

National Cancer Research Network

Submission made to the National Cancer Research Network by NZSTA on 21 August 2024 re:

- **What is important for a National Cancer Research Network to do in order to help improve cancer outcomes equitably?**
- **Who might be a member of a National Cancer Research Network? Which organisations might a National Cancer Research Network have relationships with, and of what nature?**

1. What is important for a National Cancer Research Network to do, in order to help improve cancer outcomes equitably?

1. Equitable Access to Research Participation

Inclusivity in Research: Ensure research studies and clinical trials are accessible to diverse populations, including rural, Māori, and Pasifika communities. This may involve addressing barriers such as geographical distance, cost, and cultural sensitivities.

Recruitment Strategies: Actively recruit participants from underrepresented groups to ensure research findings apply to all populations. This includes engaging with community leaders and organisations to build trust and encourage participation.

2. Cultural Competence and Responsiveness

Te Tiriti o Waitangi: Uphold the articles of Te Tiriti o Waitangi by ensuring that research is conducted in a manner that respects Māori sovereignty, values, and health perspectives. This includes involving Māori researchers and ensuring research is guided by kaupapa Māori methodologies.

Cultural Safety Training: Train researchers and clinicians to ensure they understand and respect different communities' cultural needs and preferences, particularly Māori and Pasifika peoples.

3. Collaborative Research and Partnerships

Partnerships with Indigenous Communities: Establish and maintain strong partnerships with Māori and other Indigenous communities, ensuring their voices are central to the research process. This includes co-designing research projects and sharing decision-making power.

Interdisciplinary Collaboration: Foster collaboration across disciplines, including health, social sciences, and public health, to address the complex factors influencing cancer outcomes.

4. Data Collection and Use

Disaggregated Data: Collect and analyse data disaggregated by ethnicity, socioeconomic status, and other relevant factors to identify disparities in cancer outcomes and target interventions appropriately.

Ethical Use of Data: Ensure that data collection and use adhere to ethical standards, particularly with respect to the ownership and use of data from Indigenous populations.

5. Patient-Centred Approaches

Holistic Care Models: Promote research that considers the holistic health of individuals, incorporating physical, mental, spiritual, and family well-being, particularly in line with Māori health models such as Te Whare Tapa Whā.

Support Services: Research should also explore the effectiveness of support services, such as navigation services and community health workers, in improving access to care and outcomes for underserved populations.

6. Dissemination and Implementation of Research Findings

Knowledge Translation: Develop strategies for effectively translating research findings into practice, particularly in communities often underrepresented in research. This includes working with local health providers and community organisations.

Accessible Communication: Ensure that research findings are communicated in accessible ways to all communities, using clear language and culturally appropriate channels.

7. Advocacy and Policy Influence

Influencing Health Policy: Use research findings to advocate for policies that address social determinants of health and reduce health inequities, particularly those affecting Māori and other marginalised groups.

Funding Priorities: Advocate for research funding that prioritises studies focused on reducing inequities in cancer outcomes and improving care for underserved populations.

8. Sustainability and Long-Term Commitment

Long-Term Engagement: Commit to long-term engagement with communities and continuous improvement in research practices to ensure sustained impact on cancer outcomes.

Capacity Building: Support research capacity development within underrepresented communities, including training and mentoring future researchers from those communities.

By prioritising these actions, a National Cancer Research Network can play a critical role in addressing inequities and improving cancer outcomes across all populations, particularly for Māori and other marginalised groups in Aotearoa New Zealand.

2. Who might be a member of a National Cancer Research Network? Which organisations might a National Cancer Research Network have relationships with, and of what nature?

New Zealand Speech-language Therapists' Association (NZSTA)

<https://speechtherapy.org.nz/>

Speech-language therapists involved in cancer care (e.g., for head and neck cancers) should contribute to research on treatment side effects and patient quality of life.

Examples of research focus areas: These examples highlight the diverse ways in which SLTs contribute to cancer research, focusing on improving patient care, outcomes, and quality of life through targeted interventions and interdisciplinary collaboration.

- SLTs often lead or contribute to research examining the prevalence, impact, and management of dysphagia in patients undergoing treatment for head and neck cancers.

- SLTs research the outcomes of various voice rehabilitation techniques following laryngectomy, where the larynx is removed due to cancer.

- SLTs explore the psychosocial effects of communication disorders resulting from cancer treatments, such as surgery or chemotherapy, and their impact on patients' quality of life.

- Research on the benefits of early intervention by SLTs in patients undergoing cancer treatment to prevent or mitigate speech and swallowing difficulties.

- Research on the role of SLTs in end-of-life care, including strategies for managing dysphagia and communication challenges to enhance the quality of life in terminally ill cancer patients.

- Research on the use of telehealth platforms to deliver speech and swallowing therapy to rural cancer patients, assessing outcomes compared to in-person therapy.

- SLTs contribute to research that measures the impact of speech and swallowing therapy on overall quality of life and functional outcomes for cancer patients.

- Collaborative studies with oncologists, nutritionists, and psychologists to develop integrated care plans that address the complex needs of cancer patients, particularly those with communication and swallowing disorders.