SUBMISSION

Australian Medical Research Advisory Board consultation on the Medical Research Future Fund Strategy 2021-2026



KEY CONTACT

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STATEMENT OF RECOGNITION



Canteen acknowledges Aboriginal and Torres Strait Islander peoples are the first people and Traditional Custodians of this land. We pay respect to Elders past, present and future. We are committed to providing inclusive and appropriate support for Aboriginal and Torres Strait Islander young people, their kin and community.

OVERVIEW

Canteen Australia supports young people aged 12-25 impacted by cancer, be it their own or a member of their family. Canteen works by having young people at the centre of everything we do. Our counselling services, individualised support and youth-friendly resources help young people develop skills and resilience to cope with cancer. Canteen also administers the multidisciplinary Youth Cancer Services, supporting young patients in hospitals across Australia. Young people can join our 24/7 online community or attend multi-day evidence-based programs or recreation days to connect with peers with similar cancer experiences. Guided by our internationally regarded research into the impact of cancer and best-practice care, Canteen understands how cancer is different in a young person's world.

Canteen Australia provides this submission in response to the call for consultation from the Australian Medical Research Advisory Board (AMRAB) on the Medical Research Future Fund (MRFF) Australian Medical Research and Innovation Strategy 2021-2026. Canteen Australia answered six of eight questions asked by AMRAB, and these responses were submitted online via the MRFF consultation portal and limited to 200 words per response.

Full information about the consultation opportunity is available online.

PART 1: STRATEGY

1. Could the current *Strategy* be altered to better meet the purpose set out in the MRFF Act? If so, how?

Canteen Australia reserves its response to this question.

2. What are the most critical current and future issues and factors impacting on the health system, including primary prevention, and on the health and medical research sector that the next Strategy needs to address?

The past 30 years has seen an increase in survival rates of paediatric and older cancer patients, adolescent and young adult (AYA) patients have not experienced the same improvement (Shaw et al.2011). Canteen Australia remains concerned at the levels of investment and enrolment in clinical trials for AYAs with cancer. Enrolment is lower amongst AYAs (currently, 18 % Patterson et al, 2021) and survival outcomes for certain cancers have not improved comparative to other age groups (Walczak et al, 2018). Barriers for enrolment are systemic including a lack of understanding of processes that support protocol approval; absence of paediatric-adult oncology relationships that reduce awareness of open trials, and age exclusions for adolescents who are routinely excluded from relevant adult trials and likewise young adults excluded from relevant paediatric trials (Ellis et al, 2021). The evidence to exclude based on age is currently unsupported in literature; Temrikar et al, (2020) for example report no differential effects should adolescents aged be provided access to certain lifesaving treatments. Addressing the inclusion and exclusion criteria of age is a critical issue, alongside the other systemic barriers identified benefit would come from a coordinated and nationally focused approach.

3. Suggest options for how the next Strategy could address these critical issues and factors?

Implementing the following initiatives and approach toward clinical trials in Australia will provide an opportunity to enhance the overarching framework and improve access to life saving treatments, particularly for AYAs:

- Prioritise the evaluation of inclusion and exclusion criteria with the view to the inclusion of AYAs in relevant adult and paediatric trials.
- Prioritise international collaborative research as a key strategic objective that will provide increased opportunities for Australian researchers and clinicians to influence treatment development and trial planning which is currently disadvantaged in Australia due to low yearly incidence in rare/less common cancers and complex populations.
- Leverage existing national research infrastructure to fund early phase trials.
- Support the establishment of national mechanisms that allow for central coordination and support for investigators to initiate and conduct trials.
- Invest in the establishment of a national dataset which captures trial participation, treatment, and patient outcomes; segmented by population group including AYA cancer patients.

4. Given the new and significant impact of COVID-19 on health services and health research, how should the new Strategy address COVID-19 related topics and impacts?

