

# Cancer journeys and health practitioners as gatekeepers, brokers, and boundary enforcers

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## Abstract

Cancer survival is increasingly prevalent, and the longevity of survivors enable them to provide insights into the experiences of living with cancer. The objective of this article is to consider the roles that health practitioners play that can facilitate or provide hindrances to investigations and cancer treatment following a diagnosis of cancer. From 2020 to 2022, 81 interviews were conducted with Māori and non-Māori throughout Aotearoa New Zealand identified as having survived cancer for a long time, from 4 to 37 years. Three primary roles were identified from the participants' stories: practitioners as gatekeepers, brokers, and boundary enforcers. We suggest that each of these roles is based on different forms of integrity: professional, personal, and scientific. Findings raise concerns about the potential for the healthcare system to foster iniquitous outcomes and to marginalise those who explore alternative understandings of cancer and its treatment. To better support survivorship the healthcare system could be more expansive in its approach, improve its performance in the capacity to detect cancer signals, particularly in patients with a prior history of disease, and take a more tailored approach to cancer survivorship.

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## Keywords

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## Introduction

Cancer survivorship is becoming more commonplace, as two-thirds of those diagnosed with cancer survive for longer than 5 years (Te Aho o Te Kahu – Cancer Control Agency, 2021). Issues faced by those who survive cancer for long periods are manifold (Bateman et al., 2023). Survivors have different social, cultural and economic resources that shape their capacities to negotiate or wrangle with the health system to obtain a diagnosis or treatment (Dew et al., 2024). They are required to respond to the interpersonal dynamics of choices that are made, such as making efforts to actively participate in treatment decision making (Lewis et al., 2021). They may experience the changing nature of social bonds following a diagnosis, where relationships with friends and family may, for example, be ruptured or conversely lead to better mutual understanding (Lewis et al., 2024). Survivors have variable access to compassion where compassion may be less accessible if the cancer is deemed the responsibility of the individual (Plage and Olson, 2021). Survivors undertake moral work in making sense of cancer, for example, responses including defiance, determination, and resignation (Broom and Kenny, 2021). Survivors may re-consider issues of spirituality and religion in their sense making (Vachon, 2008). The complexity and variability of cancer survivorship call for the provision of tailored and holistic support (Sperisen et al., 2024). This article considers the experiences and stories of people who have lived with cancer over a long period of time in relation to their healthcare professional interactions.

Our guide to including participants was surviving longer than 5 years when given a predicted survival rate of less than 20% for that period, as used by previous researchers (Hök et al., 2009). For some cancer types in this study the 5-year survival rate is less than 20%. Here we focus on the positions and roles that health practitioners can play in their cancer journey.

The delivery of care for cancer patients and survivors can be uncoordinated across different spaces of delivery – primary care, secondary care (use of hospitals), cancer care providers (Rosenzweig et al., 2017; Tremblay et al., 2023) and palliative care (Geerse et al., 2018). At the time of data collection, New Zealand had 20 District Health Boards, each funding and providing health services in their districts, further challenging the coordination of services. Another complexity in healthcare delivery is the presence of traditional healing practices of the indigenous Māori population. With colonisation efforts were made to suppress these traditional practices but currently Rongoā Māori providers (Māori traditional medicine providers) can be found working independently or alongside primary healthcare providers (Koea and Mark, 2020).

In Aotearoa New Zealand primary care is funded through government capitation funding and patient co-payments. Capitation funding varies throughout the country depending on the characteristics of patients enrolled in a practice, such as the age of the population and area level deprivation. Patient co-payments also vary. Public hospitals

attract no co-payments, and alongside public hospitals there is a private hospital system which is funded by patient fees, health insurance, and public funding. Medications that are placed on a Pharmaceutical Schedule are subsidised by the Government. The Pharmaceutical Management Agency (PHARMAC) determines what goes on to that Schedule. To pick up prescriptions from a pharmacy patients generally have a co-payment. Healthcare services following injury and diseases that are deemed to be work-related are funded by the Accident Compensation Corporation (ACC).

