Introduction

Cancer Council Western Australia (CCWA) welcomes the opportunity to inform the development of the WA Cancer Plan 2020-2025.

CCWA is a non-government, not-for-profit cancer organisation that has no religious or political affiliations. CCWA has been involved in the governance and distribution of peer-reviewed cancer research funding, patient support, cancer prevention, and advocacy in Western Australia (WA) for 60 years. CCWA is a leading and active member of the cancer community, which comprises people affected by cancer, whether through a personal diagnosis or as family members, carers or health professionals.

The burden of cancer in the WA community continues to be high, with more than 12,000 residents diagnosed each year and 4,000 deaths. CCWA is committed to funding research into all aspects of the cancer control continuum, including cancer prevention, detection, diagnosis, treatment and palliative care, as well as understanding and improving the psychological and social impacts of cancer. In the period 2008-2010 CCWA was the second largest funder to competitive cancer research projects in WA, after the NHMRC, committing more than $20 million over the last 6 years towards cancer research. Cancer research is part of the core business of CCWA and it is an activity the community strongly supports.

Thanks to advances in medical research, more people with cancer are being successfully treated, but with over 200 different types of cancer there is still much work to be done. It is critical that we continue to better understand the causes of specific cancer types, so that we can develop strategies to more effectively prevent these cancers from developing, and if they do develop, to identify ways to detect them early and treat them effectively.

Global health concerns are shifting. Advances in scientific discoveries and research, and better living standards, have increased the opportunity for people to lead longer and healthier lives, while reducing the incidence of infectious diseases. However obesity, malnutrition, antimicrobial resistance, and non-communicable diseases such as cancer are increasingly becoming the health burden of our century.

CCWA commends the commitment by the State Government to establish the Future Health Research and Innovation (FHRI) Fund, and supports the FHRI policy which states that “providing a strategic approach to cancer research will attract and retain top cancer specialists in WA, develop the skills of the WA cancer workforce and ensure WA patients get access to world-first treatment trials.”

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Summary of recommendations

The State Government is commended through the FHRI Fund for prioritising the clear need for a strong health and medical workforce to confront WA’s health priorities, in particular the burden of cancer in WA.

In addition to the specific recommendations outlined below, CCWA stresses the need for a proportion of the FHRI Fund to be allocated to public health research, with a focus on cancer prevention. In 2014, only 14% of the NHMRC research funding expenditure was allocated to public health research, and the overwhelming majority was spent on medical research. Public health research has a history of being underfunded in comparison to bio-medical research funding, despite its capacity to inform interventions and strategies that impact upon health on a population basis. It is critical that a proportion of the FHRI Fund goes to public health research and prevention, including support for the implementation and evaluation of large-scale, longer-term public health interventions.

CCWA supports the need for equitable distribution of research funding across the cancer continuum, that research should be embedded in each of these domains across the cancer continuum (including bio-medical/laboratory research). The cancer domains include:

1. Prevention/public health (including policy)
2. Early detection and screening
3. Diagnosis
4. Treatment (including clinical trials and drug discovery)
5. Psychosocial and survivorship
6. Palliative and supportive care

It is also essential that the State Government commits to continuous and adequately resourced governance, monitoring and evaluation of all aspects of the FHRI Fund. Monitoring and evaluation should include the establishment of an independent body which would manage the grant process, distribute the FHRI Fund, provide governance of the administration of the Fund, and oversee a clear evaluation and reporting strategy on the impact of the FHRI Fund.

In relation to the specific prompts outlined in the Research Consultation, CCWA recommends the following:

Translation between research and delivery of care; access to clinical trials for new cancer treatment and drugs

The basis of translation is discovery. There is a substantial lack of cancer discovery research in WA. This includes development of diagnostic/prognostic and therapeutic technology/drugs. This sector needs to be enhanced with respect to its work force (scientists, clinician scientists), infrastructure and integration of basic scientists into clinical services (for example, through participation in multi-disciplinary patient assessment teams).

Discovery needs to be linked to technology development including creation of a biotechnology sector in WA. This would generate investment returns and an improved career structure for biomedical scientists. It would also guarantee that our discoveries are translated in WA or at the very least, not sold to international companies.

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However, investment alone does not guarantee research success. Health services must first acknowledge that clinical trials are integral to the delivery of optimal care and make allowances for clinical research to support the conduct, resourcing and recruitment to clinical trials. Ensuring there is workforce capacity to enable research is critical to the trial’s completion, as well as governance structures to support efficient multi-centre research. Limited workforce capacity or expertise in selecting, opening and running a clinical trial contribute to poor trial recruitment and the reality that many trials open and close without recruiting any patients. Limited workforce capacity also prevents sites from participating in other activities for service planning and system improvement. Increased clinical trial capacity and capability at the health service level could be established through a dollar matching arrangement between the FHRI Fund and participating institutions over time, based on recruitment performance metrics, therefore extending the impact of the funding commitment. This will augment investment in national trials infrastructure and accelerate change. This investment would create continuity in staff levels and work-loads to enable time for clinical staff participation and offering of clinical trials in their centre. This would support the expected anticipated outcomes of the FHRI Fund by benefitting the health and wellbeing of Western Australians, enhancing the quality of the WA research and innovation ecosystem, leading to sustained employment and economic growth; and enhancing the reputation of WA as a leader in research, innovation and commercialisation. The introduction of standard measures of clinical trial activity and recruitment in WA could monitor the capacity to support clinical trials.

