Central
Cancer Network

DEEP DIVE

Kaupapa Māori Evaluation

JANUARY 2020

Taranaki Maunga
Ka noho au i te poho o Taranaki
Here I sit within the heart of Taranaki

Artwork: Jade Beazley

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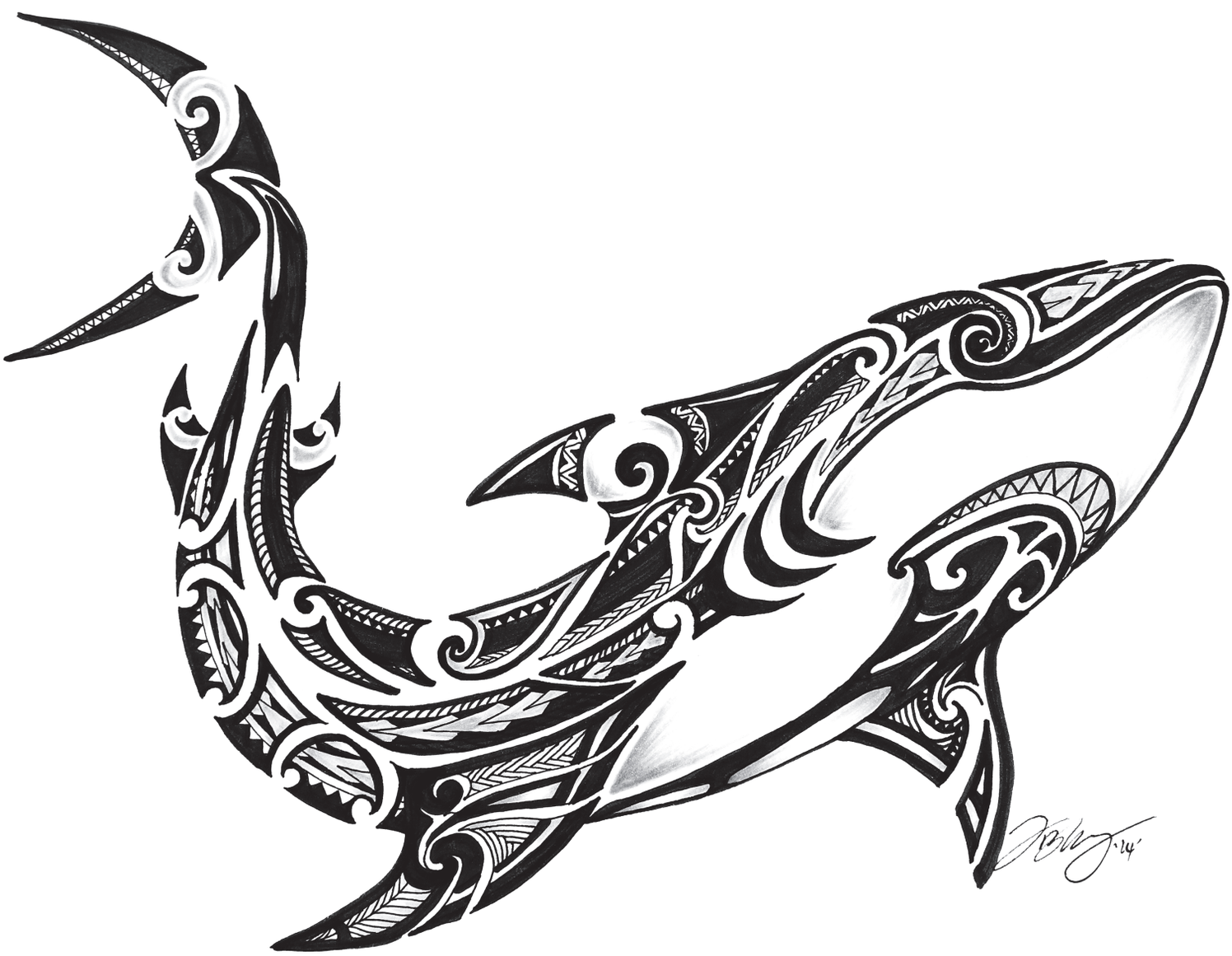

Artwork: Jade Beazley

Executive Summary

Cancer is the main cause of death of people in New Zealand and Māori have significantly higher cancer incidence and mortality than other ethnic groups.

The NZ health system has yet to adequately address cancer health inequities. Strengthened Kaupapa Māori Approaches have the potential to improve cancer outcomes for Whānau Māori across the continuum of care. The Central Cancer Network (CCN) partnered with DHB Māori health teams and local cancer stakeholders to organise a series of Māori Cancer Hui. The aim of these hui was to listen to the aspirations of Māori for Cancer Care, identify key issues and opportunities for change and then use this information to develop actions that improve cancer outcomes for Māori using a Kaupapa Māori approach.

This qualitative research project examined CCN's Kaupapa Māori Approach in engaging with Māori cancer patients and whānau through the hui design and implementation including

- Investigating the ways in which the CCN has engaged Māori cancer patients and whānau.
- Identifying the critical success factors in utilising Kaupapa Māori Approaches.
- Identifying the contextual factors impacting on Kaupapa Māori Approaches.

The Data consists of reflections from the hui organisers and participants collected through Post-hui Debriefs. 10 debrief hui were held from 17 October to 27 November 2019 in a variety of locations with 36 stakeholders who helped to organise the hui.

Within a regional DHB environment and with a range of challenges CCN successfully implemented a Kaupapa Māori Approach through organising 7 Māori Cancer Hui within the central region attended by over 1,000 members of the Māori community.

Kaupapa Māori Approaches are effective if implemented properly. This leads to a variety of benefits for Whānau Māori and Māori Stakeholders. CCN did a good job in the delivery of the hui but can do better in the future. Momentum has been built and needs to continue and be used to help improve cancer outcomes for Whānau Māori.

Background

Cancer is the biggest killer of people in New Zealand and Māori have significantly higher cancer incidence and mortality than other ethnic groups (Central Cancer Network, 2019; Central TAS, 2018; Ministry of Health, 2014b; D Sarfati et al., 2019).

Reasons for this are varied and include

- The legacy of colonisation (M. Jackson, 2013; Ka'ai-Mahuta, 2011; Laing & Pomare, 1994)
- Impact of socio-economic determinants of health (Bramley et al., 2004; Peter Crampton, Salmond, Woodward, & Reid, 2000; M. H. Durie, 2003)
- Impact of negative government policies (Dow, 1999; A. Durie, 1998; Waitangi Tribunal, 2019) R
- Racism and unconscious bias (Heather Came, Doole, McKenna, & McCreanor, 2018; C. A. Houkamau & Sibley, 2010, 2015; Nairn, Pega, McCreanor, Rankine, & Barnes, 2006; Tauri, 2005)

- Poor access to quality services across the continuum of care including health promotion (Cram, Smith, & Johnstone, 2003; Mason Durie, 1999b; Rada, Ratima, & Howden-Chapman, 1999)
- Primary care (Crengle, 2000; D. Jansen, 2018; P. Jansen, 2009; P. Jansen, Bacal, & Buetow, 2011; P. Jansen & Smith, 2006; Waitangi Tribunal, 2019)
- Screening (Curtis, Wright, & Wall, 2005; Diana Sarfati, Hill, Blakely, & Robson, 2010; Diana Sarfati, Shaw, & Simmonds, 2010; Seneviratne, Campbell, Scott, Shirley, & Lawrenson, 2015)
- Treatment (Cormack, Robson, Purdie, Ratima, & Brown, 2005; Hill et al., 2010; Seneviratne, Campbell, Scott, Coles, & Lawrenson, 2015; Slater et al., 2016; Slater et al., 2013)
- Survivorship (Egan et al., 2016; O'Brien, Signal, & Sarfati, 2018)
- Palliative Care (Lawrenson, Smyth, Kara, & Thomson, 2010; Muircroft, McKimm, William, & MacLeod, 2010; Slater et al., 2016)
- Mental Health (Cunningham, Sarfati, Stanley, Peterson, & Collings, 2015; Dockerty, Williams, McGee, & Skegg, 2000; Mason Durie, 1999a)
- Inadequate health enablers such as Cancer Data (Bramley & Latimer, 2007; Curtis et al., 2005; Swan, Lillis, & Simmons, 2006)
- Workforce (Cram, 2010, 2014; Hill, Sarfati, Robson, & Blakely, 2013)Evaluation and Quality Control (Loring, Ineson, Sherwood, & Tipene-Leach, 2019; Poynter, Hamblin, Shuker, & Cincotta, 2017)2019; Poynter, Hamblin, Shuker, & Cincotta, 2017
- Lack of Accountability (Cordery, 2008; O'Connor, 2012; Waitangi Tribunal, 2019)

While recognising the gains already made in Māori health over the past 30 years such as Treaty Settlements (Gibbs, 2006; Katschner, 2005), creation of Māori-led Hauora (Sally Abel, Gibson, Ehau, & Leach, 2005; Chant, 2011; T. Walker, Signal, Russell, Smiler, & Tuhiwai-Ruru, 2008) and a drop in smoking rates (Ball, Stanley, Wilson, Blakely, & Edwards, 2016; Glover, 2013), the NZ health system as a whole has yet to adequately address the issues identified above. Strengthened Kaupapa Māori Approaches have the potential to improve Cancer outcomes for Whānau Māori and achieve Health Equity.

The NZ health system is split into 20 District Health Boards (DHB) and 4 Regional Health Authorities (RHA). The Central Region Cancer Network (CCN) implements regional DHB cancer projects led by a Regional DHB Chief Executive, Regional DHB Planning and Funding Manager and Regional Cancer Manager. The central region covers Capital Coast DHB, Hutt Valley DHB, Wairarapa DHB, Hawke's Bay DHB, Mid-central DHB, Whanganui DHB and Taranaki DHB. The CCN partnered with the DHB Māori health teams and local cancer stakeholders to organise a series of 7 Hui with Māori. The aim of these hui was to listen to the aspirations of Māori for cancer care, identify key issues and opportunities for change and then use this information to develop actions that improve cancer outcomes for Māori using a Kaupapa Māori Approach.