Primary care practitioners (General Practitioners (GPs), nurse practitioners) are usually the first point of call for people seeking mainstream healthcare. As such they manage populations of patients with low burden of pathology, have limited access to diagnostic investigations and treatment options, and are reliant on referral to specialists to confirm cancer diagnoses and arrange treatments. They can then act as gatekeepers for referral, and have at times been critiqued by specialist colleagues for over-referring (Nixon, 2015). Gatekeeping has been associated with lower use of health services and lower expenditure (Ntais et al., 2024), but little research has considered its impact on patient outcomes (Garrido et al., 2011), although it has been hypothesised that healthcare systems with gatekeeping policies lead to lower rates of cancer survival (Vedsted and Olesen, 2011). GPs are then, in the face of uncertainty, tasked with finding the right balance between unnecessary referrals, appropriate referrals, and not referring when that is appropriate.

Uncertainty in medicine has been of enduring interest to medical sociologists and other social scientists (Bosk, 1979; Fox and Fox, 1980; Han, 2021; Light, 1979). It may be at its most pointed for GPs, but it applies across the health system as a consequence of:

numerous unknowns: whether a patient has or will develop a particular condition; how that condition will evolve; to what extent a particular treatment is beneficial; and whether a patient is receiving the right care, in the right place, at the right time, from the right people (Hillen et al., 2017: 62).

If referred, secondary care specialists can act as gatekeepers to investigations and treatments (Nixon, 2015). Decisions are made within an environment of rationing, often based on explicit guidelines or protocols (McLeod et al., 2004). Although efforts are made to govern health practitioner practices, practitioners have the capacity to circumvent rationing tools and advocate for particular patients (Dew et al., 2010).

For patients who have a life-limiting condition the consequences of not identifying the condition or the “right” people to investigate and treat the condition are consequential. The role that a practitioner takes can be crucial to health outcomes. In the following we focus on three roles that health practitioners play in the stories told to us by participants, roles that can hinder or facilitate participants in their access to mainstream health resources through their cancer journey.

In our interpretation of the roles that health practitioners take we draw on Dew’s (2001) notions of integrity in clinical practice. Dew suggests three models of practice that health professionals may take in relation to legitimising their own practices, labelled as scientific integrity, professional integrity and personal integrity models. These models can be mapped on to different roles that health professionals can take that are discussed in this paper.

The models that Dew considers are based on altruism as a stance taken by health practitioners – which although not always met in practice can be deemed an ideal. In the scientific integrity model Western science is truth and medical practice should be based on evidence verified ideally through the methodological approach of randomised controlled trials. Clinicians are positioned as elite technicians, and clear boundaries are in place to determine what is acceptable practice and what is not. In the professional integrity model practice is based on professional norms that are part of a consensus. Practitioners may be elite technicians but are also responsible for conforming to the norms of the profession, such as appropriately using resources. The personal integrity model is one where the practitioners may also act as a guide for the patient, in the sense of supporting them to fulfil their potential. In relation to this research rather than supporting them to fulfil their potential they support them in accessing resources, where the practitioner may go beyond expectations to support their patient in their journey through the health system. The practitioner is an advocate for their patient, aligning with a strong sense of personal investment in the clinical outcomes for their patient. The individual in front of the practitioner is the site of concern rather than scientific or professional norms. This tripartite model can be applied to the typology developed here where, instead of focussing on integrity in relation to the credibility of what is practised, integrity can be considered in relation to accessing resources in various ways – gatekeeping, brokering, and boundary enforcing.

## **Research design**

We interviewed people who have survived cancer for a long time (from 4 to 32 years), who can take a longer view of their journey, and here consider the stories they told where health practitioners played important roles in obtaining diagnoses, accessing treatment and ongoing support.

### *Data collection procedures*

Participants (81) were obtained through the New Zealand Cancer Registry (57), and through networks or responses to media publicity (24). The Cancer Registry was contacted to provide contact details for lung cancer registrations where the extent of disease was distant (i.e. distant metastases) and the patient had survived for 5 years or longer. We had set a target of talking to 80 people in order to increase our chances of getting diverse views within the limitation of our research resources. As we had not met our target another request was made to the Cancer Registry to provide contact details for those with 5 years or longer survival with cancer of the oesophagus, pancreas, or with sarcoma or liposarcoma where the extent of disease was distant, and those with 5 years or longer survival with brain cancer, liver cancer and endometrial cancers, for the latter two where the extent of disease was distant.