The FHRI Fund’s measures of success must include better quality outcomes for the same money, or savings, or commercial outcomes. However, data is required to measure improvements. To improve the impact of investment, the Fund should require applicants to submit a plan to translate outcomes into practice. Additionally, the Fund should implement conditions that require the researcher to commit to contributing to a broader data and knowledge base. For example, the National Institute of Health (NIH) requires funded researchers to commit to publicly disclosing their data and outcomes for use by the public. Researchers commit to contributing to the NIH’s scientific mission, and the research feeds into reports, data, and analyses of NIH research activities.

Similarly, the FHRI Fund should introduce conditions requiring funded researchers to contribute to a broader data and knowledge base through:

- Publishing outcomes and making this information publicly available for use by other researchers;
- Contributing to data collection through clinical quality registries and other sources;
- Demonstrating reform and system enabling.

Specifically, CCWA is of the view that WA should be equipped with a comprehensive and complete digital archive system, including all patient clinical data (imaging, biopsy results, tissue pathology, and treatment information). This would enable WA to lead Phase IV clinical trials, enabling the direct translation and evaluation of clinical trial results in the clinical population.

**Ethics and approval processes**

CCWA supports the concept of opt-out (or opt-in if necessary) consent for use of all clinical data in research. CCWA also supports the need for faster and easier access to ethics and approval processes.

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5 Government of Western Australia, Department of Health *Health and Medical Research and Innovation Strategy Discussion Paper* (2019), at 3.
Networking and engagement opportunities between disciplines; awareness and collaboration across health services; partnering with other government agencies and sectors

CCWA supports a detailed and transparent process for researchers to make suggestions for, and contribute to, health policy. Researchers should be recognised and rewarded for showing evidence of engagement with policy makers and other public health researchers and practitioners.

Attraction and retention of clinician researchers; opportunities for international cancer researchers to work in WA

WA’s health and medical research sector has a strong track record and performs exceptionally well on a global scale, but it is essential to continue to build and maintain capacity across the sector in order for it to support Australia’s health priorities, and to confront its cancer burden. Active research communities are vital in Australia’s major population centres, to enable the translation of research outcomes into policy, clinical practice and program and service delivery, which can significantly improve cancer prevention, care and control. A strong commitment is needed from the State Government to continue to support and strengthen the WA research community and to develop the research workforce.

Strengthening the WA cancer research workforce should be prioritised through funding dedicated teaching and research positions including in clinical settings, providing better support for early career researchers, and ensuring that strategies to involve Indigenous Australians and retain women (for example, by providing support to retain research track record during maternity leave) are in place.

WA researchers face difficulties undertaking collaborative research within Australia due to geographical distance. There is a need for ongoing State Government support to ensure collaborative research is approached fairly. In order for the Australian medical research community to move forward together, it is important that researchers based in WA are offered opportunities and support from the State Government that ensure a fair and inclusive approach to collaborative research projects, and are on par with researchers who work in Australia’s larger population cities.

Consumer participation in research

Evidenced based and locally supported consumer and community engagement should be embedded into every aspect of the FHRI Fund. CCWA is of the view that the FHRI Fund should be an opportunity to build on the current infrastructure provided by the Consumer and Community Health Research Network.

Cancer Australia has developed a National Framework for Consumer Involvement in Cancer Control (the Framework) to involve consumers in cancer research. This Framework should be a requirement for those seeking funding from the FHRI Fund. Organisations committed to improving consumer participation have developed and agreed on this Framework. It is applicable to policy, health service delivery and research activities spanning the cancer
There is sound evidence that involving consumers will lead to improved outcomes and therefore implementation of the Framework has the potential to build sustainable and effective consumer engagement for the benefit of all people affected by cancer.

The FHRI Fund should seek to integrate the following core principles of consumer engagement developed by Cancer Australia into the application for funding as well as the development, delivery, impact and reporting on cancer research. These principles aim to guide and strengthen consumer engagement in all aspects of cancer care and control and place the needs of people most affected at the centre of all policy planning, service delivery, research, information and support.

**Accomplished organisations**
Organisations integrate consumers into organisational governance and involve consumers transparently in strategic planning and decisions about resource allocation.

**Active consumers**
Consumers prepared and informed to optimise their involvement and advocate for all people affected by cancer.

**Respect and acknowledgement for cultural, social and geographical diversity**
Consumers from Aboriginal and Torres Strait Islander, culturally and linguistically diverse and regional, rural and remote communities are engaged in an appropriate and culturally safe manner.

