

He Ara Tautoko: A Psychosocial Support Framework to Address Inequities in Adolescent and Young Adult Cancer Care

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AYA / rangatahi = adolescents and young adults (young people) aged 12–24 years in the Aotearoa New Zealand cancer system

BACKGROUND

Following the introduction of six regional AYA Cancer Services in 2007 and the establishment of the AYA Cancer Network Aotearoa in 2014, resources and initiatives have been developed to specifically address the needs of AYAs aged 12–24 years, with a strong focus on reducing inequities.

Although this has contributed to a narrowing of the survival gap, five-year survival rates remain 6–9% poorer for Māori and Pasifika rangatahi compared with their non-Māori and non-Pasifika peers, reflecting the compounding impacts of colonisation and structural barriers.¹ Poorer survival has also been identified for those living outside the main treatment centres and in areas of high deprivation.

The AYA Cancer Network Aotearoa provides national leadership for service development, standards, and equity-focused resources that support consistent care across the motu (country). In 2020, the Network launched the AYA Cancer Action Plan, setting a national vision for all young New Zealanders diagnosed with cancer to have equitable access to high-quality medical and supportive care regardless of where they live, their age, or ethnicity.²

Within Aotearoa, AYA Cancer Keyworkers are specialist clinicians who coordinate age-appropriate psychosocial support, improve access to services, and advocate across cancer, community, and whānau systems. One priority within the AYA Cancer Action Plan was for the Network and Keyworkers to co-develop a national AYA cancer psychosocial support framework to guide equitable psychosocial care delivery. Evidence shows that certain psychosocial risk factors and life circumstances make it harder for some rangatahi to engage with existing structures and services.³ This stepped-care approach aims to direct the most intensive support towards those least likely to be identified and prioritised within existing systems.

AIM

To provide equitable cancer care to AYA across Aotearoa by the development of a psychosocial support framework to assist AYA Cancer Keyworkers and fellow health professionals' assessment and provision of psychosocial support care.

METHODS

The four-tier psychosocial support framework was created through iterative collaboration between the AYA Cancer Keyworkers and the AYA Cancer Network Aotearoa. Workshops with the AYA Cancer Network Aotearoa Keyworker Working Group formalised national eligibility criteria for AYA Cancer Service involvement alongside the psychosocial support framework. Clarifying eligibility reduced inappropriate referrals outside service scope, protecting finite Keyworker capacity so rangatahi with the highest cancer-related psychosocial need could access timely support.



Numerous versions of the eligibility flowchart and psychosocial support framework were developed and refined. For the eligibility framework, special cases requiring exemptions were identified, such as those young people with non-cancer diagnosis who are likely to require a bone marrow transplant. Later versions of the tiered framework included both disease/treatment factors, for example guarded or poor prognosis, in addition to psychosocial factors. Case-studies were utilised to ensure that the that there was Keyworker agreement with the prioritisation levels that the tools were generating.

RESULTS

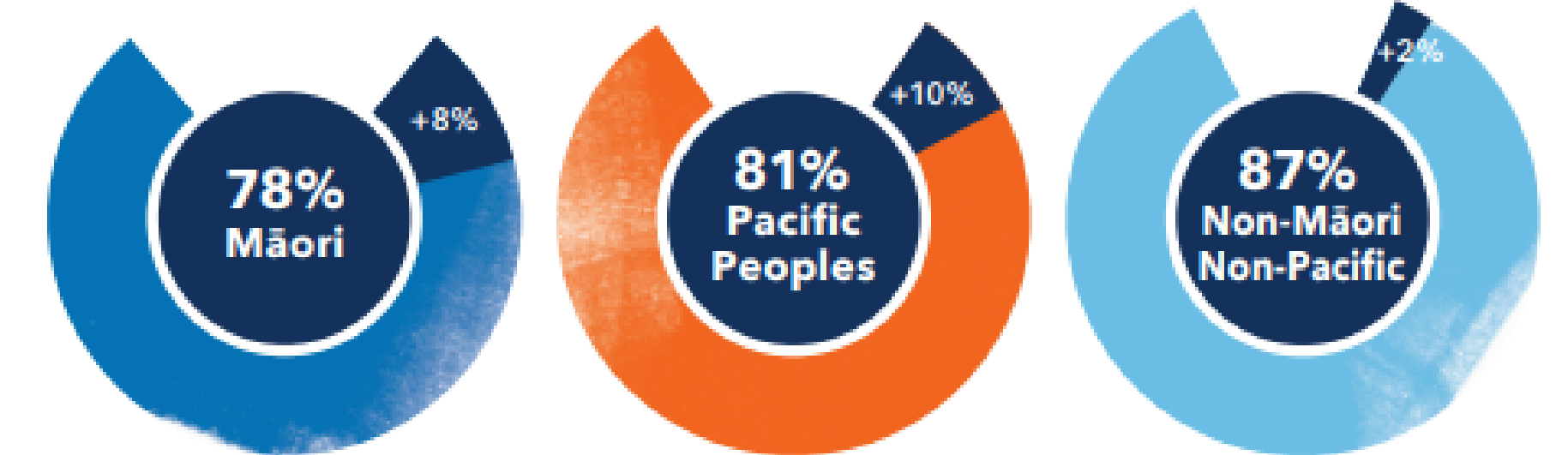
The AYA cancer service eligibility criteria support equity by ensuring specialist AYA Cancer Service resource is directed to the rangatahi for whom it was designed. This includes proactive Early AYA Support at Level 1, particularly for Māori, Pasifika, rural, and other high-risk rangatahi, ensuring those most likely to face structural barriers are considered early for possible escalation within the psychosocial support framework, even where treatment or psychosocial needs initially appear low. By reducing time spent managing referrals outside scope, Keyworkers can prioritise timely, culturally responsive care for rangatahi experiencing the greatest barriers to engagement and outcomes.