Method

Type of Research

This qualitative research project examined CCN's Kaupapa Māori Approach in engaging with Māori cancer patients and Whānau through the hui design and implementation including

- Investigating the ways in which the CCN has engaged Māori Cancer Patients and Whānau.
- Identifying the critical success factors in utilising Kaupapa Māori approaches.
- Identifying the contextual factors impacting on Kaupapa Māori approaches.

Data Collection

The data consists of reflections from the hui organisers and participants collected through Post-hui Debriefs. Purposeful sampling (Palinkas et al., 2015) was used to select the participants. The criteria for participation was attendance at 1 or more of the 7 Māori Cancer Community Hui and contribution to the organising or implementation on the day. This was mainly Māori Stakeholders but also included non-Māori. The reason for using this sampling method was because the organisers had the required expertise and knowledge (D'Amore, 2004) needed for this research.

The Post-hui Debriefs were organised initially through email and via phone call directly with Stakeholders. 10 debrief hui around 1 hour long each were held from 17 October to 27 November 2019 in a variety of locations including Palmerston North, Wellington, New Plymouth, Masterton, Whanganui and Hawke's Bay. Venues included hauora, cafes, marae, hospitals and DHBs with 36 Stakeholders participating in the discussions. The Post-Hui Debriefs were unstructured and data was transcribed on paper and repeated back to participants to verify accuracy. Unstructured interviews have strengths and weaknesses including limited application outside the sample group (Carter & Henderson, 2005) but they can also provide a more in-depth understanding of participants' perceptions, motivations and emotions (McCombes, 2019).

There were no significant obstacles in recruitment and participation other than some stakeholders being unavailable to contribute until later in the year or difficulty in finding a suitable time to meet. As such not all stakeholders who wanted to participate were able to and numbers were restricted to those who attended the 10 hui and were able to be scheduled.

Data Analysis

A retrospective descriptive and thematic analysis (Hsieh & Shannon, 2005) of the hui process was conducted using Kaupapa Māori principles (Cram, Kennedy, Paipa, Pipi, & Wehipeihana, 2015; Pohatu, 2005; G. H. Smith, 1990). While acknowledging Māori cultural heterogeneity (C. A. Houkamau & Sibley, 2010) Kaupapa Māori evaluation (Rangahau, 2019) is guided by the following 8 principles (Cram 1993, Pihama et al 2002, Cram et al 2003, Pipi et al 2004, Smith 2013, Rautaki 2018).

1. Tino Rangatiratanga - The Principle of Self-determination
2. Taonga Tuku Iho - The Principle of Cultural Aspiration
3. Ako Māori - The Principle of Culturally Preferred Pedagogy
4. Kia piki ake i ngā raruraru o te kainga - The Principle of Socio-Economic Mediation
5. Whānau - The Principle of Extended Family Structure
6. Kaupapa - The Principle of Collective Philosophy
7. Te Tiriti o Waitangi - The Principle of the Treaty of Waitangi
8. Āta - The Principle of Growing Respectful Relationships

These 8 principles constitute the basis of the Kaupapa Māori evaluation and analysis in this report. Data was categorised into the relevant Kaupapa Māori sections and is presented through 8 chapters. Each chapter starts with a summary of the principle, followed by reflections from the Post-hui Debriefs and a Discussion of the key themes. The Analysis also included Triangulation to confirm the data credibility and make conclusions (Denzin, 2012) and experiential learning which provided an in-depth understanding of a Māori context (W. J. W. Edwards, 2010).

Competencies and Bias of the Researcher

I am of Māori Ethnicity and identify as Ngāti Mahuta, Ngāti Rehua and Ngāti Maraeariki. I also have whakapapa links to Ngāpuhi, Ngāti Wai, Ngāti Whātua, Marutuahu, Ngāti te Ata, Ngai Te Rangi, Ngāti Maniapoto and Ngāti Porou. I have over 20 years experience leading teams in the Health and Disability sectors, over this time I completed a BHSc and BA in Social Science from the University of Auckland (UoA) and a Master's Degree in Management (Hon) and PGDip in Māori Health (Hon) from Massey University. While working at the UoA and DHBs I helped design and implement research projects focusing on Māori Health. This included designing surveys for the health workforce and for Whānau Māori, conducting Qualitative Interviews over the phone and in person with Māori, leading Focus Groups with Māori on Marae across the country on topics such as Māori health, Mental Health, Intellectual Disability, Health of Older People, Child and Youth Health.

As the Regional Māori Health Manager for the Northern Region I provided Māori Health Leadership and Evaluation for several large Regional DHB Health Needs Assessments including the Regional Primary and Community Care, Workforce, Frail Elderly, Mental Health and Disability Deep Dive investigations. This included developing strategic relationships with NGO and Māori providers, interviewing Māori Stakeholders and writing the Māori Health Sections of these reports. I currently work as the Regional Cancer Manager for the Central Region. I acknowledge that this constitutes bias in all aspects of this evaluation and limits the validity of the findings and recommendations but is still useful as a reflective exercise for Cancer Stakeholders both Māori and non-Māori and may help to improve awareness of the challenges of implementing Māori approaches and celebrate the successes.

Ethics

A Māori Ethical framework (M. Hudson, Milne, Reynolds, Russell, & Smith, 2010) was applied to this project using four Tikanga based principles 1) Whakapapa (relationships), 2) Tika (research design), 3) Manaakitanga (cultural and social responsibility), and 4) Mana (justice and equity). Low Risk Ethics approval for this project was approved in October 2019.

Whakapapa (Relationships)

Whakapapa was acknowledged through several avenues including recognising the existing relationships that the researcher has with the participants. The outsider/insider relationship as it relates to the role of the researcher was an important consideration for this project's recruitment process (L. T. Smith, 2013). It was expected that the insider relationship would be of benefit to this project as my existing relationships with cancer care services encouraged stakeholders to participate and share information.

Tika (Research Design)

This project applied the principle of Tika in all aspects of design and implementation being first and foremost led by Māori and supported by Māori Stakeholders. The same 8 Kaupapa Māori principles this report uses as a tool to evaluate the Māori Cancer Community Hui were also used in the design of this evaluation. I kept a reflective journal throughout the project which helped me reflect on my actions, thoughts, assumptions and their effect on the research (Lambert, Jomeen, & McSherry, 2010) and this helped strengthen the findings (Finlay, 2008).

Manaakitanga (Cultural and Social Responsibility

Manaakitanga (Mead, 2016) was acknowledged through application of the Principles of Tikanga Māori (Mead, 2016) that were implemented throughout this project such as Whanaungatanga, Tapu and Noa, Karakia, Kanohi ki te Kanohi, Kai, and Koha. One example of how I did this was through the use Karakia for each part of the process such as before and after the Post-hui Debriefs and Analysis. Kaumātua from the MidCentral DHB and Cancer society were available to provide cultural support to myself and participants throughout this project when needed. This report will be made available to all Stakeholders who participated in the Post–Hui Debriefs and used to help advance Māori Health gain.

Mana (Justice and Equity)

This research aimed to help achieve Mana Whakahaere (Autonomy) (Mason Durie, 1999b) for Māori by identifying critical success factors in how the CCN supported Māori cancer patients and their whānau through the hui process. Ensuring the mana (N. Simmonds, 2011) of each person was maintained was an essential part of the Post-hui Debriefs by ensuring that both organisers and participants were able to share their kōrero in a safe way. The findings of this report will add to the body of evidence of how Regional Health Authorities can more effectively deliver a Kaupapa Māori Approach when engaging with Māori Communities and help ensure that health service design and delivery better meet the needs of Māori.

Artwork: Jade Beazley

Chapter 1

Tino Rangatiratanga - The Principle of Self-determination

Principle Summary

Tino Rangatiratanga (Rangahau, 2019) relates to sovereignty (Maaka & Fleras, 2000), autonomy (MH Durie, 1998), control (Broughton et al., 2015), self-determination (M. H. Durie, 2013) and independence (A. Jackson, 2013). The notion of Tino Rangatiratanga asserts and reinforces the goal of Kaupapa Māori initiatives (Bishop & Glynn, 2000) allowing Māori to control their own culture (Crocket, 2012), aspirations (Herd, 2006) and destiny (Tuffin, Praat, & Frewin, 2004).

Tino Rangatiratanga is expressed within Article 2 of Te Tiriti o Waitangi affirming that Māori are able to be in control of individual and collective destiny (Forster, 2008; Humpage & Fleras, 2001; Kingi, 2007). In relation to health this aligns with the need to remove barriers and obstacles to Māori success (Heather Came, Cornes, & McCreanor, 2018; Maaka & Fleras, 2000) including challenging unconscious bias (Workman, 2016), institutional (Heather Came & Kidd, 2019) and other forms of racism (Oda & Rameka, 2012).

Current and past ways the health system has aimed to address Tino Rangatiratanga has been via Māori Health Plans such as He Korowai Oranga (Ministry of Health, 2014a) and DHB Māori health plans (O'Connor, 2012), increased participation in decision making (Signal et al., 2007), regular gathering and reporting of ethnicity data (Bramley et al., 2004), creation of Māori health providers (Kingi, 2007), recognition of Māori models of Health (Whitinui, 2011) and Māori Specific health promotion (Amohia Boulton, Gifford, Kauika, & Parata, 2011).

The recent Health Services and Outcomes Inquiry (Wai 2575) investigated over 200 claims by Māori for provision of health care. Stage 1 focused on Primary care with claimants broadly arguing that Māori are unable to adequately exercise Tino Rangatiratanga due to the poor design and delivery of the current Primary care system (Waitangi Tribunal, 2019).

Reflections from Post-Hui Debriefs

Stakeholders were generally positive around the way the Hui process addressed Tino Rangatiratanga. The approach that CCN took of engaging first with the General Managers (GM) of Māori Health and explaining their intentions to engage with whānau and seeking advice and support was understood and accepted by the majority of stakeholders. All 7 Māori health teams were very supportive of the hui taking place with Wairarapa DHB especially who took a role in all aspects of the development and delivery of the hui. Some of the other GM Māori attended planning hui but most of the teams expressed that their ability to support was limited or non-existent due to capacity constraints delivering their local DHB Māori Health Plan requirements. The GM Māori and DHB teams gave their blessing for CCN to engage directly with iwi and providers, some other Stakeholders would rather CCN have engaged directly with Iwi organisations and hauora and bypassed the DHB's entirely and some commented that it was iwi that represented Māori not the Māori health teams. A clear theme emerged that relationships between providers and DHB teams differed between each individual DHB area and that different Māori Stakeholders had different views on who represented Māori in the Health System and who

should be giving the mandate and taking the lead role in these types of hui.

