

TERMS OF REFERENCE

He Ara Tangata Consumer Reference Group

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1. Background & context

1.1 Purpose

- 1.1.1 He Ara Tangata is a consumer advisory group which provides lived experience expertise to Te Aho o Te Kahu | Cancer Control Agency (the Agency). He Ara Tangata is one of a number of mechanisms that ensure the voices of patients and whānau inform the Agency's work. The advice of He Ara Tangata supports the Agency to:
- Design and implement the Agency's work programme
 - Ensure the health sector is working towards the goals and outcomes of the Cancer Action Plan
 - Support equitable health outcomes for priority populations affected by cancer including Māori, Pacific peoples, women, people who live in rural and highly deprived areas, people with mental health problems, and disabled people.
- 1.1.2 From a practical perspective, He Ara Tangata provides advice in three different ways:
- i. Providing an overarching lived experience perspective on the Agency's work
 - ii. Providing lived experience insights and advice on individual projects where possible
 - iii. Supporting the Equity & Whānau-Centred Care team to develop tools and resources that help to embed equity and whānau-centred care into the Agency's operating processes.
- 1.1.3 The name 'He Ara Tangata' was proposed by Vivian Hahipene in 2021. "Ara" is a pathway or direction and "Tangata" is people or the public. "He" can either be singular and specific, or many and various. He Ara Tangata reflects the purpose of this group which is to advise on improving the many pathways for the people of Aotearoa who are affected by cancer.

1.2 Agency values

- 1.2.1 Te Aho o Te Kahu has four values that drive how we work:
- equity-led
 - knowledge-driven
 - outcomes-focused
 - whānau-centred.
- 1.2.2 Equity is a key driver for the Agency. In Aotearoa New Zealand, people have differences in health that are not only avoidable, but unfair and unjust. Equity

recognises that people with different levels of advantage require different approaches and resources to get equitable health outcomes. Evidence clearly shows that there are a range of inequities that impact people affected by cancer.

1.3 Operating environment

1.3.1 The Agency works closely with many health entities including:

- HealthNZ | Te Whatu Ora
- Health, Quality & Safety Commission (HQSC) | Te Tahu Hauora
- Ministry of Health | Manatū Hauora
- Pharmac | Te Pātaka Whaioranga

1.3.2 The Agency is guided by a number of laws, strategies and sector documents including:

- **Treaty of Waitangi Act 1975**, which provides for the observance, and confirmation, of the principles of the Treaty of Waitangi; and the establishment and operation of the Waitangi Tribunal.
- **Pae Ora (Healthy Futures) Act 2022**, which is the foundation for the transformation of New Zealand's health system. It aims to make quality health care accessible for everyone, no matter who or where they are.
- **New Zealand Cancer Action Plan 2019 – 2029, which** has a strong focus on achieving equity of outcomes and contributing to wellness for all. It notes six priority population groups (Māori, Pacific peoples, those who live in rural and highly deprived areas, those with mental illness and disabled people).
- **The New Zealand Cancer Control Strategy**, which was developed in 2003. The Strategy was the first phase to develop and implement a comprehensive and coordinated programme to control cancer in New Zealand. The strategy includes the purposes, principles, and goals to guide existing and future actions to control cancer.
- **He Korowai Oranga: Māori Health Strategy**, which sets the overarching framework to guide the government and health and disability sector to achieve the best health outcomes for Māori.
- **Whakamaui: Māori Health Action Plan 2020-2025**, which is the implementation plan for He Korowai Oranga: Māori Health Strategy. This plan aims to achieve better health outcomes for Māori by setting the Government's direction for Māori health advancement over the next five years.
- **New Zealand Cancer Health Information Strategy (2015)**, which sets the strategic direction for the sector over the next five years. It is a pragmatic approach to achieving the vision of comprehensive, accessible, and accurate information that supports the delivery of quality care across the cancer patient pathway.