For rangatahi progressing beyond initial contact (Level 1), equity is embedded at the centre of the psychosocial support framework. Māori, Pasifika, rural, and other structurally underserved rangatahi are prioritised for early Keyworker contact and assessment within seven days of referral.

This ensures rangatahi who face the greatest structural barriers receive timely, culturally safe, and whānau-centred support. Assessment incorporates disease and treatment factors alongside psychosocial risk indicators such as distress, barriers to care, and unmet cultural needs.

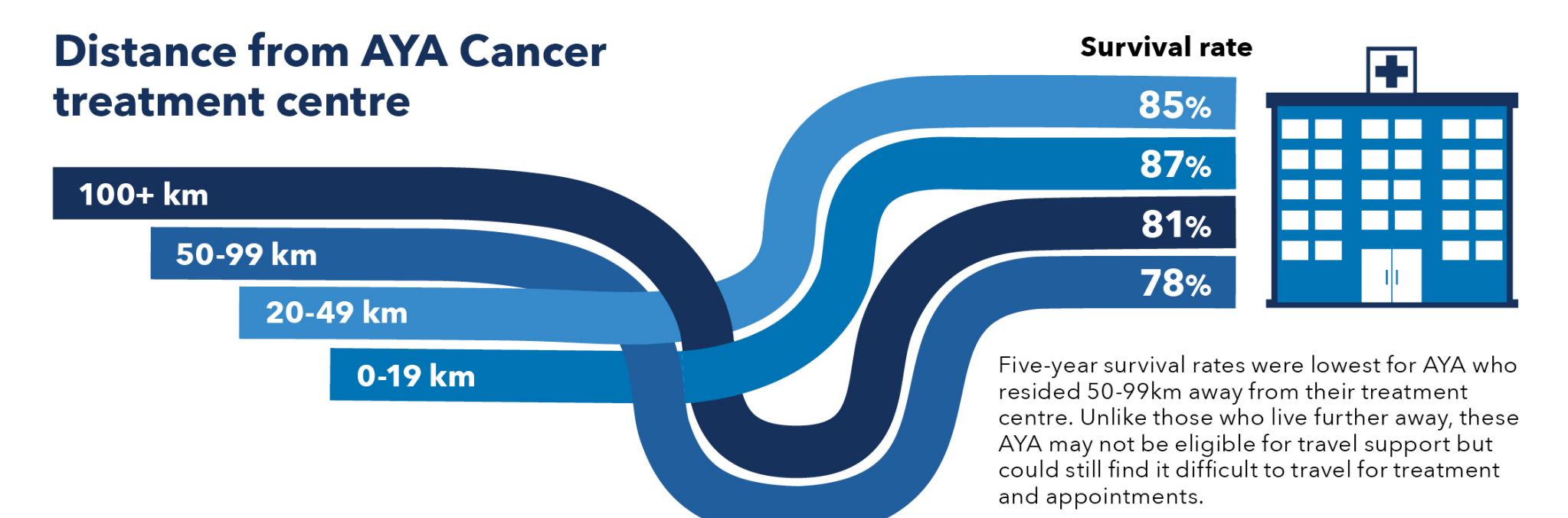
Following assessment, the framework stratifies rangatahi into four levels of psychosocial support, ranging from general information and navigation resources through to intensive, multi-agency case management.

Prioritised ethnicity - the ethnic survival gap still exists but is narrowing



The percentages in the middle are survival rates for 2008 to 2017. The smaller percentages are how much survival rates have improved over the last decade.

Distance from AYA Cancer treatment centre



Five-year survival rates were lowest for AYA who resided 50-99km away from their treatment centre. Unlike those who live further away, these AYA may not be eligible for travel support but could still find it difficult to travel for treatment and appointments.

RESULTS CONTINUED

Each increase in support level corresponds to a greater intensity of Keyworker involvement, progressing from information, navigation, and routine psychosocial assessment through to intensive case management, multidisciplinary coordination, accompaniment to appointments, and cross-agency whānau support. This graduated model further protects finite Keyworker resource by identifying rangatahi whose needs can be safely met through general resources, local care teams, or AYA Champions operating with Keyworker oversight. For those with lower levels of need, general support materials have been developed, allowing Keyworkers and multidisciplinary teams to focus their expertise on providing wrap-around, whānau-centred care for rangatahi with the highest needs.

