspects of the European responsible research

and innovation approach, the ethical framework outlined in *Te Ara Tika*, and upstream community engagement could contribute to a unique approach to responsible research in Aotearoa New Zealand. Public research institutions taking a responsible research approach would need to be explicit about the underlying values that guide decision making and should incorporate values from te Tiriti o Waitangi and the bill of rights (Royal Society Te Apārangi, 2016, 2018, 2019). Research resources should be focused on issues identified by communities as being important for them, through the development of long-lasting, authentic, reciprocal and trusting relationships with communities, iwi and hapū. Formal institutional research governance structures are one way this might be achieved, where space is created to engage a diversity of views and assess the research in a holistic way. This process would be separate from standard ethical procedures, which are focused more specifically on projects. The responsible research approach will require support through science funding, resourcing of developing and maintaining long-lasting relationships.

1 <https://neac.health.govt.nz/>.

2 <https://data.govt.nz/about/government-chief-data-steward-gc/ds/data-ethics-advisory-group>.

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