Many stakeholders commented that giving the majority of the decision making on the delivery and design of the hui to Māori Stakeholders showed respect from CCN for the autonomy of Māori and respected their Tino Rangatiratanga. For many Stakeholders this was a new experience. They consistently expressed that they had become accustomed to being excluded from decision making processes and/or having their decisions ignored or marginalized. Local Tangata Whenua felt involved in the process through participating in the choosing of speakers, leading the pōwhiri process and setting the tikanga processes for the day. This included the choosing of venues, Kapahaka, kai and decisions re koha for presenters, stalls, health promotion banners and other items that they deemed important for the hui. While most providers felt that negotiation with CCN on how the budget used was fair some providers felt that they were not adequately consulted on the decision making processes. This was especially apparent when CCN decided that certain types of payments were out of scope of the hui Kaupapa or were excessive such as koha for certain groups to attend or prices for food and other items.

Concerns were raised that Māori had been consistently let down in the past and that given the positive momentum the hui had created it was important to deliver on the results of the hui and to keep working this way regularly. Although increased autonomy was seen as a good thing by most, a challenge for some providers was the lack of accountability between providers with some either refusing to participate in the hui or agreeing to participate but then leaving halfway with tasks not being completed. Many felt that there was a lack of a process to address broken commitments.

Many non-Māori stakeholders were unprepared and not used to being part of a Māori led process. They had been used to being in control of most of the decision making processes in cancer engagement and had felt challenged and excluded from the hui process. Many questioned the need for the hui and impact they might have. While some of these stakeholders had changed their perceptions post-hui once they saw the results, others were still unhappy that decisions had been devolved to Māori.

Discussion

Most stakeholders were happy with how CNN respected their Rangatiratanga and how decisions were made but true Tino Rangatiratanga would be for CCN to give the $10,000 budget allocation directly over to iwi to deliver the project, however this presents several challenges as CCN is restricted by DHB processes and accountable for the budget and how it is spent (Brinkerhoff, 2004). CCN advocating and securing approval for budget to be spent on Māori projects requires for the deliverables to be specific and achieved by the end of each project (Mays, 2013). This created a negotiation space between Māori stakeholders and CCN where key decisions were discussed and agreed to. The decision making power was not equal in this relationship, as the gate keeper of funds CCN had the ability to veto any decision that it deemed inappropriate and is a reflection of how the system currently functions (Humpage, 2003). True Tino Rangatiratanga in the NZ health system is yet to be realised and unless significant changes are made is unlikely to be realised. The recent Waitangi Tribunal Claims into health may help to achieve this (Waitangi Tribunal, 2019)but in the current environment CCN's attempt to empower Māori as much as possible through shared decision making is a step in the right direction (Harwood, 2010).

Another consideration for CCN has been who are the 'right' Māori to engage with? While it is true that in modern times the crown has recognised iwi as the appropriate level of Māori engagement (Bourassa & Strong, 2000)

within DHBs the GM Māori Health and Māori health teams lead Māori health engagement and projects. It is completely appropriate for CCN as a representative of the DHBs (Central Cancer Network, 2019) to seek direction from the established leadership structures for Māori health within DHBs which are the GM Māori instead of going directly to iwi, hapū, whānau and hauora. This also allows for alignment with local priorities and avoids duplication (Ahuriri-Driscoll et al., 2007).

Capacity from the Māori health teams to support regional kaupapa is a definite issue. It is understandable that Māori health teams are stretched to support regional work as they focus mainly on the delivery of the DHB Māori Health Plans and actions. This has led to many of the staff within the Māori health teams being unavailable to assist as much as they would have liked. This lack of capacity was also felt by non-DHB Māori stakeholders. To adequately address the needs of Māori health both DHB and non-DHB staff need to be better resourced to support regional work. Without this regional health work and regional projects are unlikely to adequately meet the needs of Māori.

It is clear that institutional racism (C. A. Houkamau & Sibley, 2015) and unconscious bias (Heather Came, Doole, et al., 2018) has been experienced throughout this process from a range of stakeholders. Part of the problem is that many non-Māori remain unconscious that their actions contribute towards racism (R. Harris et al., 2006). This includes debating the need for Māori approaches (H. M. Barnes, 2000), resistance to shifting resources and budget from Pākehā projects to Māori projects (Scott, 1994), unwillingness for Māori to lead their own projects (S. Walker, Eketone, & Gibbs, 2006), a lack of awareness of the ineffectiveness of current approaches to meet the needs of Māori (G. H. Smith, 2012) and being offended or taking personally Māori challenges to the status quo (A. M. Barnes et al., 2012).

Artwork: Jade Beazley

Chapter 2

Taonga Tuku Iho - The Principle of Cultural Aspiration

Principle Summary

This principle highlights the importance of Te Reo Māori - Māori language (Reedy, 2000), Tikanga Māori - Māori customs and practices (Mead, 2016) and Mātauranga Māori - Māori knowledge (Hikuroa, 2017) as essential to a Māori way of knowing and understanding the world.

Te Reo Māori is an essential part of Māori identity (MH Durie, 1995) and began to be revitalised in NZ in the 1980s (Gallegos, Murray, & Evans, 2010) through the creation and promotion of Kohanga Reo (Tangaere, 2006), Kura Kaupapa Māori (G. H. Smith, 2012) and the Waitangi Tribunal Claim into Te Reo Māori (Tribunal, 1986). This resulted in Māori language being promoted in public schools (A. Macfarlane, Glynn, Cavanagh, & Bateman, 2007), used in the justice system (Tribunal, 1986), the naming of government departments (Sissons, 1993), Māori Radio (Beatson, 1996), Māori TV (J. Smith, 2016) and many other areas of NZ society (Kearns & Berg, 2002). While variation exists Te Reo Māori has also extended to the delivery of primary care (S. Pitama, Ahuriri-Driscoll, Huria, Lacey, & Robertson, 2011), health promotion (Henwood, 2007), mental health (Johnstone & Read, 2000), hospital treatment (Hatcher, Coupe, Wikiriwhi, Durie, & Pillai, 2016) and palliative care (Simpson, Berryman, Oetzel, Iti, & Reddy, 2015).

Tikanga Māori may vary between iwi and can change over time (Mead, 2016) but includes principles like whanaungatanga -relationship building (Huriwai, Robertson, Armstrong, Kingi, & Huata, 2001), kotahitanga - co-operative co-existence (Chant, 2011), kaitiakitanga - guardianship (Roberts, Norman, Minhinnick, Wihongi, & Kirkwood, 1995), manaakitanga - hospitality (Barnett, 2001) and pōwhiri - traditional welcome (McClintock, Mellsop, Moeke-Maxwell, & Merry, 2012). Mātauranga Māori (Hikuroa, 2017) spans Māori knowledge (M. Jackson, 2013), culture (Wirihana, 2008), values (Harmsworth, 2002) and world view (Ofahengaue Vakalahi & Taiapa, 2013). This includes concepts such as Tapu - sacredness (Te Awekotuku, 1999), whakapapa - family history (Te Rito, 2007), connection to whenua – ancestral land (East, 2014), the use of whakatauki - Māori proverbs (Pohatu, 2003), karakia - prayers and chants (Shirres, 1986), waiata - songs (Sadler, 2017), mauri - life force (Henare, 2001) and wairua - spirit (Kennedy, Cram, Paipa, Pipi, & Baker, 2015). Māori knowledge is often undervalued in health care (Savage, Macfarlane, Macfarlane, Fickel, & Te Hēmi, 2014).

Reflections from Post-Hui Debriefs

Stakeholders commented that Te Reo Māori was used throughout the whole process including during the pōwhiri, kapahaka performances, karakia throughout the day and many whānau spoke in both English and Te Reo Māori during the focus groups.

The series of 15 Māori cancer health promotion banners designed in partnership by CCN and tangata whenua were seen by many as a positive use of Te Reo Māori, that inspired whānau through whakatauki and imagery that respected their whakapapa, identity and worldview. For example, the Whanganui banner used a well-known whakatauki ‘Ko au te awa. Ko te awa ko au’ and showed an image of local Māori paddling down the awa in a waka. The Taranaki banner showed the local maunga and the Porirua banner showed the use of rongoā Māori.

Stakeholders acknowledged the use of and importance given to Tikanga Māori and Mātauranga Māori throughout the hui. Each hui began with a pōwhiri led by tangata whenua, supported by local kapahaka groups. Kai was provided following the pōwhiri and during lunch providing an opportunity for whakawhanaungatanga to occur.

Rongoā Māori, mirimiri, kairaranga and Hauora groups featured throughout all 7 hui with whānau consistently commenting that this created a Māori environment which helped them to feel safe to discuss the difficult topic of cancer. Stakeholders and CCN showed kotahitanga and manaakitanga to each other in the planning process through regular contact and collaboration and during the implementation process through the CCN team coming the day before each hui to setup the venue, giving presentations and facilitating the focus groups. One challenge for stakeholders was the limitation to only 1 Hui per DHB area. Many saw this as affecting how many whānau could attend due to locality. Some had concerns that many whānau would miss out because of this, especially in rural areas and that this needed to be addressed either through more hui in the future or increasing the number of whānau attending each hui. The setting of Tikanga usually ran smoothly with tangata whenua leading the process but some providers commented on some unintended breaches of Tikanga from CCN staff, these were isolated to 1 Hui. Reasons for this were identified as a lack of understanding of the local Tikanga from CCN staff, although CCN had cultural support for their own team on the day provided by the CCN kaumātua and support from local kaumātua at each event. The local kaumātua went home early and the hui was not closed in an appropriate way.

Discussion

The use of Te Reo Māori throughout the CCN hui was appropriate and via multiple mediums. While it is true that many Māori are not fluent Te Reo speakers or understand Te Reo at a proficient level (Bauer, 2008), as a part of the health system CCN still has a duty of care to support the spread and revitilisation of Te Reo Māori (Bright, Barnes, & Hutchings, 2013). The use of whakatauki (Metge & Jones, 1995) and positive images to inspire whānau (Henwood, 2007) to adopt healthy behaviours (Mason Durie, 1999b) is a needed change from the consistent rhetoric of bombarding Māori with the negative consequences of behaviours such as smoking (Maibach & Parrott, 1995). Part of why this is effective is because it supports the development of a secure Māori identity (Jahnke, 2002), through connection to reo (S. N. Zealand, 2015), connection to iwi (Webber & Macfarlane, 2017) and connection to whenua (Carr, 2007).

