# Mapping a route to Indigenous engagement in cancer genomic research

*Kimiora L Henare, Kate E Parker, Helen Wihongi, Cherie Blenkiron, Rawiri Jansen, Papaarangi Reid, Michael P Findlay, *Benjamin Lawrence, *Maui Hudson, *Cristin G Print*

**Precision oncology guided by genomic research has an increasingly important role in the care of people with cancer. However, substantial inequities remain in cancer outcomes of Indigenous peoples, including Indigenous Māori in Aotearoa New Zealand (New Zealand). These inequities will be perpetuated unless deliberate steps are taken to include Indigenous peoples in all parts of cancer research—as research participants, in research leadership, and in research governance. This approach is especially important when there have been historical breaches of trust that have discouraged their participation in health research. This Personal View describes a precision oncology research roadmap for neuroendocrine tumour research, which seeks to reflect the values of New Zealand's Indigenous Māori people. This roadmap includes facilitating ongoing dialogue, Māori leadership, reciprocity, agreed kawa (guiding principles), tikanga (cultural protocols), and honest monitoring of what is and what is not being achieved. We challenge cancer researchers worldwide to generate locally appropriate roadmaps that honestly assess their practices to benefit Indigenous people internationally.**

*Lancet Oncol* 2019; 20: e327–35

*These authors contributed equally

**Auckland Cancer Society Research Centre** (K L Henare PhD), **Department of Molecular Medicine and Pathology** (C Blenkiron PhD, Prof C G Print MBChB), **Te Kupenga Hauora Māori** (Prof P Reid MBChB), **and Maurice Wilkins Centre for Molecular Biodiscovery** (Prof C G Print), **University of Auckland, Auckland, New Zealand; Discipline of Oncology, University of Auckland, Auckland, New Zealand** (K E Parker PhD, Prof M P Findlay MD, B Lawrence MBChB); **He Kamaka Waiora, Waitemata and Auckland District Health Boards, Auckland, New Zealand** (H Wihongi PhD); **Auckland, New Zealand** (R Jansen MBChB); **Te Pua Wānanga Faculty of Māori and Indigenous Studies, University of Waikato, Hamilton, New Zealand** (M Hudson MHSc); **and He Oranga Hauora Healthier Lives National Science Challenge, University of Otago, Dunedin, New Zealand** (Prof C G Print)

Correspondence to:
Prof Cristin G Print, Department of Molecular Medicine and Pathology and Maurice Wilkins Centre, University of Auckland, Auckland 1142, New Zealand
**c.print@auckland.ac.nz**

## Introduction

Large-scale genomic studies of multiple cancer types (eg, the International Cancer Genome Consortium)[1] have transformed our scientific understanding of cancer and have facilitated precision oncology in which clinical care is guided by individualised genomic information about each patient's cancer. Precision oncology includes sequencing genes in individual tumours,[2] along with minimally invasive diagnostic methods such as circulating-DNA liquid biopsies.[3] Precision oncology has met major challenges;[4] however, clinicians have high expectations for its use,[5] and the approach is beginning to change clinical practice.[6] The effect of precision oncology has reached some Indigenous peoples, including Māori whānau (families) with cancer. An example in Aotearoa New Zealand (New Zealand) is the discovery of specific germline mutations in *CDH1*, a tumour-suppressor gene that encodes cadherin-1, among Māori whānau with hereditary gastric cancer.[7] The discovery not only provided a better understanding of this cancer, but also resulted in the development of new diagnostics to identify high-risk patients who can now consider surgery as a treatment option.[8] This research was designed with ongoing consultation and input from the whānau. However, this example is uncommon and most research is not done in this way, which leads to a risk that any potential benefit might be reduced for Indigenous peoples. This Personal View describes the development of a precision oncology research roadmap for a New Zealand cancer research programme, which has been guided by the values of Indigenous people (New Zealand Māori). The roadmap includes monitoring of what is and what is not being achieved, and aims to prevent perpetuation of health inequities and to ensure that potential benefits gained from its research reach all of New Zealand. We challenge cancer researchers, internationally, to honestly assess their practices and their benefits to Indigenous peoples.

