16th September 2019

Re: Submission on the Inquiry into Health Inequities for Māori

Tēnā koe,

Thank you for the opportunity to participate in the Inquiry into Health Inequities for Māori. This submission is written on behalf of STIR: Stop Institutional Racism. Formed in 2013, STIR is a network of public health professionals and scholars committed to ending institutional racism within the administration of the public health sector. The current core membership includes Professor Tim McCreanor, Dr Maria Baker, Dr Heather Came, Dr Nicole Coupe, Dr Sarah Herbert, Lisa McNab, Grant Berghan, Trevor Simpson, Ngaire Rae, Emma Rawson, Claire Doole and Miriam Sessa. Collectively we have decades of experience working within the wider public health sector. Further, we are a national network of over 300 STIR Associates working across the health sector.

Our submission is structured in four sections, the first of which outlines STIR's position on the proposed inquiry which will focus on the issue of cancer care including barriers that Māori experience relating to prevention, screening, diagnosis, treatment, cures, and palliative care among Māori. Sections two to four outline what we argue to be the core values needed to address health inequities among Māori in the context of cancer care. These are: honoring Te Tiriti, embracing anti-racism praxis and pursuing health equity. Importantly, we assert that these values must be reflected at all levels of the cancer care continuum where there is engagement and involvement of practitioners, managers and policy makers. We must all be held accountable for our professional practice in these key areas. We conclude with a list of recommendations for the Māori Affairs Committee to consider in the rolling out of their inquiry into health inequities for Māori.

1. **The issue of cancer care including barriers that Māori experience relating to prevention, screening, diagnosis, treatment, cures, and palliative care among Māori.**

First, we assert that equitable cancer care for Māori is an urgent priority and, that the ongoing disparities at all stages along the cancer care continuum between Māori and non-Māori is unjust, preventable, and therefore entirely unacceptable.
Second, we applaud the Māori Affairs Committee for focusing their inquiry on:
- collating existing statistics and evidence regarding Māori cancer health and identifying significant inequalities
- studying the higher incidence rate Māori experience with specific cancers compared to non- Māori
- identifying specific sets of issues experienced by Māori health service users
- investigating and critiquing the lower engagement rate for Māori with prevention, early detection, screening programmes, treatment, and medication
- looking at the role primary and health professionals play in improving cancer survival rates for Māori
- researching how to best design, develop, and roll out an early detection and/or wellbeing programme

- identifying where whānau 'touch' the system to find 'moments of impact' where bias (unconscious or deliberate) consistently occurs
- exploring a conceptual best practice whānau-centric model of cancer care.

Third, we acknowledge the new draft National Cancer Action Plan (Ministry of Health, 2019) which is guided by being equity-led, knowledge-driven and outcomes-focused. We assert however, that it was challenging to clearly locate the priorities for Māori. Rather, Māori were described in various sections throughout and in the context of presenting an issue, and/or alongside Pacific Island peoples. Whilst we recognise that there are certainly similarities, it is important to recognise Māori as requiring culturally responsive and effective cancer care action as an equally governing partner and as outlined in Te Tiriti o Waitangi.

Further, while there is acknowledgement of the disparities across the cancer care continuum between Māori and non-Māori the challenge remains to transform this rhetoric into clear and observable changes in health outcomes for Māori. As Dr. Nina Scott; Chair of Hei Āhuru Mōwai, the Māori Cancer Leadership Board, asserts "accelerated Māori partnership is critical to ensure the plan can be translated into action" (Waikato District Health Board [WDHB], 2019). This requires Māori to have equal decision-making power in the context of cancer care.

We support the need to increase the Māori health workforce across the cancer care continuum and to develop new roles to better support whānau-centred and holistic approaches in cancer control. We argue this is necessary in order to deliver improved and equitable outcomes for Māori. The last cancer control workforce stock take was completed over a decade ago, with little investment since, into this crucial sector to build the Māori workforce.

We agree there is a need to improve service delivery models of care to more effectively meet the needs of Māori, including kaupapa Māori and Māori led options as well as integrating and recognising Māori health models, rongoa Māori & other healing approaches. Given the cancer diagnosis disparities between Māori and non-Māori and the need for earlier detection among Māori, we agree there is a need to review screening programmes for Māori and to increase opportunities for whānau centred care options. Further, initiatives to better support young Māori women to stop smoking must be expanded.

More broadly, kaupapa Māori research and evaluation capacity and capabilities must be increased and Māori leadership and partnership at all levels of the system must be prioritised. A critical part of improving cancer care is research and the translation of what works for Māori. A Māori research agenda and centre is needed to ensure that what's known about Māori and cancer is available for use by people with cancer, their whānau, practitioners, policy makers and researchers.

