



# RR-CLaN

*Rural Research Collaborative Learning Network*

## **Demystifying Consumer and Community Involvement in Research**

Wednesday 5 April 2023, 3:00-4:00pm  
AEST

Seminar presented by:

**Associate Professor Chris  
Williams**

Research Development Manager,  
Mid North Coast Local Health District

Principal Research Fellow with  
University Centre for Rural Health,  
The University of Sydney

# Acknowledgement of Country



# Please ask questions



# Housekeeping



**Keep your microphone on mute during the session**

# Introducing you to today's presenter



## **Associate Professor Chris Williams**

Research Development Manager | Mid North Coast Local Health District  
Principal Research Fellow | University Centre for Rural Health



**Health**  
Mid North Coast  
Local Health District



University Centre for  
**RURAL HEALTH**  
education • research • workforce



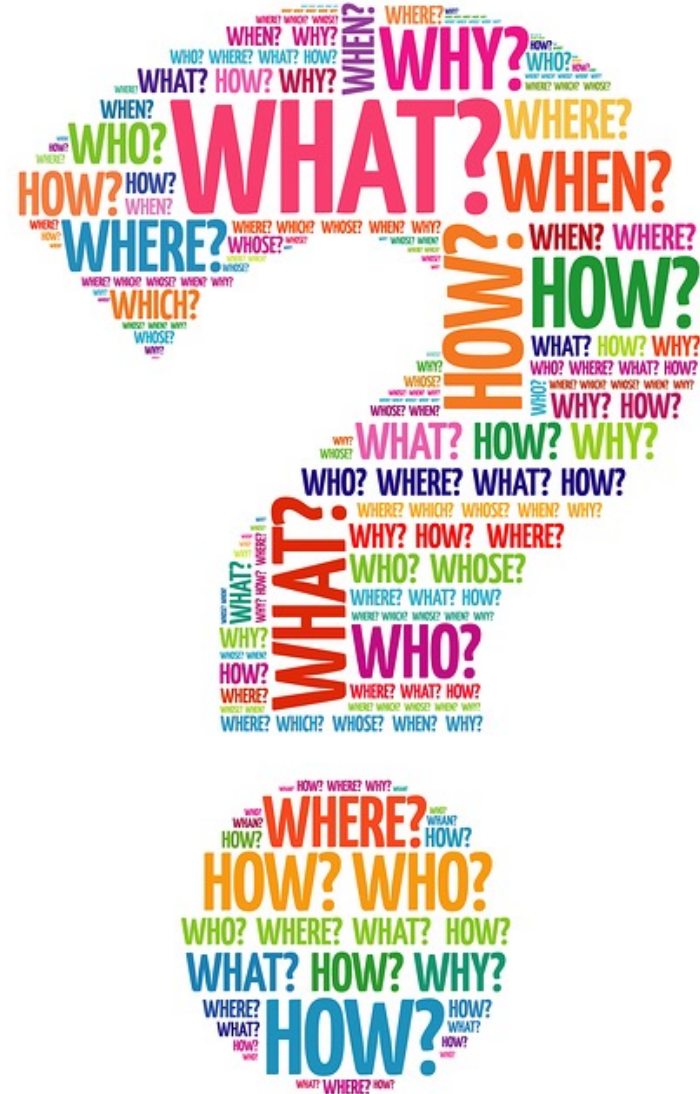
# Demystifying CCI

# Overview

- 'The Why'
- Terminology and concepts
- Where, what, how (core standards)
- Your role in CCI

1.