## Equity challenges in cancer care and genomic research

The impact of cancer is disproportionately high among Indigenous populations and available data might underestimate true incidence and mortality.[9,10] Globally, cancer among Indigenous peoples has been largely overlooked, which prompted the inaugural World Indigenous Cancer Conference, which was held in 2016,[11] and the Indigenous Peoples and Cancer Symposium, held in 2018.[12,13] In New Zealand, the situation is acute, where cancer mortality among Māori is higher than in non-Māori populations, even when Māori have the same or lower incidence of certain types of cancer.[14] These disparities occur despite the responsibility of the New Zealand health system to ensure that Māori have "at least the same level of health as non-Māori."[15,16] This responsibility is defined by the Treaty of Waitangi, a founding document of New Zealand signed between Māori and the British Crown in 1840. The Treaty of Waitangi affords the British Crown the right to govern New Zealand (Article I) but maintains the rights of Māori people to own and manage Māori assets (Article II), and to enjoy the rights and privileges of British people (Article III).[17] The rights and privileges promised in Article III underpin the responsibility of the British Crown, and thus the New Zealand Government, to ensure health equity for all populations and the protection of Māori cultural concepts, values, and practices.[15] These treaty rights are embedded in the New Zealand Public Health and Disability Act 2000.

Many factors contribute to poor cancer outcomes among the Māori,[14,18] not least because cancer care pathways are not equitable for Māori and non-Māori people,[19,20] which compounds the burden of incidence. However, the roots of health inequity start long before clinical intervention is required, particularly through current and historical effects on the social determinants of health and inequity.[21,22] Since medical research provides the evidence base that determines future clinical care, health inequity could be exacerbated if Indigenous peoples are omitted from research. Therefore, we suggest that participation of Indigenous peoples, including Māori, in cancer genomics research is important to ensure that Indigenous peoples receive equal benefit from precision oncology in the future. Considering these points, it is disturbing that Indigenous peoples appear to be under-represented as leaders and participants in cancer genomic research, as well as being under-represented in the genomic data generated by this research.[23,24]

Important reasons exist why Indigenous populations might be reluctant to participate. Barriers to access include a mistrust of biomedical and genetic researchers[25–27] and inadequate cultural sensitivity of clinical services and researchers.[28] Although Aramoana and Koea[29] were able to identify 17 publications in which Indigenous peoples were involved in genomic research and biobanking, 15 of which were from outside New Zealand, a scarcity of precision oncology clinical studies or trials exists that explicitly aim to both include and benefit Indigenous peoples. However, a key cause of mistrust is past misuse of tissues donated by Indigenous peoples for research, extending to the genetic data derived from the donated tissue. A pertinent example in New Zealand was the use of genetic information regarding a *MAOA* 30 bp repeat polymorphism,[30] the so-called warrior gene, to incorrectly attribute social traits to Māori people.[31,32] The implications of researchers misusing samples from Indigenous populations contrary to how Indigenous people view ethical consideration of the original donation are clearly illustrated by the Havasupai case against Arizona State Board of Regents and researchers at Arizona State University.[26,27,33–35] When researchers make questionable decisions, a mistrust of genetic and biomedical researchers by Indigenous peoples should be expected.

## Addressing equity challenges in research

In 2016, a team of Māori researchers, ethicists, lawyers, and cultural experts published *He Tangata Kei Tua: Guidelines for Biobanking with Māori*,[36] and *Te Mata Ira: Guidelines for Genomic Research with Māori*.[37] These culturally informed guidelines incorporate key findings from their 3-year project, Te Mata Ira,[38–40] and extend on previous guidelines for Māori health research ethics, *Te Ara Tika Guidelines for Māori Research Ethics: a Framework for Researchers and Ethics Committee Members*.[41] Unsurprisingly, a wide range of views were expressed by Māori informants involved in the project,[40] consistent with previous studies on genetic testing, biobanking, and genetic engineering.[28,42,43] No single view is representative of all Māori or other Indigenous groups, and no single set of guidelines will cover all issues of importance for Indigenous peoples with respect to genomic research.[25,29,40] However, emerging from these studies is a willingness of Māori and other Indigenous groups to participate in genomic research, conditional on appropriate reciprocity and protection of tissue, DNA, data, and culturally appropriate processes.[29] Notwithstanding these points, very few examples exist of robust, culturally safe cancer genomic research programmes that facilitate reciprocal collaboration with Indigenous peoples.