Information was sent to local community newspapers stating that we were undertaking a research project exploring “through interviews the experiences of people who have lived with a diagnosis of cancer for some time and longer than was expected at the time of diagnosis.” Participants who responded to this and those identified through our own

networks provided diagnosis information directly, which our clinical advisor (ED) assessed to ascertain if they survived longer than clinically expected. If so, they were invited to participate in the study. All participants were contacted by letter, and those that expressed interest in the research were followed up with a fuller information sheet and consent form and a time for an interview was arranged.

Participants were interviewed from 2020 to 2022 from throughout Aotearoa New Zealand. Forty-six were interviewed in person, but in response to COVID restrictions, seven were interviewed via video-links and 28 by phone, with 1 participant with hearing difficulties preferring to respond via email. Thirty-six participants were male and 45 female, 23 were Māori and 58 non-Māori, and the age range was 19–97 years. Time since first diagnosis ranged from 4 to 32 years. The most common primary diagnoses were related to the brain (28), lung (16), breast (10) and pancreas (7), with a range of other cancers including mesothelioma, melanoma, and bowel. Data from this research is not publicly available.

Narrative interviews were used to obtain participants' accounts of cancer survival, an approach deemed appropriate to obtain time-based experiences (Riessman, 2008). A timeline was used to identify major events, turning points, disruptions, significant changes and so on (Patterson et al., 2012). Participants were asked what led up to their diagnosis, what treatment occurred, what part they played in the decision making, what if any non-conventional or non-medical approaches they took, who helped in the process, what they would say to someone who was given a cancer diagnosis, and what has helped in their trajectory? Interview length ranged from 21 to 144 minutes with a total of 72 hours of audio-recordings.

## *Ethics*

Ethical approval was given by the Central Health and Disability Ethics Committee (ref 20/CEN/46). Information sheets noted that the research was confidential, that participants had the right to not answer any question, they could ask for the recorder to be turned off at any time, and they could withdraw from the study within 6 months of the interview being undertaken. Information sheets provided contact details of the interviewer and principal investigator if they had any questions or problems, and contact information for cultural support and health and disability support if required. In the few cases where participants visibly expressed distress during the interview they were offered the opportunity to take a break, discontinue the interview, or reschedule.

## *Analysis strategy*

For this article KD, KC, RE, and CC closely read the transcripts from interviews they collected, and used descriptive coding (Gibbs, 2007) to identify issues related to obtaining a diagnosis, access to treatment and on-going monitoring. The team met at a writing retreat to consider the material identified using these codes. We considered in particular two of the basic questions Charmaz suggests when undertaking an intensive reading of collected data: what is going on? what are people doing? Through this process the variable roles played by health practitioners were apparent. We observed in the data that

health practitioners (GPs, hospital doctors such as oncologists and surgeons, doctors running trials, and nurses) can take on a great variety of roles (advisor, educator, friend and so on). In the following we focus on the specific roles that functioned to facilitate or hinder access to the resources of mainstream medicine, as these played a critical role in participants' journeys. We have organised these into the roles of gatekeeping, brokering, and boundary enforcing, which we consider in the following section. All names given to participants are pseudonyms.

## Gatekeeping

In Aotearoa New Zealand GPs act as gatekeepers in terms of referral to specialist care and accessing diagnostic tests. GPs could facilitate quick access to further health care resources for participants if they had concern about their symptoms. However, delays in diagnosis for participants was not uncommon, even for participants with a prior history of cancer. In taking a more cautious approach to diagnosis, these GPs were acting as gatekeepers in the system, enacting professional integrity. Gatekeeping could be overturned by changed circumstances, when participants experienced more serious symptoms, when participants deliberately or coincidentally obtained referrals from a different practitioner, or by intervention from a friend or family member. That is, the gates could be pushed open, even if initially shut, and so the same GP could take on a different role depending on the context.

Peter had seen his GP for "something" going on in his chest, but it was not until he collapsed that follow-up scans revealed lung cancer. Anthony's GP ordered blood tests when he had stomach pain, but as they were "100% perfect" nothing further was done until his partner, a nurse, was able to get him admitted for a scan in a public hospital, where a neuroendocrine tumour of the pancreas was found. Tūi saw a locum when her usual GP was away. The locum, unlike her usual GP, had enough concern about her symptoms that he referred her urgently to hospital where endometrial cancer with metastases was found, and she was immediately referred for palliative care. In other cases, GPs diagnosed irritable bowel syndrome long before a neuroendocrine tumour of the pancreas was diagnosed, epilepsy was diagnosed before a brain tumour was found, and an ulcer was diagnosed before colon cancer was found.

