



RESEARCH  
ADVANTAGE

# HEALTH PROFESSIONALS RESEARCH EDUCATION PROGRAM –

## Session 4: CONSUMER AND COMMUNITY ENGAGEMENT IN RESEARCH



12.30 – 2.00pm Thursday 12 November 2020  
Zoom MEETING ID: 9657 4825 105 and password 169760



# ACKNOWLEDGEMENT OF COUNTRY

## TRADITIONAL OWNERS

The University of Newcastle acknowledges the traditional Aboriginal owners of the lands within our footprint areas:

- Awabakal Nation
- Darkinjung Nation
- Biripai Nation
- Worimi Nation
- Wonnarua Nation
- Eora Nation

**Callaghan and NUSpace**  
**Central Coast, Ourimbah Campus**  
**Port Macquarie Campus**  
**Williamtown Hub**  
**Upper Hunter Hub**  
**Sydney Campus**

We also pay respect to the wisdom of our Elders past and present.



# EXPERT FACILITATOR

**NICK GOODWIN**



**Director - Central Coast Research Institute**  
**Director of Research - Central Coast Local Health District**



# EXPERT PRESENTER



**Mrs Sarah Lukeman**  
**Community Engagement Coordinator**  
**Hunter Cancer Research Alliance**



**Health**  
Hunter New England  
Local Health District



**Health**  
Central Coast  
Local Health District

# Being a consumer representative

Sarah Lukeman

*Community Engagement Coordinator*

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4042 0174



**HCRA**  
HUNTER CANCER  
RESEARCH ALLIANCE

*Working in partnership with:*



THE UNIVERSITY OF  
**NEWCASTLE**  
AUSTRALIA



**Health**  
Hunter New England  
Local Health District



**Cancer Institute NSW**



# The start of my cancer journey

March 2006



# Single Arm, Multi-institutional, Phase II trial for previously untreated APL patients

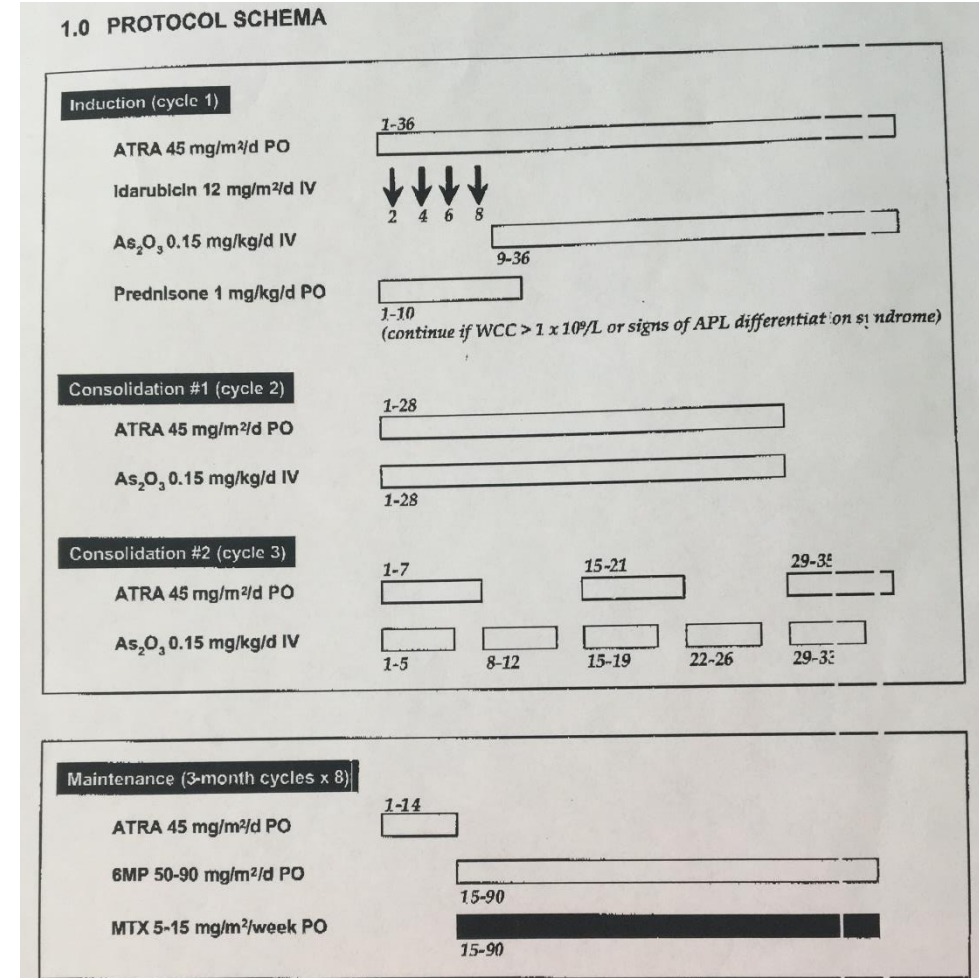
**T(15;17) translocation**

**PML-RARA transcription error**

- Myeloid differentiation disrupted
- Programmed cell death stopped

## ALLG APLM4 Protocol

- Idarubicin - cytotoxic
- all-trans retinoic acid (ATRA) - differentiation
- IV Arsenic Trioxide ( $As_2O_3$ ) – differentiation, apoptosis





# The start of my cancer journey

March 2006



May 2006







September 2006



2007



October 2008

The end of my cancer journey?