## The New Zealand NETwork! project: PUKUmahi!

The PUKUmahi! (NETwork!) project is a multidisciplinary translational research initiative to improve care of people in New Zealand with neuroendocrine tumours. The project has developed with guidance from the Unicorn Foundation New Zealand, a neuroendocrine tumour patient support group. Neuroendocrine tumours are complex tumours that usually arise from hormone-producing cells, most commonly in the gastrointestinal tract, pancreas, and lung.[44] Incidence in New Zealand is approximately 380 cases per year.[45] Therefore, most New Zealand cancer specialists typically see only one or two cases per year; thus, building clinical expertise is difficult. The PUKUmahi! project aimed to: develop a detailed neuroendocrine tumour registry in New Zealand (including the relative effect of neuroendocrine tumours on Māori and other populations); better understand the biology of neuroendocrine tumours by applying pathology and genomics to tissue collected retrospectively or donated by newly diagnosed patients; and establish a national multidisciplinary medical framework for neuroendocrine tumours informed by the registry and genomic information acquired. However, despite the good intentions of non-Indigenous researchers leading this project, it was recognised that if research protocols are not co-led and co-curated with Māori,[46] then Māori health outcomes from the project might be further impeded and the benefits to Māori will be less likely to be accessed. This concern about the participation of Māori in genomic research drove the development of a roadmap for engagement with Māori, which is described here.

## Roadmap for engagement with Māori

Engagement involves reciprocal communication and relationship building between two or more stakeholders. Engagement with Māori for research in general has been promoted by guidelines and published examples on how to incorporate the Treaty of Waitangi principles of partnership, protection, and participation into research strategies through engagement with institutional consultation mechanisms and Māori health researchers.[41,17,47–49] The PUKUmahi! project has a mainstream approach to its research design. In other words, PUKUmahi! is not designed to focus on Māori only, but is designed to use a suggested classification that acknowledges aspects of research pertinent to Indigenous people, which “may or may not have direct relevance to Māori”.[41] Nonetheless,

