

# Medical Research

# Future Fund

Webinar – MRFF Principles for Consumer Involvement  
3 August 2023

## Co-hosts

- Dr Masha Somi, Chief Executive Officer, Health and Medical Research Office
- Mr John Stubbs AM, Chair, MRFF Consumer Reference Panel

# Agenda

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## 1. Introduction and background

- Masha Somi (Chief Executive Officer, Health and Medical Research Office (HMRO))
- John Stubbs (Chair, MRFF Consumer Reference Panel (CRP))
- Caroline Homer (Deputy Chair, Australian Medical Research Advisory Board (AMRAB))

## 2. Consumer involvement in health and medical research – how and why:



Bernadette Brady



Yvonne Cadet-James



Merryn Carter



Tom Snelling

## 3. Questions and Answers

# Consumer Involvement in the MRFF

## 2015-2021

Some practices & processes in place to encourage consumer engagement in the MRFF

...but we wanted to do more...



## 2022-onwards

Working with the CRP to strengthen consumer involvement in the MRFF

## 2022

Established the  
**MRFF Consumer Reference Panel**

*“to provide advice to the CEO of HMRO on strategies for strengthening consumer involvement in MRFF implementation”*

Initial deliverables:

- Develop **principles** for consumer involvement in MRFF-funded research projects
- Reviewing and providing **advice on MRFF processes**, e.g. grant guidelines, assessment processes

**Done**

**In progress**

# Refresh of the MRFF assessment criteria

## Criterion 1 – Project Impact

In your response to this criterion, you should ensure that you:

- articulate how the program of research will address a systemic and significant health care or health system need that is of value to the community, health service providers, and health system managers.
- demonstrate how the proposed program of research will strengthen capacity within the health sector for research, innovation and knowledge exchange.
- demonstrate how the views and values of consumers, the community, health providers and/or other end users have informed the proposed research, including how the needs and priorities of consumers (particularly those with lived experience and their carers) have informed the research question.
- ....

## Criterion 2 - Methodology

In your response to this criterion, you should ensure you clearly articulate:

- the research question and the proposed approach for addressing it, including (as appropriate) tools and techniques, participants (e.g. diversity of participants), interventions, controls, statistical approaches, and strategies for data collection and use
- how consumers will be involved in the proposed research, including their contributions throughout the life of the project
- arrangements for project governance and oversight to support its successful delivery.
- appropriate milestones, performance indicators and timeframes.

## Criterion 3 - Capacity, Capability and Resources

In your response to this criterion, you should ensure that you demonstrate:

- the research team has an appropriate mix of skills (scientific, project management, etc) to undertake the proposed research
- the research team includes individuals that bring diverse experiences and expertise (e.g. across disciplines, genders, cultures, lived experience relevant to the research question, career stages and research sectors)
- the research team has the skills, experience and capacity to involve and support consumers (including those with lived experience) in the proposed research, and ensure that this is done appropriately and effectively
- the commitment of partners to the project and how they will support (through financial and in-kind contributions) its successful delivery.

NB: Yellow text = additions from the late 2022 refresh

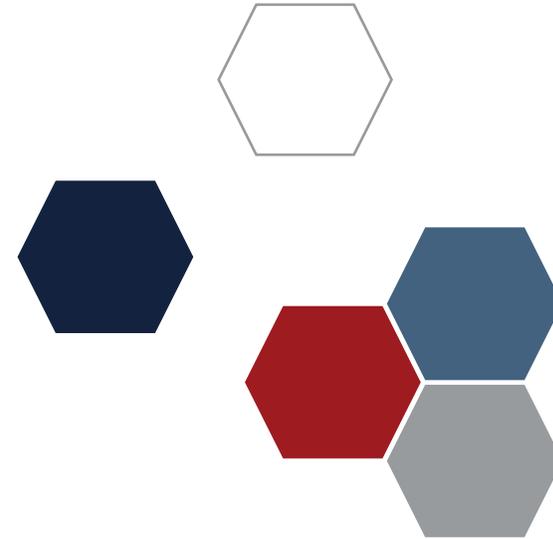
# Providing advice on MRFF processes

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- ✓ Light-touch review of **assessment criteria** descriptors
- ✓ Pilots in the 2023 MRFF Consumer-Led Research Grant Opportunity:
  - Consumer Involvement Statement – 2 pages in grant application
  - Greater consumer involvement in assessment – multiple consumers as full, scoring panel members
- ✓ Review of the draft *NHMRC/MRFF Statement on Sex, Gender, Variations of Sex Characteristics and Sexual Orientation in Health and Medical Research*
- Reviewing **grant opportunity guideline** templates
- Inputting into **research topics/prioritisation**
  - Future Consumer-Led Research Grant Opportunities
    - MRFF Preventive and Public Health Research Initiative - \$100 million over 10 years from 2022-23 allocated to a Consumer-Led Research stream
- Further implementation of the CRP principles, e.g.
  - Guidance for researchers, e.g. costs associated with consumer involvement can be included in MRFF applications



Mr John Stubbs AM



Chair  
MRFF Consumer Reference Panel

# Principles for Consumer Involvement in Research Funded by MRFF

~ *WHY?* ~

The inclusion and strengthening of the consumer voice will **improve the quality, relevance** and **impact** of MRFF-funded research, through:

- **More, safe, diverse** and **effective** consumer involvement
- Recognising the **valuable perspectives** that Australians with **lived experience** as patients, clients, service users and carers bring to research
- Recognising the **diversity of our Australian population** and the importance of including these varied life experiences, values and cultures in our research
- Helping researchers, research organisations, consumers and other relevant stakeholders by providing **guidance on what ‘good’ consumer involvement looks like**

# Principles for Consumer Involvement in Research Funded by MRFF



*Scan me!*

*Or visit:*

<https://www.health.gov.au/resources/publications/principles-for-consumer-involvement-in-research-funded-by-the-medical-research-future-fund?language=en>

A **consumer** is a person with lived experience as a patient, client, potential patient, user of health services, and/or providing support as a carer, family or community member

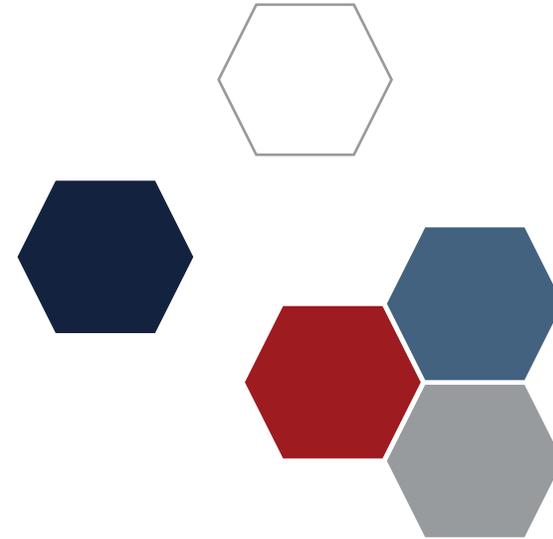
*\*Document includes implementation ideas and examples of what ‘good’ consumer involvement looks like*

## Principles for Consumer Involvement in Research Funded by MRFF (*cont.*)

- **In every type of research**, including basic science, public health, preventive health, translation and clinical research.
- **At all stages of research**, from defining the need/priority of a research question, refining the research question and research design through to conduct of the research and sharing and translation of results.
- **In partnership with researchers**, with consumers respected and recognised for the valuable and complementary knowledge, expertise and perspectives they bring to the research.
- **Effectively**, with sufficient time, resources and depth of relationships to enable consumers to understand and actively engage with and contribute to the research.
- **Sensitively and safely**, through research teams with strong and broad capacity and capabilities in consumer involvement, appropriate training and a supportive environment for consumers, and clearly defined and agreed roles.
- **With broad diversity and equity**, with the goal of increasing involvement of priority populations through culturally safe and appropriate engagement.



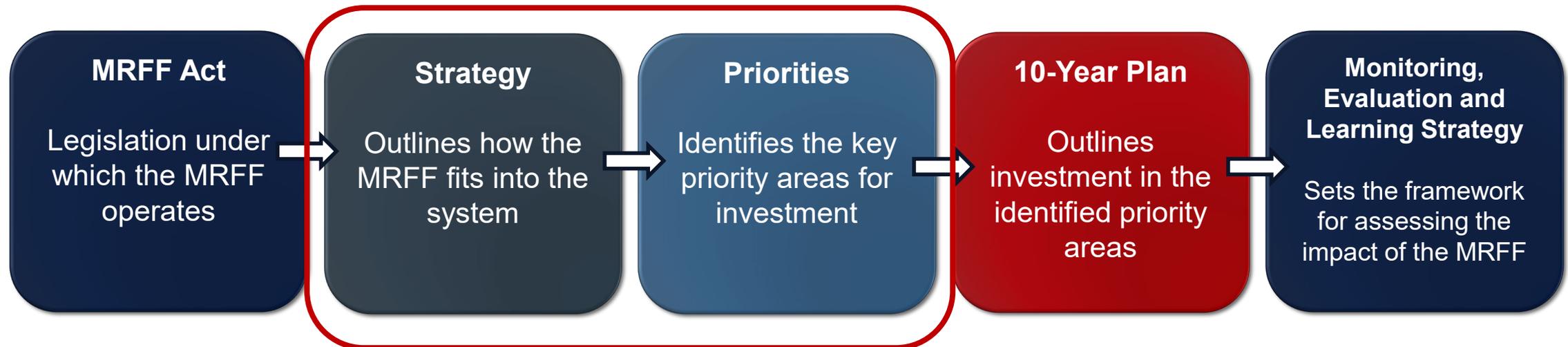
**Professor Caroline Homer AO**



**Deputy Chair  
Australian Medical Research Advisory Board (AMRAB)**

## Message from the Australian Medical Research Advisory Board (AMRAB)

- AMRAB advises the Minister for Health and Aged Care on prioritising spending from the MRFF
- Responsible for developing the *Australian Medical Research and Innovation Strategy* and the *Australian Medical Research and Innovation Priorities* via a **public consultation process**



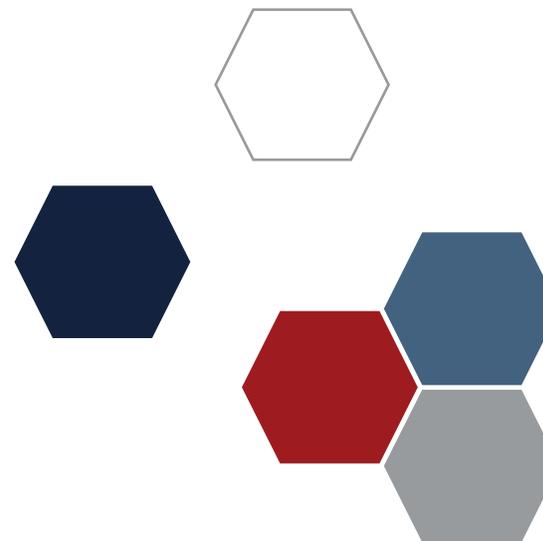
## AMRAB support for the MRFF Consumer Involvement Principles