Delays in diagnosis occurred even with a history of cancer. Barbara had a lump in her breast 10 years after treatment for breast cancer, but her male GP said it was a cyst. Six months later, she asked a female GP if she should do something about it and was told to go straight to the original surgeon, which she did, to find that she had cancer that had metastasised. Deborah, with a history of breast cancer, was "prescribed inhalers and anti-allergic medications" before lung metastases were found. Eight years after a breast cancer diagnosis, Susan had trouble breathing and was told by her GP that it was a cough and, as she had a history of mental health issues, was offered an antidepressant. She went back to her GP again and was sent to emergency as her GP could not find breath sounds in one of her lungs. A CT scan identified lung metastases. Christine, with a history of breast cancer, had a tortuous pathway before her intense back pain was found to be the result of a tumour and fractured vertebrae. Initially, her pain was not checked out, but then she was admitted to ED where pneumonia was thought to be the explanation, and

then a CT scan was thought to have identified osteoporosis. She happened to be working at ACC and in work contact with medical advisors. An advisor suggested he could refer her to a particular orthopaedic specialist. The specialist diagnosed the tumour from the X-rays she showed him. This process to identify cancer took around 7 months.

GPs could be compromised in making referrals even when there were clear reasons to do so due to system constraints, such as holiday periods. Mary was given an initial diagnosis of lung cancer in Australia and was told by her Australian doctors that she would need to be seen in 1 or 2 weeks when she returned to New Zealand. She returned in December, the start of the summer holiday period, saying that “it was all slowed down because all the admin staff were on Christmas holiday” and did not get treatment until March. Susan was given a “likely three-month prognosis” but as it was coming up to Christmas, she was not able to see the oncologist until February or March and so saw an oncologist in the private system.

These examples of delayed or missed diagnosis are harrowing for each individual but are indicative of a systemic issue where access to services may be limited and are rationed. Patient co-payments may further limit access for some. In many cases, a high threshold must be met before further diagnostic inquiries are made. In addition to the high threshold, systemic issues could cause problems, such as health staff needing to take holidays.

In the secondary care setting, oncologists and other specialists acted as gatekeepers to cancer medications, and diagnostic and monitoring resources. Some participants were concerned about cancer treatments being withdrawn, treatment being stopped, or monitoring being withheld. The withholding could be contingent on a variety of factors, including assessments of the participant’s response to treatment and their likelihood of surviving.

Barbara would not tell her oncologist of new symptoms but waited to find out what diagnostic information the oncologist had when being seen. She did not “want to tell her anything that would stop her treating me,” or to have her dose reduced, “because as long as I can take it and it’s knocking this (the cancer) inside, I’ll put up with all that other crap.” Christine said that making it to the 5-year mark made her “even more frightened because the Tamoxifen stopped, and in my own head that meant that I had nothing.” Gabrielle had to have a second round of chemotherapy stop, and although she knew that was necessary because the chemotherapy was “bad on your body, you kind of want it and you are kind of scared when you stop.” From these participants’ perspectives, having medications could give hope and stave off fear.

For some, hope might not be offered. Cam collapsed at work and at the hospital he was told that he was thought to have a terminal brain tumour and that “it would be a waste of time” to go to another hospital for treatment, so “go home and wait ‘til it gets you.” His wife expressed unhappiness about this, and he was eventually sent for possible treatment. Susan had a mastectomy and chemotherapy following a diagnosis of breast cancer. Four years later it was found to have spread to her lungs and bones and she had more chemotherapy. She was monitored by the public health system and after another 2 years “when I was diagnosed with the brain mets, they said we won’t treat you, we won’t test you and no more appointments. So basically, nothing. Sorry.” Whereas secondary care initially took on this gatekeeping function, Susan asked a locum GP if she

could continue some medications, which were provided to her, and because she was still alive 3 months later, her oncologist then offered her a CT scan. Michael was diagnosed with mesothelioma, and at the time of diagnosis, he also had pneumonia. His wife said:

they weren't really worried about the pneumonia because they thought he was pretty much dead anyway. We actually had to push our GP, and he was really good, and got more antibiotics.

Beatrice had radiotherapy for her adenocarcinoma of the lungs but declined chemotherapy. She wanted to be monitored so she could see what was happening but was told they only "scan for treatment." She argued that chemotherapy would cost more – and her oncologist "is quite good. . .he scans me about once a year."