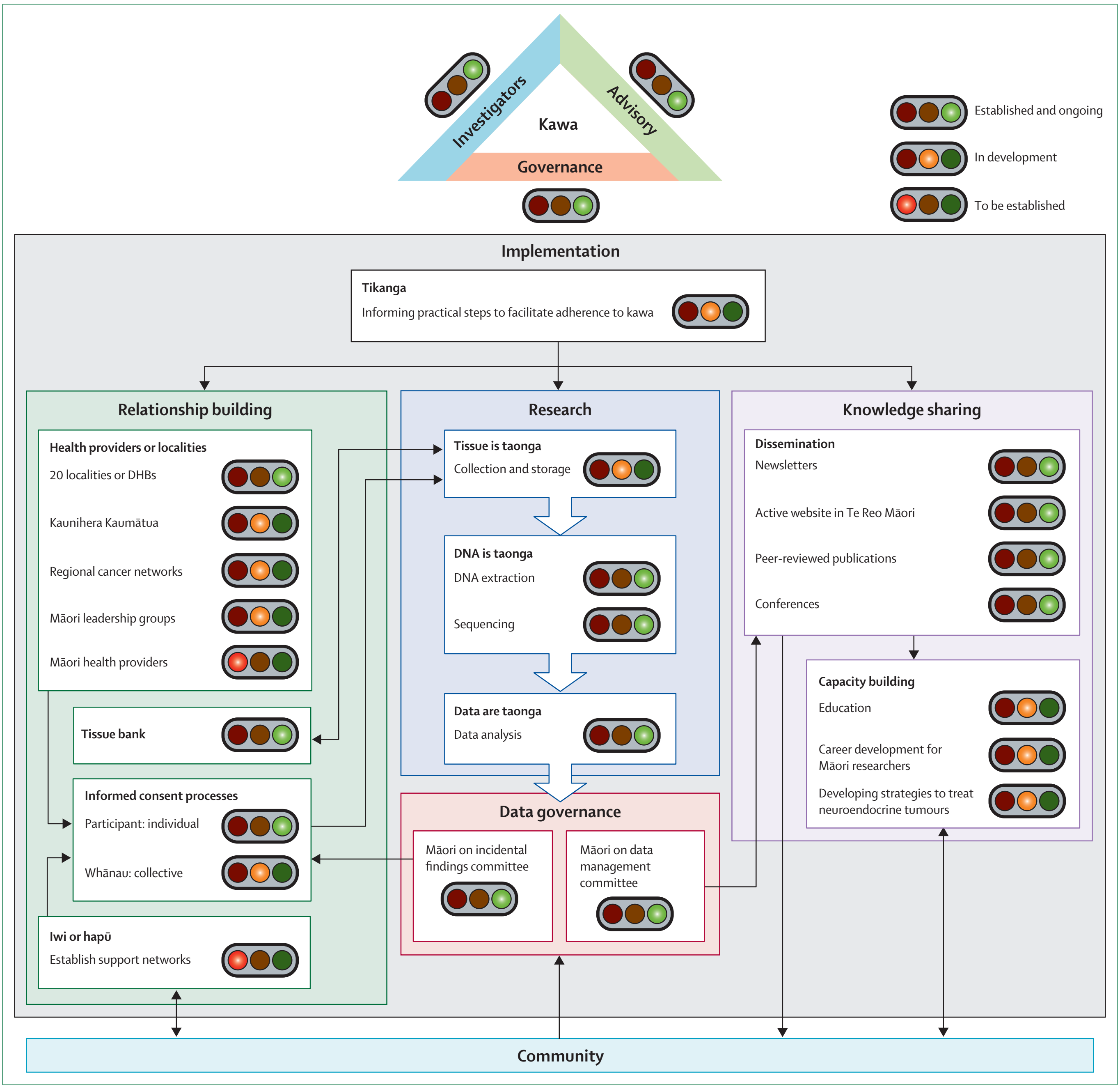

*Figure:* **PUKUmahi! roadmap for engagement with Māori**

A traffic light system indicates what progress has been made along the roadmap at the time of writing and reflects the dynamic nature of the framework. A green light indicates that a process, role, or partnership has been established and is running, but might be subject to change or adjustment as needed. An amber light indicates that processes, roles, or partnerships are currently in development, while red lights indicate those yet to be established. For example, aspects of the study have been presented at both national and international conferences, and in peer-reviewed publications,[45,50,51,52] warranting green lights in the category of knowledge sharing by dissemination. In many cases connections (or roads) are one-way (single-headed black arrows), reflecting that input from one hub to another is mostly unidirectional. However, other roads are bidirectional (double-headed black arrows), reflecting either direct reciprocity between stakeholders (eg, reciprocal capacity building between community and researchers), or multiple functions served by one stakeholder (ie, storage and care of unused tissue gifted by participants, along with providing tissues for the retrospective part of PUKUmahi!). DHB=district health boards.

For **Māori Dictionary** see https://maoridictionary.co.nz

### *Panel*: Glossary of Māori terms

The definitions used here are interpretations for the purposes of the roadmap project, and do not exhaustively include their full meaning or description of their normal use. Definitions were sourced from Māori Dictionary, an online resource based on *Te Aka Māori-English, English-Māori Dictionary and Index*.[53]

Hapū: kinship group, clan, tribe, or subtribe
Iwi: extended kinship group, tribe, or nation
Kaitiaki: guardian with the responsibility to look after specific resources
Kanohi ki te kanohi: face to face (stative) or in person
Karakia: incantation, prayer, or ritual chant
Karakia whakawātea: to remove tapu (restriction)
Kaumātua: elder
Kaunihera Kaumātua: council of elders or district health board Māori advisory group
Kawa: guiding principles
Kia hiki te mauri o te kaupapa: ensuring the integrity of the process; refers to the level of integrity of the project
Kia pūmau te mana o te tangata: upholding prestige and control of the person; refers to the level of control of the person
Kia tau te wairua o te tangata: calming or settling of the spirit of the person; refers to the level of comfort for participants
Koha: gift, present, offering, donation, or contribution
Mahi: work
Puku: tumour or swelling
Pukumahi: hardworking or diligent
PUKUmahi!: The NETwork! research project
Rangatiratanga: chieftainship
Tangata whenua: Indigenous people
Taonga: precious, treasure, or anything prized; applied to anything considered to be of value, including socially or culturally valuable objects, resources, phenomena, ideas, and techniques
Tapu: restricted or restriction
Te Reo Māori: the Māori language, the indigenous language of New Zealand
Tikanga: cultural protocols
Whānau: family group or extended family