The value of hui as a way of stakeholders connecting with whānau has been reaffirmed (Lacey, Huria, Beckert, Gilles, & Pitama, 2011). Through the hui CCN gave Stakeholders and whānau a forum and opportunity to express tikanga Māori and matauranga Māori in a positive way including through pōwhiri (Roa & Tuaupiki, 2005), kapahaka (Papesch, 2015), kai (Jackson, 2018) and kanohi ki te kanohi kōrero (Cheung, Gibbons, Dragunow, & Faull, 2007). CCN did an excellent job in supporting Tikanga Māori processes throughout the hui. This is shown by the positive feedback from Stakeholders and whānau that they felt safe and able to express their identity of Māori and the improved relationships built among whānau and stakeholders.

There have been some examples of Tikanga processes breaking down at the CCN end. This is unfortunate but is also a reflection of the current state of the system (Johnstone & Read, 2000), where a largely non-Māori workforce is encouraged to meet the needs of Māori (Roorda & Peace, 2009) but currently does not have the full spectrum of skills needed to achieve this (DeSouza, 2008). Money and people resources to deliver projects has been a tension throughout this process and although CCN has tried its best to address this, increasing resourcing for Kaupapa Māori projects allows for greater opportunities to reach more people and bring them together – kotahitanga (Chant, 2011) and to do so in a Māori way – Manaakitanga (Williamson & Neill, 2014), requires more Māori staff (Ratima et al., 2007), further cultural competency training for non-Māori staff (Waitoki, 2012) and/or further cultural support contracted in for future hui (Hemopo, 2004).

Artwork: Jade Beazley

Chapter 3

Ako Māori - The Principle of Culturally Preferred Pedagogy

Principle Summary

This principle acknowledges teaching and learning practices that are unique to Māori (Rangahau, 2019) and that are preferred by Māori. This is based on Mātauranga Māori (Hemara, 2000) and may include students and teachers at the centre of the educative process (Mason Durie, 2006), life-long intergenerational learning (Bishop, Berryman, & Ricardson, 2002), gradual learning from a familiar starting point (Gibbons, 2010), recognition and encouragement of giftedness (Tapper, 2012), and learning and teaching conducted from the students' strengths (Joyce, 2012). This can be through wānanga (S. Edwards, 2013), marae (Passells & Ackroyd, 2006), whānau hui (Mutch & Collins, 2012), pōwhiri (Rata, Liu, & Hutchings, 2014), kapahaka (Whitinui, 2008) and tikanga processes (Salter, 1998).

The historical focus from non-Māori has been on the gap between Māori and non-Māori educational performance but does not adequately take into consideration the differences between non-Māori and Māori on what they deem is important (Hemara, 2000). An example of this in health is the ideology that if Māori health literacy is improved through increasing awareness of risk factors then it will result in improved health outcomes for Māori (Lambert et al., 2014) that is if Māori just understood that smoking (Glover & Cowie, 2010) is bad for them or if they knew more about nutrition (Crengle et al., 2014) or the consequences of gambling (Bellringer, Pulford, Abbott, DeSouza, & Clarke, 2008) or understood the benefits of regular exercise (Sushames, van Uffelen, & Gebel, 2016) then their health would improve. While it is true that an increase in knowledge does help to make more informed decisions, this approach alone fails to adequately take into consideration the socioeconomic realities of Māori (Bécares, Cormack, & Harris, 2013), fails to acknowledge the current health system is tailored and biased to the needs of non-Māori (Heather Came, 2014) and that non-Māori approaches are not applicable or effective to improving health outcomes for Māori (Hodgetts, Masters, & Robertson, 2004).

Reflections from Post Hui Debriefs

Most stakeholders commented that the series of hui was a unique, innovative and new way of engaging with Māori in cancer and that they had never been part of this type of hui before. However, most of these Stakeholders also commented that although this was a new approach in cancer it is not a new approach to Māori but instead a return to a traditional way that Māori discuss issues through hui and wānanga. Stakeholders felt that this was achieved by including multiple forms of traditional learning and teaching such as holding hui (C. P. Jones, Jones, Perry, Barclay, & Jones, 2009) where possible, pōwhiri, the inclusion of kaumātua, kuia, rangatahi and tamariki and having speakers that were familiar to the community talking about kaupapa that was relevant to them.

Having Māori ways of learning and doing in places of prominence and at the front of the hui was seen as showing the importance and value of these taonga to all who attended. While stakeholders were keen to have the hui on marae they also realised that given the large

numbers of whānau involved it was impractical and would not fit everyone. Stakeholders were happy with moving hui to larger venues like race courses and churches so that more whānau could attend.

A theme emerging from some stakeholders was that they were excited about promoting their Kaupapa and services and that the hui gave them a vehicle to do so. Unfortunately this came at the expense of listening to whānau. Regularly presenters had greatly exceeded their allocated speaking time and this reduced the amount of time in the focus groups. The focus groups were consistently high jacked by several providers who tried to dominate the conversations or tried to dispute whānau complaints about their services whether specifically aimed at their service or not. In 1 hui, presentations from providers and selected whānau dominated the entire day and focus groups had to be cancelled due to time running over. This was a concern to other stakeholders who were unhappy that CCN had come to listen to whānau but had instead exposed them to excessive presentations from a few stakeholders and spent limited time listening to whānau.

Stakeholders commented that it was a breath of fresh air for a hui to be focused on the positives instead of the negatives. Whānau are used to being involved with hui that are focused on the different types of illness especially on issues like cancer that are associated so strongly with death. Instead of focusing on the disease and its treatment of cancer, the hui had focused instead on wellness and prevention in a Māori way.

Most stakeholders were keen to keep meeting regularly and to keep co-designing projects together in a similar way. Māori stakeholders commented that having an event instead of just meeting to talk was more productive. Some stakeholders were unhappy that they had not had a more prominent role in the design of the hui and that they were not chosen as presenters or their kaupapa did not feature prominently throughout the process. Many non-Māori stakeholders in particular were unconvinced that a focus on prevention was the correct course of action and that CCN should be mainly focusing on cancer treatment. This is partly due to personal opinion but also because CCN has historically focused on treatment, due to national priorities, the high costs of treatment and a view of many stakeholders that prevention is the responsibility of other services. Some of these stakeholders also questioned the validity of a hui approach but did also acknowledge that many Māori groups and stakeholders showed up who were usually difficult for them to engage with or hard to reach.

Discussion

The hui/wānanga approach has been successful in including traditional forms of Māori learning and teaching such as pōwhiri (Maged, Rosales-Anderson, & Manuel, 2017), kanohi ki te kanohi (Hoskins, 2010), waiata (Wirihana & Smith, 2019) and tikanga (Timoko, 2014). Another reason for the success has been the decision to include the entire whānau whether old or young. This acknowledges the importance of intergenerational learning (Papuni & Bartlett, 2006) through both the older and younger generation leading different aspects of the hui (Katene, 2010), sharing their knowledge, feelings and experiences (Alterio & McDrury, 2003), and supporting one another in their speaking and exposure to the wide range of stakeholders participating (Slater et al., 2013).

The energy of stakeholders to promote their services should be seen as a positive thing and CCN should continue to support them to connect with whānau and communities, however, an unfortunate consequence has been that many whānau missed out having an opportunity to speak and this has taken away some of what the hui intended to achieve. This also highlights the balance between working with stakeholders to achieve an outcome while also being mindful of the competing priorities of stakeholders (Shore, 2010) as these do not always align. Possible solutions for this may include

increasing community engagement (Spears et al., 2014) through having more hui in the future across a variety of related kaupapa but also being clear about intended outcomes from the beginning (Mackert, Ball, & Lopez, 2011), clarifying processes during the engagement process with stakeholders through clear and consistent communication (Knauss, Damian, Cleland-Huang, & Helms, 2015)and ensuring that facilitators and MCs have the needed skills (Wardale, 2008) and mana (Henare, 2001) to keep the hui kaupapa on track if time limits are exceeded (Botella, 2008) or kaupapa starts to go off track.

Focusing the hui on positive kaupapa and Māori focused solutions such as wellness and prevention instead of focusing on the negatives like specific types of cancer and treatment has been successful. Having a section on treatment is definitely needed. Definite inequities and barriers exist for Māori (Central TAS, 2018) and high cost is a factor (Matheson & Loring, 2011) but taking such a narrow view to cancer excludes the wider issues that cause the inequities (McPherson, Harwood, & McNaughton, 2003) and perpetuates outcomes and a system that only looks at the bottom of the cliff instead of reducing the burden by preventing the illness in the first place (Petersen, 2009). It is clear that although some non-Māori still perceive many Māori Whānau and Stakeholders as difficult to engage with without taking ownership of their own inadequacies in engaging with Māori and that their service may not meet the needs of most Māori. What is apparent is that Māori providers and whānau are extremely keen to be involved as long as it is done in a Māori way (Wilson, 2008) which includes being Māori led (Mane, 2009), Māori driven and with participation in all aspects of design, delivery, teaching and learning (B. Jones, Ingham, Davies, & Cram, 2010).

Artwork: Jade Beazley

Chapter 4:

Kia piki ake i ngā raruraru o te kainga - The Principle of Socio-Economic Mediation

Principle Summary

This principle focuses on addressing the need to alleviate the disadvantages experienced by Māori communities due to socioeconomic determinants of health (Rangahau, 2019). For Whānau Māori this includes disparities in employment (Poata-Smith, 2013), education (Marie, Fergusson, & Boden, 2008), housing (C. A. Houkamau & Sibley, 2015), transport (Raerino, Macmillan, & Jones, 2013), access (Seneviratne, Campbell, Scott, Coles, et al., 2015) and money for treatment related costs (Hill et al., 2013). For Māori kaimahi and providers this includes the same disparities for whānau but also a lack of support through career pathways (Bishop, Berryman, Cavanagh, & Teddy, 2009), Māori skill sets being undervalued (Bevan-Brown, 2011), being underpaid (Clendon & Walker, 2011) and Māori Health being underfunded within the DHB system (Longmore, 2019) and for NGOs (Mathews, 2018).