The withdrawal of treatments or monitoring raises several issues. Patients may withhold information for fear of being denied medications. For others, the fear and anxiety that denying medications may provoke is considerable, even when medications have the potential to do more harm than good in a clinical sense. And for Beatrice, given a short prognosis of 3–6 months but living longer than that expectation without relying on the expense of conventional medicine had the potential to deny her access to diagnostic information.

Gatekeeping is a necessary aspect of healthcare systems but can deny participants access to important resources. Denial of access may occur as a result of misdiagnosis occurring in a primary care system where access to diagnostic resources is more limited but could also result from GP expectations of their patient, most clearly seen where a patient may be positioned as prone to anxiety, as with the case of Susan who was offered an antidepressant when telling her GP about her breathlessness. Even in secondary care settings with greater diagnostic facilities, participants could be misdiagnosed and so have delayed access to treatment. A systemic source of gatekeeping includes fewer providers being available during holiday periods, and another is grounded in the professional integrity of a practitioner that requires efforts to use resources efficiently and so not waste them on cases where treatment is perceived to have little or no clinical benefit. Participants also talked of practitioners who put in extra effort to facilitate access to resources, to which we now turn.

## Brokering

Participants talked of health practitioners moving beyond systemic constraints and business as usual approaches to take a brokering role, acting as intermediaries in facilitating participants accessing resources. Practitioners then advocated for their patients with an element of personal investment drawing on a sense of personal integrity. John had a long history with pancreatic cancer that had at various stages spread to his lungs and liver, with multiple operations and regular monitoring. At one hospital visit he was told by a hospital doctor he saw to "go away, see you in two years' time." But as he was walking out of the hospital

one of the senior doctors said where are you going? I said I have been told to go. He said you come back here, and they scanned me and of course it (the cancer) was back.

The chance encounter of passing a senior doctor interested in his case and prepared to obtain further testing made a difference, with that doctor brokering access to further diagnostic tests.

Noah felt that his GPs were not giving his pain issues enough attention. Part of the problem was he often saw different GPs, with many locums. It took a nurse practitioner to advocate for Noah, who argued with the locum GP to get further checks. What the locum thought was probably gall stones turned out to be a pancreatic tumour. In this instance a nurse practitioner drew on whatever goodwill she had with the locum GP to support the patient.

Alan's brain surgeon who "for his own professionalism went into bat for me. . . argued and argued and argued and disagreed" with the view of others that Alan had a stage two tumour. On further testing at another hospital, it was found that his tumour was stage three, thus requiring more intense therapy, which Alan then received.

It was not always clear why practitioners advocate for a particular person, but sometimes there were suggestions. Andrea had malignant melanoma that had been misdiagnosed by a pathologist as benign. When the malignant melanoma was correctly identified she was placed on a vaccine trial. She stated that the specialist worked especially hard to get her on the trial even though the misdiagnosis was not his fault: "I think he felt really bad. . . that a mistake was made." The specialist's personal efforts appear to be motivated to make amends for a system failure.

Brendan, a medical professional, was able to go on a trial as "being medical I knew the ropes I suppose." He was also 1 of only 100 people in New Zealand offered a medication at no cost to themselves that was not funded by PHARMAC, the New Zealand agency that determines which medications are subsidised by the state. He explained that the drug company wanted New Zealand doctors to have experience using the medication. Health professionals acted as intermediaries so Brendan could access these extra resources, with Brendan's connections to the health system (social capital) and knowledge of the health system (cultural health capital) working in his favour.

We see in these illustrative examples the contingent nature of outcomes. Systemic issues like discontinuity of care or diagnostic failures could lead to delays, but in these examples, we see nurse practitioners and doctors pushing for optimal care for patients. Patients can then have vastly different experiences, where in some cases a condition that needs attention is downplayed by practitioners, and in other cases practitioners work hard to resist that downplaying.

Considering who is more or less likely to be advocated for is important in a context of health inequities and variable life expectancies across ethnicities. Bernadette had what she called doolallies, a "dizzy thing." She formed a close relationship with her endocrinologist that included Bernadette working at the endocrinologist's clinic so that she could witness a doolally, which turned out to be caused by an insulinoma. Bernadette "used to work in her office putting letters in envelopes and do a walk around the hospital again and again." She did not have a witnessed doolally, but her endocrinologist did identify her unusual condition from an MRI scan, and Bernadette was told on more than one occasion that she was "so lucky" to have that endocrinologist. Presumably, Bernadette was considered by the endocrinologist as someone who could be accommodated in the office space, perhaps an accommodation that would not be given to everyone.