**Dedicated professionals**
Clinicians, managers, health professionals, planners, researchers and policy makers engage with consumers respectfully and as equals.

**Confirmed outcomes**
Measurable outcomes agreed with consumers are used to build the evidence of meaningful and sustained consumer engagement.

**Act ethically, responsibly, honestly and transparently**
Ethical, accountable behaviour is practised by all people and organisations involved in cancer control.  

**Career opportunities for cancer researchers; job security for cancer researchers; workplace support for cancer researchers**

There is a strong need for conditions that better support early career researchers to establish independent early research careers. Although we have an excellent education system that produces highly skilled early career researchers who are recognised worldwide, Australia is increasingly losing talented early career researchers overseas, and to other career paths, because support for young researchers is lacking.

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State-wide model for collection and sharing of cancer data

CCWA supports investment of the FHRI Fund in analytical capability and transparent, real-time reporting across the system to ensure timely and targeted information to drive safety and quality, to support decision making for high value healthcare and innovation, and to support patient choice. Priorities for implementation include Implementation of modern governance for more timely and comprehensive whole-of-government and research access to data linkage services for more effective research, service planning and investment to meet community needs.

CCWA is of the view that a State-wide model for collection and sharing of cancer data represents an important opportunity for WA. WA has a well-confined, stable population and is the ideal testing ground for precision-medicine approaches and Phase IV trials, and for validation of outcomes derived elsewhere. This would be an opportunity for WA to lead the development of implementation methods for precision medicine in cancer. An opt-out consent process would also be needed, together with the legislated participation of private providers.

Storage and access to data and biological samples for research

WA cancer researchers currently have limited access to imaging (notably MRI and PET imaging) and associated analytics expertise for cancer research studies. In particular, WA is struggling to supply demand with only one cyclotron for production of imaging and therapy radiopharmaceuticals, and no dedicated research imaging scanners. The use of imaging and imaging analytics is rapidly expanding in cancer research, and other Australian states are significantly more advanced than WA in this capacity.

CCWA also supports the need to standardise the collection, storage and access of biological samples in order to increase the capability of individual biobanks to interact with other key datasets.

Conclusion

The cancer burden in Australia is steadily increasing and it is absolutely essential that cancer research remains a priority. Cancer research priorities should cover the full spectrum of cancer prevention, care and control, including but not limited to research into the areas of prevention, early detection, treatment, supportive and palliative care, and translation of research into practice.

More generally, funding for research should reflect the serious threat that chronic, lifestyle-related diseases pose to Western Australians and the critical need for a strong, cohesive approach to chronic disease prevention.
6 June 2019

WA Cancer and Palliative Care Network Policy Unit
By email: WACPCN.PolicyUnit@health.wa.gov.au

To whom it may concern,

I write to express the Public Health Association of Australia (PHAA) WA Branch’s support of the submission made by Cancer Council WA for the WA Cancer Plan 2020-2025 – Research Consultation. PHAA WA Branch strongly believes that funding for cancer research should include a focus on cancer prevention and the translation of research into practice.

PHAA is recognised as the principal non-government organisation for public health in Australia and works to promote the health and well-being of all Australians. PHAA seeks better population health outcomes based on prevention, the social determinants of health, and equity principles.

Cancer Council WA reports that historically, funding for cancer medical research has provided great advances for the community, with many people being successfully treated for their cancer prognosis. However, with over 200 different types of cancer currently identified there is more to be done. This highlights the importance of adequate funding for prevention research, as well as for research into new and emerging cancers to ensure that there are appropriate strategies for prevention, early detection, and treatment.

PHAA WA Branch supports the position of Cancer Council WA to maintain commitment to “funding research into all aspects of the cancer control continuum”\(^1\). In particular, PHAA supports the endorsement of funding for public health research. PHAA is a strong supporter of evidence based prevention policy and research as demonstrated in the PHAA Policy Position Statement on Breast Cancer Screening.\(^2\) We acknowledge that traditionally public health research has been underfunded in comparison to bio-medical research, but see this as a great opportunity to refocus future funding. PHAA endorses the position of Cancer Council WA for equitable distribution of funding to the five domains:

1. Prevention/public health
2. Early detection and screening
3. Diagnosis
4. Treatment (including clinical trials)
5. Palliative and supportive care (including psychosocial care)

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\(^1\) Submission: WA Cancer Plan 2020-2025 – Research Consultation

We strongly support Cancer Council WA’s position around research transparency, contribution to health policy, and the improvement of researcher’s recognition in Western Australia.

We appreciate the opportunity to support the submission made by the Cancer Council WA to continue to support vital cancer research. We recognise that the cancer burden in Australia is rising and that research should reflect the priority areas of prevention, early detection, treatment, supportive and palliative care, and translation of research into practice.

Yours sincerely,

Ms Hannah Pierce
President, Public Health Association of Australia WA Branch