

# Response ID ANON-QZ7X-DDVX-G

Submitted to **Medical Research Future Fund consultation to inform the third Australian Medical Research and Innovation Priorities 2020-2022**

Submitted on **2020-10-06 17:15:29**

## Introduction

### 1 Full name

**Full Name:**

Canteen Australia

### 2 Submission type

Organisation affiliated

### 3 Organisation type

Non-government

### 4 Organisation sub-type

Consumer

### 5 Residential state or territory

Victoria, New South Wales, Australian Capital Territory, Queensland, Northern Territory, Western Australia, South Australia, Tasmania

### 6 Do the current Priorities remain relevant in the contemporary environment for continuation for a further 12 months?

**250 word limit:**

Yes. Canteen is of the view that the current priorities remain relevant.

### 7 Should any of the Priorities be emphasised or de-emphasised for the next 12 month period?

**If you answered YES, please indicate what specific priorities and why? (max 250 words):**

Global Health and Health Security

This priority should be expanded to facilitate international collaborative research into rare and chronic conditions. Low yearly incidence in rare cancers and complex populations, including adolescents and young adults (AYAs), makes drug development and clinical trials difficult through domestic investment and effort alone. Opportunities to set priorities and progress promising treatments largely fall to more populous countries. Despite potential benefits, there is little international coordination of efforts for these cancers, contributing to the minimal pharmaceutical industry focus on these patients.

Australia's researchers have few opportunities to influence treatment development and trial planning for rare cancers, particularly at early stages in the drug discovery pipeline. Previous MRFF investments in rare diseases need to be extended to facilitate international collaboration across the drug discovery, development and trials pipeline, opening opportunities for Australian investigators to have a global impact.

Consumer Driven Research

Consumer driven research is even more critical with the additional burden of COVID-19 and its impacts for cancer patients. Cancer patients are experts in their treatment and care; maintaining their voices ensures a critical perspective when conducting research and evidence translation for service delivery development. Canteen supports and partners with young people impacted by cancer in research and research priority setting activities; and when developing and evaluating programs and services. Another important consideration is evaluating consumer partnerships in research to determine whether these initiatives are effective, and to identify elements that are critical to their success.

**If you answered NO, please indicate what specific priorities and why? (max 250):**

### 8 Are there any unaddressed gaps in knowledge, capacity and effort across the healthcare continuum and research pipeline that would warrant changes to the Priorities?

**If you identified a gap, please explain how it should be addressed in the 2020-2022 MRFF Priorities (max 250 words):**

Not-for-profit Health sector

A gap in the MRFF Priorities remains a focus on the community-based, not-for-profit health sector, a critical third sector of the Australian health system, targeting a multitude of health conditions, delivering essential services, support and resources and relieving considerable burden on the primary and acute care sectors.

Addressing the sub-optimal integration of effective services delivered by the not-for-profit health sector presents opportunity to better meet the needs of patients and families while reducing burden on acute and primary care settings. Effective integration depends to a large degree on having a robust evidence-base for the services offered by this sector. It is critical to ensure that the not-for-profit 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.

While the Department of Health captures some of the services and resources within its definition of Primary Health Care, this concept of the “first (primary) layer of services encountered in health care” is not necessarily reflective of the way in which these services work. While some take a self-referral approach or disseminate publicly available resources, others require referrals or GP mental health/chronic disease management plans to access Medicare-funded services. Further, the variety of settings in which care is delivered and greater complexity of service delivery modalities (e.g. online service delivery) make the not-for-profit health sector sufficiently distinct to warrant a distinct focus. We therefore strongly advocate for a specific community-based, not-for-profit health sector priority.

We propose the establishment of a standalone priority focused on this sector which would broadly address enhancing the evidence-base for the health services, programs, interventions and resources provided by this sector. This priority should invest in initiatives that increase levels of evidence and capacity to conduct research and evaluation in the sector to embed a culture of evidence-based development. Proposed initiatives could include:

- The establishment of a not-for-profit sector-wide research network
- Conducting health system research focused on integrating community-based and not-for-profit 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 sector
- Extending medical record infrastructure and population and disease registry data capture into the not-for-profit health sector.

This priority will need to be matched by a substantial long-term investment which could include targeted MRFF funding to leading organisations in this sector to carry out priority initiatives, competitive grants for discrete research and implementation projects and programs offered via the NHMRC or other granting organisations, investment in capacity building initiatives such as research fellowships and direct infrastructure investment.

**If you identified a second gap please explain how it needs to be addressed in the 2020-2022 MRFF Priorities (max 250 words):**

A gap in the Priorities remains any focus on cancer survivorship. AIHW data published in 2019 reported over 1 million Australians living in Australia who are either living with or have lived with cancer. With an estimated 150,000 new cancer diagnoses expected in 2020 and almost 70% of these Australians expected to survive for five years or more, the population living with the late effects and chronic health impacts of their cancer and treatment will continue to dramatically increase every year.

Cancer follow-up approaches predominantly emphasise the monitoring of cancer recurrence and second primaries while paying insufficient attention to psychosocial needs, late effects of cancer and treatment and management of other chronic illnesses.

The Clinical Oncology Society of Australia (COSA) Model of Survivorship Care specifies:

- a survivor centered, integrated and coordinated approach to care;
- a focus on health promotion, disease prevention and management, and
- a need for equitable access to treatment support.

In commenting on implementing this model, COSA noted that a substantial program of national translational research was required, including identifying barriers and facilitators, consultation with local stakeholders and tailoring implementation strategies to specific contexts and services. In coming years, it will be critical for consistent, coordinated and well-funded survivorship research to be conducted across primary, community and acute care settings around the country to maximise outcomes for Australian cancer survivors, their families and communities.

Canteen strongly endorses the establishment of a cancer survivorship priority and funding, with specific consideration and investment in AYA cancer survivors.

This investment should focus on the implementation of a national model of cancer survivorship care that appropriately leverages all sectors of the Australian Health system, including primary and acute treatment sectors along with the community-based, not-for-profit health sector. This priority and investment should support long-term, nationally coordinated translational research, professional development, monitoring of quality of care indicators and benchmarks and ensuring care is responsive to the needs of distinct populations such as AYAs, CALD and Indigenous Australians.

AYA cancer survivors are a critical population to consider in this priority investment. With their high survival rate, many years of life in which to manage the chronic disease impacts of their cancer and treatment and complex needs driven by their life stage, a tailored approach to their survivorship is required.

This priority will need to be matched by a substantial long-term investment, which could be disseminated via multiple existing and newly established channels. These could include targeted MRFF funding to leading organisations in this sector to carry out priority initiatives, competitive grants for discrete research and implementation projects and programs offered via the NHMRC or other granting organisations, investment in capacity building initiatives such as research fellowships and direct infrastructure investment.

**9 Is there an opportunity to consolidate the Priorities for the remaining twelve months of the Strategy?**

**Max 250 words:**

Keeping priorities that consider investment in research across the healthcare space, including the not-for-profit sector is key to maintaining a strong sector faced with challenges such as the current COVID-19 pandemic.

**10 Do you have any additional comments in regards to the Priorities for 2020-2022?**

**Max 250 words:**

**11 Do you consent to components of your submission being made publicly available?**

Yes