Health consumer insights

Pip Brennan, Executive Director, Health Consumers' Council

HEALTH CONSUMERS' COUNCIL
YOUR VOICE ON HEALTH

WAHTN
Western Australian Health Translation Network

Consumer and Community
Health Research Network

Cancer Council
WA

Acknowledgement of Traditional Owners

We acknowledge the Whadjuk Noongar people who are the Traditional Owners of this Land and pay respect to all Elders past, present and future. We extend our respect to all other Aboriginal and Torres Strait Islander Cultures.

We asked WA health consumers and community members about their views of health and medical research

- 101 respondents
- 77% had some involvement in research

Key takeaways

- **People value health and medical research**
- They are **willing and want to be involved**
- Generally **people have had positive experiences** of their involvement
- There are **opportunities to improve how research is communicated** about
- There are **opportunities to continue to extend the role of consumers** and community members in research
- **WA has good examples** to share with others
- There's a **recognition of WA's limited resources** and how to make best use of these

Key themes from consumer surveys

- Opportunity to **improve communication** about research
  - Of opportunities – there was the suggestion of a single website where consumers can learn about opportunities
  - Of outcomes
    - To the public in general
    - To participants
      - Results of the overall research
      - People’s individual health results
  - To support implementation of best practice
    - How can consumers with lived experience help to get the word out?

Key themes from consumer surveys

Role of consumers in research

- Opportunity to extend beyond current practice
- Involve people earlier
- Recognise the value
- Ensure the experience is valuable and purposeful
- WA has good examples to share– i.e. funding consumer participation

Resources and funding

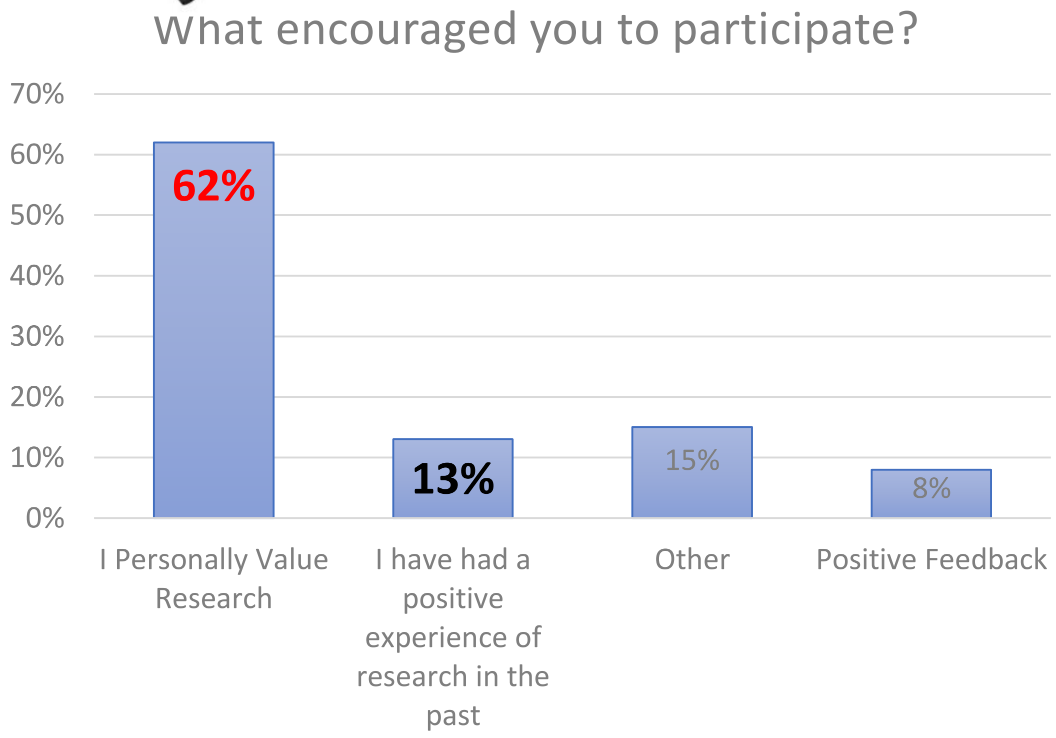
- Recognition of WA's limited resources and how to make best use – learn from and collaborate with international partners
- Prioritisation of resources
  - Ensure participation is equitable across groups in community
  - Ensure it is based on valid input – both hard data and lived experience

Why and how people do get involved in research?

- Being invited by a university researcher
- Being recommended to get involved by a health professional

Other

- Involved in a consumer organisation – often CCHRN



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- *"lived experience"*
- *"evidence from well designed research is crucial to establishing good health care systems"*
- *"rapport with one of the investigators"*
- *"to give back to community"*
- *"I was co-opted and didn't understand what I was doing."*