There must be a stronger focus on achieving equity of outcomes and contributing to wellness for Māori. Better recognition and support of Hei Āhuru Mōwai (National Māori Cancer Leadership Group) is necessary to ensure Māori experience high quality equitable cancer services. Lastly, and importantly, we believe there is a definite and clear need for a National Māori Cancer Control Framework which draws on mātauranga Māori, to provide high level guidance and direction to address disparities and improve outcomes for Māori. This, we feel, is fundamental to improving cancer care for Māori across the care continuum.

Cancer is a significant and enduring public health issue in Aotearoa. Of concern is the sustained, disproportionate and unjust burden of this disease on Māori in comparison to non-Māori (Cormack, Purdie & Robson, 2006). The New Zealand health system is more likely to fail Māori across multiple points and levels of the cancer care continuum (Cormack, Robson, Purdie, Ratima, & Brown, 2005; Hill et al., 2010). Moreover, total cancer incidence is around 20% higher in Māori compared with non-Māori New Zealanders while mortality is almost twice as high (Cormack, Purdie & Robson, 2006). Such engrained

inequities suggest inaction within the health system to adequality uphold Māori rights to health care, thus perpetuating ongoing inequities. This is unacceptable.

Another explanation for this is the foundation of bio-western ideologies within the New Zealand health system which has manifested sustained privilege for non-Māori adults for decades (Cormack et al., 2005; Herbert, Came, McCreanor & Badu, 2019; Hill et al., 2010). Māori do not necessarily operate within bio-western paradigms so the ongoing colonial narrative that dominates the cancer care continuum continues to negate the holistic approach Māori often favor. This must be urgently addressed, and realignment of the cancer care continuum must more effectively meet the needs of Māori.

Cancer survival has multiple complex drivers, the most important of which are levels of co-morbidity and stage of diagnosis. However, the stark and ongoing ethnic inequities are indicative of both health system privileges and health system failures (Signal, 2016). The manifestations of structural disadvantage are not necessarily limited to any one step in the cancer journey but, rather, are small, incremental and accumulating (Hill, Safarti, Robson, & Blakely, 2012). Differential access to primary care, screening and quality treatment for Māori can be seen within different regions and over most cancer types. Such evidence highlights institutional racism existing within the NZ health care system (Signal, 2016). The impact of racism in cancer doesn't just insult Māori bodies, it assaults mana, wairua, mauri and whakapapa (Goza, 2017). The decolonisation of the cancer continuum is a rights-based assertion that demands equality for Māori bodies, spirits and minds both individually and collectively.

The prevalence of institutional racism; patterns of differential access to resources, cultural assets, social legitimation, and political power that privilege one group over another (Came 2014), can also be seen in cancer risk-reducing strategies. Māori communities are often burdened by socio-economic disadvantage, overcrowding, lower education levels, mental health challenges and commercially driven carcinogens such as tobacco, alcohol and unhealthy food. There is increasing incidence and mortality in several obesity related cancers (Teng et al., 2016). The emerging role of commercial determinants and their operation within the trade and political economy thus require critical analysis and scrutiny (Kickbusch, Allen, & Franz, 2016). What is more, there is a growing need to contain the reach of BIG industry, such as tobacco, alcohol as they are causing cancer. Commercial determinants of Māori health including the role of industry lobbyists within politics, must be recognised and discussed.

2. **Honour Te Tiriti**

In addition to those foci identified above, the Māori Affairs Committee must also consider the political powers of Pharmac and their role in determining cancer treatment. There are systemic issues around procurement, chronic underfunding of services, the absence of monitoring and accountability of generic providers and persistent health inequities. There are also political factors at play in New Zealand with how decisions are made regarding the determination of what drugs will be funded and made available to Māori. The public case of Malcolm and Wiki Mulholland fighting for life extending drugs has raised challenges of Māori women with advanced cancer in having access and affordability of cancer treatment. These drugs had to be self-funded and Māori often live in circumstances where this is impossible. While the government has announced an additional $60 million dollars for PHARMAC to fund new medicines, including cancer treatments, there must be a clear commitment to ensuring this funding works towards equitable access, affordability and thus availability of such drugs and treatment for Māori. Honour Te Tiriti

A genuine commitment to honouring Te Tiriti o Waitangi involves meaningful and substantive relationships between: the Ministry of Health; District Health Boards; and other related Crown entities, with, iwi; hapū; and Māori health providers. Rather than Māori participating as stakeholders, they should be equal partners in the design and administration of the cancer care continuum. This would require Māori health leaders, practitioners and academics to be recognised as experts in Māori cancer care, and

their knowledge trusted as offering solutions to and improvements from current cancer care data.