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- AMRAB strongly supports the *Principles for Consumer Involvement in Research Funded by MRFF*
  - Consumer involvement is **critical** to get the **greatest impact** from our tax payer-funded research
  - Statement of **what best practice looks like**
  - It's not 'mandatory', but a statement of future intent and **an excellent guide**
  - **Start doing what you can now**
  - It's a learning process and takes time and resources
    - Don't let perfect be the enemy of good
    - It's not just on researchers, but requires support from their organisations and all aspects of the system, including funders



**Dr Bernadette Brady**



**Clinical Specialist Physiotherapist**

**Physiotherapy Department & Department of Pain Medicine, Liverpool Hospital**

**Conjoint Senior Lecturer, Physiotherapy, Western Sydney University**

**Clinical Senior Lecturer, The University of Sydney**

# Engaging Culturally & Linguistically Diverse Communities in Research Consumers

**Bernadette Brady, PhD**

Specialist Physiotherapist / Clinical Senior Lecturer

Liverpool Hospital / University of Sydney

[Bernadette.Brady@health.nsw.gov.au](mailto:Bernadette.Brady@health.nsw.gov.au)

> 50% non-English speaking<sup>1</sup>

Fairfield LGA most disadvantaged in Sydney Metro<sup>2</sup>

High refugee resettlement<sup>3</sup>

## Health Challenges

- Disproportionate burden of disease
- Different belief systems & values
- Engagement = Outcomes



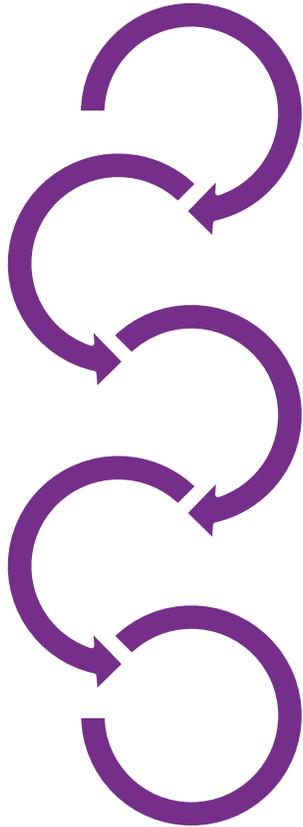
<sup>1</sup>ABS Census 2020

<sup>2</sup>SEIFA 2016

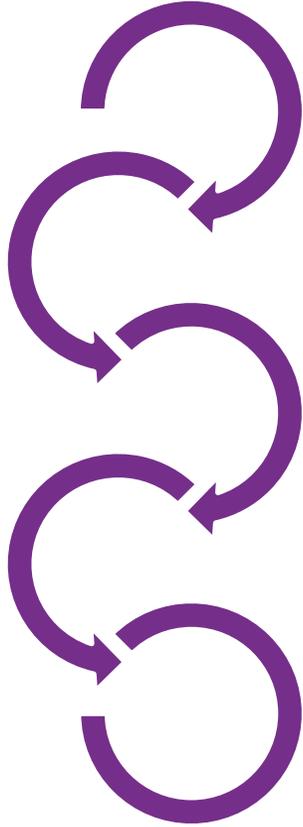
<sup>3</sup>Doherty 2017

# Working towards co-production

- Relationship building



# Working towards co-production



- Relationship building
- Understanding consumer perspectives

## **An exploration of the experience of pain among culturally diverse migrant communities**

Bernadette Brady<sup>1,2</sup>, Irena Veljanova<sup>3</sup> and Lucinda Chipchase<sup>2</sup>

## **Pain experiences of Hindi-speaking Indian migrants in Sydney: a qualitative study**

Pavithra Rajan<sup>a,\*</sup>, Claire E Hiller<sup>a</sup>, Andrew Leaver<sup>a</sup>, Sarah Dennis<sup>a,b,c</sup>, Kathryn Refshauge<sup>a</sup>, Bernadette Brady<sup>a,b</sup>

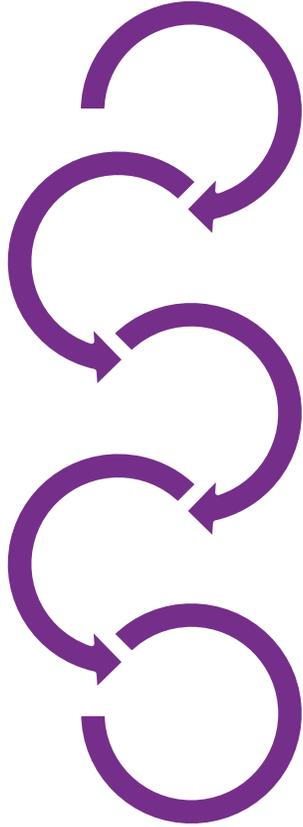
## **The Intersections of Chronic Noncancer Pain: Culturally Diverse Perspectives on Disease Burden**