we used guidelines[36,37] derived from New Zealand's Te Mata Ira project to design a roadmap for engagement, which facilitates partnership with Māori, aiming to avoid a repeat of past transgressions involving tissues and genetic data obtained from Indigenous populations. The national scale of the project also provides an opportunity for ongoing development of Māori research capability in genomics and precision oncology. The PUKUmahi! roadmap (figure) has two sections: governance and implementation. A traffic light system indicates the progress made (or not) along the roadmap at the time of writing, and reflects the dynamic nature of the framework. A green light indicates that a process, role, or partnership has been established and is running, but requires continued effort and might be subject to change or adjustment as needed. An amber light indicates that processes, roles, or partnerships are currently in development, while red lights indicate those yet to be established. Lights can change colour in either direction as a process becomes established (from red to amber to green), or as a process requires reconsideration (from green to amber to red). We recognise that the remaining amber and red lights indicate where we have fallen short at the time of writing; we need to pay urgent attention to these issues and also acknowledge that we have made several mistakes along the way. An important part of this partnership has been, and will be, learning from these mistakes.

## Governance and kawa

Guidelines[36,37] derived from the Te Mata Ira project emphasise the two cooperating Māori concepts of kawa (guiding principles) and tikanga (cultural protocols; panel). Kawa provide a frame of reference for project governance by defining "core values and ethical principles that underpin a Māori worldview".[37] In the genomic research space, kawa are the principles that inform the responsibility of researchers accepting donated tissues for research,[38] decision making,[39] and relationships between researchers and communities.[40] Tissue and DNA are considered tapu (restricted), because DNA connects to whakapapa (genealogy), where genomic material contains information about the family and not just the individual. The same considerations extend to genomic data by association,[38] necessitating that data are treated with the same care as tissue. For the benefits of genomic research to be fully realised, genomic data need to be made available to researchers outside the immediate research team.[54] However, data sharing needs to be governed to protect privacy, avoid discrimination, and to avoid harm due to inappropriate data use or reporting.[55,56] The requirement for data sharing might be in direct conflict with the kawa that guide the project. Protection of whakapapa is paramount to Māori communities,[38] and thus also needs to be a high priority for researchers who are accepting tissues from Māori for research. In this context, kawa are founded on the basis of recognition that donated human tissue is not just a koha (gift), but it is taonga (precious), tapu (restricted), and is given conditionally. As such, the responsibility to take care of the tissue is also gifted by working within the agreed conditions.[37]

Kawa can be further defined by the concepts of comfort, control, and integrity,[37] which have been incorporated into the project's roadmap. Kia tau te wairua o te tangata (calming or settling of the spirit) refers to the degree of comfort of people with cancer who participate in this research and underpins policy for decision making, research, and engagement with stakeholders.[37] As the research progresses, comfort of participants and whānau might diminish over time if they are unaware of what is happening with the research, or specifically the tissue, DNA, or data. Diminishing comfort is potentially amplified by reports of misuse in other studies (eg, in the case of the so-called warrior gene).[30] Potential also exists for comfort to improve during the research process.

Kia pūmau te mana o te tangata (upholding prestige and control)[37] refers to the degree of control of individuals (participants) and collectives (whānau, hapū [kinship group], and iwi [tribe]) by recognising rights and interest in relation to their tissue, DNA, and data; or rangatiratanga (chieftainship) as indicated in Article II of the Treaty of Waitangi. Ultimately, the decision to participate is in the control of the participant. However, Māori cultural protocols favour collective authority,[28] owing to the importance of whakapapa and relevance beyond the individual. Whānau have a stake in matters involving the DNA of a whānau member. Therefore, an expectation exists among Māori that collective consent is sought and gained at the whānau level, with support from the hapū and iwi. Policies would work to provide sufficient time for participants to make an informed decision, including consultation with whānau, hapū, and iwi as necessary. However, questions remain regarding what whānau consent looks like, and what processes are appropriate for informed whānau consent, an area of ongoing research in New Zealand.