# My cancer journey continues

Leukaemia  
Foundation  
'Light the  
Night'  
inaugural  
Ambassador

Singleton  
Relay for  
Life

CCNSW  
Consumer  
Involvement  
in Research  
training

Cancer  
Voices  
NSW  
Executive

HNE LHD  
Cancer  
Clinical  
Network  
Leadership  
Committee

2008

2014

2016

2020

Biggest  
Morning  
Tea;  
Daffodil  
Day;  
Afternoon  
Teal

CCNSW  
Advocate  
training

HCRA  
Consumer  
Advisory  
Panel (CAP)

Upper  
Hunter  
Cancer  
Action  
Network  
Chair

HCRA  
Consumer  
Engagement  
Coordinator



# My cancer journey continues

## Blood journal

Leukaemia Foundation  
'Light the Night'  
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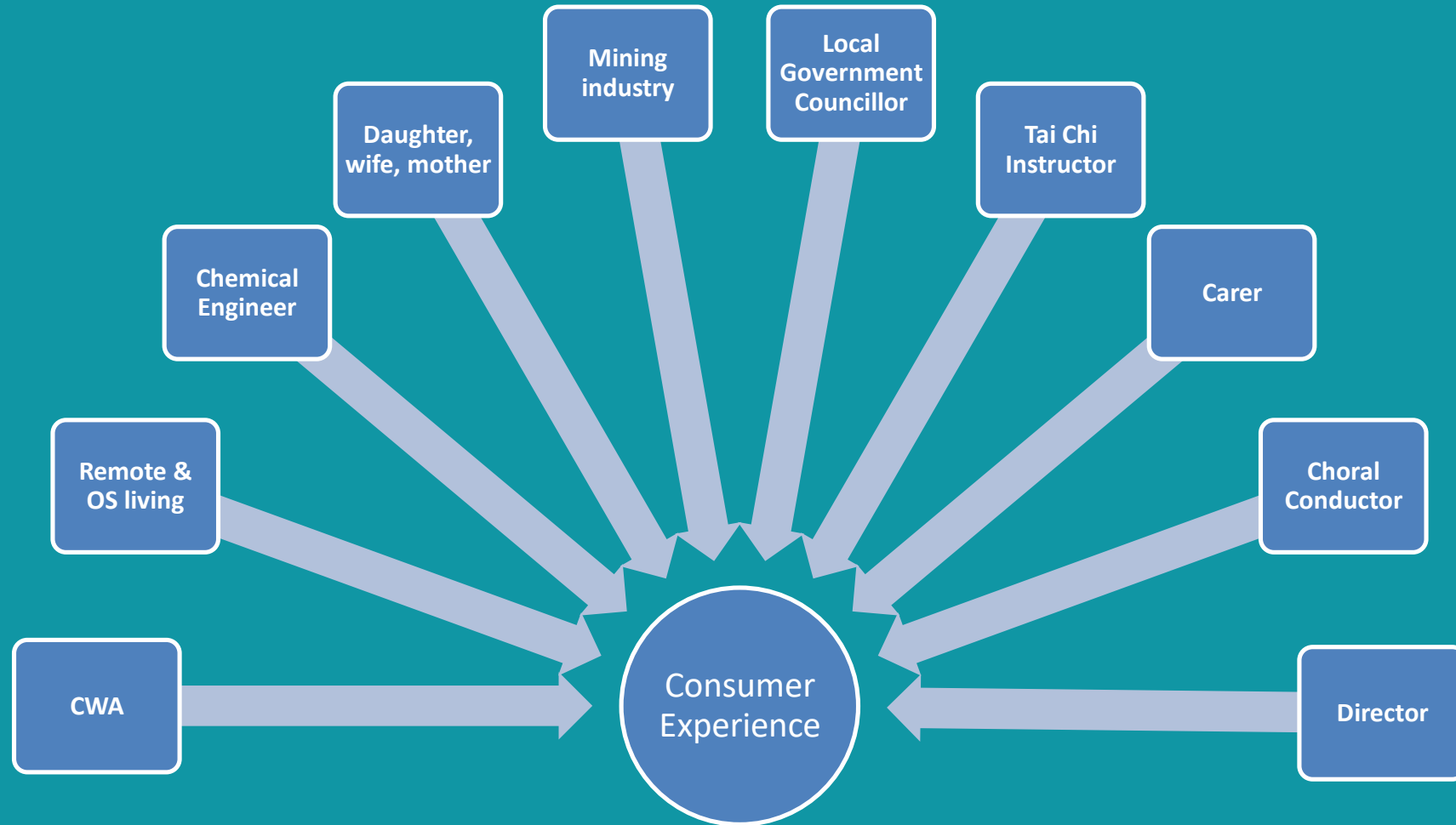
HCRA  
Consumer  
Advisory  
Panel (CAP)