Aaron's case shows many instances where extra effort was put in so he could access unfunded treatments. Aaron, aged 31 at the time of diagnosis, was put on a vaccine trial that included immunotherapy for melanoma. The trial was for those with a high risk of recurrence of melanoma but currently in remission. Once on the trial, a "blue dot" appeared on his neck that turned out to be melanoma recurrence and should have ruled him out of the trial, but the doctors running the trial and the oncologist pushed him through anyway and he had surgery on his neck.

I think, especially because I was young, and otherwise healthy, they definitely did what they could to get me in the trial.

Aaron felt that the oncologist's brokerage to get him on to trials helped his survival and noted a conflict for the health professionals in that "they want good quality research. . . but they probably care more about their patients and making sure their patients get the best treatment." Aaron here references a clash between different forms of integrity, scientific and personal. Later, Aaron was put on another trial of an immunotherapy treatment for active melanoma, requiring further brokering from his oncologist. A swelling was found in his optic nerve which "can be a sign of metastasis in your brain, which would then rule me out of the second trial." His oncologist said, "we'll just ignore that" to make sure he could get on the trial. Later, when his oncologist was overseas, he was found to have high creatinine levels, which could have put him off the trial. Aaron argued that he had high creatinine because of a cramp he had, not the trial drug, but the registrar and another oncologist called in disagreed. However:

thanks to the research nurse, because she was there, and while she took our side, she didn't do it actively because you know. . .they're the oncologists, but she basically said afterwards, like, I'm not going to . . .write anything down and submit it to the clinical trial, we'll just wait for your oncologist to get back.

When his oncologist returned, he was happy for Aaron to continue on the trial. In Aaron's case we see a concerted effort by health professionals to gain him access to potentially beneficial treatments, even with the prospect of undermining the integrity of clinical trials.

The postcode lottery, where health services are not universally accessible across geographic locations (Redhead and Lynch, 2024), could also impact on participants as not all District Health Boards offered the same services. Two participants who lived in one city were able to access brain tumour treatment in another city, even though that was not available in their own area. They felt that they were lucky to be given this chance, a chance brokered by their health professionals.

Patients can then be treated quite differently depending on who their treating doctor is, how they are categorised, their own capacities, social, cultural, and financial, and what their region offered. Treating people differently may be justified but also runs the danger of exacerbating inequities if people are given preferential treatment based on assumptions about who is worthy of extra effort.

## Boundary enforcing

For some participants, their ways of being and understandings of health and illness could be incommensurable with Western medicine, and this was more often the case with Māori participants. Whereas gatekeepers and brokers are primarily dealing with material resources (access to diagnostic investigations and/or treatment), boundary enforcers are primarily dealing with epistemic resources, in determining what ways of knowing can be drawn on as a resource and what ways of knowing are to be excluded. As such they are drawing on their sense of scientific integrity. Gieryn argues that what he calls ideologists of a profession undertake boundary work which has, as one of its goals, the “monopolization of professional authority and resources” (Gieryn, 1983). Gieryn’s focus was on the rhetorical style of boundary work of professions in demarcating themselves from rivals. We consider here ways in which boundary work can be seen in encounters between patients and the medical system. Boundary work that enforces demarcation can and does have implications for accessing material resources.

The Māori world (*te ao Māori*) is incommensurable with the Western world in many ways, and patients and their *whānau* (family) were already negotiating dual or multiple worlds prior to the current episode of cancer. Participants talked of encounters with health professionals that gave a sense of these worlds being made incompatible, that meant for some participants limited or no further contact with conventional health personnel. The professional authority of the health personnel was left intact but that could come at the cost of patient disengagement from the state supported health system.

Ruru took a comprehensive, holistic approach to her own healing, integrating *rongoā* (often described as Māori herbal medicine along with physical treatments such as massage), *wairua*/spiritual practices, and mind-body-spirit connexion, which the medical system did not accommodate:

this archaic medical system we currently live in, needs to stop living in a tunnel and ignoring all the very obvious remedies that are all around, and have been around since the dawn of time.

