

Cancer Council Western Australia's Research Funding Program

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research



prevention



support

About Cancer Council WA

We are the leading cancer charity in WA.

Our Vision

Achieve a cancer-free future for our community

Our Mission

Work with our community to reduce the incidence and impact of cancer



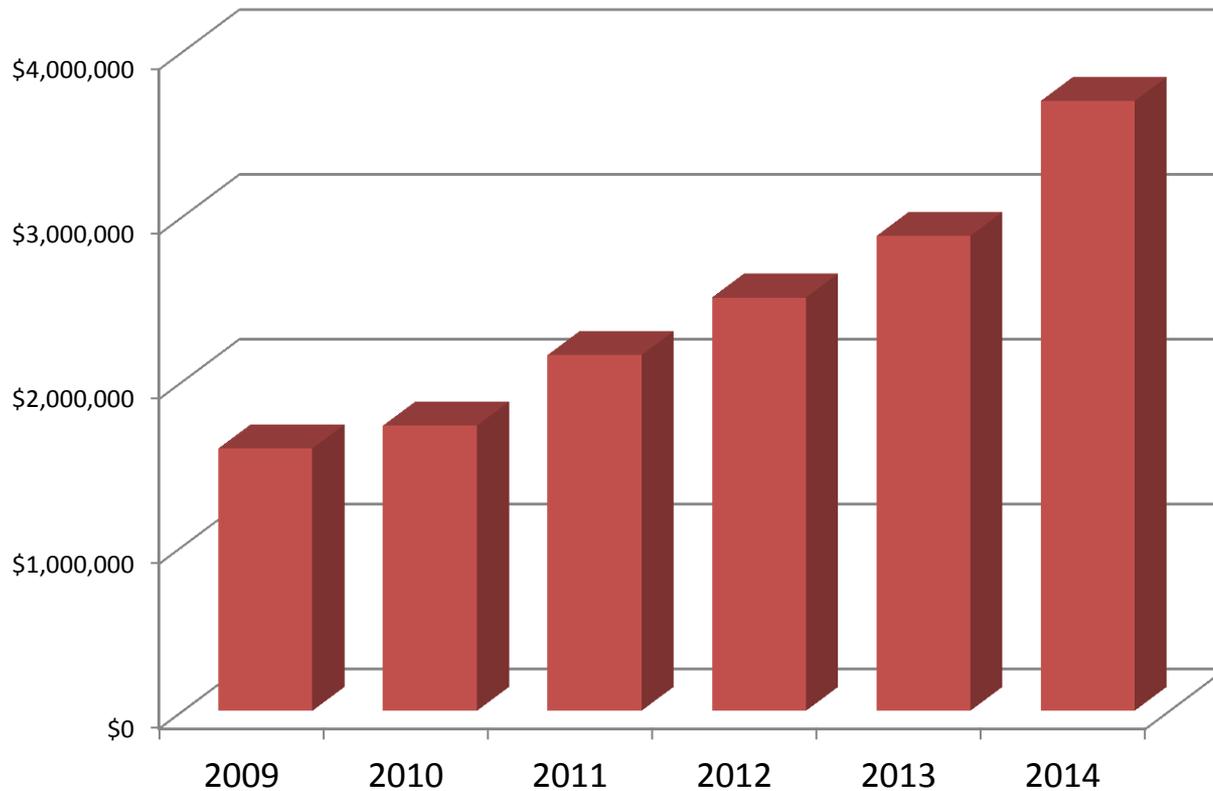
Research Funding Program Aim

To help ensure WA has a skilled, productive and effective cancer research community.



Ultimately, a strong cancer research culture in WA will translate into improved outcomes for cancer patients and better early detection and prevention.