# WHY CCI?

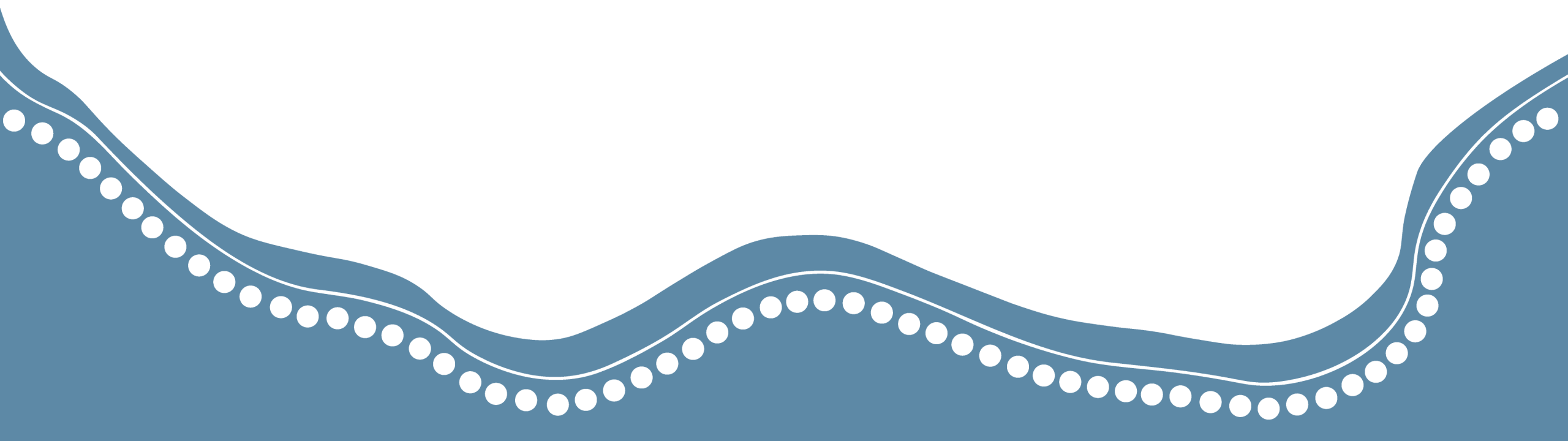




# Purpose.....



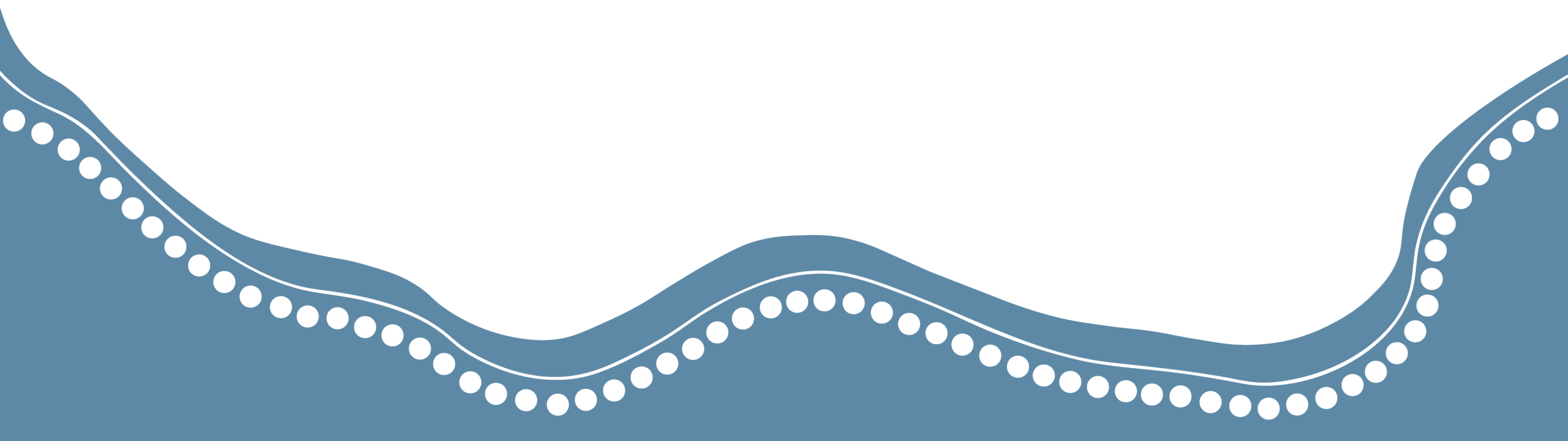
- Why do you need involvement from patients?



# Purpose.....



- Why do you need involvement from patients?
- How do you want to influence CCI?