Bernadette Brady, MManTherapy,<sup>\*,†</sup> Irena Veljanova, PhD,<sup>‡</sup> and Lucinda Chipchase, PhD,<sup>\*</sup>

## **A Mixed-Methods Investigation into Patients' Decisions to Attend an Emergency Department for Chronic Pain**

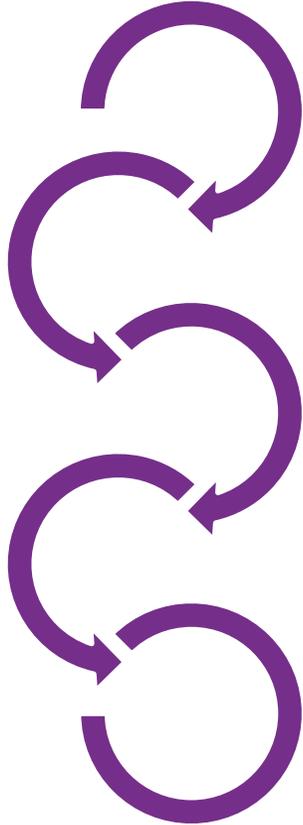
Bernadette Brady , PhD,<sup>\*,†,‡</sup> Toni Andary, BAppSc,<sup>§</sup> Sheng Min Pang, BAppSc,<sup>‡</sup> Sarah Dennis, PhD,<sup>‡,†</sup> Pranee Liamputtong, PhD,<sup>\*,||</sup> Robert Boland, PhD,<sup>‡,§</sup> Elise Tcharkhedian, B Physio,<sup>†</sup> Matthew Jennings, BAppSc,<sup>\*,†</sup> Natalie Pavlovic, BAppSc,<sup>§</sup> Marguerite Zind, MA,<sup>\*</sup> Paul Middleton, MMBS, MD, MMed,<sup>†,||,\*,††,‡‡</sup> and Lucy Chipchase, PhD<sup>\*,§§</sup>

# Working towards co-production



- Relationship building
- Understanding consumer perspectives
- Deriving questions from community priorities & interests

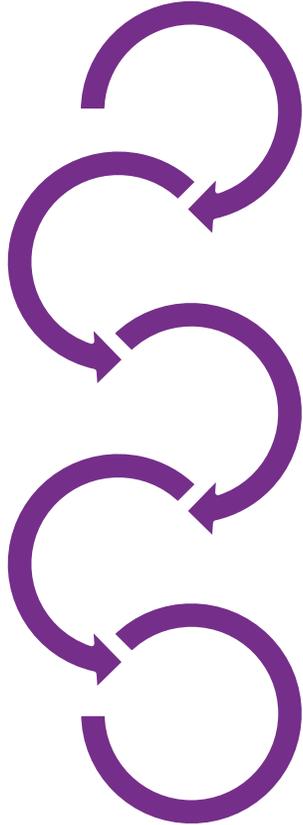
# Working towards co-production



- Relationship building
- Understanding consumer perspectives
- Deriving questions from community priorities & interests

**The Natural Helper approach to culturally responsive disease management: protocol for a type 1 effectiveness-implementation cluster randomised controlled trial of a cultural mentor programme**

# Working towards co-production



- Relationship building
- Understanding consumer perspectives
- Deriving questions from community priorities & interests
- Opportunities for meaningful engagement in research activities

# Consumer Advisory Group Activities

Culturally appropriate in-language participant information videos



## Intervention Design

A peer mentor program for patients from CALD communities with chronic & complex conditions.

### Natural Helper Program

Name: \_\_\_\_\_ Date: \_\_\_\_\_



MENTOR HANDBOOK

Do you enjoy helping others? Join Natural Helper Program

Do you have a chronic condition?  
If you have a long term condition and have completed treatment, we would like to speak to you!

Are you from Arabic, Assyrian, Vietnamese or Pacific Islander communities?  
If you are \_\_\_\_\_ KEEP READING!

**WHO IS A NATURAL HELPER?**  
A 'natural helper' is a volunteer who has successfully completed a treatment and wants to share their experiences with others from a similar culture.

**DO YOU LIKE HELPING OTHERS?**  
If you have answered 'YES' you may be a 'NATURAL HELPER' without knowing it!  
Supporting someone who is struggling with their illness and sharing your experience could improve someone's health and well-being.

**YOU COULD MAKE A BIG DIFFERENCE**

**WHAT DO NATURAL HELPERS DO?**  
Natural Helpers are part of the healthcare team.  
They listen to patient's problems, give advice about how to cope better and share their knowledge with the healthcare team.  
Natural Helpers are making the local health district a better place for all!

**WHAT IS INVOLVED?**  
You will...  
• Attend a brief training program to build your confidence mentoring others  
• Volunteer with this clinic at a time suitable for you. This could be once a week, once a fortnight or less often.  
• Speak with patients about their experience and provide them support as they progress through treatment.