For Ruru there was a lack of cultural understanding and competence within the mainstream medical system. She felt repeatedly dismissed, misdiagnosed, and not listened to by doctors who did not understand her cultural and spiritual world. This went back many years before her cancer diagnosis, where initially she was prescribed antidepressants, but she told them:

They actually make me feel worse. There’s something wrong inside of me. It’s not in my mind. There’s something wrong inside, inside me, but doctors. . . just wouldn’t listen.

Ruru tells of being given a biopsy without being informed that it was about to happen and the shock it caused left her vomiting in the toilet. These experiences combined with her different worldview led her to a view that “we don’t even need them; we don’t even need the hospitals.” She refused to go back to the hospital after that experience, viewing them as “maintaining sickness.” Having to find her own path, Ruru used black market marijuana, which she swears helped her, and worked with a *rongoā* practitioner who, among

other things, was able “to help me understand that what my body had gone through physically, in my mind, my emotions and my spiritual side were connected.” When asked what had helped her, she also stated “my ancestors.” For Ruru there was a disconnect between a Western biomedical model and holistic Māori health perspectives.

Another Māori person, Emma, was diagnosed with a brain tumour. She tells of her treatment from her initial doctor being so poor that she told him to “fuck off.” Her worldview included one outside of modern science, believing she was not going to die,

because my ones up there [her dead relatives] didn't want me and I didn't want to go up there, . . . They used to come and see me all the time when I was up there. They were always warm. . . . Yeah, my Mum and Dad, my grandfather and all of them.

For some Māori participants there was a gulf between their understanding of health and wellbeing and that of Western medicine, with health professionals maintaining these boundaries through an incapacity to engage with a Māori world of reality.

For non-Māori there could also be incommensurability between systems, with some participants perceiving conventional medicine as not being interested in unexpected or exceptional survival. Beatrice was given 3–6 months to live and embarked on her own journey of healing, that included the use of cannabis and finding her joy. She did have radiotherapy so that she could return home to say goodbye to her family, but then declined offers of chemotherapy to focus on the quality of her life with the little time that she was told she had left. However, she continued to live and was interviewed 4 years after her diagnosis. When asked if she had talked to her GP and oncologist about her use of cannabis she stated: “I've told them, they are not interested.” She thinks they should “take some interest, be curious you know,” but in her case they were not. Michael has mesothelioma and has worked out a health regime with this wife. He gets monitored as a requirement for receiving accident compensation, and said to the interviewer:

You're the first person that's ever asked us these questions. . . every three months, I've got to go and get my medical certificate. And we went in one day. . . and there was a new doctor in. She had just come over from UK. And she'd spent a lot of time with meso patients in the UK. And she looked at my X ray and said, how many months have you been diagnosed? And I said nine years. She said oh okay, signed the form and handed it over. No 'what have you done? How have you done it'? Yeah. It's like they're not allowed to ask questions, you know, they are not allowed to look into this seedy side of the health system.

Beatrice and Michael tell of a lack of interest in their survival beyond clinical expectations. We can only speculate as to why this might be the case, and one possibility is that their stories of survival are not compatible with the stories of unexpected survival in biomedicine, where they may more likely be explained away as cases of spontaneous remission or regression (Papac, 1996) and so not require any further engagement.

When worlds are constructed as incommensurable patients can turn away from mainstream medicine, and mainstream medicine reduces its chances of learning from engagement with patients. Incommensurability has been, in the stories of our participants, constructed by the health providers in mainstream medicine, through such things as

showing no interest in their survival, or the health supporting practices of participants being dismissed by health professionals. This lack of engagement may be because any patient practices having an impact are considered inconceivable or their practices are regarded as irrelevant, so ignoring them preserves the scientific integrity of medicine.

## Discussion

Gatekeepers and brokers can hinder or facilitate patient access to healthcare resources. In any health system rationing occurs, and gatekeepers may act in support of accepted forms of clinical rationing, aligning with professional integrity. Brokers may bend the rules to facilitate access to care, or obtain access to appropriate care against resistance from other health professionals, drawing on personal integrity.