# Research, Evaluation, QI...it all matters!

- Patients do better in research active health systems
- 85+% of patients believe clinicians and health services should undertake evaluation and research
- Health research does not always produce the type of evidence needed to improve care

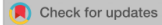
<https://www.thelancet.com/series/research/2014>

# What makes more research useful?

Feature	Questions to Ask
Problem base	Is there a health problem that is big/important enough to fix?
Context placement	Has prior evidence been systematically assessed to inform (the need for) new studies?
Information gain	Is the proposed study large and long enough to be sufficiently informative?
Pragmatism	Does the research reflect real life? If it deviates, does this matter?
Patient centeredness	Does the research reflect top patient priorities?
Value for money	Is the research worth the money?
Feasibility	Can this research be done?
Transparency	Are methods, data, and analyses verifiable and unbiased?

doi:10.1371/journal.pmed.1002049.t001

**Ioannidis JPA** (2016) Why Most Clinical Research Is Not Useful. PLoS Med 13(6): e1002049. <https://doi.org/10.1371/journal.pmed.1002049>



## CO-PRODUCTION OF KNOWLEDGE

## Co-production of knowledge: the future

## A new collection highlights the role of co-production in strengthening health systems

S Redman,<sup>1</sup> T Greenhalgh,<sup>2</sup> L Adedokun,<sup>3</sup> S Staniszewska,<sup>4</sup> S Denegri,<sup>5</sup> on behalf of the Co-production of Knowledge Collection Steering Committee

Co-production is a collaborative model of research that includes stakeholders such as patients, the public, donors, clinicians, service providers, and policy makers. It is a sharing of power, with stakeholders and researchers working together to develop the agenda, design and implement the research, and interpret, disseminate, and implement the findings.

Co-production has been embraced because of its potential to improve the quality and relevance of research and its effect on policy and practice.<sup>1-3</sup> This is nicely captured in the Thai concept of the “triangle that moves the mountain,” whereby researchers, citizens, and policy makers work together to achieve change.<sup>4</sup>

develop shared expectations.<sup>12</sup> Critically, trust is built by working together over time—sharing views and tackling challenges as a team.

Trust is particularly important in working with less powerful stakeholders.<sup>4,7,13,14</sup> In low and middle income countries funders and donors may need to reorient their views to place more trust in local knowledge<sup>15,16</sup>; new kinds of funding from USAID and other donors have supported initiatives to build trust and facilitate co-production.<sup>15</sup> In Australia, research involving Aboriginal people has often been perceived as exploitative. Despite this history, long term partnerships, leadership by Aboriginal communities, commitment to capacity building, and upfront agreement about who determines priorities

<sup>1</sup> Sax Institute, Sydney, Australia

<sup>2</sup> University of Oxford, Oxford, UK

<sup>3</sup> Doris Duke Charitable Foundation, New York, USA

<sup>4</sup> Warwick Research in Nursing, Warwick Medical School, University of Warwick, Warwick, UK

<sup>5</sup> Academy of Medical Sciences, London, UK  
Correspondence to: S Redman

Cite this as: *BMJ* 2021;372:n434

<http://dx.doi.org/10.1136/bmj.n434>

Published: 16 February 2021

# Why involve consumers?

## Practical reasons

- Alternative views increases relevance
- Support design and improve quality
- Support recruitment

(Kirwan et al. 2016)

- awareness, trust, normalise risk vs reward

(Caldwell et al. 2010; Massett et al, 2017)