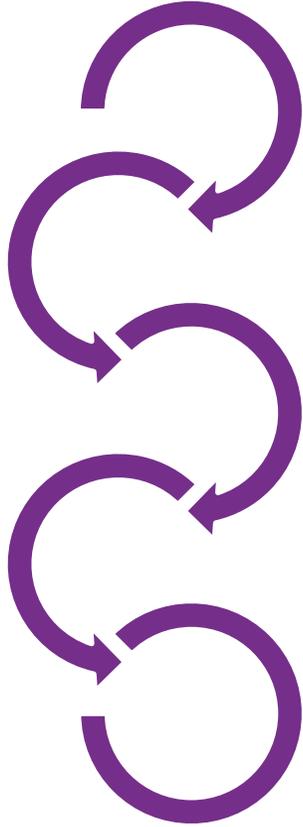
**HOW DO I SIGN UP?**  
For more information please contact the project coordinator:  
Gotta Saberi  
Liverpool Hospital PH: (02)87388199  
gotta.saberi@health.nsw.gov.au

Project Team:  
Bunamette Brady, PhD, Research Fellow  
SWSLHD Multicultural Health Service  
Partners from the Ingham Institute, WSU, Uryd & UNSW

NSW Health South Western Sydney Local Health District  
Manduku Budiyani Gumal

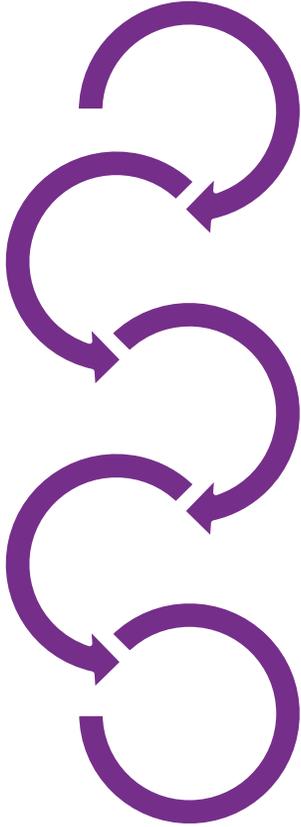
## Project Promotional Materials

# Working towards co-production



- Relationship building
- Understanding consumer perspectives
- Deriving questions from community priorities & interests
- Opportunities for meaningful engagement in research activities
- Continuous negotiation/re-negotiation

# Successful co-production



- TIME
- HARNESSING DIVERSE MOTIVATIONS
- FLEXIBILITY
- CAPACITY & LITERACY BUILDING

# ACKNOWLEDGEMENTS

Consumer Advisors

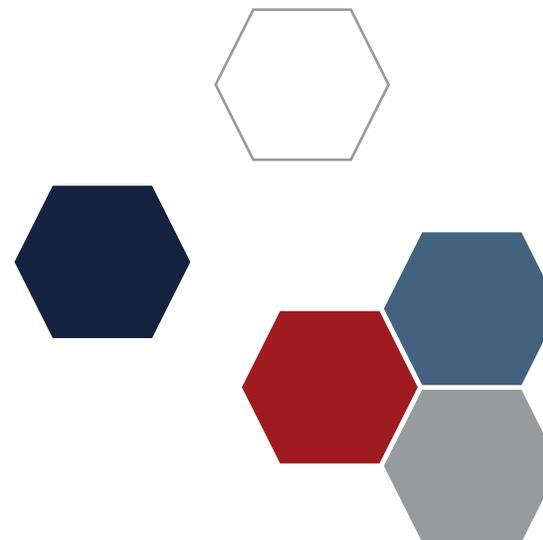
CORE Community Services

SWSLHD Multicultural  
Health Service





**Professor Yvonne Cadet-James**

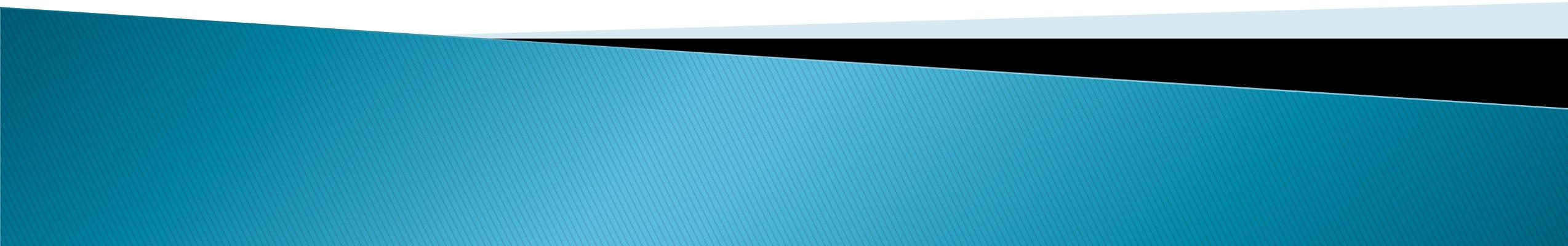


**Adjunct Professor  
Indigenous Education and Research Centre and the Office  
of the Provost, James Cook University**

# **Aboriginal and Torres Strait Islander Consumers in Research**

**Presentation for The Medical  
Research Future Fund Webinar**

**Professor Yvonne Cadet-James**



## ***Acknowledgement:***

*I acknowledge the Traditional Owners  
and Custodians of the lands on which I present today.  
I also acknowledge the Traditional Owners and Custodians  
of the lands across the nation where participants are  
located*

*I acknowledge ancestors and elders – the creators and  
holders of unique knowledge systems who  
have cared for this land over time and made a significant  
contribution to the nation and its people*



# Introduction

- ▶ Gugu Badhun Nation; Co-Director Dijma Gugu Badhun Research Centre
- ▶ Background as a RN and RM – with 45 years in health field
- ▶ Academia – Health Sciences, Public Health & Indigenous Health research
- ▶ Research interests include Empowerment, Social, Emotional Wellbeing, Mental Health, Maternal, Adolescent and Child Health.
- ▶ I have been asked to talk about my experience working with consumers in Indigenous Health Research



# MRFF Principles for Consumer Involvement in Research Funded by the Medical Research Future Fund

“The object of the Medical Research Future Fund (MRFF) is to improve the health and wellbeing of Australians. Our collective ability to achieve this is enhanced by effectively involving consumers in the prioritisation, design, conduct, translation and evaluation of research funded by the MRFF as well as in the selection of funded research projects”.