This principle highlights the need for projects targeted at Māori to be of direct and indirect benefit to Māori communities (S. Walker et al., 2006) and acknowledges the success and appropriateness of Māori approaches (Oetzel et al., 2017) in addressing socio-economic determinants . This includes financial support for whānau on the day through koha (Dudley, Wilson, & Barker-Collo, 2014), kai (Wham, Maxted, Dyall, Teh, & Kerse, 2012) and transport (Raerino et al., 2013) but also assurances that the time spent in discussion will be used for activities that will be of benefit to the community such as being used for the foundation of future projects and programs of benefit for Māori (Greenaway & Witten, 2005). This also includes adequate funding and prioritisation of items that will help to create an environment that meets the needs of Māori (Bevan-Brown, 2005) such as utilising marae (Hook, 2007), Māori traditional practices like raranga (P. Walker, 2004) and spiritual practices like karakia (A. Macfarlane et al., 2007).

Reflections from Post Hui Debriefs

Most stakeholders commented on the range of negative pressures whānau Māori experience in their cancer care including a system that doesn't meet the needs of Māori, financial issues, consistent lack of a mechanism to effectively hear a Māori voice, racism in the health system and that these all contribute to the inequities that exist for Māori Cancer. Stakeholders also pointed out the successes achieved from Māori centred approaches but that these approaches are consistently marginalised and underfunded. They expressed frustration with the difficulty of attending these types of hui for Māori kaimahi when they knew that it would clearly benefit Māori but because they are stretched in their current contracts and deliverables are limited in how they can contribute and support. The 7 Community hui were seen by many as a first step on the way to addressing these issues. This included CCN providing $10,000 for each hui so that it could be run in a Māori way. This was seen as critical because of the inadequacies of the current health system to implement Kaupapa Māori engagement approaches without specific funding and skilled staff to do so.

Most stakeholders felt that CCN supported many whānau to attend through working with hauora to promote the event through their networks, funding the venue, funding for vans and buses to pick up whānau from rural communities,

excellent kai and providing a $20 koha for all whānau who participated in the discussions. Most stakeholders attended as part of their contracts or unpaid to support the Kaupapa but were happy that CCN provided travel assistance to ensure kaimahi could come and provide koha for kapahaka roopu, kaumātua, kairaranga, mirimiri, rongoa practitioners and selected Māori stakeholders. This was seen as supporting Māori to lead a Māori event in a Māori way and alleviating pressure for whānau to attend and contribute to the kaupapa.

The negotiation of how funds were approved by CCN for use was generally seen as fair but some stakeholders were upset during this process expecting to have full autonomy and control over how money was spent. Some felt that 1 hui was not enough and that more should have been done so that many more whānau could attend including doubling the number attending or having 3-4 hui per DHB area. Some stakeholders also felt that they should have been paid to attend or paid more than they were given as koha to attend and saw this as CCN's role to pay for this from the $10k budget or from other sources. Some felt that the $20 koha was an insult to whānau and did not value their time adequately.

Others felt that several stakeholders exploited the process and turned it into a fundraising opportunity, trying to get paid more than they should to support the day, bringing in an excessive number of staff, providing minimal support or substandard services on the day while expecting to be paid as much as possible. Expectations from stakeholders is high that CCN and wider health system continue with this type of approach on a consistent basis across a range of kaupapa because it was highly successful and useful to Māori.

Some non-Māori Stakeholders disputed the use of CCN funds for this type of hui especially when funding and resources meant less funding for other projects focused on treatment or the entire community. They saw the prioritisation of Māori as unfair and unjustified. Most Pacific stakeholders were very supportive of the Māori Hui and viewed it as a good approach that could be extended to Pacific communities in the future.

Discussion

It is clear that negative pressures continue to be a barrier for Māori across a range of indicators. CCN providing $70k and 2 Project Managers towards the hui development and implementation was an excellent way to help mitigate these negative pressures. The money was well used on koha, kai, travel, venue, Māori providers of mirimiri, rongoa, raranga, kapahaka and kaumātua cultural support. This helped create an environment that was appealing to whānau and for them to participate in the event. While this can be seen as a success for CCN and Māori Communities it is has also highlighted the need and demand from Māori communities and stakeholders for more support across Māori health.

While it is true that Māori health is usually a priority in Health Plans (Ministry of Health, 2014a) this is not always true when it comes to being accountable to Māori around what has been spent (Dwyer, Boulton, Lavoie, Tenbensel, & Cumming, 2014) and achieved or in more cases not achieved (O'Connor, 2012). Funding and focus is regularly tokenistic in nature (Manson, 2012) and the increased funding through the hui is seen as a good thing but only a first step. Expectations have now been raised from both community and stakeholders that this type of approach will continue. This presents a challenge for CCN and the rest of the health sector to step up and meet the needs of Māori. This should be seen as good news for the health sector because it shows that relationships have improved and that when hui are adequately funded it allows for Māori to be engaged in a much more meaningful way. This can be an approach that other regional networks can emulate.

Some stakeholders were seen as greedy by other stakeholders but this holds little merit as Māori stakeholders are comparatively underfunded (Pack, Tuffin, & Lyons, 2016) compared to non-Māori approaches and consistently expected to provide services and or support to whānau for little or nothing (Robson, Ellison-Loschmann, Jeffreys, & McKenzie, 2019). While equity may be a current priority (Gurney, Campbell, Jackson, & Sarfati, 2019)& Sarfati, 2019 and understood in theory, by many in the health sector the implications of equity are yet to be realised when it comes to prioritising funding for Māori led approaches (Mathews, 2018) and brings into question the current funding models. There are no magic pots of funding for Māori health and more often than not Māori health has to compete for funding with other projects and groups. For equity to be truly realised requires the shifting of current funding from projects and programs of work that have little benefit for Māori to those that do have a tangible and meaningful effect and the development of a workforce that can effectively implement those approaches (T. Walker et al., 2008).

These discussions are difficult for some non-Māori who do not want to give up funding to support Māori health projects because they see it as unfair even when presented with clear inequities between Māori and non-Māori (Heather Came, Doole, et al., 2018). This raises the importance of not only addressing racism but also basing funding decisions on robust research, data and evidence (G. R. Palmer, 2000) instead of the personal views of a limited number of health leaders.

Artwork: Jade Beazley

Chapter 5:

Whānau - The Principle of Extended Family Structure

Principle Summary

The principle of Whānau sits at the core of Kaupapa Māori (Rangahau, 2019). The importance of whānau has been reaffirmed through Māori health models like Te Whare Tapa Whā (Mason Durie, 1998) and the national Whānau Ora program (Mataiti, 2011). The principle of whānau sets a challenge for those implementing a Māori approach to ensure that whānau (Harmsworth, 2005) and all manuhiri (Godfery, 2016) are treated in a respectful way. The building and maintaining of whānau relationships is a key part of Māori culture and society (Mason Durie, 2006) and this is done within the context of whenua and environment (Mark & Lyons, 2010). Those seeking to deliver Kaupapa Māori approaches should ensure that adequate time (Mason Durie, 2007) and an appropriate environment is available for whakawhanangatanga relationship building to occur (McMurchy-Pilkington, 2013). This can be done through Mihi Whakatau (Pere & Barnes, 2009) or Pōwhiri (McClintock et al., 2012), the sharing of kai (Carpenter & McMurchy-Pilkington, 2008), inclusion in group discussions and supporting all members of whānau including the old (MH Durie, 1999) and young (S. Edwards, McCreanor, & Moewaka-Barnes, 2007) to feel welcome.

The principle of whānau also includes those who are not directly related by blood and this may include whangai (McRae & Nikora, 2006), friends (Dew et al., 2015) and or non-Māori (A. Jones, 2012). In the spirit of whanaungatanga people should feel included and welcome. Exclusion is not in the spirit of whanangatanga and this is regularly shown by tangata whenua in the welcoming of manuhiri onto marae (Austin, 2011) and into Aotearoa as immigrants (Sue Abel & Mutu, 2014). Whānau related principles of Tuakana-Teina (Ware & Walsh-Tapiata, 2010), respect for elders (O'carroll, 2013), respect for the roles of tāne (Love, 2017) and wāhine (Pihama, 2001) throughout a Māori engagement process is all part of whakawhanungatanga.

Reflections from Post Hui Debriefs

All Māori stakeholders agreed that the approach CCN used for the Hui aimed to put whānau first. Some stakeholders were keen to have only those who actually have or have had cancer attend, while other stakeholders agreed with the CCN approach to include the entire whānau, acknowledging that whānau are consumers of cancer services before they get cancer and in the support of loved ones with cancer. The decision to focus the kaupapa on Māori cancer but to allow non-Māori to attend if they wished was seen as being in the spirit of whakawhanaungatanga by most, although some stakeholders were unhappy that some non-Māori tried to dominate the conversations and should not have spoken when it was clearly a Māori Kaupapa. Some stakeholders felt that non-māori should not have been allowed to attend at all.

Many stakeholders commented that attendance was great because cancer is important to whānau, clear communication from CCN that this was about whānau and not about CCN coming to dictate to them or inform them about a health Kaupapa and that whānau would be a central feature of the hui. A theme emerged that whānau were "sick of being told what to do" and brought to pākeha health Kaupapa, led by pākeha, done in a pākeha way, promoting services that did not meet their needs and that

the approach from CCN was the exact opposite of this kind of approach.

Stakeholders commented that whānau were very happy to be able to have a forum for them to discuss cancer amongst their peers and extended whānau. Many whānau had never talked to anyone about their cancer before and that the hui became part of the healing process, both physically, emotionally and spiritually. Having their mamae acknowledged and kōrero heard was seen by stakeholders as an essential part of designing and realigning services to meet the needs of whānau Māori. Some Māori stakeholders were unhappy at the day and commented that whānau had already given similar kōrero in the past and they were sick of having to repeat themselves and the kōrero going nowhere.