Māori health providers who offer cancer care support, screening, and other related services must also be funded reflective of their status as Te Tiriti partners, and the amount of work required to remove the current burden of disease carried by Māori whānau due to cancer. Current funding levels to Māori providers are clearly inadequate to meet cultural health needs (Ministry of Health, 2017).

Tikanga should be normalised within and across the cancer care continuum, and health systems should be configured in a way that reflects Māori aspirations and world views. The performance of the cancer care continuum should be tracked against holistic Māori measures as well as quality and quantity of life measures. In a critical study of approaches to weight loss, Warbrick, Came, and Dickson (2018) found that initiatives that draw on, or are underpinned by indigenous knowledge, are more relevant for Indigenous peoples and could lead to better health outcomes.

A politically and culturally astute cancer care continuum would recognise culture and wairuatanga as critical dimensions of hauora (Barnes et al., 2017; Marsden, 2003), therefore having important impacts on individuals and their whānau experiencing cancer. It would embrace collaborating across Government to ensure all Māori have equal access to the prerequisites of health and no longer live in circumstances which put the health of whānau at risk (Came, McCreanor, Doole, & Rawson, 2016). In addition, intergenerational trauma and the legacies of colonisation would be recognised as drivers of health inequities (Chin et al., 2018; Kingi et al., 2017; Pihama et al., 2014).

Further, Māori health has been a stated government priority in health policy for decades (Department of Health, 1988; King & Turia, 2002; Ministry of Health, 1998, 2014). Data released by the Ministry of Health (2011, 2017) demonstrates investment in Māori health has not supported this prioritisation; with less than 3% of Vote Health allocated to Māori health. STIR maintains policy without adequate resourcing becomes rhetoric and undermines genuine efforts to improve Māori health outcomes, in this case, as is reflected in the ongoing disparities among Māori in relation to cancer and cancer care.

If Te Tiriti were embraced as the core health policy there would be a strong emphasis on accountability and transparency to enable Māori to enact their right to monitor the Crown's progress (Reid & Robson, 2007). Non-performance in relation to Māori health outcomes would not be acceptable. In the current racial climate, transparency is critical as is a planned response to implementing Te Tiriti, ending racism and improving Māori health outcomes. All sectors within generic service delivery need to be monitored in relation to Māori health equity, Tiriti responsiveness, and anti-racism plans (Came & Tudor, 2017).

3. Embracing anti-racism praxis

Institutional racism within the New Zealand public sector, as outlined in reports such as Puao te Ata Tu (Ministerial Advisory Committee on a Māori Perspective for the Department of Social Welfare, 1988) and He whaipānga hou (Jackson, 1988), remains rampant across the public sector (Human Rights Commission, 2011). Such racism disproportionately impacts Māori and is thus a significant issue to address in the context of cancer care. Eliminating racism needs to be the responsibility of all involved in the administration of the public health system, the cancer care continuum and embedded in individual and team key performance indicators.

Historically Crown agencies response to this racism in the health sector can be characterised by denial and inaction (Came, McCreanor, Manson, & Nuku, 2019). Likewise, evidence presented by claimants in the recent stage one WAI 2575 health kaupapa hearings, consistently spoke of the gap between policy rhetoric and practice on the ground.

Came and Griffith (2017), in their anti-racism framework for allies working in public health, identified several core elements of anti-racism praxis. These include i) engagement in reflexive relational praxis, ii) utilisation of structural power analysis, iii) uptake of socio-political education, iv) engagement with monitoring and evaluation and v) systems change approaches. We advocate that these core elements need to be woven through professional competency documents and tertiary education curricula for all health professionals. Additionally, they must be at the fore of the review of the cancer care continuum if we are to create meaningful and impactful change for Māori in the context of cancer care.

Anti-racism literature strongly supports addressing institutional racism using a systems change approach (Came, 2012; Griffith et al., 2007). A systems change approach is suited to complex and persistent problems and conveniently dovetails within the existing health sector quality improvement system (Health Quality and Safety Commission, 2018). It involves forming a change management team, undertaking socio-political development and using action research cycles to identity and then disrupt sites of racism in a cycle of incremental change and continuous learning. The systems change approach to make a real difference for Māori, is one that includes Māori voices, resonates with Māori culture and preferences, and incorporates multiple, collective dimensions of Māori knowledge that contribute to a holistic approach and Māori aspirations.

We require a national plan/strategy to end racism in Aotearoa and something tailored specifically for the health system and within the context of cancer care in Aotearoa. The Committee for the Elimination of all forms of Racial Discrimination (CERD, 2017) in their concluding recommendations on the New Zealand State report in 2017 recommended New Zealand urgently develop a national action plan. Came and McCreanor (2015) have articulated four pathways to addressing institutional (and every day) racism that could populate such a plan. These include i) addressing historical racism, ii) enhancing racial climate, iii) transforming public institutions and iv) mobilising civil society.