Upper  
Hunter  
Cancer  
Action  
Network  
Chair

HCRA  
Consumer  
Engagement  
Coordinator



# A consumer is more than their cancer





# Who is a typical consumer?

- Make a positive out of something terrible – carer or patient
- Want to share their story and are not easily upset
- Want to see results of research put into practise as soon as possible
- Have a whole life of experiences to contribute
- Often don't want payment
- Usually trained and networked with other consumers
  
- Consumer cannot be a trial participant on that particular project

Consumer Involvement - active partnership, doing projects **with** consumers, rather than **about** or **for** consumers



# My work as a Consumer Involved with Research

## Cancer Voices

- Executive Committee since 2017
- 2019 matched with Catherine Carmichael, Australia Centre for Blood Diseases (ACBD)
- Consumer representative at workshops, forums and conferences
- Review of Consumer involvement in research program

## CCNSW

- Consumer Panel for Research Grants
- PhD selection panel
- Saving Life leader 2015; 2018
- CanAct leader
- Attend annual research awards

## HCRA

- CAP member since inception in 2016
- Matched with Pradeep Tanwar since 2017
- PhD selection panel
- Grant selection panel
- Strategic Review process
- HNE CCNLC consumer rep



# What can a consumer do?

- Provide consumer voice for a particular project
- Advisory group member for department or program
- Involvement at strategic level, such as steering group or advisory council
  
- Assist with plain language or lay summaries
- Review draft questionnaires, consent forms, information sheets.....
- Assist with dissemination of findings through networks, interviews and public presentations
  
- Research buddy – long term relationship
- Panel member for research grants or PhD selection





## CONSUMER ADVISORY PANEL (CAP)

The HCRA CAP was established in 2016 and enables community members to share unique perspectives to ensure cancer research in the Hunter is informed and guided by the needs of our community.

### Who can be a consumer advocate?

- Survivors of cancer
- Patients
- Carers of patients
- Family members

To find out more visit [hcra.com.au](http://hcra.com.au)



**HCRA**  
HUNTER CANCER  
RESEARCH ALLIANCE

# CAP Activity in 2020

**35 consumers**

**8 completed Cancer Council NSW consumer in research training**

**10 research project requests**

- 6 successfully connected
- 7 different consumers

**1 consumer involved with strategic review**

**1 consumer on funding panel**

**2 consumers on Community Engagement Committee**





# To pay, or not to pay?

Good consumer involvement is about establishing and building good relationships - this will cost more money and take more time.

Not involving them:

- compromise the relevance of your research
- translating the results into policy and practice may be difficult if community needs and priorities are different to yours

If you do not offer payment is the diversity of your consumer representatives sufficient?



# Take home messages

- **PICF are very important**
- **A consumer will help you focus on translation of your work**
- **A consumer is more than their patient experience**
- **A trained consumer is an integral member of your research team**



**Engage with a Consumer today!**



# EXPERT PRESENTER



## Professor Debbie Plath

**Consumer and Community Involvement  
Research Associate**



# Consumer involvement in research

Debbie Plath

[Deborah.Plath@health.nsw.gov.au](mailto:Deborah.Plath@health.nsw.gov.au)



# NSW Regional Health Partners



NHMRC accredited  
Centre for Innovation  
in Regional Health

- Established by 8 strategically aligned partners
- Health-led
- Supporting research that translates into more effective practice



# What is Consumer Involvement in Research?

- The **expertise of people with lived experiences** of health conditions, and the use of associated health services, is drawn upon ...
- ... in the conceptualisation, design, implementation and/or translation of health research
- Consumers are involved so that research can lead to more **relevant, responsive and effective health services**

# Key points to consider

- Who are the consumers?
- Where are they?
- Why involve consumers?
- When should I involve consumers?
- What does consumer involvement look like?
- Barriers and enablers for consumer involvement
- Resources and supports for researchers.

# Who are the consumers?

- People with perspectives to offer the research, based on personal, lived experiences (e.g. as a patient/service user, family member or carer)
- People who will be impacted by research outcomes
- Think laterally
- Aim for diversity
- Consider relevance to your project
- Have a role description & statement of purpose



# Where do I find consumers?



- Professional networks / clinical practice
- Peak organisations and consumer organisations (condition specific or related)
- Advertising / social media
- Call for EOIs
- Past study participants / research register – But check with HREC first
- “Snowball” contacts
- Consider: Relevance, Diversity & Purpose



# Why involve consumers?



## 1. Democratic values:

- \* Rights of public to influence use of public funds / Researcher accountability
- \* Relevance of research to public interests
- \* Public confidence in research (NHMRC; Brett et al., 2014)

## 2. Quality of research:

- \* Alerts researchers to new perspectives to inform research aims, design, recruitment strategy, outcome measures, consent process, ethics (Anderst et al., 2020; Staley, 2015)
- \* Improves recruitment, retention and diversity of study participants (Crocker et al., 2018; Ennis & Wykes, 2013; Johns, Whibley & Crossfield, 2015)