- **Ola Manuia: Pacific Health and Wellbeing Action Plan 2020-2025**, which sets out priority outcomes and accompanying actions to improve the health and wellbeing of the growing Pacific population living in New Zealand.
- **The New Zealand Disability Strategy 2016-2026**, which sets out the vision for New Zealand to be a non-disabling society and guides the work of government agencies on disability issues.
- **Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996**, which establishes the rights of consumers, and the obligations and duties of providers to comply with the Code. It is a regulation under the Health and Disability Commissioner Act.

2. Appointment process

2.1 Appointing members

- 2.1.1 All He Ara Tangata members are appointed by the Chief Executive of Te Aho o Te Kahu, on the recommendation of the Equity Director. Appointments are based on having lived experience of cancer, their skills, experiences, and the varying perspectives they may offer.
- 2.1.2 Members will be appointed for a period of 24-months from the date of their first appointment. Members will have the option of renewal for a maximum of 12 months, after the first 24-month period has been completed. The maximum period that a person may serve as a He Ara Tangata member is 36 months, although this may be extended at the discretion of the Chief Executive.
- 2.1.3 The membership of He Ara Tangata should reflect a diversity of views, experiences and expertise. Due to the clear cancer inequities that Māori currently experience, the Agency aims for Māori to comprise 50 percent of the membership.

2.2 Ex-officio members

- 2.2.1 He Ara Tangata is supported primarily by the Equity & Whānau-Centred Care team, including the Equity Director and a Senior Advisor who are ex-officio members of the group. In addition, members will have regular opportunities to engage with the Chief Executive. This will primarily be via the quarterly meetings (see 3.1).

2.3 Appointing a Chair

- 2.3.1 A Chair will be appointed each year. The Chair can be nominated by the Equity Director or by the Chief Executive of the Agency. The Agency can also appoint a Co-Chair or Deputy Chair if needed.

2.4 Secretariat support

- 2.4.1 Agency kaimahi | staff will provide secretariat support including the scheduling of meetings, distribution of meeting agendas/papers, and recording of the minutes. The secretariat will also arrange travel bookings where needed for in-person meetings.

3. He Ara Tangata meetings

3.1 Quarterly meetings

- 3.1.1 He Ara Tangata will meet quarterly, a total of four meetings per year. This will usually comprise of two online meetings and two kanohi ki te kanohi (face to face) meetings per year. Additional meetings may be held at times, where requested by the Agency and agreed to by a majority of members.
- 3.1.2 The agenda will be circulated at least seven days prior to any meetings. Draft minutes will be circulated no later than three weeks following the meeting date. Final copies of minutes will be provided to the members and will be available to other relevant stakeholders on request. Information will be made available in accessible formats as required.
- 3.1.3 Each quarterly meeting will ideally include opportunities for members to:
- be updated on key issues and opportunities across the cancer control sector
 - be briefed on projects of particular interest
 - provide updates on any work they are doing to support the Agency.
- 3.1.4 He Ara Tangata members are expected to attend all meetings in full wherever possible. Meeting locations, times, and formats will aim to ensure that all members can participate fully. Where the Chair is unable to attend, the Equity Director or Deputy Chair will be asked to chair the meeting.

3.2 Quorum and decision making

- 3.2.1 The quorum for each quarterly meeting will be half the number of He Ara Tangata members, plus one. Ex-officio members do not count towards the quorum.
- 3.2.2 He Ara Tangata is an advisory body to the Agency, not a decision-making body. The group may however make recommendations to the Agency. These will ideally be made by consensus but may not necessarily be unanimous.

3.3 Meeting attendees

- 3.3.1 Additional contributors including kaimahi | staff of the Agency will be invited to quarterly meetings as and when appropriate.
- 3.3.2 The Chair(s) of He Ara Tangata and the Equity Director may invite additional attendees to meetings. These invitees could be any person(s) whose qualifications or experience would be of assistance to the Group in its role when considering a particular matter. These guests will be entitled to take part in the discussions of the meeting but will not take part in decision-making by members.
- 3.3.3 Invited experts are not eligible for meeting fees but, with the prior approval of the Secretariat, may have travel and other expenses reimbursed if required.