National tools supporting equitable triage and access

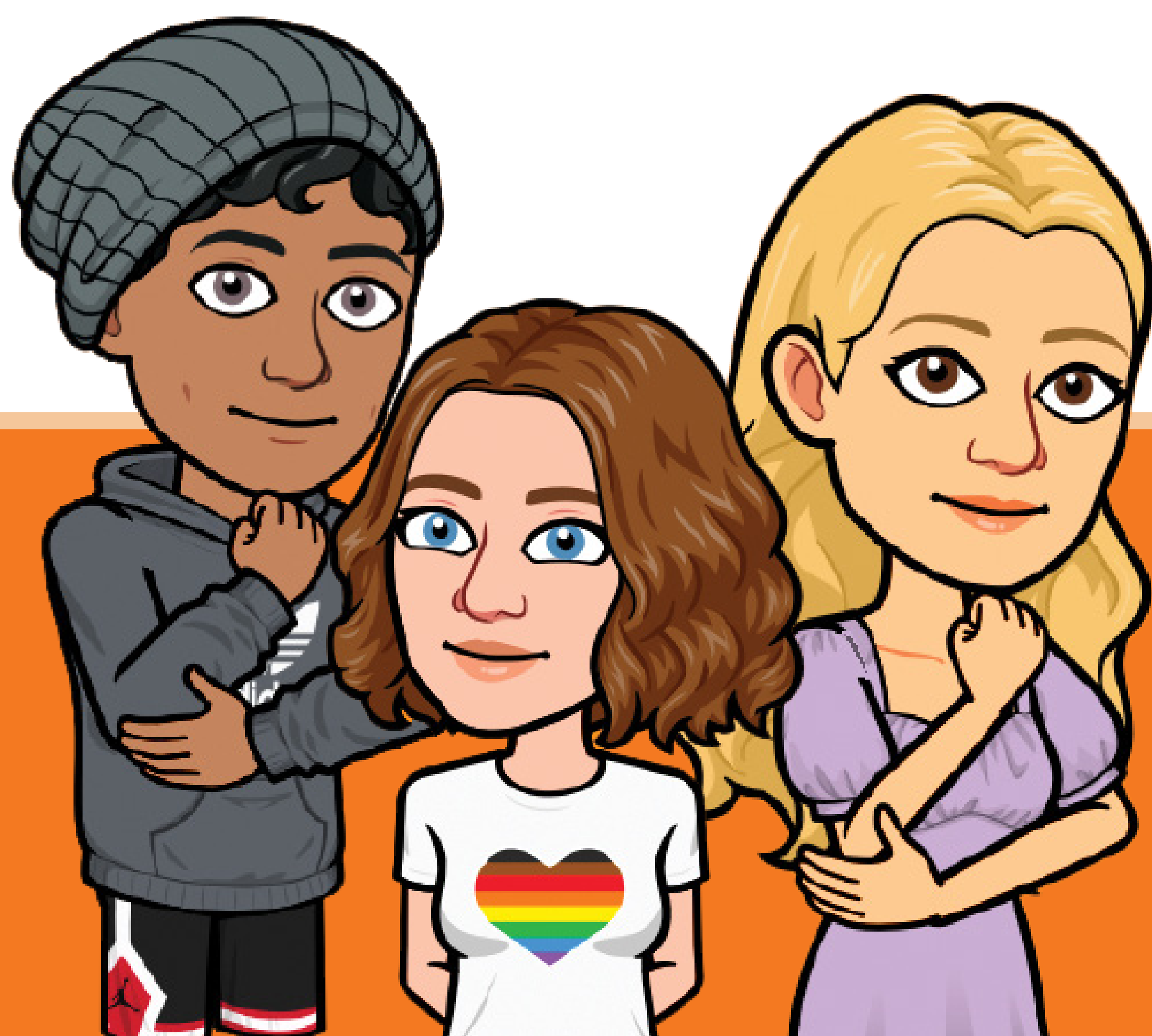
Standardised eligibility criteria protect specialist Keyworker capacity, while the psychosocial support framework matches the intensity of care to clinical, psychosocial, and structural need, ranging from general support and navigation through to intensive multidisciplinary and whānau-centred case management.

CONCLUSION

The AYA framework is currently being implemented across Aotearoa, with formal evaluation planned. Anticipated benefits include a shared language for describing psychosocial need, improved consistency of triage, and more efficient allocation of Keyworker and multidisciplinary team resources. By embedding explicit eligibility boundaries and equity-based psychosocial triage into routine cancer care, this framework provides a scalable systems approach to improving access, consistency, and outcomes for underserved AYA populations across Aotearoa, with potential relevance for Indigenous cancer services internationally.

REFERENCES

- Ballantine, K, Moss, R, & Watson, HJ. (2020). *Adolescent and young adult cancer incidence and survival in Aotearoa 2008-2017*. Auckland, New Zealand: AYA Cancer Network Aotearoa
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Scan the QR code for copies of the AYA cancer service eligibility criteria and psychosocial support tiered framework.



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