## 3. Consumer and community capacity building:

- \* Skill and knowledge development e.g. Indigenous communities (Anderst et al., 2020)

## 4. Funding imperative

# When should I involve consumers?

- Depends on the project, research program and research team
- Take a developmental approach – Steps toward a CCI vision for your research program
- Consumers can be involved throughout the whole research process
- Or at particular phases:

**Priority setting**

**Research conceptualisation & design**

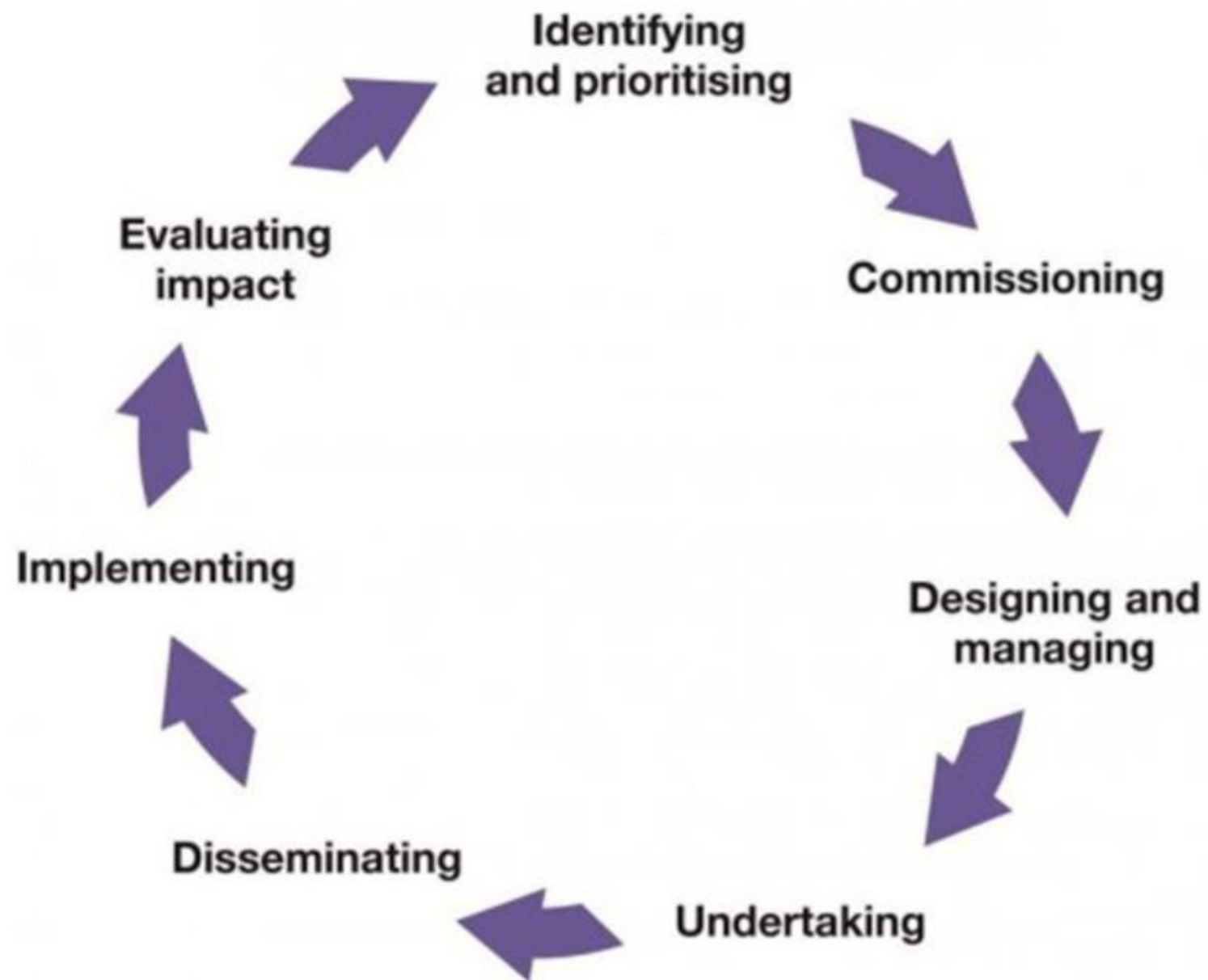
**Grant application**

**Implementation**

**Dissemination**

**Translation**





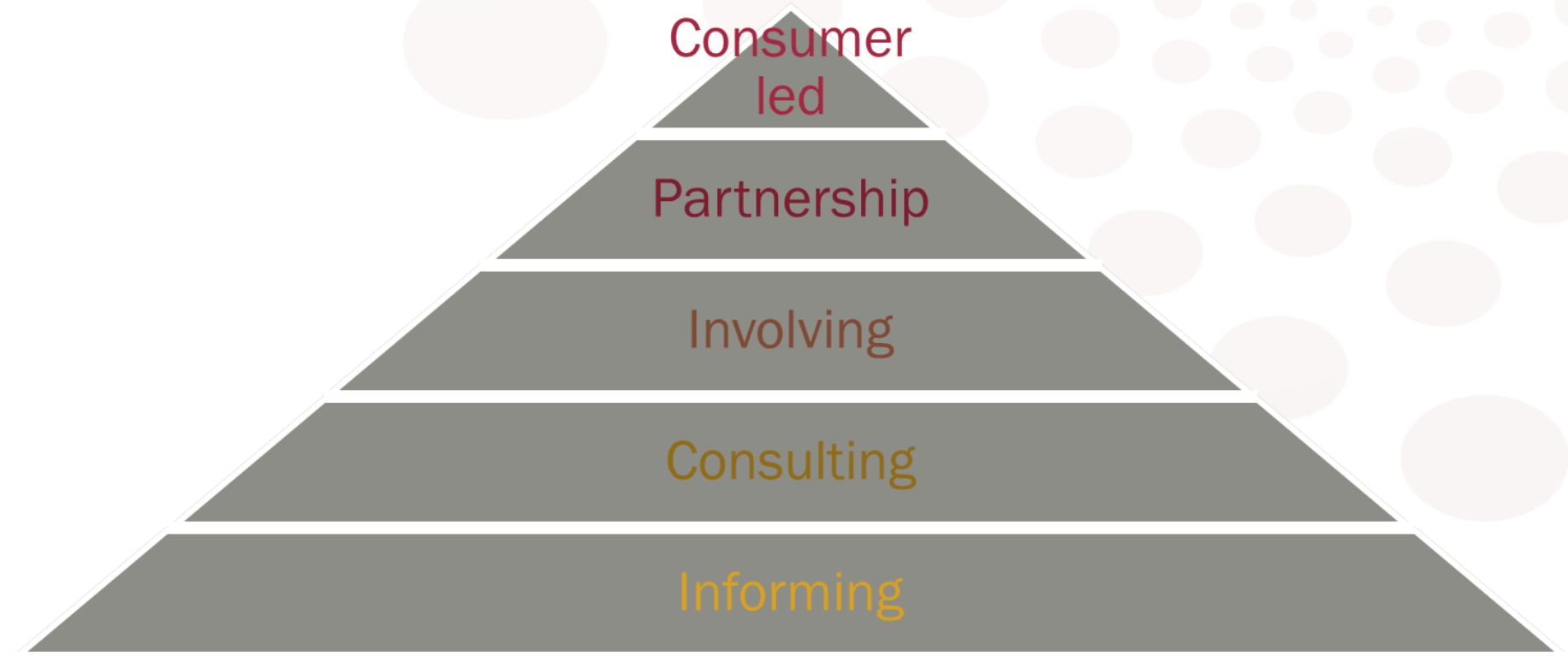
*Figure taken from INVOLVE (2012) Briefing notes for researchers.*

# What does consumer involvement look like?

- Plan for consumer involvement that is:
  - **Relevant** to the project objectives
  - **Meaningful** for consumers
  - **Adds value** to research project
- Possibilities include:
  - Consumer consultation
  - Consumer Advisory Committee
  - Consumer Reps on Research Advisory Committee
  - Consumers as CI / AI / members of research team
- Activities may include:
  - Consultation on **research priorities** or research question/s
  - Defining the **characteristics of study participants**
  - Designing **intervention regimes** that support retention of study participants
  - Input into decisions on **outcome measures**
  - Reviewing **recruitment material**
  - Participating in **recruitment, data collection and data analysis**