Many non-Māori stakeholders who attended had a positive experience and were happy to be part of the process, listening to whānau experiences were seen as helping them with planning and service delivery for the future. Some stakeholders felt that there was not enough time and that there should be more stories from patients and whānau and less from providers. Other stakeholders understood the need for whānau to have their say but were also keen to have more time to be able to connect whānau to their services through more presentations and time with the provider stalls at the hui. While accepting that everything could not have been done all on the same day, most stakeholders agreed that this meant that more hui on a variety of kaupapa needs to happen in the near future and regularly.

Discussion

CCN put whānau first by including the wider whānau (Kara et al., 2011) instead of just cancer patients and survivors. This acknowledges the important role that whānau play in the care of cancer patients (T. Walker et al., 2008) but also acknowledges that whānau are consumers of cancer services across the continuum of care including health promotion (Carson et al., 2014), primary care (P. Jansen & Smith, 2006), screening (Curtis et al., 2005) and engagement with hospitals during treatment (T. Walker et al., 2008). Many whānau attended because of the cancer kaupapa being important to whānau (Kennedy & Cram, 2010) but also because of clear communication (Lorna Dyall et al., 2013) that it would be whānau Māori focused (Nikora, 2007), Māori led (Ellison-Loschmann & Pearce, 2006) and done in a Māori way (S. Walker et al., 2006). This also highlights the importance of networks (Mason Durie, 1999a) and positive endorsement through word of mouth (Moorfield, 2006) to having successful hui with whānau.

Some Māori stakeholders dominated conversations with whānau. This is unfortunate at a whānau centric hui but a consideration is that Māori stakeholders and providers are still whānau Māori. Improved facilitation may help to improve future discussions. Speaking was a form of healing for both whānau (Ott Anderson & Geist Martin, 2003) and stakeholders most of whom had whānau who had passed of cancer. The tensions for speaking times was unfortunate but also understandable. Stakeholders are keen for whānau to be aware of their services and to say their peace. What is clear is that there is a great demand for speaking time in a hui setting from whānau Māori, Māori stakeholders and non-Māori stakeholders and that this could be addressed by more hui on a regular basis (Mathews, 2018). However, calling whānau to a hui and then not giving them a chance to speak is not tika and while surveys may have been one way to address this it does not excuse a lack of speaking time for whānau due to stakeholders dominating presentations and discussion, after all it was supposed to be a whānau focused hui. There is no easy answer as to how to address this, on one hand CCN was trying to listen to whānau but also trying to improve relationships with Māori stakeholders. Telling Māori stakeholders to not talk or trying to restrict their presentations so that whānau can have adequate time to speak is a tension that needs careful management. Improved relationships with stakeholders and more regular hui in a range of venues in the future may help with this.

Artwork: Jade Beazley

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Chapter 6:

Kaupapa - The Principle of Collective Philosophy

Principle Summary

The principle of Kaupapa recognises the collective vision and aspirations of Māori instead of just the individual or a few (S. Walker et al., 2006). This includes connections to hapu (Mahuika, 2008), iwi (Kawharu, 2000) and the wider Māori Community (G. Smith, Hoskins, & Jones, 2012).

Non-Māori stakeholders have a history of consulting with only a few Māori or with Māori who align with their personal views (Milkaere, Tomas, & Johnston, 2003)and presenting it as a Māori voice. This can be either deliberately done (Kingi, 2007) or due to misunderstanding or miscommunication (Kingi, 2007). This is commonly seen in Treaty processes (A. M. Barnes et al., 2012) or health consultation (Sheridan et al., 2015) where non-Māori decide who are the 'right' Māori to engage with or in health where clinicians think they had a good consult but this was not the experience of the Māori patient (S. Walker et al., 2006).

The wānanga and hui engagement processes are good for gathering a collective Māori voice (Hayward, 1999) because it allows for Māori to share views and ideas within a public forum (Heather Came, 2014). These ideas can be discussed, debated and refined so that an accurate view of the whole community can be heard (Harmsworth, 2005).

Reflections from Post-Hui Debriefs

Stakeholders felt that part of the reason for the success of the hui shown by 1,000 Māori attending was that the kaupapa was important to Māori and that the timing was right. The CCN hui were seen as a great idea but also they are long overdue, should have happened earlier and should continue to happen regularly. Stakeholders felt that the wider Māori community are consistently excluded from planning and decision making processes and instead the health system relies on a few Māori to represent the views of all Māori. Stakeholders also commented that Māori are consistently engaged with on individual kaupapa such as cancer, diabetes or mental health instead of these issues being discussed in the context of their wider needs, including health, whānau and other factors. The CCN hui was seen as effective because of the holistic approach taken in the design and implementation instead of discussing only cancer and CCN were seen to be making a genuine effort to include as many Māori as possible. Some Māori Stakeholders did not want non-Māori attending because they felt they would try to dominate the kaupapa with their own views.

Stakeholders commented that Māori communities are tired of being engaged on kaupapa only to have their opinions ignored or not presented in an accurate way. The CCN hui were seen as successful in allowing for discussion to happen in an open forum where Māori could share their views in a safe environment supported by their whānau, peers and wider community. This safety made it more likely for Māori to share their true feelings instead of saying nothing because of a lack of confidence that their opinion is actually valued. Issues were discussed in a positive way because Māori felt backed up when hearing the kōrero of others who agree with their opinions and also felt like their voice would actually contribute to some tangible actions.

Stakeholders consistently said that this process was good for the wider Māori health community and stakeholders which are spread out in the DHBs, PHOs, hauora and other related services. The hui environment gave stakeholders the

chance to engage with each other, work together on a useful project and meet new services. This was the case for both Māori and non-Māori stakeholders, with Māori feeling happy that non-Māori stakeholders got a chance to see how a Kaupapa Māori process is done properly and also for non-Māori stakeholders who commented that it gave them a chance to connect with communities and Māori providers who usually did not want to work with them. Several non-Māori stakeholders were still unsure as to why so many Māori showed up to the CCN hui but not to several DHB Māori engagement hui they had previously attended. They also questioned the value of using the holistic approach instead of more of a focus on cancer treatment which they viewed as more relevant and important.

Discussion

Many Māori still don't trust the health system and regularly feel marginalised. CCN has done a good job in starting to address these issues in the cancer space through large numbers of the Māori community attending the hui to share their voice. Māori are clearly uphappy with how they have been engaged with by health services in the distant and more recent past (Parry, Jones, Gray, & Ingham, 2014), feeling that it has been token consultation (Bourassa & Strong, 2000) and they have felt dictated to (Parry et al., 2014) and not willing to share their true views (Cram et al., 2003). This creates difficulty for roopu like CCN when they want to engage in a positive way because trust (Mooney, 2016) needs to be built first before anything meaningful can be achieved for example, when hui engagement began the Hawke's Bay area was in the middle of a battle between local iwi and the DHB over a baby uplift from the hospital (Gilbert, 2019). This made things understandably difficult when CCN as a representative of the DHBs wanted to engage on a cancer project. CCN's Māori focused approach (S. Walker et al., 2006) helped mitigate this thorough respectful engagement with iwi and hauora. Trust needs to be further developed through Māori led approaches (P. Walker, 2004) on a regular basis to keep momentum going in this kaupapa. Including non-Māori in these hui could also help to raise awareness of Māori approaches (Stoner et al., 2015), reduce bias (C. Houkamau & Clarke, 2016) and continue to build goodwill between Māori and non-Māori stakeholders.

The CCN Hui showed that when a Kaupapa is important to Māori and done in a Māori way, then Māori will show-up to support. Timing is important and the Māori community seemed ready for a forum to share their collective views in a meaningful way. It is understandable that including non-Māori in the hui had mixed reactions but did honour the principle of Whanaungatanga (S. Walker et al., 2006) by being inclusive and showing manaakitanga. However, Māori were still adamant for the kaupapa to be kept Māori and this became an issue when non-Māori ignored requests to keep quiet during discussions so whānau Māori could have their say. This also raises questions around what it means to be Māori? Whānau Māori include non-Māori spouses (Callister, 2003), mixed ethnicity (Ip, 2013) and close non-Māori friends. Having too many non-Māori in discussions can make it difficult for Māori to adequately express their views and decisions around exactly who should be included in Māori hui in the future is important to those attending and should be done in close consultation with Māori stakeholders (Lowe et al., 2009).

Another key issue is what the kōrero is used for. Māori want their voice to be heard (Henry & Pringle, 1996) but more importantly they want their voice to be used to improve outcomes for their whānau (H. M. Barnes, 2000). Māori being wary of their concerns being ignored (L Dyall & Hand, 2003) is a concern that needs to be addressed through putting community voice into true action through proper engagement (AF Boulton, Gifford, & Potaka-Osborne, 2009), courageous plans that address equity (Ministry of Health, 2014a) and regular evaluation (McLean et al., 2009) in partnership with Māori to ensure that those plans are effectively actioned (Signal et al., 2007).

Artwork: Jade Beazley

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Chapter 7

Te Tiriti o Waitangi - The Principle of the Treaty of Waitangi

Principle Summary

The Treaty of Waitangi is New Zealand's founding document (M. S. Palmer, 2008) and highlights the special relationship between Māori and the Crown. Chamberlain (Chamberlain, 2018) identifies that the Treaty of Waitangi is mentioned in many DHBs' organisational strategies, with some DHBs specifically acknowledging and taking action on the principles of the Treaty of Waitangi. Treaty principles include:

- Partnership: working together with iwi, hapū, whānau and Māori communities to develop strategies for Māori health gain and appropriate health and disability services(M. L. Hudson & Russell, 2009);
- Participation: involving Māori at all levels of the sector in planning, development and delivery of health and disability services(Fitzgerald, 2005)
- Protection: ensuring Māori enjoy the same level of health as non-Māori and safe-guarding Māori cultural concepts, values and practices(Baker, Baxter, & Crampton, 2019).

Some DHBs have taken steps to implement the Treaty principles of partnership, protection and participation implicitly in recognition of the important role the health sector plays in acknowledging the indigenous rights of Māori and therefore the status and rights of Māori to achieve equitable health outcomes in comparison with the rest of the population (Bloomfield, 2018).

However, this alone is a limited view of the Treaty and this report will recognise the Māori version of the Treaty, Te Tiriti o Waitangi (Stokes, 1992), the importance of the 4 articles of the Treaty to Health that affirm the tangata whenua status of whānau, hapū and iwi in New Zealand and their rights of citizenship (Heather Came, Cornes, et al., 2018; Mulholland & Tawhai, 2010; Tawhai & Gray-Sharp, 2011). The articles provide a basis through which Māori may critically analyse relationships (R. B. Harris, Cormack, & Stanley, 2013), challenge the status-quo (Mahuika, 2008), and affirm Māori rights (Rangahau, 2019).

