

# AYA cancer care in New Zealand – A way forward



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## Background

### Small Numbers, Big Challenges for AYA Cancer Care in New Zealand (NZ)

Every year in NZ around 200 young people are diagnosed with cancer. The AYA Cancer Incidence and Survival in NZ 2000 to 2009 report undertaken in 2013 identified a number of serious and significant concerns regarding outcome disparities and inequalities for certain ethnic, disease specific and age related populations within the AYA cohort.

In response to these findings the AYA Cancer Network Aotearoa was funded and established by the NZ Ministry of Health to provide national strategic direction and leadership of AYA cancer care in NZ.

NZ's large geographical size (relative to the size of the UK), small population (4.6 million), and health system structure (20 District Health Boards - organisations that fund and deliver health care across a defined geographical area), presents unique challenges.

To address this challenge the Network has committed to the development of a national strategy for AYA cancer care. Several key pieces of work have been, or are being, undertaken to guide its progression. This has included the development of the AYA Cancer Standards of Care (SOC) and the implementation of an online self-review tool process.

### AYA Standards of Care



The SOC are divided into three sections, all with equal importance and designed to complement one another.

#### Service Provision for Adolescents and Young Adult Cancer Patients in New Zealand

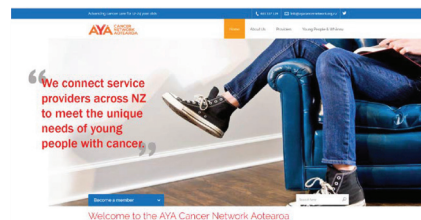
Aim: To achieve excellence in AYA cancer care in New Zealand with the goal of improving survival outcomes and supporting AYAs to transition to healthy functioning adults.



## Methodology

### Online self-review tool

This tool encourages providers to work collaboratively to implement the AYA standards of care in driving quality improvements locally and nationally.



The tool supports providers and DHBs to:

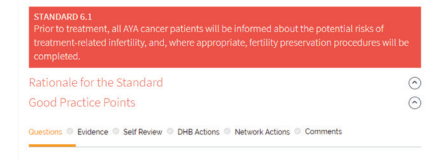
1. Understand what is working well in the delivery of care and support to AYAs
2. Determine areas where further service improvements are required
3. Develop a DHB service delivery plan that links to the national strategy for AYA cancer care

### Process

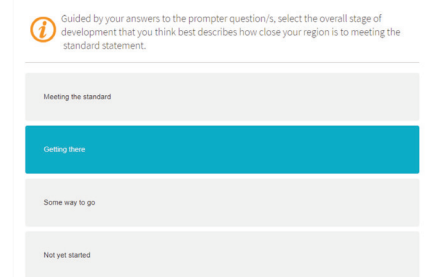
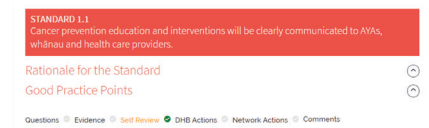
The network provides secretariat support throughout the online process. Contributors are identified ensuring wider sector representation. Contributors are provided with instructions and sent out a unique password. While there are a total of 30 standards, only 8 are required to be reviewed in the first 18 months. Six of these have been predetermined following workshops with governance, keyworkers and AYAs themselves; the remaining two are decided by each DHB.

### Online self-review tool

Contributors are asked to provide input only where they have the relevant knowledge, expertise or familiarity, working through each of the sections as shown below.

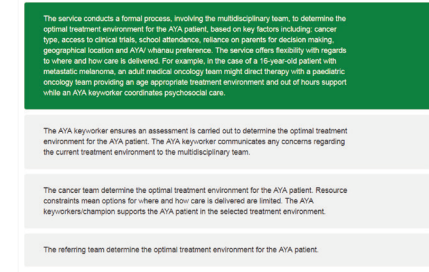


- **Self-prompter/Self Review:** Providers reflect on and review the current delivery of care been provided to AYAs.