Boundary enforcing is a means of stabilising what is conventional medicine, and, as Gieryn would argue, maintaining its professional authority (Gieryn, 1983). The work of stabilising the boundaries of medicine has been given much attention by sociologists (Brosnan, 2015) and here we see it in interpersonal interactions between cancer patients and health professionals. A boundary is maintained between the epistemic resources of conventional medicine and the epistemic resources of other modes of healing that then preserves the scientific integrity of medicine. Boundary enforcers work to maintain the pure categories that the moderns, as Latour (1993) refers to them, believe in, so ignoring the “unruly hybrids” of “all of culture and all of nature” (Blok and Jensen, 2011: 55). Such boundaries can be incompatible with a holistic Māori view of health and wellbeing. Boundary enforcement can be viewed in contrast to Fricker’s call for mutual epistemic recognition between generic epistemic equals (Fricker, 2018). Fricker argues that the ethos of mutual epistemic recognition “pervades the everyday interactions of people who look to each other for epistemic goods such as reasons, evidence, information, and social interpretations, and it defines the spirit in which we inquire, debate and discuss together” (Fricker, 2018: 4). However, there are many examples of medically trained practitioners extending boundaries or developing unruly hybrid practices that may be in the spirit of mutual epistemic recognition, such as using alternative medicines (Dew et al., 2008), or engaging with Māori understandings (Koea and Mark, 2020), signalling possibilities for different health care practices.

There were cultural and systemic barriers experienced by Māori patients, who often found the mainstream medical system to be dismissive of the more holistic cultural and spiritual emphasis of a Māori world. This led to a lack of trust and so increasing the chance of Māori not making optimal use of mainstream medicine. Our participants’ stories document how the medical system was unable to accommodate alternative views and approaches. Participants told of a lack of interest shown by conventional practitioners in cases where participants had positive outcomes without relying on conventional medicine.

A lack of continuity of care can increase mortality rates (Pereira Grey et al., 2018). For many participants, delays in diagnosis could be an outcome of not seeing the same GP over time. In addition, the gatekeeping role of primary care meant there were issues around getting a timely diagnosis, with the GP thinking the patient’s symptoms or concerns were the result of a more benign disease. To better detect the signals of cancer at

the primary care level may require better access to diagnostics in the community, such as to CT scans and radiology. Delayed diagnoses are even more troublesome when patients with a history of cancer have metastatic disease misdiagnosed.

Some participants spoke of their anxiety when medications were to be stopped. Some participants would withhold information from health professionals to avoid having medications stopped or reduced in strength. Given that health professionals may reduce the dosage and stop prescribing a medication on clinical grounds, there does not appear to be a simple solution to this concern. However, a greater awareness of the issue may facilitate conversations on this between patients and health professionals.

Many participants spoke of what they perceived to be the extra effort that practitioners put into their care. This raises the issue of who gets the benefit of this extra effort. The research findings are suggestive that this is more likely to occur where the patient and the health professional can engage closely and have similar levels of cultural capital. In other cases, health professionals are making their own call on the extra effort, that may relate to the age of the patient (as with Aaron), or the professional standing of the patient (as with Brendan). Such discretionary and contingent decision-making by health professionals may increase the chances of iniquitous outcomes. Greater diversity in the healthcare workforce could provide some address to concerns about inequity (Crampton, 2020), as could the utilisation of decision-making frameworks that take into account the social and structural determinants of health (Smith, 2023).

Finally, we have examples in our research of brokering by health professionals that may undermine the integrity of clinical trials, a clash between personal and scientific integrity. Health professionals face conflicting values when having their patients on clinical trials, one of advocating the best for the patient, and another of promoting the evidence base of medical practice. This conflict may require greater attention.

Given the complexity of issues in medical practice at, systemic, professional, personal, relational, and interactional levels, we cannot expect easy answers to concerns about equity, epistemic recognition, competing demands, resource allocation decisions and so on. Health professionals can base their decisions on different forms of integrity, professional, personal, and scientific, that can be in conflict. At the interpersonal level greater consideration to enhancing a tailored approach, and a greater toleration of curiosity, may be called for.

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## Ethical considerations

The Central Health and Disability Ethics Committee approved our interviews (ref 20/CEN/46) on April 12, 2020. Participants gave written consent.

## Informed Consent

Information sheets were provided to all participants. Prior to the interviews study participants were given an opportunity to ask questions. Consent was given to take part in an audio-recorded interview and for findings to be used in academic publications and conference presentations. Participants could opt to receive the transcript of their interview and also to receive a report on the research.

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## Declaration of conflicting interests

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## Data availability statement

Data is not publicly available.

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