4. Fees and travel costs

4.1 Meeting fees

- 4.1.1 He Ara Tangata advisory group members can claim meeting fees for their attendance at meetings and their contribution to Te Aho o Te Kahu work projects/programmes as requested and agreed. These fees are set in line with the Department of Prime Minister and Cabinet Fees Framework¹:

Description	Fee for members	Fee for Chair
Full Day Fee (Meetings that are 4-8 hours)	\$375.00 (meeting fee) \$187.50 (preparation time) \$562.50 (total)	\$500.00 (meeting fee) \$250.00 (preparation time) \$750.00 (total)
Half Day Fee (Meetings that are 3-4 hours)	\$187.50 (meeting fee) \$187.50 (preparation time) \$375.00 (total)	\$250.00 (meeting fee) \$250.00 (preparation time) \$500.00 (total)
Short meeting fee (Meetings less than 3 hours)	\$46.90 per hour (meeting fee) No preparation time paid	\$62.50 per hour (meeting fee) No preparation time paid
Additional support for individual projects (e.g. reviewing documents)	\$46.90 per hour	\$46.90 per hour

¹ <https://www.dpmc.govt.nz/sites/default/files/2024-09/co-22-2-revised-fees-framework-v2.pdf>

4.2 Travel expenses

- 4.2.1 The Agency will cover all actual and reasonable travel expenses so that members can attend face to face meetings. Wherever possible, the Secretariat will make the necessary bookings and arrangements. If members incur legitimate expenses directly out of pocket for attending face to face meetings, they shall submit a claim for reimbursement to the Secretariat.
- 4.2.2 All claims must be supported by appropriate documentation and must be submitted within 30 days of the meeting. Members seeking guidance on what legitimate expenses are can ask the Secretariat for advice. Where possible, guidance should be sought in advance of incurring the expense. Expenses incurred that do not meet relevant criteria will not be reimbursed.

4.3 Supporting individual projects

- 4.3.1 When Te Aho o Te Kahu project teams require a lived experience voice for their projects, then an *Expression of Interest* form (Appendix One) will be completed and submitted to the Secretariat. This will be distributed to He Ara Tangata for their review, with decisions made on if/who the representative from He Ara Tangata will be on the project team.
- 4.3.2 When members contribute to specific projects/programmes in this way, they will be paid for their time. These costs will be included in the project budget and the project Senior Responsible Officer (SRO) will approve such payments. This will be agreed between the SRO, project manager and He Ara Tangata member prior to the work being completed.

4.4 He Ara Tangata members who are also public sector employees

- 4.4.1 After reviewing clauses 75-79 of the Cabinet Fees Framework² and consulting the Public Service Commission | Te Kawa Mataaho, the Agency confirms that:
- I. People with lived experience of cancer who are also public sector employees are welcome to apply to become a member of He Ara Tangata.
 - II. For clarity, the Agency defines 'public sector employees' as anyone who works within either the core public sector or the wider State sector. The wider State sector includes organisations outside the State Sector Act, such as the New Zealand Police, the New Zealand Defence Force, Crown entities, state owned enterprises and other statutory boards which have employees.
 - III. Any public sector employees applying to become a member of He Ara Tangata must have the support of their line manager.

² <https://www.dpmc.govt.nz/sites/default/files/2024-09/co-22-2-revised-fees-framework-v2.pdf>

- IV. Where a public sector employee is appointed to He Ara Tangata, they are appointed due to their lived experience of cancer (not due to their public service role or as a representative of their organisation).
- V. If a public sector employee is appointed to He Ara Tangata, the Agency will need to confirm they have the consent of their Agency Chief Executive.
- VI. Public sector employees cannot be double paid for their time (i.e. public sector employees cannot receive the He Ara Tangata meeting fee and their ordinary pay for the same period of time). People in this situation should discuss the situation with their line manager when first appointed to He Ara Tangata. Their options are:
 - a. Seek approval from their manager to take unpaid leave to attend He Ara Tangata meetings. This will allow them to claim the meeting fees outlined above.
 - b. Seek approval from their manager to attend He Ara Tangata meetings during their usual day of work. In this scenario, members will not be allowed to claim meeting fees.
- VII. Te Aho o Te Kahu is happy to assist in these conversations and/or provide documentation to He Ara Tangata members to support the discussions with their line manager and/or agency leaders.