Research Funding 2009-2014



- Our money comes from public donations

Our Research Funding Program structure

Fund **people** and **projects**



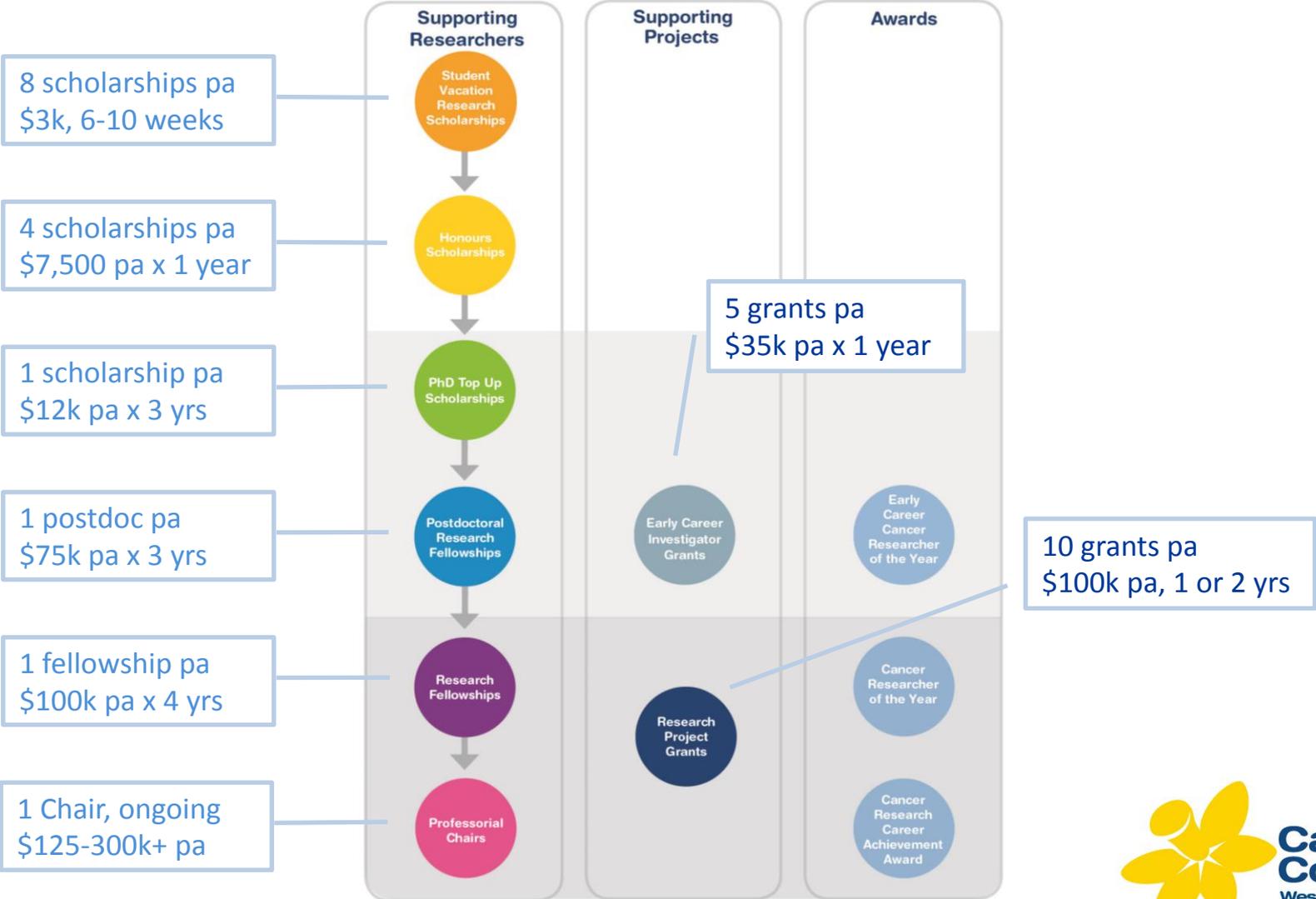
The person : enabling progress at every career stage for the best researchers



The project : grants for talented cancer research teams to DO the work

Most funding open to ALL types of cancer related research.

Research Funding Program



How we assess grants

- Grants are reviewed by members of our Research Grants Advisory Committee or Sub-committees
- Committee composition:



- Committee guiding principles
 - That all steps are taken to ensure **objective external assessment and review** is applied to the allocation of research funds
 - That the **research community** of WA are considered as **respected and equal partners** in the challenge to learn more about cancer
 - That representation on the committee will come from a **wide range of institutions and disciplines** involved in cancer research in WA and from **community representatives** with a **personal connection** to cancer

Changes to community involvement

- Changes this year
 - Increasing the number of community representatives
 - New community criteria
 - New training for community representatives
- Why involve the community in grant assessment?
 - Lots of reasons! E.g.:
 - Help ensure the research we fund is relevant to the WA community
 - Provide a broader perspective to our decisions
 - Accountability to our donors
 - Improve how the results of research we fund are communicated to the wider community.

Community Criteria

- Will be assessed by community representatives only
- Responses need to be in plain language

Section B1: Plain language summary

Section B2: Community review criteria

1. Research outcomes and the extent of potential benefit (impact)
 2. Pathway for realising the benefit (translation)
 3. Equity
 4. Community (consumer) involvement
- Designed to match the Cancer Australia and Cancer Council NSW criteria as closely as possible

How are final rankings determined?