4. Pursuit of health equity

Central to the pursuit of health equity is honoring te Tiriti o Waitangi and embracing anti-racism practice as outlined above. We concur with Pickett and Wilkinson (2011) that an unequal society compromises the collective health of our nation. We encourage concerted meaningful efforts to create a more equal Aotearoa. This will involve radical rethinking of social and economic policy. We need to lift people out of poverty and homelessness (Boston & Chapple, 2014; Peters & Christensen, 2016) and reconfigure our tax system so proportionally those with the most wealth/income contribute most into the collective pool. These interventions need to be targeted to alleviate the pressures on Māori whānau.

The average Māori household income was $22,500 (Statistics New Zealand, 2013). This level of income is not a living wage, it does not cover the real costs of essential whānau needs as well as energy, health, communication and education costs (Living Wage Aotearoa New Zealand, 2017). The pursuit of health equity requires BIG picture thinking about social justice and fairness and some of this reality is beyond the traditional scope of the health sector. We need to embrace health in all policies and champion the use of whānau ora impact assessments (Ministry of Health, 2007) and apply an Equity Lens so we determine the expected health effects of ALL economic and social policy in this country. This aligns with the Governments stated intent for a wellbeing budget.

Recent work by Chin et al. (2018) argues that monitoring, evaluation and adequate investment are central to achieving health equity. This means increasing the monitoring of generic health services delivered to Māori and higher standards of accountability. The previous removal of the requirement of District Health Boards to produce stand alone Māori health plans has been a digression from the pathways to achieve health equity over the years, and in contrast with the need to strengthen accountability mechanisms (Came & Tudor, 2017).

Since the release of the National Advisory Committee on Health and Disability (1998) landmark report on *The social, cultural and economic determinants of health in New Zealand* health policy has consistently included rhetoric around addressing the determinants of health. STIR argues it is more critical now to focus on these drivers of ill health. The health sector needs to determine what our contribution is to address the determinants of health and move past empty rhetoric. If we are serious about addressing the drivers of inequality, we need to co-ordinate our response and invest in upstream solutions. We need to prioritise investment in public health and ground up approaches which will make cascade savings in clinical treatment costs.

Chin et al. (2018) argued underscoring effective health equity work needs to be a commitment to authentically share power and foster tino rangatiratanga. Within the health sector we also need to have free, frank and fearless discussions about racism, colonialism, white privilege and look beyond the daily challenges of administering a complex system. STIR would like to hear less excuses about why the health system is failing Māori and see progress in alleviating health inequities.

5. Recommendations:

- Māori be given equal governing power across the cancer care continuum
- Increased investment to increase Māori workforce in cancer care
- Screening programmes for Māori are reviewed
- Kaupapa Māori research and evaluation capacity and capabilities are increased including the establishment of a Māori research agenda and specialised Māori Centre for Research Excellence across the cancer care continuum
- Māori leadership and partnership at all levels of the cancer care system are prioritised
- Hei Āhuru Mōwai (National Māori Cancer Leadership Group) is resourced and supported to help ensure Māori experience high quality and equitable cancer services
- A National Māori Cancer Control Framework is developed to address Māori Cancer priorities
- Culture, wairuatanga and mātauranga Māori are embedded across the cancer care continuum
- A commitment is made to addressing the causes of the causes (e.g. intergenerational impacts of colonization, social determinants) of ill health among Māori
- A review of PHARMAC is undertaken in relation to how they may contribute to observed inequities between Māori and non-Māori across the cancer care continuum
- Prioritising funding to work towards equitable access, affordability and availability of drugs and treatment for Māori
- Accountability in monitoring of actual improvements for Māori across the cancer care continuum
- Evaluation of all funding decisions and outcomes to consider how they impact Māori
- Implementation and evaluation of a whole-of government national action plan to address the commercial determinants of health
- A genuine commitment is made to strengthen substantive relationships across the sector
- Trusting Māori expertise, knowledge and leadership within cancer care is a given
- Funding decisions that reflect the amount of work required to remove the current burden of disease carried by Māori whānau due to cancer, especially for Māori health providers
- Accountability and transparency of Crown decisions about cancer care is ensured
- Adequate and equal monitoring of health service providers delivery of cancer care is ensured
- Eliminating racism in the administration of the public health system and the cancer care continuum must be prioritised
- The core elements of anti-racism praxis be woven through professional competency documents and tertiary education curricula for all health professionals
- Concerted and meaningful efforts are made to create a more equal Aotearoa involving radical rethinking of social and economic policy

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For STIR: Stop Institutional Racism.

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