Article 1: From a health system perspective this involves sharing power through including Māori in decision making processes through robust representation at all levels of health. Came et al identifies that this is somewhat reflected within core NZ health policy documents such as He Korowai Oranga (A King, 2002), the New Zealand Health Strategy (Annette King, 2000) and the subsequent refreshes in 2014 and 2016 (Heather Came, McCreanor, Doole, & Rawson, 2016; N. Zealand, 2016).

Article 2: Requires that Māori are able to exercise tino rangatiratanga (sovereignty)—being in control of individual and collective destiny (Forster, 2008; Humpage & Fleras, 2001; Kingi, 2007; Maaka & Fleras, 2000). This includes removing barriers and obstacles to Māori success including removing institutional racism. This also includes forums and mechanisms to realise Māori aspirations. Māori providers and/or Māori health promotion have been common expressions of tino rangatiratanga (Berghan et al., 2017)

Article 3: Involves addressing Health Equity (Sheridan et al., 2011) and the wider determinants of health (D. Jansen, 2018; Solar & Irwin, 2010) through ethical decision making (Hoskins, 2012)

and practical application through specific Māori health projects done in a Māori way (Sally Abel et al., 2005).

Article 4: This is recognition of Te Reo Māori, Tikanga Māori and Mātauranga Māori (B. Jones et al., 2010; Mead, 2016; Sporle & Koea, 2004) including Māori Models of Health (Mason Durie, 1999b; O'Brien et al., 2018; Rochford, 2004)

Durie identifies that the TOW was about designing a future where Māori world views, rights and leadership would be reflected in everyday day life and the ways public policies would be determined (Tawhai & Gray-Sharp, 2011). Implications for health include the need for strong Māori health leadership (Ratima et al., 2007), Māori health clinical expertise (S. G. Pitama et al., 2017) and Māori health research expertise (B. Jones et al., 2010) and to be involved with all aspects of the scoping (Lampel & Jha, 2007), planning (Harmsworth, Barclay-Kerr, & Reedy, 2002), decision making (Mason Durie, 1999b), data gathering (Moeke-Maxwell, Nikora, & Te Awekotuku, 2013), data interpretation (R. C. Walker et al., 2017), future state (Katene, 2010) and model of care formation (Lyford & Cook, 2005). Also, the decision of who leads health projects for Māori should be decided by Māori (Tupara, 2012) and that for them to be relevant and legitimate, iwi should not just be consulted but instead be full partners (N. B. Simmonds, Kukutai, & Ryks, 2016) and their aspirations and recommendations for the delivery of services for their people should be heard and valued (Bargh, 2016; Heather Came, Cornes, et al., 2018; P. Crampton, 2018; Reid, 2018; Tamihere, 2018).

Reflections from Post Hui Debriefs

Te Titriti o Waitangi themes are threaded throughout this report, to avoid duplication I will instead identify where the other chapters relate to the Treaty Articles.

Tino Rangatiratanga - The Principle of Self-determination

This directly relates to TOW Article 2.

Taonga Tuku Iho - The Principle of Cultural Aspiration

This directly relates to TOW Article 4.

Ako Māori - The Principle of Culturally Preferred Pedagogy

This directly relates to TOW Article 3.

Kia piki ake i ngā raruraru o te kainga - The Principle of Socio-Economic Mediation

This directly relates to TOW Article 3.

Whānau - The Principle of Extended Family Structure

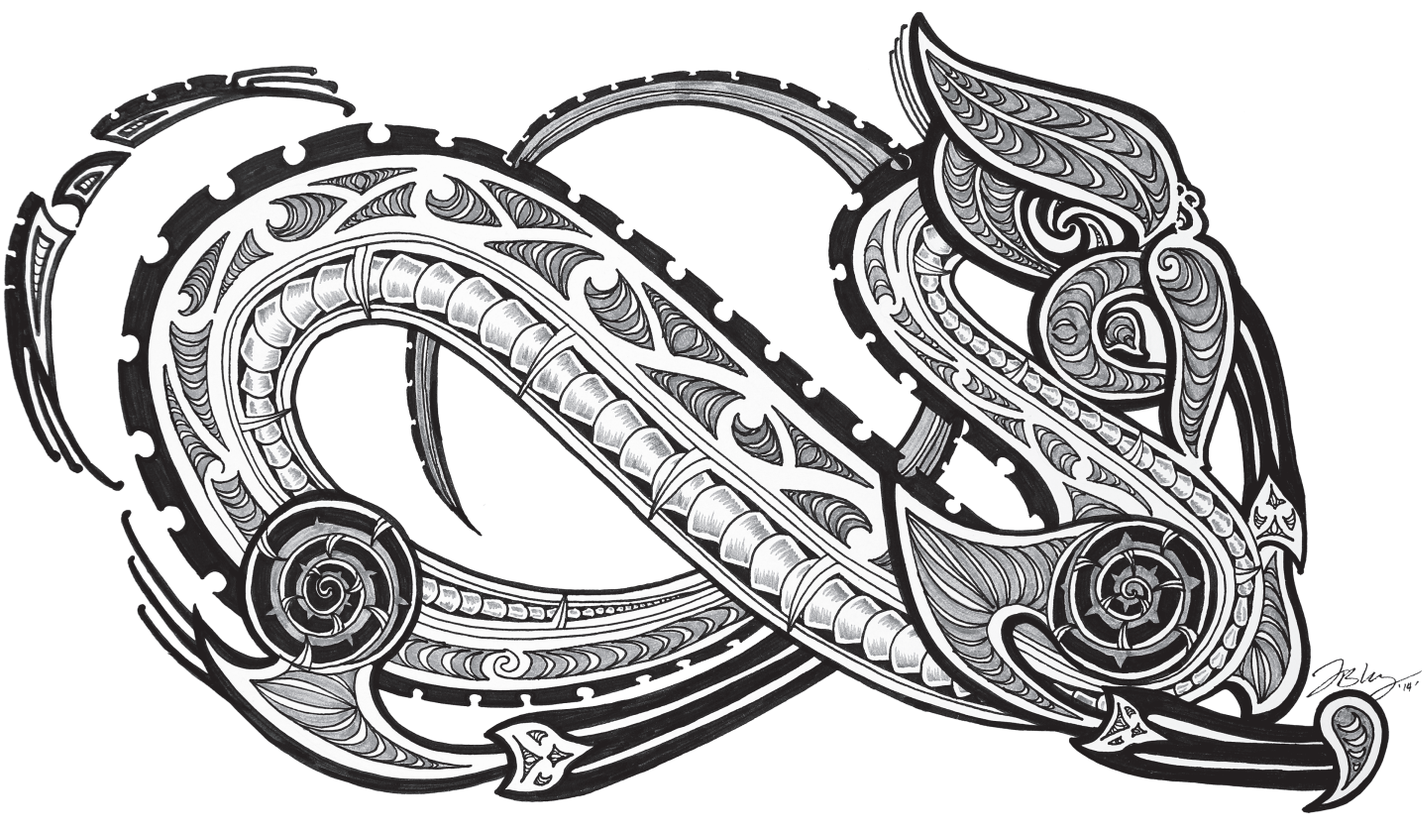
This directly relates to TOW Article 4.

Kaupapa - The Principle of Collective Philosophy

This directly relates to TOW article 4.

Āta - The Principle of Growing Respectful Relationships

This directly relates to TOW article 1.



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Artwork: Jade Beazley

Chapter 8

Āta - The Principle of Growing Respectful Relationships

Principle Summary

The principle of Āta was developed by Pohatu as a transformative approach to Social Services (Pohatu, 2005). It acts as a guide to understanding relationships with Māori and acts as a guide to building and nurturing relationships with Māori (Rangahau, 2019). This may include

Āta focuses on our relationships (Mason Durie, 2007), negotiating boundaries (White & Ladley, 2005), working to create and hold a safe space with corresponding behaviours (Kirkham et al., 2002).

Āta reminds people of how to behave (Holmes, Marra, & Schnurr, 2008) when engaging in relationships with Māori people (McCreanor & Naim, 2002), Kaupapa (Bishop & Glynn, 2000) and environments (Bevan-Brown, 2005).

Āta intensifies peoples' perceptions through providing a quality space of time (Cram et al., 2003) and place (Rewi, 2013), demands effort (Ryan, 1997) and energy (Spiller & Stockdale, 2013) of participants, conveys the notions of respectfulness (Brannelly, Boulton, & te Hiini, 2013), reciprocity (Henare, 2001), reflection (Kerr, Penney, Moewaka Barnes, & McCreanor, 2010), critical analysis (Jackson, 2015), discipline (A. H. Macfarlane, 2007) and ensures that the transformation process is an integral part of relationships (Blundell, Gibbons, & Lillis, 2010).

Āta incorporates the notion of planning (Harmsworth et al., 2002) and strategy (HA Came & da Silva, 2011).

Reflections from Post Hui Debriefs

Most stakeholders agreed that the hui process had improved the relationship between CCN and Māori communities. The hui had also improved the relationship between CCN and Māori stakeholders, DHBs and Māori stakeholders and between different Māori stakeholders themselves. This was eye opening to many Māori stakeholders who commented that they seldom are able to meet in this way and reaffirmed to them the need to work together collaboratively regularly and as the norm.

The time and effort to achieve this was acknowledged by most stakeholders, including the engagement process 6 months before the hui began, the freeing up of CCN staff to engage effectively and the allocation of a significant amount of budget $70k in total over 7 Hui. This was viewed as CCN showing respect to Māori communities and stakeholders through the principle of reciprocity and not just CCN coming and asking Māori for help without giving back something in return. Some stakeholders were unhappy with the engagement process in the design of the hui, saying that some CCN staff did not properly engage with them pre-hui and it seemed that they had been dumped with a large kaupapa and expected to deliver it themselves. They were also unhappy with the communication around the decision making processes, that this was unclear and that they expected to have full control over all aspects of the hui.