- Independent cancer researchers \Rightarrow assess against scientific criteria
- Community representatives \Rightarrow assess against community criteria

❖ Fellowships, Postdoc fellowships, ECI Grants:



❖ Project Grants:

- Bit more complicated because of NHMRC step
- Still working out details but community criteria will be the same
- Further info will be in Guide to Applicants

How are final rankings determined? (cont)

- ❖ Student scholarships (vacation, honours, PhD):
 - Only small changes to current system
 - Criteria assessed by researchers and / or community representatives depending on what is appropriate
 - Exact criteria vary by grant, but roughly:

Criteria	Researchers	Community Reps
Academic record	✓	
Scientific excellence	✓	
Track record	✓	
Outcomes	✓	✓
Career aspirations	✓	✓
What will gain personally	✓	✓
Plain language summary		✓

How to answer the community criteria

research



prevention



support



Community Criteria

Recap:

- Will be assessed by community representatives only
- Responses need to be in plain language

Section B1: Plain language summary

Section B2: Community review criteria

1. Research outcomes and the extent of potential benefit (impact)
2. Pathway for realising the benefit (translation)
3. Equity
4. Community (consumer) involvement

Plain language summary

- Important for all our grants
- Quality assessed by community representatives
- Spend time getting your plain language summary right
- About content, structure and style
- See our guidance doc for more info
- Get a non-scientist to proof-read your summary (a good role for a consumer / community rep)
- Being able to explain your research in plain language is important in interviews too

Research outcomes & extent of potential benefit

“Identify the anticipated direct outcomes of your proposed research. Describe how these outcomes have the potential to have a direct, beneficial impact on either the incidence or impact of cancer on our community. This includes short, medium and long term outcomes. If applicable, describe any particular relevance of the research to Western Australia and / or any specific benefits to the people of Western Australia from the research taking place here rather than elsewhere.”

Research outcomes & extent of potential benefit

- Consider benefits from the perspective of the general public as well as those more directly affected by cancer
- Examples:
 - Identifying the mechanisms by which cancers arise.
 - Developing ways to personalise cancer treatments.
 - Identifying and/or testing effective ways of preventing disease.
 - Identifying those at high risk of developing cancer.
 - Improving existing or identifying new cancer care delivery approaches, treatments and / or diagnostic methods.
 - Improving access to information, and the quality of information available.
 - Easing physical and/or mental suffering of those affected by cancer.
 - Maintaining or rebuilding dignity and quality of life.

Pathway for realising the benefit (translation)

“Provide a clear description of the steps required to reach the stated benefits of the research. This may include further steps beyond the scope / timeframe of the proposed research.”

Pathway for realising the benefit (translation)

- Benefit = final benefit, directly applicable to humans
- Further steps often required to realise research benefits.
- These steps might include:
 - additional laboratory based research,
 - testing on humans,
 - changes in clinical practice,
 - product development,
 - regulation and / or policy changes.
- Steps beyond your research / involvement should be included if required to reach the end benefit

Pathway for realising the benefit (translation)

- Strongly advise:
 - Using **numbered steps** to delineate the pathway
 - The pathway should describe the steps required to realise the **benefits** of the research, rather than the results
 - Make sure there are **no major gaps**
 - It is **not appropriate** to restate the aims or objectives of the research
 - Include estimates of **broad timeframes** for each step

Equity

“Explain which patient group(s) will benefit the most from your research (e.g. type or stage of cancer) and any equity implications. For research involving people, justify the selection of the study sample and explain why you have included and excluded particular groups who could potentially benefit from the outcomes of this research. If relevant, outline how the proposal addresses an under-studied or under-served population and / or a population with a high burden of disease or poorer outcomes.”

Equity

- Equity in research = striving for equal benefit from research
- No one 'right' answer
- Equity of opportunity + equity of outcome
- Explain the rationale behind your focus / study sample
- How could the benefits of the research be expanded to other groups in the future?
- Will your research benefit populations with poorer outcomes e.g.:
 - patients with specific tumour types or specific age groups
 - Aboriginal and/or Torres Strait Islander people
 - people of culturally and linguistically diverse backgrounds
 - patients in regional / rural locations

Community involvement

“Outline how community representatives (consumers) have been involved during the development of the research proposal and the plan for ongoing community involvement in the research. Explain how this / these community representative(s) are ‘qualified’ to be involved.”

Consumer / community involvement

- What is it?
 - Consumers, community members and researchers working together to shape decisions about research priorities, practice and policies.
 - An active **partnership** that is sensitive to changing needs and priorities.
 - Conducting research that is **with** the community rather than **to** or **for** the community¹
- Who qualifies as a consumer / community representative?

NHMRC: ‘Patients and potential patients, carers, organisations representing consumers’ interests, members of the public who are targets of health promotion programs and groups asking for research because they believe that they have been exposed to potentially harmful circumstances, products or services’.

Ref: 1. McKenzie A. Haines H. Consumer and Community Participation Fact Sheet P01: Why Involve Consumers and Community Members in Research, Revised (2014)
2. Cancer Australia, ‘Consumer Reviewers for Cancer Australia’s Priority-Driven Collaborative Cancer Research Scheme: Expression-of-Interest Background Information’ (Cancer Australia, 2012), p. 1.