People’s experience of research

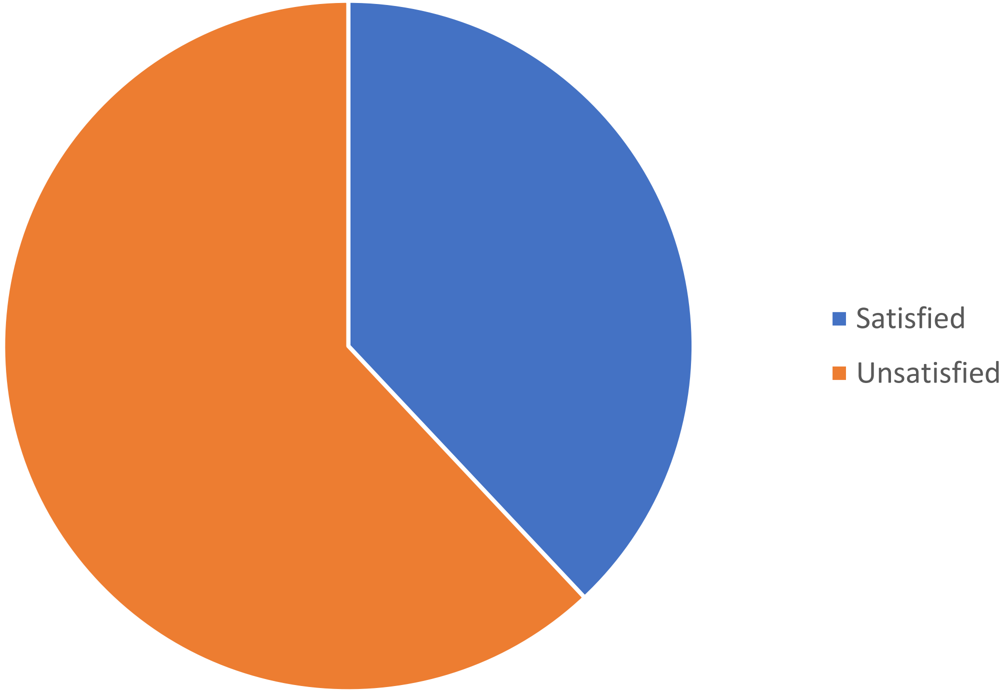
Most people have a positive experience

- Over 81% of respondents had a positive, or extremely positive experience of their involvement in research
- 96% of people would encourage others to be involved in research

But they do have some concerns……

- Time commitment
- Security of personal information
- Possible negative side effects

How satisfied are you with the level of involvement that the community members currently have in research?



Priorities for research – most things are important – some are more important than others…

MENTAL HEALTH

PREVENTATIVE INTERVENTIONS

CHRONIC ILLNESS

HEALTHY AGEING

CANCER

ANTIBIOTIC RESISTANCE

GENETICS AND INHERITED DISEASE

What roles do you believe community members should play in medical research?

- <u>**Be involved**</u> as a research participant 87.91%
- Be involved in setting priorities for medical research generally 80.22%
- Contribute samples or information 79.12%
- Be involved in evaluation of the research 69.23%
- Be involved in research design of medical research projects 67.03%

Other suggestions

- Advocate for research in the public – linking to lived experience
- Gather data as peer researchers
- Use networks to recruit participants and disseminate results
- Receive results

WA Cancer Healthcare & Research Sample

The study had 63 respondents in total (to date – still open)

- 60% of people had lived experience of cancer
- 26% of people were carers for someone with cancer

Of the people diagnosed with cancer (n=38):

- 53% had not been involved with cancer research
- 13% had been involved in clinical trials
- 13% in collection samples
- 13% as a research participant
- 13% as a researcher themselves
- 2.6% (n=1) in an exercise cancer trial

Opportunity to engage more with the community on cancer research

Most people strongly agree that cancer research is important for improving health care (over 85%)

Most people agree or strongly agree that Western Australia is supporting relevant cancer research (64%)

Many people felt unable to answer a number of the questions which could suggest there are more opportunities to communicate regularly about issues relating to cancer research. For example:

- 29% unable to answer whether Western Australia has sufficient cancer research expertise
- 38% unable to answer whether there is sufficient access to clinical trials in Western Australia
- 29% unable to answer whether researchers appropriately involve people with cancer when developing research activities
- 33% unable to answer whether researchers clearly communicate the results and outcomes of research activities to people with experience of cancer

Cancer research priorities – everything is important

- improve accuracy and speed of cancer diagnosis (94%)
    - while all were high priority, most respondents identified this as a high priority
- new possible cancer treatments and cures (91%)
- cancer prevention and screening programs (91%)
- Provide and communicate access to clinical trials (88%)
- Research how best to deliver cancer healthcare services that are suitable for cancer patients and their carers (85%)

Other priorities for cancer research?

- Wide range of answers
- Some mentioned more than once:
  - Children and young people
  - Cancer recovery and following up with people after care
  - Consumers are interested in being involved in research
  - It’s important to learn and apply research findings from overseas – WA shouldn’t “go it alone”

Useful links

- WA Health Consumers' Council www.hconc.org.au
- WA Consumer and Community Health Research Network

https://www.involvingpeopleinresearch.org.au/

- Cancer Council WA

https://www.cancerwa.asn.au/cancer-research/

- UK INVOLVE, National Institute for Health Research

https://www.invo.org.uk

- UK James Lind Alliance Priority Setting Partnerships

http://www.jla.nihr.ac.uk/

Photo by Adi Goldstein on Unsplash

"Consumer and community involvement is about

research being carried out ***with or by*** *consumers and community members*

rather than to, about or for them."

NHMRC https://www.nhmrc.gov.au/sites/default/files/documents/reports/consumer-community-involvement.pdf