During the delivery of the hui most stakeholders were happy with the level of respect given to iwi, hapū and whānau who attended through the pōwhiri process, environment created on the day

through the holistic approach and the amount of quality kōrero that was heard from whānau. The provision of koha and support with transport was seen as helpful to the whānau relationship and was laying a good foundation for future work in each community. The high profile given to Rongoā Māori and Māori Cancer Consumers was appreciated and helped to connect traditional models of healing with modern ones. Even though the 7 Community Hui had not focused on stakeholders many stakeholders thought this was fine because CCN had already planned for 4 Māori Cancer Stakeholder Hui to be held across the region immediately after the community hui had all ended. This was seen as the forum for stakeholders to discuss issues and potential areas they could collaborate together on that they didn't get the opportunity to do during the community hui. CCN was clear to stakeholders that the findings of each hui would be collated into a Report in 2020.

Most stakeholders were extremely happy with the hui outcomes and are keen to start engaging immediately on new kaupapa with CCN. Many providers were happy with the level of follow-up they received post-hui including panui, emails, phone and zoom meetings and kanohi ki te kanohi meetings where possible. Some providers did not feel that they were engaged with enough post-hui and that communication following the Community Hui was poor. They had an expectation that CCN would come back to their roopu on a more regular basis and work with them on new kaupapa immediately. They saw this an opportunity to transform the way DHBs and Māori work together and were anxious to keep the momentum from the hui going.

Discussion

CCN has successfully improved relationships with Māori through the hui process, this includes both Māori communities and stakeholders. For whānau this was through the support given on the day through the Pōwhiri, Koha, Kai, Māori Presentations and Group Discussions. The negotiating of boundaries has been successful with most stakeholders happy with the process and respect shown through funding, good communication and sharing of decisions. For those stakeholders who were unhappy with their level of engagement during the hui, it should be acknowledged that not every stakeholder will be happy with every aspect of what is delivered but what is more important with respectful relationships is that the boundaries are a negotiation (Mason Durie, 2007) not dictated and that discussions are open and honest (S. Macfarlane, 2013). CCN should be open to changing plans to meet the needs of Māori (Tipene-Leach, Able, Haretuku, & Everard, 2000) and put plans in place for how to mitigate the needs of those who are not happy. CCN should continue to communicate regularly (Cheyne & Tawhai, 2008) and on an agreed

timeframe and way that stakeholders are happy with (Kenney, Phibbs, Paton, Reid, & Johnston, 2015) to find common ground for how to develop and deliver future projects with stakeholders.

Relationship building is an ongoing process and it needs money (Ellison-Loschmann & Pearce, 2006), skilled staff (Ratima et al., 2007) and better negotiation of the space (Mason Durie, 2007). CCN spent significant time and resources in engaging with Māori to design the hui but the initial work spent developing makes things easier for future hui and less resource has to be spent on development of relationships and can now shift to improving relationships and co-designing more projects. One observation is the lack of strong pre-existing relationships with Māori pre-hui which shows the opportunities CCN has missed in the past. The reason for this lack of engagement with Māori in a meaningful way can partly be laid at the lack of accountability at a national level for DHBs and regions to work with Māori in the cancer space (Dwyer et al., 2014). While it could be argued that cancer and Māori health plans at national and regional levels gives a mandate to engage, this is regularly not implemented (O'Connor, 2012) and DHBs and regions are not adequately held to account for a lack of relationship building

with Māori and Māori health in general (Heather Came & Tudor, 2017). The CCN hui have shown that when you do it right relationship wise with Māori, work will gain momentum quickly. Māori are not resistant they just want Māori projects to done in an appropriate way. Mana needs to be equal and Māori need to lead these projects (Ellison-Loschmann & Pearce, 2006) together with existing DHB staff and not be dictated to.

An unforeseen result of the hui was the increased relationships between Māori stakeholders themselves who do not get together to work on projects as much as they would like. This identifies a need that there are still some missed opportunities and unmet needs in Māori health for staff and resourcing to be allocated for more joined up approaches in the future. This is not only the responsibility of the existing Māori health teams who are already over stretched but is a wero to DHBs and regional leaders to ensure that Māori health projects are prioritised with staff and resources and not just in plans. This will require shifting of funds and shifting of priorities within existing work programs to adequately achieve (Dwyer et al., 2014).

Conclusion

Cancer is the biggest killer of people in New Zealand and Māori have significantly higher cancer incidence and mortality than other ethnic groups. The NZ health system has yet to adequately address this issue and strengthened Kaupapa Māori Approaches have the potential to improve cancer outcomes for Whānau Māori and achieve health equity.

Within a regional DHB environment and with a range of challenges CCN successfully implemented a Kaupapa Māori Approach through organising 7 Māori Cancer Community Hui within the Central Region attended by over 1,000 people. This has been shown in this report via the 8 Kaupapa Māori Evaluation Chapters which explored the ways CCN engaged, the success factors and the contextual factors.

Tino Rangatiratanga - The Principle of Self-determination

The current regional DHB system limits the effectiveness of how its arms can apply true Tino Rangatiratanga. In the meantime Tino Rangatiratanga can be exercised by including Māori in decision making processes through the hui design and implementation. CCN achieved this by engagement with the DHB Māori health teams, NGO stakeholders and Whānau Māori and consistently negotiated how this was done. Racism and unconscious bias are still significant issues in the achievement of Tino Rangatiratanga with some stakeholders having difficulty handing over decision making to Māori.

Taonga Tuku Iho - The Principle of Cultural Aspiration

The inclusion of Te Reo Māori, Tikanga Māori and Matauranga Māori was a key component of the hui success. The hui created an environment where Whānau Māori felt safe and this was achieved through Pōwhiri, Kapahaka, Karakia, Kaumātua, Kanohi ki te Kanohi Kōrero, Raranga, Rongoā, Miirmiri, Whakatauki, Kai, Koha and Kotahitanga throughout the design and implementation. Some breaches of Tikanga did occur and is a reflection of the current workforce not having the right expertise to implement all aspects of Tikanga. This will require more Māori in the Workforce, more cultural training for staff and/or more cultural expertise on the day.

Ako Māori - The Principle of Culturally Preferred Pedagogy

The hui process involved several forms of preferred pedagogy that met the needs of Māori including learning and teaching from the stakeholders to whānau and vice versa. The positive approach of Wellness and Prevention instead of Illness and treatment was well received. Racism and unconscious bias persists in engagement processes with some stakeholders persisting to acknowledge

the inadequacies of current services to address equity or the need to change their personal approaches to meet the needs of Māori.

Kia piki ake i ngā raruraru o te kainga - The Principle of Socio-Economic Mediation

Negative pressures remain a barrier for Māori accessing and engaging with health services and also for Stakeholders providing Kaupapa Māori Services to Māori. CCN helped to mitigate these pressures via significant funding to assist Māori attending through good communications, travel assistance, koha for participation, creation of a Māori environment by financially supporting Māori stakeholders to attend and support the Kaupapa. Racism and Bias still remains a barrier to funding Māori projects, with Māori competing with other groups and Kaupapa for the same funding pools. This can be mitigated by using research, data and evidence to justify spend and shifting funding from existing projects to those that are proven to improve Māori Health outcomes.

Whānau - The Principle of Extended Family Structure

Cancer is an important kaupapa for the entire whānau and CCN effectively put whānau first by not just inviting cancer patients and survivors but inviting the whole whānau. This recognised the role of the wider whānau in the support of those with Cancer and as consumers of Cancer services across the continuum of care. Māori stakeholders hold dual roles as both providers of services and consumers of services and providing adequate time and space to hear the voice of all whānau will require more hui in the future, on a more regular basis in a variety of venues.

Kaupapa - The Principle of Collective Philosophy

CCN effectively heard a collective Māori voice through the hui process. Māori have felt marginalised by engagement processes in the past that have been tokenistic and dictatorial. This has led to a lack of trust in the health sector and Māori feeling that their voice has not been put into action. This lack of trust was initially a barrier for CCN engaging with Māori but now that trust has been built the wero is now with CCN to ensure that voice of Māori is put into action and momentum is kept.

Te Tiriti o Waitangi - The Principle of the Treaty of Waitangi

Te Tiriti o Waitangi remains important to Māori and themes from the 4 articles are found throughout the report chapters.

Āta - The Principle of Growing Respectful Relationships

Through the hui process CCN has improved its relationships with Māori individuals, whānau, stakeholders and community. Respect was shown to whānau throughout the engagement process and on the day through the use of Māori approaches. Respect was shown to stakeholders through funding, project support, project management and shared decision making in the design and implementation. Relationships need to be maintained and improved through regular communication and follow-up hui. Stakeholders also were able to improve relationships with each other and this identified current missed opportunities in the health sector for Māori stakeholders to collaborate on wider projects. This is partly due to a lack of accountability and funding but also requires support from health leadership at all levels.

Recommendations

Kaupapa Māori approaches are effective if implemented properly. This leads to a variety of benefits for Whānau Māori and Māori stakeholders. CCN did a good job in the delivery of the hui but can do better in the future. Momentum has been built and needs to continue and used to help improve Cancer

Outcomes for Whānau Māori.

Kaupapa Māori approaches in health require strong leadership at all levels, nationally, regionally, DHB and Hauora. The New National Cancer Agency in partnership with Hei Āhuru Mowai (National Māori Cancer Leadership group) has the potential to ensure that this happens across the cancer continuum of care.

There are currently opportunities to collaborate that are not being capitalised on and will require more cross sector partnerships across the Health, Education, Justice, Business and Community Development Sectors.

Relationships need to be improved internally within DHBs, between Māori and non-Māori Stakeholders, between Māori communities and stakeholders and between government agencies

Kaupapa Māori approaches are only as good as the kaimahi who deliver them and this requires a competent Māori Workforce and non-Māori Staff that support Māori led approaches.

Recent plans at a national level by Tumu Whakarae (National GM Māori) and DHB CEOs to increase and improve the Māori health workforce have the potential to improve outcomes for Māori in cancer. As such these should be supported and implemented across the cancer continuum of care.

This also includes improvements to Cultural Competency training for non-Māori staff, ensuring that Kaupapa Māori Skill sets are given higher value during the employment process and that Māori staff are mentored and supported into leadership positions.

Acknowledging and addressing Racism and Unconscious Bias at all levels remains an important issue that needs to be addressed across the cancer continuum of care.

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