Consumer / community involvement

- Who is not a community representative:
 - Other researchers (especially if connected to your research / working in your lab)
 - Clinicians / practitioners representing their professional role
 - The subjects of your research are not automatically community representatives, ie if you are performing a clinical trial on 100 patients you can't claim that these patients are all community representatives. Sometimes some of the subjects of a research project may also act as community representatives e.g. by sitting on a steering group. Whether this is appropriate requires careful consideration of issues around ethics, confidentiality and potential bias.

Consumer / community involvement

- Some examples:
 - Provide informed input on strategic priority setting and direction
 - Work with researchers to define or refine the research topic
 - Provide informed input on research design and proposed methods
 - Participate in project advisory committees
 - Conduct lay reviews of research proposals
 - Participate in recruiting participants to research
 - Assist researchers to develop links to hard-to-reach populations
 - Conduct reviews of participant information sheets and consent forms
 - Assist researchers to pilot a research questionnaire
 - Support the development of plain language summaries
 - Assist in disseminating information to the wider community

NOTE: You don't have to do all of these in 1 project!



Consumer / community involvement

- But I do basic science in a lab and my work doesn't involve patients, how can I involve community members?
 - You can still involve community members, but involvement may look different to e.g. a clinical trial
 - Consider having a “research buddy”
http://www.involvingpeopleinresearch.org.au/images/pdf/fact_sheet_m07_research_buddies.pdf
 - Community members can help with:
 - Making sure your plain language summaries are easy to understand
 - How to communicate the value of your research to the wider public
 - Communicating the results of your research to interested parties

Consumer / community involvement: benefits

- What are the benefits?
 - Research is more relevant to the community
 - Greater transparency, accountability and openness
 - Encouragement
 - Improved research design and implementation ⇒ better chance of success
 - Improved recruitment processes
 - Better dissemination of research results
 - Helps to translate research findings into practice

References:

McKenzie A. Haines H. Consumer and Community Participation Fact Sheet P01: Why Involve Consumers and Community Members in Research, Revised (2014)
<http://consumerinvolvement.canceraustralia.gov.au/researchers>



Consumer / community involvement: benefits

If we have the attitude that involving consumers and the community will improve our research ... it means our research may be more relevant...we may go into a new research area because the community thinks its important and we respond to it. ... The way that we then feed our research back to people means that that will enable them to use the research information in ways that improves their health and their well being.

Professor Fiona Stanley

When you get women involved in breast cancer control, it actually encourages the clinicians and the researchers. Some of them, the researchers especially, might be looking down test tubes or working in a path lab or that sort of work..., and they go to these committees and they're all kind of thinking the same way, and then there's a woman amongst them who is actually at the end of all this work. And she's saying, "Don't give up. Keep going." She could almost be like a coach who says, "We need answers to this. This is for my daughter." So often just by having a person affected by cancer, not only do you get a better outcome, but actually the people on the committee get a reality check and they can be further encouraged.

Lyn Swinburne, consumer, Founding CEO Breast Cancer Network Australia

References:

McKenzie A. Haines H. Consumer and Community Participation Fact Sheet P01: Why Involve Consumers and Community Members in Research, Revised (2014)

<http://consumerinvolvement.canceraustralia.gov.au/researchers>



Community involvement: tips

- Tips for application:
 - Many opportunities for consumer / community involvement in *all* stages and *all* types of research ⇒ answering n/a will score you zero!
 - Some examples here:
http://consumerinvolvement.canceraustralia.gov.au/sites/default/files/doc-lib/accessible/researchers/r5.3-17_guide_areasconsumerinvolvementresearch.pdf
 - Look at the different ways community members can be involved & work out what will add value to your research
 - What is reasonable and appropriate will vary depending on the nature of the research
 - Research design + throughout the research
 - Must be specific to the research
 - Two-way conversation (ie not just dissemination)
 - Ideally consumer / community reps should be:
 - named
 - trained
 - networked

Consumer / community involvement: help

- Lots of guidance out there, e.g.
 - <http://www.involvingpeopleinresearch.org.au/>
 - <http://canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/national-framework-consumer-involvement-cancer-control>
- Free 1 day training course on Friday 1 May:
Involving consumers in cancer research
 - Contact us to register or for more details

Where can I get further information?

- Cancer Council WA website:
 - This presentation
 - ‘Community Review Criteria for Cancer Council WA Research Grants: Guide for Applicants’
 - ‘Writing ‘Plain Language’ Summaries: Guidance for Researchers’
 - Consumer Involvement in the Research Funding Program: Frequently Asked Questions
 - The ‘guidance for applicants’ for the specific scheme you are applying for
 - If your query is not answered by any of the guidance documents, you can contact us at:
 - Email: research@cancerwa.asn.au
 - Phone: 9388 4342