## Other (normative) reasons for CCI

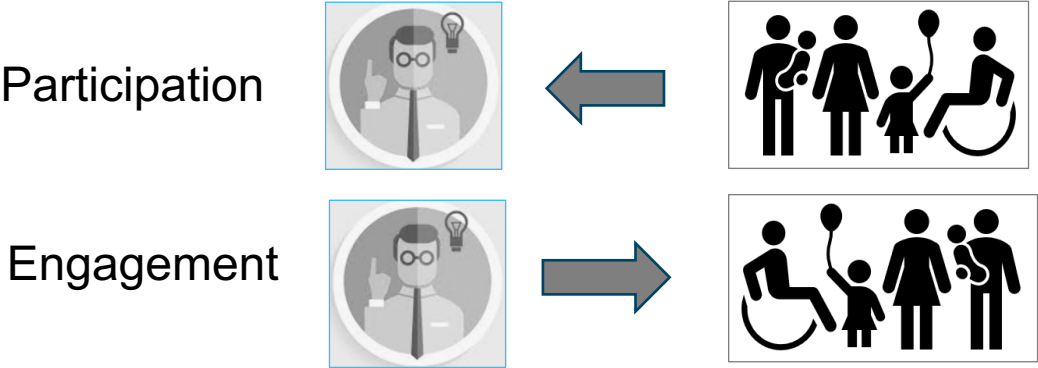
- The public's right to have a say in research funded by tax-payers
- Shift away from paternalistic science
- The Partnering with Consumers accreditation standard extended to clinical trials and LHD research
- Increasingly a funding requirement = success

2.

# Demystifying terms and concepts

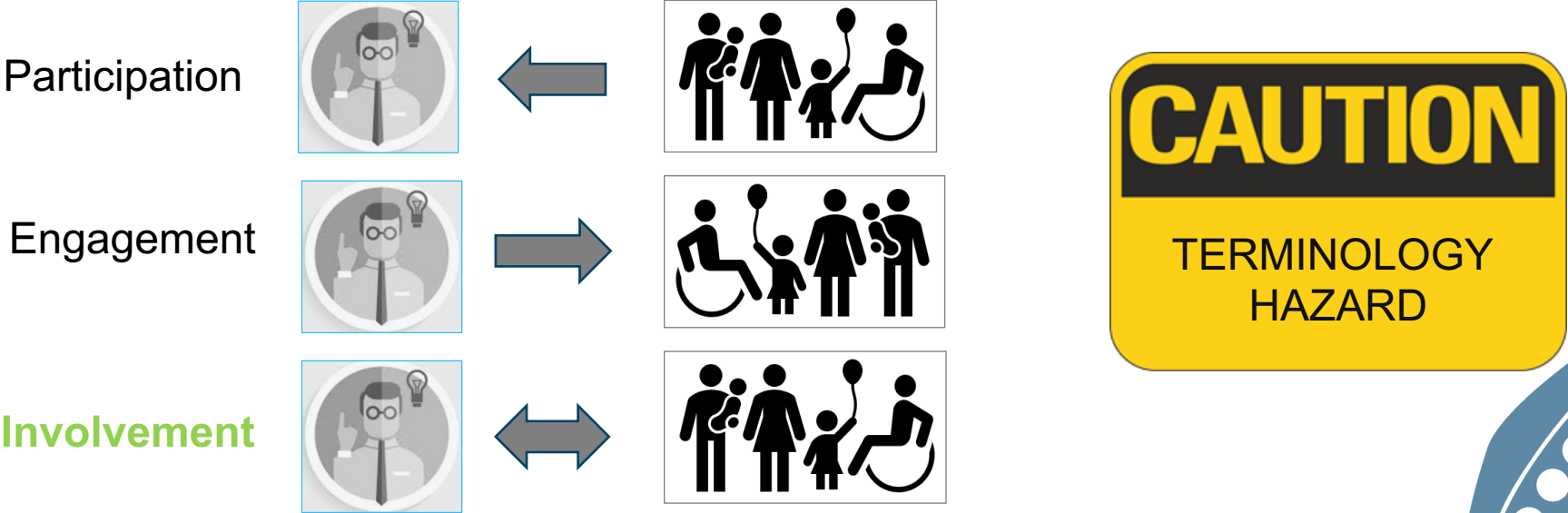


# WHAT IS CCI?





Active involvement to help **shape decisions** about health research priorities, policy, practice and translation.