Kia hiki te mauri o te kaupapa (ensuring the integrity of the process) refers to the degree of integrity needed for each step in the research project.[37] Integrity recognises the responsibility gifted to the researchers and the need to maintain the trust of the participants by working within the agreed parameters under which tissues were donated. For example, a concern among Māori is whether samples or data are sent overseas for analysis with technology or skillsets not yet available in New Zealand. In this case, concern arises over whether appropriate protections are in place to prevent unspecified use by third parties. As part of maintaining the integrity of the process, conditions under which the tissue was donated should be imposed upon collaborators overseas, maintaining the responsibility gifted to the researchers.

## Kaitiaki

As part of governance, kaitiaki (guardian) groups can be established to serve as stewards for participants, their tissue or DNA, and their data, and providing culturally informed oversight. They can act to safeguard the rights and interests of patients and extended whānau using negotiated boundaries and restrictions while supporting the research to improve Māori outcomes. The terms of reference and role of such groups are currently being explored in New Zealand, including the potential right for kaitiaki to veto proposed research when necessary. Predictably, establishing kaitiaki groups that are afforded the power of veto to prevent research going ahead is a concept that we believe might make researchers nervous. By contrast, this approach might be an appropriate and necessary part of a trusting research partnership with Māori, especially given past research transgressions that have caused harm to Māori and to other Indigenous peoples. Establishing such a governance group without sufficient power for a kaitiaki to use when appropriate could be perceived as tokenistic or a disingenuous façade of control. More importantly, without sufficient power, such a group is vulnerable to marginalisation. Furthermore, inclusion of mandated kaitiaki might add another layer of control and transparency for patients, depending on the power afforded to them and the terms of reference defining their role.

## Tikanga

Tikanga are protocols that enable researchers to adhere to the kawa.[38] Conceptually, tikanga can be established to address the spiritual, psychological, and physical dimensions of using tissue, DNA, and data in genomic research. A holistic view, including spiritual dimensions, is not generally considered in scientific research programmes, perhaps because such elements are not generally acknowledged by western science.[57] However, appropriately incorporating tikanga offers a platform to address health from an Indigenous perspective.

Careful consideration of how tikanga can be appropriately incorporated into genomic research requires collaborative relationships with Māori, and an understanding of Māori world views. Guidelines[37] deriving from the Te Mata Ira project describe three phases of genomic research where tikanga should be incorporated. These phases include: the point of consent and gifting of the tissue (including tissue, extracted genetic material, data, and responsibility), when the tissue is in the care of the researchers, and at the conclusion of the research when the koha and responsibility for its care are returned to the participant and community (ie, either the tissue itself, or as information or reports).[36]

An amber light in some positions of the roadmap (figure) indicates that tikanga are incorporated into NETwork! project activities, but that more needs to be done to properly address this aspect. For example, PUKUmahi! meetings with stakeholders are usually opened with pōwhiri (a welcoming ceremony) and karakia (incantation or prayer) held by kaumātua (elders) from mana whenua (the local tribal authority who have jurisdiction over the land), and the consent form for PUKUmahi! provides an option for unused tissue to be disposed with an appropriate karakia. However, these first steps could be improved, for example, by also establishing a means for karakia whakawātea (an incantation to remove restrictions) during collection to address anxieties that the participant and whānau might have.[36]

## Implementation

The implementation of the PUKUmahi! roadmap consists of three co-dependent strands: relationship building, research, and knowledge sharing (figure). A project such as this with a national reach involves establishing working relationships with 20 localities for logistical and administrative reasons. As indicated by the green light, relevant clinical localities have approved the project. To facilitate participation by Māori within the project, PUKUmahi! recognised the need to establish local Māori support and guidance at each locality. The PUKUmahi! project has been presented to the Māori Leadership Group of the Northern Regional Cancer Network. However, we have yet to do the same with each of the other Regional Cancer Networks and are yet to establish working partnerships with all Māori health providers, some of whom are actively involved in research to improve cancer care pathways[7,58,59] and can offer important insights into cancer care pathways for Māori.[60] Establishing some, if not all, of these relationships could help to provide formal and meaningful local support and knowledge, when needed, as a Māori patient with a neuroendocrine tumour is diagnosed or recruited from that locality.