“Consumers bring a broad range of valuable perspectives and experiences, such as diversity in culture, linguistics, gender and ability, that can improve the quality, relevance and impact of research”.

(The Hon Mark Butler MP Minister for Health and Aged Care, 2023)



# Indigenous Researchers



Indigenous people continue to share their rich culture, their knowledge systems, science and respect for the land and environment.

- Indigenous peoples are the oldest researchers in the world conducting research into all aspects of life for survival, to gain and build on existing knowledge and to discover new knowledge.
- This included research that resulted in inventions, innovation and the development of unique knowledge systems in the areas of science, physics, engineering, medicine, astronomy, agriculture, aquaculture, anthropology and the arts as examples.



# Context

- As Aboriginal and Torres Strait Islander people consumers are our families and communities
- We belong to our nation or language groups as Traditional Custodians of the lands which are traced back to our ancestors
- We are members of complex kinship systems which govern our social organisation and determines our commitments and obligations within our kinship groups
- We have in common - connection to the land, sea, waters, animals, plants, environment, celestial bodies
- We are bound by common rules of social order, engagement and respect across nation/language groups which underpins how we conduct research

# Community Partnership In Research

## ➤ Principles of Co-production

- Researchers, practitioners, and members of the public collaborating to develop research.
- Researchers and end-users working together as peers to ensure that the purpose of the research, the research methodology, and the application of research outputs are relevant to, and appropriate for the end users.



## ➤ Community Engagement

- Existing relationships or growing relationship
- Understanding community priorities and needs
- Understanding community profiles and dynamics
- Making connections with Elders, Councils, relevant stakeholders
- Meetings with organisations and community groups
- Involvement in all aspects of the development of the research protocol and ethics application

# Community Partnership in Research

Identify roles with Community Members

- ▶ Chief & Associate Investigators, Advisory Group members, project & research officers, community researchers.
- ▶ Employment opportunities
- ▶ Skills – engagement, recruitment, data collection & analysis, writing, knowledge translation.
- ▶ Training required to strengthen capacity & capability for community and researchers.
- ▶ Project Plan and Research Agreement – working together to determine roles and responsibilities, engagement and feedback process; milestone meetings, training dates, mediation processes

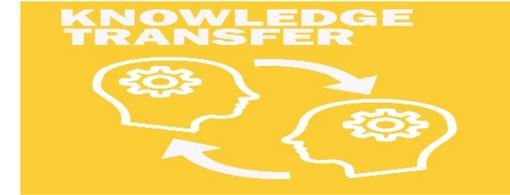


# Community Partnership in Research

## Research Benefit, Impact & Translation

Determine with community;

- ▶ How will the research benefit the community and/or broader society?
- ▶ What impact will the research make on their economy, society, environment or culture?
- ▶ A process of integrated knowledge translation which occurs at each stage of the research to inform the next stage, rather than just at the end – the co-production of knowledge, its exchange and translation into action.
- ▶ A plan for knowledge translation at community, organization and government levels.
- ▶ Reflections on the planning and conduct of the research – lessons learnt.

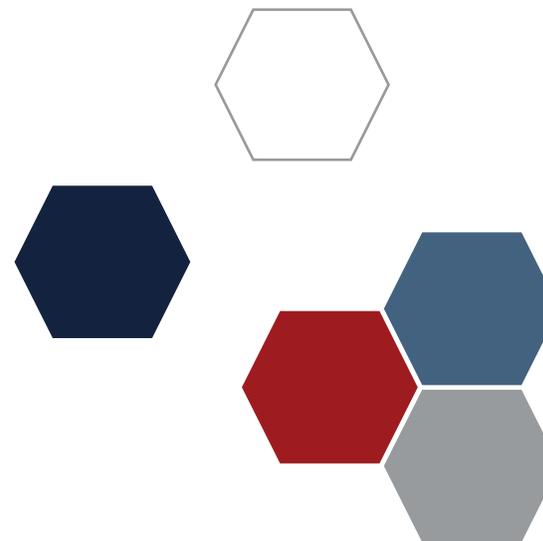


# Thank You





**Merryn Carter**



Walter and Eliza Hall Institute (WEHI) Breast Cancer Lab (consumer advocate)  
Breast Cancer Trials Australia New Zealand Consumer Advisory Panel (member)  
MRFF Consumer Reference Panel member

# How consumers are involved in basic health research (and why that matters)

3 August 2023

**merryn carter**

health consumer advocate | WEHI | Breast Cancer Trials ANZ | MRFF

# Two examples of consumer involvement

- **1998: Breast Cancer Trials Australia/New Zealand (BCT)** establishes its Consumer Advisory Panel (CAP), recognising the value and importance of consumer input to the planning and conduct of clinical trials research. CAP has members from both Australia and New Zealand.
- **2013: The Walter and Eliza Hall Institute (WEHI)** becomes one of the first medical research institutes in Australia to actively involve consumers working in partnership with researchers. The Consumer Program has grown from 6 consumers to currently 103 with more recruitment necessary.