The rapid shift to digital and telehealth under COVID-19 initiatives has shown promising benefits, particularly in increasing accessibility of healthcare. We acknowledge the AMRAB priority area of 'Digital Health Tools' within the MRFF research agenda, and advocate for this area to be lifted into a strategic focus area under the 2021-2026 Strategy. With ongoing uptake of digital and telehealth mechanisms and advocacy for these to become a permanent fixture of the Australian healthcare system, research is needed to ensure that quality, consistency, and equity of health care remains. We recommend that validated tools and clinical assessment mechanisms being used in the digital and telehealth environment be subject to evaluation to understand their applicability and resources dedicated to support any necessary adjustments. Additionally, developing a greater understanding about the holistic use of digital and telehealth services is required. Lifting 'Digital Health Tools' into the strategy as a strategic focus area will give necessary emphasis to ensure that all health research initiatives consider the impact of digital implementation, and, become an assessment criterion—as appropriate—for MRFF research grants.

PART 2: PRIORITIES

1. Could the current *Priorities* be improved to better address the requirements under the MRFF Act? If so, how? This could include consideration of what elements of the Priorities work well to guide MRFF investments and what could be improved for research translation and impact? *Canteen Australia reserves its response to this question.*

2. What are the most critical current and future issues for the health system and the health and medical research sector that the next Priorities need to address through research translation/implementation?

Canteen acknowledges the current priority area focused on support for health professionals to conduct research. As we have done in the past, we advocate for a stand-alone priority focussed on the not-for-profit (NFP) health sector. This is a critical third sector of the Australian Health System, targeting a multitude of health conditions, delivering essential services, support, and resources, and relieving a considerable burden on the primary and acute care sectors. A key challenge for the Australian health system is ensuring the optimal utilisation of all sectors and services. Notwithstanding the additional pressures on the health care system because of COVID-19, the acute and primary care sectors are overburdened and not consistently able to address the needs of patients—particularly those with complex and chronic illnesses. Effective integration (including systems as well as focus areas, such as physical and mental health) depends to a large degree on having a robust evidence-base for the services offered by all health care sectors. It is also critical to ensure that the NFP health sector has the capacity and infrastructure to evaluate their services, conduct and participate in health services research and leverage data to drive continuous improvement.

3. Suggest options for how the next Priorities could address these critical issues?

Establishing a stand-alone priority focussed on the, NFP health sector will enhance the evidencebase for the health services, programs, interventions, and resources provided by this critical third sector of the Australian Health system. It will also support the integration of this sector into the continuum of care across health sectors. Specific initiatives under this priority area could include:

- Financial support from the MRFF to NFP health organisations to deliver integrated and holistic health initiatives
- Establishment of NFP sector-wide research network
- Conducting health system research focussed on integrating NFP health sector service providers into models of care
- Building capacity to conduct evidence-based service development and translational research and evaluation within and/or on behalf of the NFP health sector
- Extending medical record infrastructure and population and disease registry data capture into the NFP health sector

Acknowledging this as an AMRAB priority for the MRFF research agenda would elevate and make eligible, NFP led research projects and partnership approaches across all healthcare sectors. There would also be a considerable opportunity to advance policy development, competitive grant funding and cohesive representation and consultation opportunities across healthcare sectors further enhancing AMRAB's priority area focused on addressing gaps for research with those with lived experience.

4. Given the new and significant impact of COVID-19 on health services and health research, how should the new priorities address COVID-19 related topics?

COVID-19 has changed the landscape of healthcare across Australia—including increased reliance on community and home-based care. The NFP health sector have significant visibility and connection with the community being activated and relied on to supplement the acute and



primary health care settings. This has been evidenced by the NFP health sector being recruited to support the COVID-19 vaccine administration program; rolling out and endorsing public health messaging, and, with the mental health impact of COVID-19 one of the most widely documented impacts (AIHW, 2021), the NFP health sector have provided mental health support to health care sector workers and communities at large. Canteen Australia acknowledges that the COVID-19 environment, more than ever, has highlighted the social determinants of health (AIHW, 2020); this coupled with an increasing focus on a values-based health care framework which prioritises integrating care in the health system across sectors, including social care (Zonneveld et al, 2020), the inclusion of a priority area focused on the NFP health sector would be both timely and necessary to ensure ongoing strategic partnerships which ensure integrated practice.

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