  - Planning for and taking part in **dissemination** activities
  - Participation in **co-design / translation** of findings



# Levels of Consumer Participation



Based on Sherry Arnstein (1969). A Ladder Of Citizen Participation

Enablers	Barriers
<b>Early and “fit-for-purpose”</b> engagement	<b>Researcher time and resources</b> to engage consumers
<b>Good relationships</b> between research team members, including consumers	<b>Lack of diversity</b> amongst consumers and research team members
<b>External relationships</b> – e.g. media, funders	<b>Lack of preparation of consumers</b> (knowledge, skills, assertiveness needed for participation)
<b>Involvement by consumer organisations</b> , who have representatives who are supported	<b>No compensation or remuneration</b> for consumers, (inequity with researchers)
<b>Mutually shared understanding</b> of objectives and outcomes (of project, committee etc.)	Consumers pushing own <b>vested interests</b>
<b>Motivation</b> of consumers	<b>Lack of clarity in roles</b> and purpose
<b>Genuine desire</b> to use research to make things better	<b>Organisational culture / terminology</b> that is alienating
<b>Accessible language</b> that is culturally appropriate	<b>Lack of skills, competence and policies</b> to facilitate consumer involvement
<b>Time</b> to plan and engage	<b>Difficulty finding consumers</b> , including consumers being “ <b>time poor</b> ” and unable to engage
<b>Flexible, inclusive</b> processes	<b>Scepticism</b> amongst researchers, leading to <b>tokenism</b>