Relationship building with prospective participants and their whānau usually begins at the time of seeking informed consent. Being available to answer questions and discuss the research in person is part of the process which is helpful; requesting consent kanohi ki te kanohi (face to face) is an important part of tikanga Māori.[28] Consent is an emotionally sensitive proposition, as the participant and whānau will be coming to terms with the cancer diagnosis and having to make important decisions related to care. Whānau might also draw on the support of hapū or iwi members to guide their decision making, and established relationships with Māori at each locality could facilitate this process. On rare occasions, archival tissues might need to be accessed where informed consent cannot be obtained retrospectively. In these cases, a strong argument for public good must be made, and consultation, to determine the appropriateness of access under these circumstances, should be done with patients, community groups, local Māori, and regulatory bodies such as central ethics committees. The process of consultation for permission ought to be seen as a powerful opportunity to facilitate relationship building, which should continue throughout the life of the project to build capacity, share knowledge, and disseminate findings. Whatever the consent process, the roadmap described here is focused on relationship building, aiming to develop a mutually beneficial relationship, sharing knowledge, building capacity, and expanding comfort zones on both sides.

## Incidental findings, data disclosure, and reciprocation

Some genomic incidental findings generated in this project might be valuable to patients and their whānau, hapū, or iwi in ways that go beyond immediate cancer care. These incidental findings include identification of genetic cancer predisposition in a whānau, which could lead to prophylactic screening tests for whānau members. Therefore, an important aspect of the project was the establishment of a multidisciplinary Incidental Findings Committee consisting of patient advocates, scientists, lawyers, ethicists, and clinicians, including lay people and Māori, who collectively could assess the appropriateness of sharing incidental findings with participants.

Managing access to patient data generated through the project is a complex task. As discussed, a tension exists between freedom of access to data to facilitate research that will benefit patients, and a level of data governance that is acceptable to Indigenous participants. Different degrees of sensitivity associated with genome sequencing exist, and the intricacies of this matter have yet to be fully explored for this project, or even internationally. The project acknowledges a general aversion from Māori to making whole-genome sequences freely available on public databases where data can be used for projects that do not have the support of the relevant Māori or tribal communities, especially if linked with markers of ethnicity, which differ from self-identified ancestry measures. By contrast, access to clinically relevant DNA sequence information might be important for both Māori and non-Māori research participants. To manage these issues, project data are deposited in an archive, from where they can only be accessed by collaborators outside the project after they, and their research plans, have been approved by a data management committee.[50] This committee will have Māori representation and shared governance with investigators. Several international archives that allow access filtering by data management committees, such as the European Genome-phenome Archive,[61] are becoming available and are agreeable to high-impact journals.[53]

Reciprocity is also an important part of research involving Indigenous peoples;[27,39,41,48] thus, showing how researchers intend to reciprocate, beyond technical and analytical work, is essential. Our long-term vision to deliver public benefits, through appropriate representation of Māori in prevalence and genomic data involved in improving precision oncology, is an example of reciprocity. Provision of incidental findings, especially genomic information relevant to patients and their whānau, in an appropriately supported manner can be seen as another form of reciprocation, as are the benefits that arise from strong relationships with Māori, and the avenues of communication they create. Benefits of these relationships might include a reduced likelihood of problematic use or reporting of Māori data; a reduced likelihood of establishing policies and processes that are harmful to Māori or undermine Māori rights; promotion of Māori ways of being and knowing; and improved ways of working together and sharing knowledge.[48] Knowledge sharing is an immediate, tangible approach to reciprocity that we have invested time and resources into.

In consideration of the taonga (treasure) and responsibility gifted to us for research, we have established several ways in which we share information, which is beyond the classic academia-centred approaches of peerreview publication and conference attendance. An active website is available, and has been translated into Te Reo Māori—the indigenous language of New Zealand. Translating the project details and technical terminology serves two key functions: to improve access of information to Māori families and to promote Te Reo Māori as a living language through the development and use of contemporary terminology. PUKUmahi! is the Māori name given to the NETwork! project, combining puku—one of the meanings of which is tumour—and mahi (work); pukumahi also means diligent and hardworking, perhaps reflecting the volume of work involved in such a project.