5. Media and Confidentiality

5.1 Media requests & personal views

- 5.1.1 If a He Ara Tangata member receives a media request or media enquiry relating directly to the work of the Agency or He Ara Tangata, they are to direct the enquiry to the Agency's Equity Director; and inform the Chair(s) of He Ara Tangata.
- 5.1.2 Members may comment in public and to media, provided they are clear that:
 - Their comments reflect their personal views, not those of He Ara Tangata or the Agency; or
 - Their comments are on behalf of another group that the member belongs to.

5.2 Official Information Act requests

- 5.2.1 All information held or produced by He Ara Tangata, including that held or produced by the Agency, is subject to the Official Information Act 1982³. The Secretariat is responsible for responding in a lawful manner to any Official

³ <https://www.legislation.govt.nz/act/public/1982/0156/latest/DLM64785.html>

Information Act requests He Ara Tangata may receive. In doing so it will coordinate with the Chair of He Ara Tangata and the Equity Director.

5.3 Publication of He Ara Tangata membership and meeting minutes

- 5.3.1 The Agency may list the membership of all advisory groups including He Ara Tangata on the agency's website. Short profiles of He Ara Tangata members may also be published on the website. All profiles will be agreed to by individual members before being published.
- 5.3.2 He Ara Tangata meeting minutes will not be routinely published on the website but will be made available upon request via the OIA process.

6. Code of Conduct

6.1 Expectations

- 6.1.1 The Code of Conduct sets out expectations for the general conduct of He Ara Tangata members. It is expected that all He Ara Tangata members will:
- work in an inclusive manner where diverse voices of all He Ara Tangata members are listened to and heard equally in an environment of trust and respect.
 - attend all scheduled meetings in full and undertake any required pre-meeting reading to ensure they can engage fully at each meeting.
 - work transparently and consistently with all privacy, security, and legal requirements, including but not limited to the requirements of the Official Information Act 1982⁴ and the Privacy Act 2020⁵.
 - maintain and safeguard the confidentiality of information submitted to them or obtained in carrying out their role (this includes agenda material, documents and other matters forwarded to members, unless otherwise specified by Agency representatives).
 - disclose any real, potential, or perceived conflicts of interest as they arise and agree to the appropriate management of these conflicts, in the manner determined by the Chair(s).
 - only claim for legitimate expenses they may incur.
 - adhere to the Terms of Reference.

⁴ <https://www.legislation.govt.nz/act/public/1982/0156/latest/DLM64785.html>

⁵ <https://www.legislation.govt.nz/act/public/2020/0031/latest/LMS23223.html>

6.2 Breach of Code of Conduct

- 6.2.1 Any breach of the Code of Conduct will be escalated to the Chair(s) and the Agency's Director Equity (directly or via the Secretariat) and they will determine an appropriate response. If the breach is made by the Chair(s), then the Director Equity will determine the appropriate response.
- 6.2.2 The suspension or removal of a He Ara Tangata member for a Code of Conduct breach is decided collectively and agreed to, by the Equity Director and the Chair(s). For the suspension or removal of the Chair(s), the decision is made by the Agency's Chief Executive and implemented by the Equity Director.

7. Review of Terms of Reference

- 7.1 The Terms of Reference will be reviewed every 24 months by the Agency, with the next review due in August 2027. The review will be placed on the agenda for discussion at a He Ara Tangata meeting prior to any changes being confirmed.