# Resources and support for researchers

- NSW RHP Website (currently being updated):  
<https://nswregionalhealthpartners.org.au/consumer-and-community-involvement/>
- NSW RHP CCI consultation service for researchers. Appointments:  
[Melissa.Holmes@health.nsw.gov.au](mailto:Melissa.Holmes@health.nsw.gov.au)
- NHMRC - Consumer & Community Engagement resources: <https://www.nhmrc.gov.au/about-us/consumer-and-community-engagement>
- Australian Clinical Trials Alliance – Consumer Involvement Toolkit:  
<https://involvementtoolkit.clinicaltrialsalliance.org.au/>
- Monash Partners free online training modules on Consumer and Community Involvement in research: <https://monashpartners.org.au/education-and-training/cci/>
- Cancer Australia downloadable guide on consumer involvement in research:  
<https://consumerinvolvement.canceraustralia.gov.au/researchers>
- International CCI Organisations:
  - INVOLVE (UK): <https://www.invo.org.uk/resource-centre/>
  - PCORI (USA): <https://www.pcori.org/engagement>
  - SPOR (Canada):  
<https://www.bcsupportunit.ca/resources/patient-engagement-health-research-how-guide-researchers>



# References

- Anderst, A., Conroy, K., Fairbrother, G., Hallam, L., McPhail, A. & Taylor, V. (2020). Engaging consumers in health research: a narrative review. *Australian Health Review*, 44: 806-813.
- Arnstein, S. R. (1969). A Ladder Of Citizen Participation, *Journal of the American Institute of Planners*, 35(4): 216-224. (Seminal article)
- Brett, J. et al. (2014). A Systematic Review of the Impact of Patient and Public Involvement on Service users, Researchers and Communities. *The Patient: Patient-Centred Outcomes Research*, 7(4): 387-395.
- Cancer Australia and Cancer Voices Australia (2011). *National Framework for Consumer Involvement in Cancer Control*, Cancer Australia, Canberra, ACT. Pp. 36-37.
- Crocker, J.C. et. Al. (2018). Impact of patient and public involvement on enrolment and retention in clinical trials: systematic review and meta-analysis, *BMJ*, 2018: 4738.
- Ennis, L. & Wykes, T. (2013). Impact of patient involvement in mental health research: longitudinal study. *The British Journal of Psychiatry*, 203: 381-386.
- Johns, T., Whibley, C., Crossfield, S. (2015). Closed Study Evaluation: Measuring Impacts of Patient and Public Involvement and Research Quality and Performance Report. *National Institute for Health Research*. UK.
- Staley, K. (2015). 'Is it worth doing?' Measuring the impact of patient and public involvement in research. *Research Involvement and Engagement*, 1, 6.

[nswregionalhealthpartners.org.au](http://nswregionalhealthpartners.org.au)

# EXPERT PRESENTER



**Dr Anthony Brown**

**Executive Director, Health Consumers NSW**



# Involving Health Consumers in Health and Medical Research

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**Dr. Anthony Brown**

Executive Director

Health Consumers NSW

[www.hcnsw.org.au](http://www.hcnsw.org.au)

**Health Professionals Research Education Program**  
***Consumer and Community Engagement in Research***

**12 November 2020**

[www.hcnsw.org.au](http://www.hcnsw.org.au)

# Health Consumers NSW

is the statewide, independent, member based charity that provides a voice for people using the health system (health consumers) to shape health policy, services, and health and medical research in NSW.

Can assist in locating trained and experienced consumers

[www.hcnsw.org.au](http://www.hcnsw.org.au)



***Nothing about us without us!***

# Definition

Consumer engagement [*involvement*] is the active public involvement in research priority setting, question development, methodological choice and translational inquiry.

Anderst et.al. (2020)



# Benefits of Involving Consumers in Research

## To the public

- Relevance to community
- Public awareness
- More effective translation of research

*Nothing about us without us*

## To researchers and research institutions

- Ensures research priorities meet public expectations
- Public confidence / ownership of results
- Increased participation

R4Me, HCNSW (2017)

Howe (2018)



# Why Involve Consumers in research?

- Human rights / democracy
- Benefits / evidence
- Funding bodies – NHMRC
- Journals – BMJ
- **Growing consumer expectations**



### Stakeholders



### Users



# Spectrums of engagement



Diagram adapted from Fig 1: Spectrum of Engagement, *Stakeholder Engagement: A Good Practice Handbook*, International Finance Corporation, 2007. [www.ifg.org](http://www.ifg.org)

# Involving Health Consumers in Research

**Published 2017**

Partnership with



# What impacts on Consumer Involvement?

- 1. The type of research**
- 2. Consumer Availability**
- 3. Funding Consumer Involvement**
- 4. Finding the 'right' consumer**
- 5. Consumer training and support**
- 6. Researcher Beliefs and Culture**
- 7. Researcher Training**
- 8. Clarity around roles and expectations**
- 9. Language**

# Key themes from consumers

- Being Valued and Listened to
- Support and Training for Consumers
- Training of researchers
- Being involved throughout the research cycle
- Involvement at all levels of research / across all levels of engagement
- Improved Communication
  - Researchers & Consumers
- Use of technology