**merryn carter**

health consumer advocate | WEHI | Breast Cancer Trials ANZ | MRFF

# HOW consumers are involved in basic health research

## At Breast Cancer Trials

- the Consumer Advisory Panel is asked to **review and provide feedback on all Trial Concepts, Protocols and Patient Information and Consent materials** (PICFs, forms and sometimes videos)
- CAP members share the load of this review work, contributing as their time allows
- the trial **protocol documents can be extremely long and complex**; my experience at WEHI provided great training for this work
- consumer review of trial designs provides **critical participant perspective**, helping **ensure trial participation is made as comfortable, safe and convenient as possible**
- consumer review of PICFs helps ensure they are **as easy to understand as possible**, **increasing the likelihood of trial participation**

**merryn carter**

health consumer advocate | WEHI | Breast Cancer Trials ANZ | MRFF

# HOW consumers are involved in basic health research

## At WEHI

- researchers are now assigned **teams of consumers**, to prevent consumer fatigue
- this allows the consumers to **support each other, spread the work load** (perhaps most important at grant application review time), and brings **different perspectives and skills** to the table
- consumers are involved in **reviewing public presentations** and **conference posters** to **ensure clear language**, are **advocates for WEHI**, can act as **mentors for early career researchers** and **speak alongside their researchers** when discoveries are made
- consumers **meet quarterly with their research team/s** to discuss and keep up to date with research progress

**merryn carter**

health consumer advocate | WEHI | Breast Cancer Trials ANZ | MRFF

# HOW consumers are involved in basic health research

## At WEHI

- at these meetings, **researchers present reports** on their work, ensuring consumers' knowledge of the **research aims, techniques and outcomes**, and enhancing the researcher's **ability to communicate their research in lay language**
- discussion provides opportunities for **questions, ideas, clarifications, and sharing of thoughts and experiences from different perspectives**
- Two projects involving WEHI have **received MRFF funding** recently: the "GLIMMER" research program for glioblastoma (an aggressive brain cancer with a five-year survival rate of just 5%) received \$4.6m, and a WEHI-led collaboration with Peter MacCallum Cancer Centre received over \$900,000 to develop a cancer vaccine for patients with limited treatment options. There are high level consumer engagement **consumer reference groups/steering committees for both of these projects.**

**merryn carter**

health consumer advocate | WEHI | Breast Cancer Trials ANZ | MRFF

# WHY consumers are involved in basic health research

**“it is now widely accepted that consumers and community members add value to health and medical research and have a right and responsibility to do so.”**

*(Expectations and Value – Framework for Effective Consumer and Community Engagement in Research, NHMRC 2020)*

- *“Nothing about us without us”*
- It grounds the work in ‘real world’ perspectives and people’s lived experiences of health conditions.
- Health and medical research is a ‘public good’. For accountability and transparency, the public should be involved.

*From Increasing Consumer and Community Involvement in Medical Research, Robyn Smith, Melbourne Academic Centre for Health, 2021*

**merryn carter**

health consumer advocate | WEHI | Breast Cancer Trials ANZ | MRFF

# WHY consumers are involved in basic health research

- When consumer involvement activities and consumer-researcher relationships are **genuine, mutually respectful** and **well supported**, they have **positive impacts** on individual consumers and researchers, **on the research process and outcomes**, and for the organisation.
- There is a clear role for consumers to contribute to **setting research agendas, planning and developing research direction** and in **communicating and disseminating research outcomes**.
- From *Increasing Consumer and Community Involvement in Medical Research*, Robyn Smith, Melbourne Academic Centre for Health, 2021
- PLUS, in my experience, **consumer involvement helps researchers write better grant applications, and communicate their research aims, plans and results more clearly. This helps better communicate the role of medical science and discovery to the public.**

**merryn carter**

health consumer advocate | WEHI | Breast Cancer Trials ANZ | MRFF

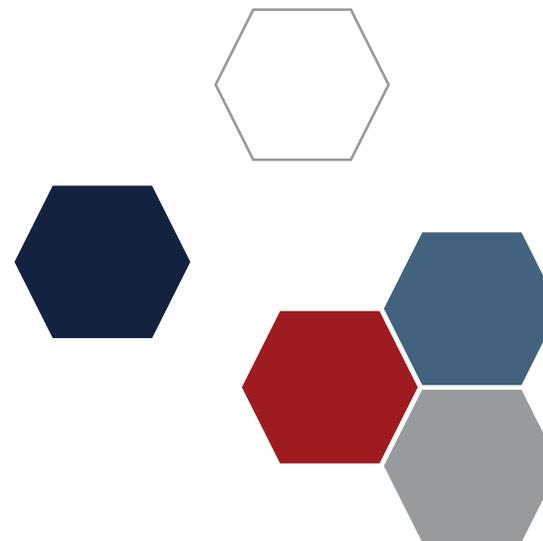


Australian Government

Department of Health and Aged Care



**Professor Tom Snelling**



Director of Health and Clinical Analytics, School of Public Health,  
University of Sydney

Infectious diseases physician, Sydney Children's Hospitals Network

# Involving consumers in clinical research

Tom Snelling

**Health & Clinical Analytics,  
School of Public Health**



THE UNIVERSITY OF  
**SYDNEY**



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# Ongoing, productive relationships

- Once-off vs continued vs on-going
- Responsive vs agenda-setting
- Advisory vs steering