# Common terms

- **Consumers** – patients and potential patients, cares and others who use health services
- **Communities** – groups of people sharing common interest (cultural, social etc.), not always with geographical association
- **CCI partner** – a consumer or community member involved in clinical research/evaluation (advisor, representative)
- **End-user** – any person or groups including patients, communities, clinicians and policy makers that can use research to make decisions

# Terms and Concepts – levels of involvement



CCI partners and non-researcher clinicians lead decisions about what to research and operationalise those ideas in partnership with researchers

Shared power and responsibility between researchers, CCI partners and clinicians, for all aspects of a project through active, ongoing partnership

Researchers seek CCI partners' and clinicians' input on specific issues where such input has a real potential to help shape a decision or action

CCI partner and clinician feedback is sought on an aspect of a project but is not acted upon, or where it is initiated with little or no scope for CCI partners/clinicians to influence the project

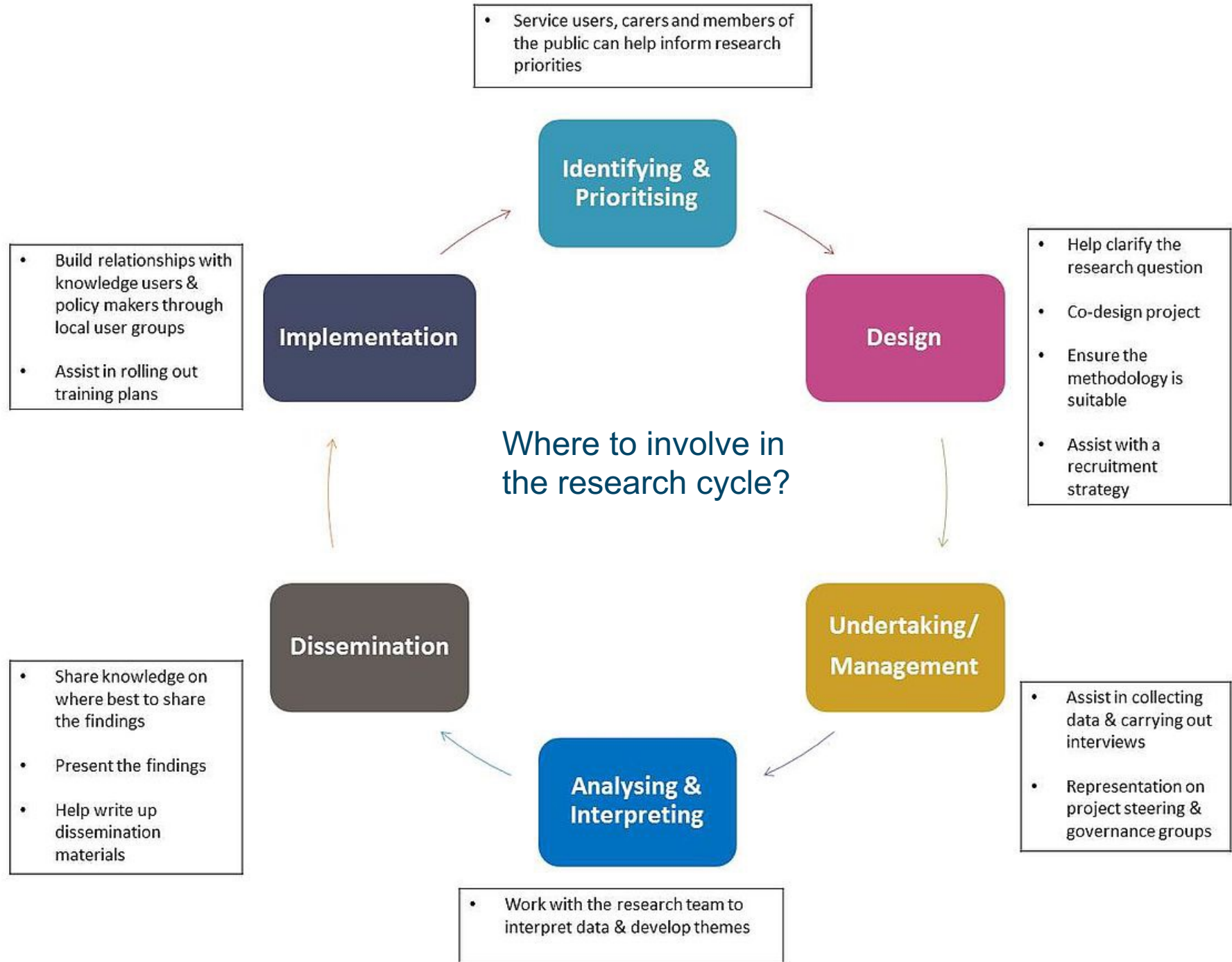
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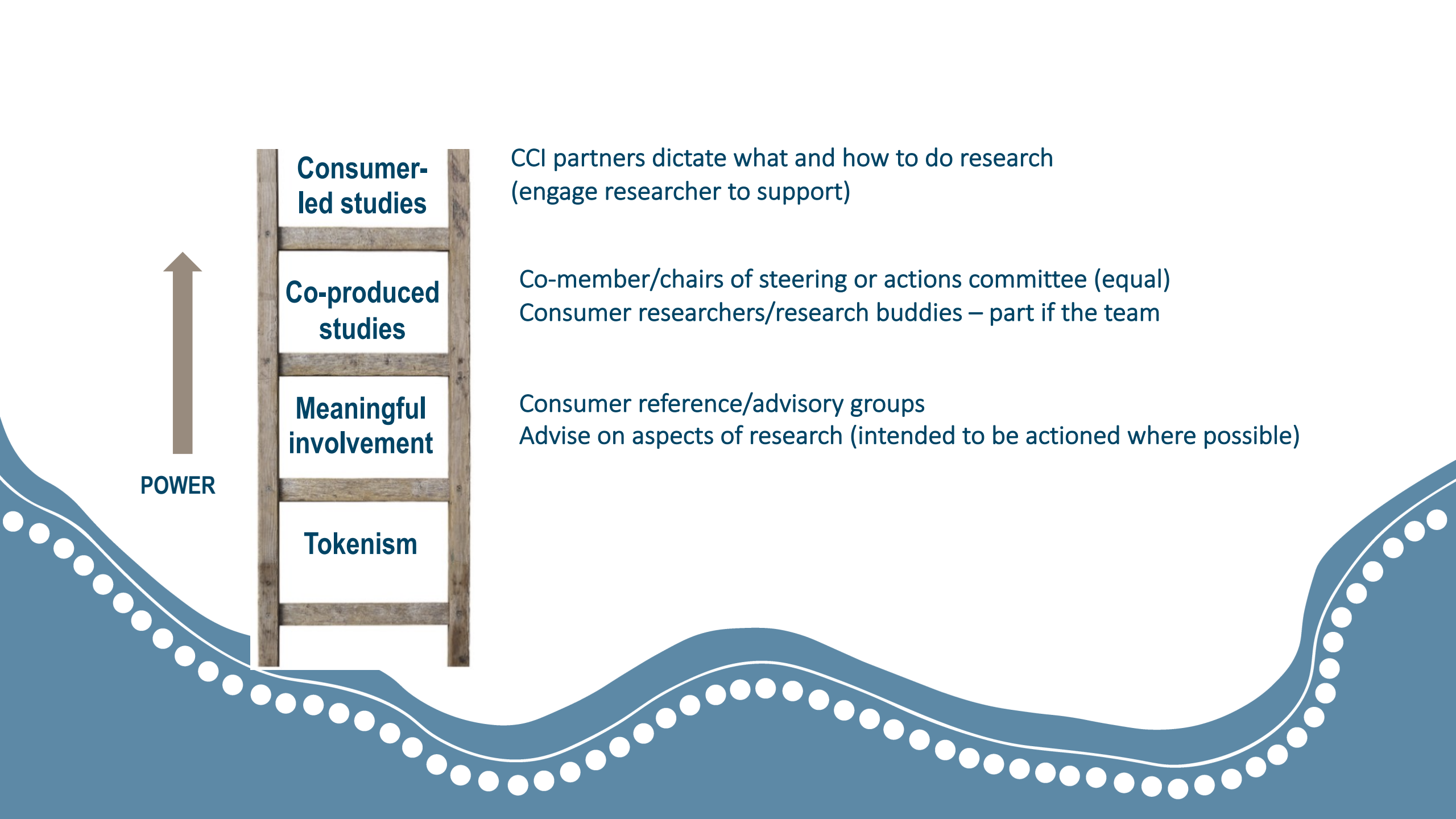
## How to:

- Options for where to involve
- Options for how to involve
- Other core needs/standards for success



# WHERE





↑  
POWER



CCI partners dictate what and how to do research  
(engage researcher to support)

Co-member/chairs of steering or actions committee (equal)  
Consumer researchers/research buddies – part of the team

Consumer reference/advisory groups  
Advise on aspects of research (intended to be actioned where possible)

Tokenism

HOW



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE  
**FINAL RESEARCH REPORT**

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## Developing a Guide on How to Involve Patients in Research Studies

C. Daniel Mullins, PhD<sup>1</sup>; Hillary A. Edwards, MPH<sup>1</sup>; Jennifer Huang, PhD<sup>2</sup>; Liz Jansky, PhD<sup>2</sup>

Mullins et al,  
2020

# Research Process

## Engagement Methods

	PLAN			RESEARCH				SHARE			
	Find Questions	Rank Questions	Phrase Questions	Select Outcomes	Describe Patient Journey	Plan for Research	Collect Data	Review	Translate	Share	Evaluate
	Find questions that matter to the community	Rank questions to select the most important ones	Phrase questions in the patient voice	Select outcomes that matter to patients	Develop a framework based on the patient experience	Make a plan to do the research & analyze data	Decide how and when to collect data	Figure out if results are believable and meaningful	Make the research results easy to understand	Share the findings with the community & others	Evaluate whether patients were meaningfully involved
Community Partnerships	3	3	3	2	2	2	2	2	2	2	2
Focus Group	3	2	3	3	2	1	1	2	2	2	2
Interview	3	2	2	2	2	1	1	2	2	1	2
Meeting	2	2	2	2	2	2	2	2	2	2	2
Print Material	1	1	1	1	2	1	0	1	2	2	1
Social Media	2	2	2	1	2	1	1	1	2	2	0
Story-telling	2	1	3	2	2	1	1	2	2	2	1
Survey	2	2	2	2	2	1	1	2	2	1	2
Research Member	2	2	2	2	2	3	3	3	3	2	2

COLOR KEY - Level of Recommendation

Note: Shading indicates least recommended or appropriate (lightest color) to most recommended or appropriate (darkest color).

0 Low	1 Low-Moderate	2 Moderate-High	3 High
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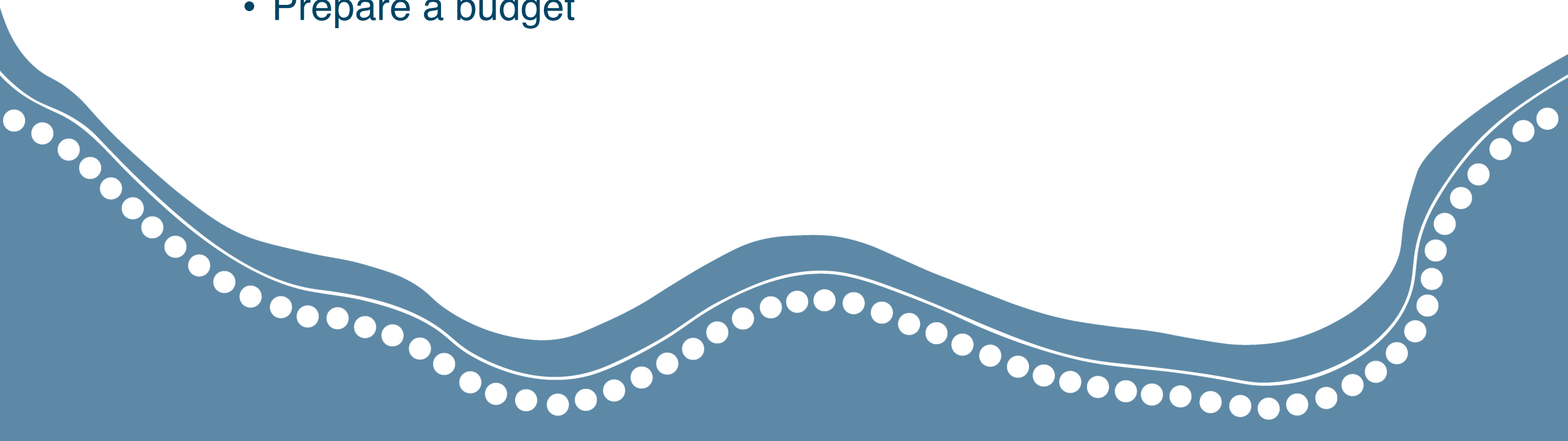