# What can consumers do?

- Be more involved in the ethical review of projects
- Better understand consumer experience of clinical trials
- Create standing consumer panels
- Develop a guiding set of principles of around engaging consumers research
- Create a consumer involvement logo or tick

# Partnership with Sydney Health Partners



- Advanced Health Research and Translation Centre
- Translating research into evidence-based healthcare
- Sydney, Northern Sydney and Western Sydney LHDs; the Sydney Children's Hospital Network (at Westmead), the University of Sydney, and ten affiliated medical research institutes

## *Project with HCNSW*

- Mapping consumer and community involvement in SHP
- Identifying best way SHP and HCNSW can add value
- Will develop training (for consumers and researchers)
- Identify additional resources / structures

# Initial Findings

Survey / Interviews / Workshop with consumers, researchers and other key staff

- Good examples of involvement across all partners
  - Funded and non-funded
  - Small, medium, and large scale initiatives
- Researchers, clinicians and consumers working across service delivery and research
- Health services have established engagement infrastructure
- Engagement infrastructure in research less developed
- Strategic leadership / governance unclear

# Resourcing and Support

- Training for consumers, researchers, and clinicians
- Enhancing capacity of consumers, researchers and clinician through connecting people and creating networks
- Guidance on policies and processes (eg remuneration and recognition of consumer and community involvement)
- Pathways for connecting consumers, the community, and researchers
- Pathways for consumer researchers to get involved and enhance their skills and capabilities

# Next steps

- Training for consumers, researchers, and clinicians
  - Pilot in December with SHP (virtual)
  - available beyond SHP in 2021
- Identify resources and structures that are needed to build consumer and community involvement
- Producing report – released February 2021
- Ongoing work with NSW AHRTCs, consumers and researchers

# References

Anderst, A., et al. (2020). "Engaging consumers in health research: a narrative review." Australian Health Review

BMJ, Guidance for BMJ Patient and Public Reviewers, accessed <https://www.bmj.com/about-bmj/resources-reviewers/guidance-patient-reviewers> 5/9/20

Research4Me, Health Consumers NSW, (2017) Involving Health Consumers in Health and Medical Research: Enablers and Challenges from a Consumer Perspective, Health Consumers NSW and Research4Me. [https://www.hcnsw.org.au/hcnsw\\_resource/involving-health-consumers-in-health-and-medical-research-enablers-and-challenges-from-a-consumer-perspective/](https://www.hcnsw.org.au/hcnsw_resource/involving-health-consumers-in-health-and-medical-research-enablers-and-challenges-from-a-consumer-perspective/)

Hooton, A. and J. McCarthy (2019). The 'eight-minute' cure: how transvaginal mesh sentenced thousands of women to a life of pain. The Good Weekend Magazine, 15 June <https://www.smh.com.au/lifestyle/health-and-wellness/the-eight-minute-cure-how-transvaginal-mesh-sentenced-thousands-of-women-to-a-life-of-pain-20190611-p51whn.html>

Howe, A. (2018). "Principles of patient and public involvement in primary care research, applied to mental health research. A keynote paper from the EGPRN Autumn Conference 2017 in Dublin." European Journal of General Practice **24**(1): 167-170.



# Q&A PANEL



**Prof Debbie Plath**



**Dr Anthony Brown**



**Mrs Sarah Lukeman**



**Prof Nicholas Goodwin**



# RESOURCES



<https://nswregionalhealthpartners.org.au/consumer-and-community-involvement/>

1. Local Consumer Registers or Committees
2. Tools for Consumer Involvement
3. Plain Language Resources
4. Consumer Advocates, Networks and Professional Organisations
5. Videos Demonstrating Consumer Involvement
6. Publications and Reports on Consumer Involvement in Research

# RESOURCES

<https://www.hcnsw.org.au/news-resources/tools-and-resources/>

## Tools and resources

Our tools and resources hub offers links to a wide range of online materials that we think you might find useful. With a growing collection of good quality resources already available, we want to ensure you don't have to reinvent the wheel. We have included links to useful documents, factsheets, guidelines and other websites.

We have organised the tools and resources according to whether they are aimed at:

- Health Consumers
- Consumer Representatives
- Health Services
- Consumer / Community Organisations

In this section you will also find the consumers toolkit which supports consumers to engage and takes you on a step-by-step process to get involved and make a difference.



# RESOURCES



<https://hmri.org.au/participate-research>

## **Participate In Research**

At any time, there are hundreds of thousands of clinical trials and research projects taking place across the world in a wide range of disease and health areas including stroke, cancer, asthma and more.

Those who participate in clinical trials and other studies are often the first to access and benefit from new and emerging treatments across a range of areas.

You can learn more about how to access the latest medical research through a research project or clinical trial below.

There are a number of research projects that allow eligible people to access emerging medical research and treatments in a range of areas.

Those involved also have the satisfaction of one helping someone else with an illness, providing important scientific information that will be used to develop new disease treatments and improve already existing ones.