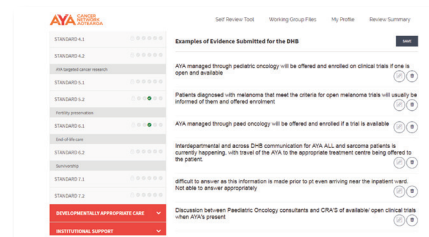


### Standard 4.1 The Treatment Plan

1. Does the current decision making process outline how and where an AYA patient should receive their treatment e.g. paediatric vs adult or locally vs regionally?



- **Evidence:** Contributors document how the standard is currently being delivered in their region.



- **Suggested DHB actions** are actions that individuals/services feel they can commit to in the near future to progress forward in meeting the standard.
- **Suggested Network actions** are suggested steps that the Network could undertake at a national level to contribute to the standard being delivered across NZ.

### Site Review Meeting

A meeting is hosted by the DHB and facilitated by the Network at the end of the self-review period. This is attended by key stakeholders, to prioritise, develop and finalise a DHB service development plan.

Upon development of the plan it is the responsibility of the local AYA governance group to undertake regular monitoring and updating of their service development plan. Every 12-18 months a formal review with the network will be undertaken.

## Results

### Participation

Within the first two months of launching the tool 6 of the 20 DHBs have completed the process. The remaining DHBs are scheduled for completion by April 2018. The participation rate from contributors invited to complete the self-review tool (up to 150 individuals for some DHBs) is currently around 25%.

Feedback indicates that although not all invited contribute, the inclusion of their name in correspondence regarding the tool has led to increased awareness of the purpose and need for the Network.

### Usability

Evaluations completed to date on usability have been rated positively. This positivity has been shared between regions potentially contributing to its growing success.

### Quality Focus vs. Compliance

Engaging DHBs with this process has been easier than expected, especially as this is not currently a mandated process. Based on feedback this is likely a consequence of removing compliance or benchmarking frameworks as utilised in similar standards. The sole focus and goal is to instead drive quality improvement initiatives.

### Wider Sector Representation

Wider sector representation has occurred in the completion of the process. The joint development plan recognises the value that different services and professionals play and emphasises the need to collaborate and work in partnership.

### Translating theory into action

The prompter questions and progress chart have been found useful when interpreting theory into practice. It allows and encourages contributors to reflect and review current care delivery methods and identify potential next steps for service development.

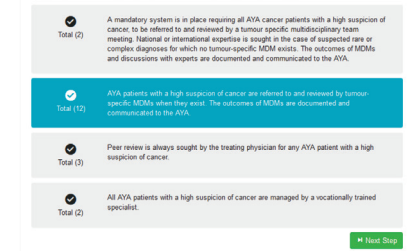


### Anonymity

The tool assures anonymity to support honest reflection and a forum to share suggestions and experiences. The network is able to show the region tallied responses to the questions to give an indication of the regions overall self-determined rating.

### Standard 2.1 Referral to the right expertise

1. Are systems in place to ensure all AYA cancer patients are referred to and reviewed by an appropriate tumour group expertise and multidisciplinary meeting?



### A3 editable plan

Feedback indicates that the printable plan shows cases the commitment made by many individuals and services in progression of AYA cancer services, holding many to account rather than the few.



### National strategy

From this process a national strategy can be developed to reflect the nation's needs and experiences. This drives regional buy in and commitment. It also benefits DHBs whose capacity and resource availability restricts their ability to develop and implement significant changes and advancements in the delivery of care to their often small AYA population.

## Conclusion

The self-review process is a unique way to promote and develop initiatives that aim to address the unacceptable disparities identified within NZ's AYA cancer population. This process is proving to promote collaboration within DHBs and across NZ, resulting in the commitment to governed local development plans that will link to the national strategy. These plans and strategies will also be supported in the near future by a patient experience survey.