Another key area of reciprocation and knowledge sharing for PUKUmahi! is capacity building for Māori researchers. A severe shortage exists of Māori with the expertise to conduct genomic research, analyse genomic data, or to fulfil genetic counselling roles in the community. Addressing this shortage is essential to achieving mutually beneficial community engagement, particularly for facilitating appropriate design of genomic research, for empowering whānau, hapu, or iwi collective consent processes, and for dissemination of research findings. This goal has not yet been achieved; however, opportunities we could take to facilitate capacity building for Māori in these areas exist. An example is the Summer Internship for Indigenous Genomics Aotearoa, a programme that introduces Māori and community members to genomics; biostatistics; ethical, legal, and social implications; and emerging cultural protocols, which is based on a programme originally established in the USA by the Summer Internship for Indigenous peoples in Genomics (SING) Consortium.[27,62]

## Conclusion

Genomics and precision medicine are transforming clinical care for people with cancer. Substantial inequity remains in the health outcomes of Indigenous people with cancer worldwide, including Māori in New Zealand. This inequity is multifactorial, and partly attributable to disparities in timely access to, and through, patient care pathways. However, we suggest that future inequity could be perpetuated by current ethnic disparities in leadership of, and participation in, cancer genomic research, and in the data this research generates, which in turn underpins future patient care. In this Personal View, we challenge the clinical, research, and patient communities to reduce inequity by generating inclusive research platforms that are conducive to true research partnership with Indigenous communities. Published guidelines on ethics for health research involving Māori,[41] genomic research,[37] and biobanking[36] have been instrumental in generating the PUKUmahi! research platform that we have used as an example. In New Zealand, Māori and non-Māori researchers alike have reason to place an especially high priority on equity in genomic research.

### Search strategy and selection criteria

This Personal View does not present an exhaustive search of the literature in this field; however, during the paper's preparation, PubMed was searched for articles published in English using the terms ("Indigenous people" OR "Māori") intersected with the MeSH term "research design".

We have described the interaction of researchers on one project, in one country, with one Indigenous population. However, while observing this experience, similar principles are likely to be relevant for cancer researchers engaging with Indigenous peoples in other countries. Indigenous scientists and allies of the SING Consortium recently published a framework for enhanced ethical genomic research with Indigenous peoples.[27] In addition to the drive of most genomic researchers to improve outcomes for all people, researchers and health-care providers in New Zealand operate in the context of the Treaty of Waitangi, under which inequity is untenable both in current health-care practices and in genomic research that will shape aspects of future health care. Possibly the most valuable insight gathered from the PUKUmahi! roadmap project was that close partnerships can extend the comfort zone of non-Indigenous genomic scientists to a point where inequities can be addressed, not only for Māori, but for all population groups as participants in and beneficiaries of research. Not only do the underlying principles described in this roadmap align with the themes that emerged from previous studies examining barriers to the participation of Indigenous peoples in biobanking and genomic research,[29] but they also extend beyond genomics research to include indgenous populations in all aspects of health research. With the right guidance, these principles are relevant to other research fields, including those beyond medicine.

### Contributors

KEP, CGP, BL, and KLH built stakeholder relationships. KLH collated information and views for the roadmap. KLH, KEP, HW, PR, MH, and CGP designed the roadmap. KLH, CB, and MH designed and prepared the figure. RJ, KLH, and PR did language translation. KLH and CGP did the literature search. KLH, KEP, PR, BL, MH, and CGP wrote the manuscript. BL, CGP, and MPF led and designed the project. CGP and BL secured funding for the roadmap project. All authors reviewed the manuscript.

### Declaration of interests

BL, KLH, and CGP report grants from Translational Medicine Trust, during the conduct of the study. KLH reports a grant from the Health Research Council of New Zealand (project grant 15/446) during preparation of this manuscript. HW reports work for the Waitemata and Auckland district health boards and has an interest in Māori health. CRP reports grants from The Maurice Wilkins Centre for Biodiscovery and He Oranga Hauora Healtheir Lives National Science Challenge. All other authors declare no competing interests.

### Acknowledgments

We would like to thank the members of Te Mata Ira, PUKUmahi! and He Oranga Hauora Healtheir Lives National Science Challenge research teams, including the participants, stakeholders, and iwi who contributed to the guidelines informing this roadmap. KH's