## **Research Register**

The Research Register recruits a central database of people who are interested in contributing to medical research. The Register helps researchers access to the type of people they require in their efforts to improve the health of the community.

**[Learn more about the research register](#)**

## **Stroke Research Register - Hunter**

The Stroke Research Register - Hunter recruits a database of people with stroke, living in the Hunter region, who are willing to be contacted to participate in research at a later date. The Register will be a centralised process for contacting people with stroke who would like to take part in research.

**[Learn more about the Stroke Research Register - Hunter](#)**

# MEMBER SUPPORT

[Home](#) » [Member Support](#) » [Consumer Matching Service](#)

## CONSUMER MATCHING SERVICE

The purpose of this service is to enable HCRA researchers to establish meaningful partnerships with community members who are willing to provide advice and assistance in cancer research from a consumer perspective. The HCRA Consumer Advisory Panel is a group of community volunteers who are available to provide input on many aspects of research projects. Some examples may include:

- Providing feedback on marketing materials, information sheets & questionnaires
- Assisting with the preparation of research lay summaries & presentations
- Providing feedback on study design, concept development & project priorities from a community perspective
- Promotion of research projects to funders, potential funders, cancer support groups and the general public



### CONSUMER ADVISORY PANEL

Read more about the CAP...

[READ MORE](#)



## HOW DO CONSUMERS HELP?



Comment on the design and development of cancer research projects



Help ensure the language used in research information is appropriate and easy to understand



Present to cancer support groups and the general public about HCRA



Sit on funding panels to award HCRA grants

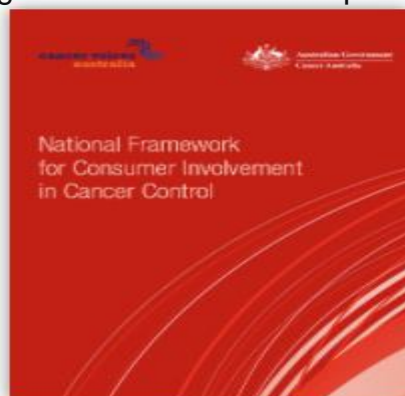
## RESOURCES

HCRA researchers requesting to use this service must read the [Consumer Involvement – Tools for Researchers](#) document produced by Cancer Australia.

Researchers should also be familiar with the [National Framework for Consumer Involvement in Cancer Control](#) developed by Cancer Australia and Cancer Voices in 2011.

[https://consumerinvolvement.canceraustralia.gov.au/assets/involve/files/doc-lib/accessible/researchers/booklet\\_researchers\\_201212.pdf](https://consumerinvolvement.canceraustralia.gov.au/assets/involve/files/doc-lib/accessible/researchers/booklet_researchers_201212.pdf)

[https://www.canceraustralia.gov.au/sites/default/files/publications/national\\_consumer\\_framework\\_web\\_504af020f2184.pdf](https://www.canceraustralia.gov.au/sites/default/files/publications/national_consumer_framework_web_504af020f2184.pdf)





## NEWCASTLE OFFICE

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For further information please contact the HMRI  
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P: 02 4042 0010  
E: [info@hmri.com.au](mailto:info@hmri.com.au)

## Contact us

Here are a few ways to get in touch with us

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**Email:** [info@hcnsw.org.au](mailto:info@hcnsw.org.au)

**Postal address:** Suite 3/Level 8, 280 Pitt Street, Sydney NSW 2000

## CONTACT US

- 02 4042 0439
- [hcra@newcastle.edu.au](mailto:hcra@newcastle.edu.au)

# WHAT'S NEXT?



Wed 18 Nov, 10-11:30AM  
**What's New and Lessons Learned for  
Inclusion in the 2021 ARC Discovery  
Projects Rounds**

Wed 25 Nov, 10:30-12PM  
**Finesse your Grant Proposal [Project  
Description]**



**2021 SAVE THE DATES**

**Thursday 12noon – 2pm**

11 March

10 June

2 September

11 November

## Responsible Conduct of Research

This self-paced e-learning module provides a brief overview of the Australian Code for Responsible Conduct of Research and an understanding of your obligations when undertaking research.

### Access via Discover

<https://discover.newcastle.edu.au/course/view.php?id=106>

# ARE YOU UNDERTAKING RESEARCH?

Make sure you read the *Australian Code for the Responsible Conduct of Research* and know how it applies to you



Scan me

**Fairness** in the treatment of others



**Respect** for research participants, the wider community, animals and the environment



**Rigour** in the development, undertaking and reporting of research



**Recognition** of the right of Aboriginal and Torres Strait Islander peoples to be engaged in research that affects or is of particular significance to them



**Accountability** for the development, undertaking and reporting of research



Have you seen conduct that you think breaches The Code?



Scan me

**Transparency** in declaring interests and reporting research methodology, data and findings



**Honesty** in the development, undertaking and reporting of research



**Promotion** of responsible research practices



# THANK YOU

## Stay safe See you in 2021



Health  
Hunter New England  
Local Health District



Health  
Central Coast  
Local Health District