WESFARMERS  
CENTRE OF VACCINES  
& INFECTIOUS DISEASES

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## Diversity of perspectives

- E.g. BEAT-CF CRG
  - People with CF
  - Parents, carers and partners
  - Males to females
  - Regional/ remote
- Be careful of isolating people (e.g. CALD, adolescents, Aboriginal and Torres Strait Islander people)
  - Research buddies



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# Priorities

- Needs to be done before the funding is requested
- Distinguish research from service/ care needs
- Priority = need x opportunity
- Priority setting:
  - Informal vs formal



James  
Lind  
Alliance

Priority Setting Partnerships

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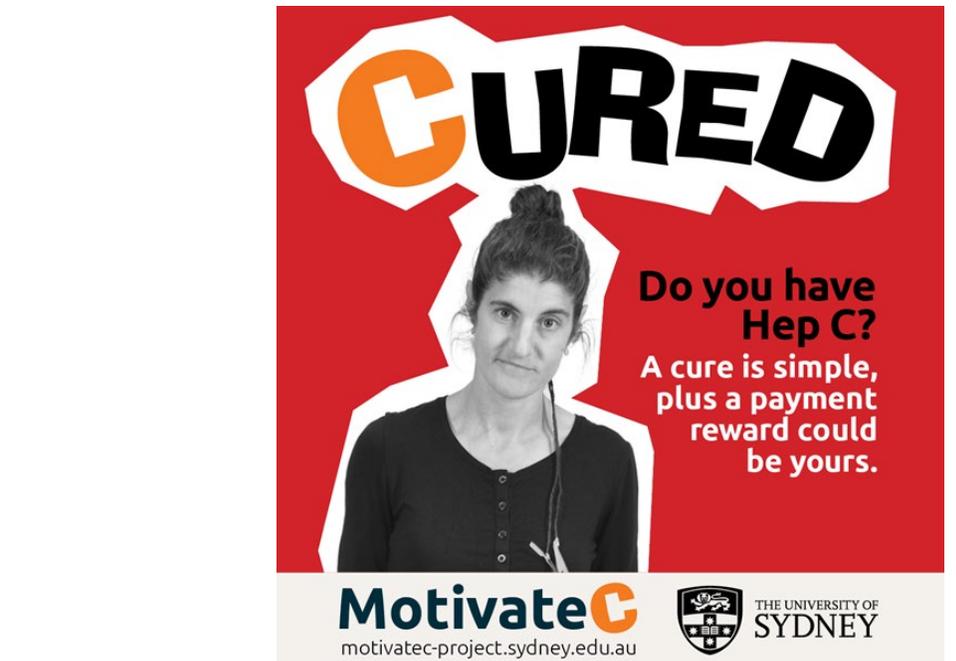
## Design: Framing of the research question

- What decision do we want to inform, rather than what hypothesis do we test, e.g.:
  - Question: **Should** a **person** with **Disease Y** be treated with **new Drug X** instead of the existing **standard of care**?
- PICO (population, intervention, comparator, outcome)
- Whose decision: policymaker versus clinician versus consumer perspective

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## Design: Intervention

- What interventions/ comparators are of interest?  
reasonable?



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## Design: outcomes

- What outcomes are relevant? 'patient-centred' benefits/toxicities/ costs
- Core Outcome Sets



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# Conduct

- When, where, how, and by whom...
  - potential participants are identified, notified/ referred, informed, consented?
  - interventions are delivered?
  - data is gathered? (including testing)



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# Dissemination

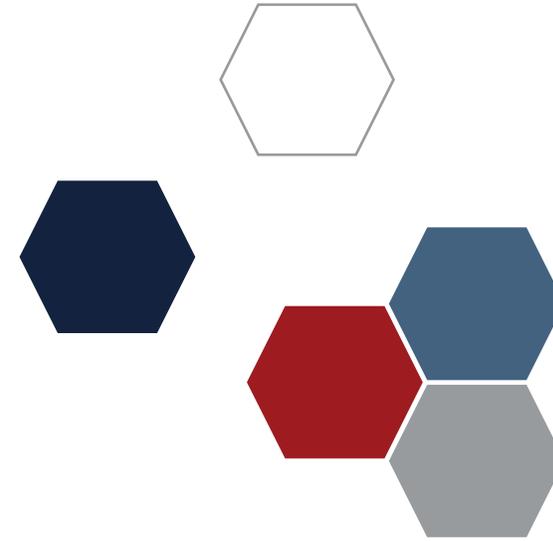
- When, where, how, and by whom...
  - Study results are reported to participants, stakeholders (including the target population), the broader community.

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## Acknowledging...

- Mitch Messer
- Ada Parry
- Cath Hughes AM
- Anne McKenzie AM





# QUESTION & ANSWER SESSION

(please type in questions in the webinar chat function)

# Thank you for your time



## Subscribe to MRFF News

<https://www.health.gov.au/initiatives-and-programs/medical-research-future-fund/mrff-news>



## Nominate for an MRFF Grant Assessment Committee (GAC)

<https://www.nhmrc.gov.au/2021-22-medical-research-future-fund-mrff-grant-opportunities>



## Register for MRFF grants opportunities

<https://www.grants.gov.au/>



## Check out the grant opportunity forecast

<https://www.health.gov.au/our-work/medical-research-future-fund/mrff-grant-opportunities-calendar>



## Follow Health Twitter for MRFF updates

@healthgovau  
#MRFF



## Send any questions to

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