# Core standards: Planning

- What problem are you trying to solve with CCI?
- At what stage should you involve?
  - Have an awareness of how insights from patients can help
  - Consider who is your target audience and how will you find them (diverse and inclusive)

# Core standards: Planning

- What method will you use?
  - Is this a sharded decision?
- Are you are paying CCI partners?
  - Prepare a budget

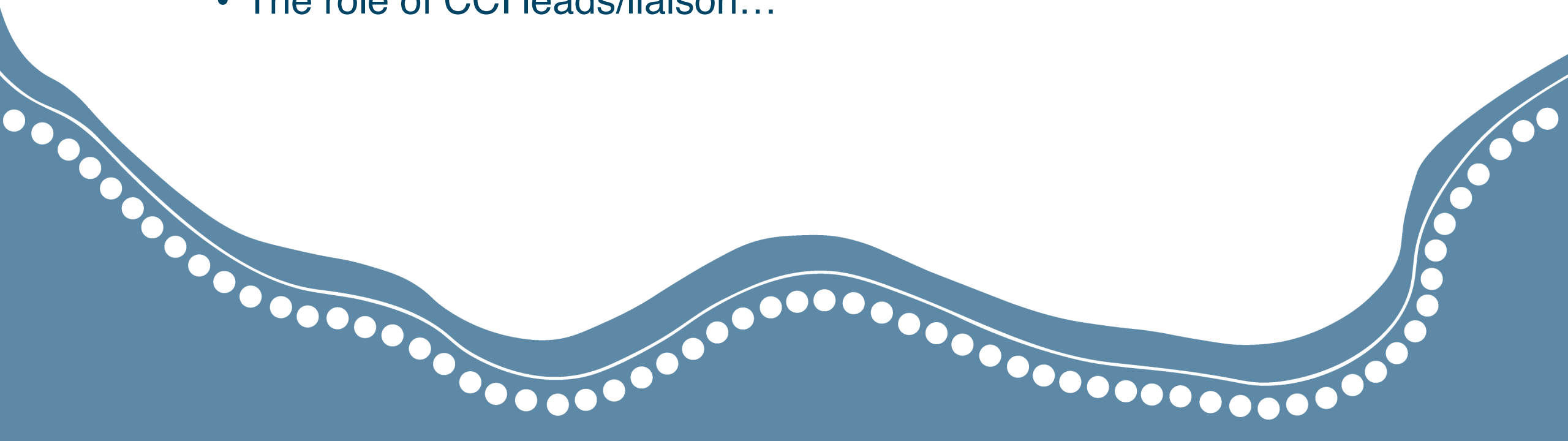


# Core standards: Preparing and managing

- How do you create the right environment for CCI success?
  - What skills/training/ongoing support do CCI partners need?
  - What skills do you need to ensure CCI is as intended?
- What CCI culture does your organisation have?
- Why would patients want to be involved?

# Core standards: Preparing and managing

- How do you managing expectations of those involved?
  - Clarify with suitable documentation, remuneration, check points, CCI leads/liaison...
- How do you maintain effective communication?
  - The role of CCI leads/liaison...



# Core standards: Evaluating and concluding

- Consider impact of CCI on the research
- Measure experiences of those involved
- Make change (pick a new journey)
- Provide feedback
- Acknowledge contributions
- Consider new opportunities/roles

# Tools and resources 1



## Involving Consumers in Health and Medical Research Handbook

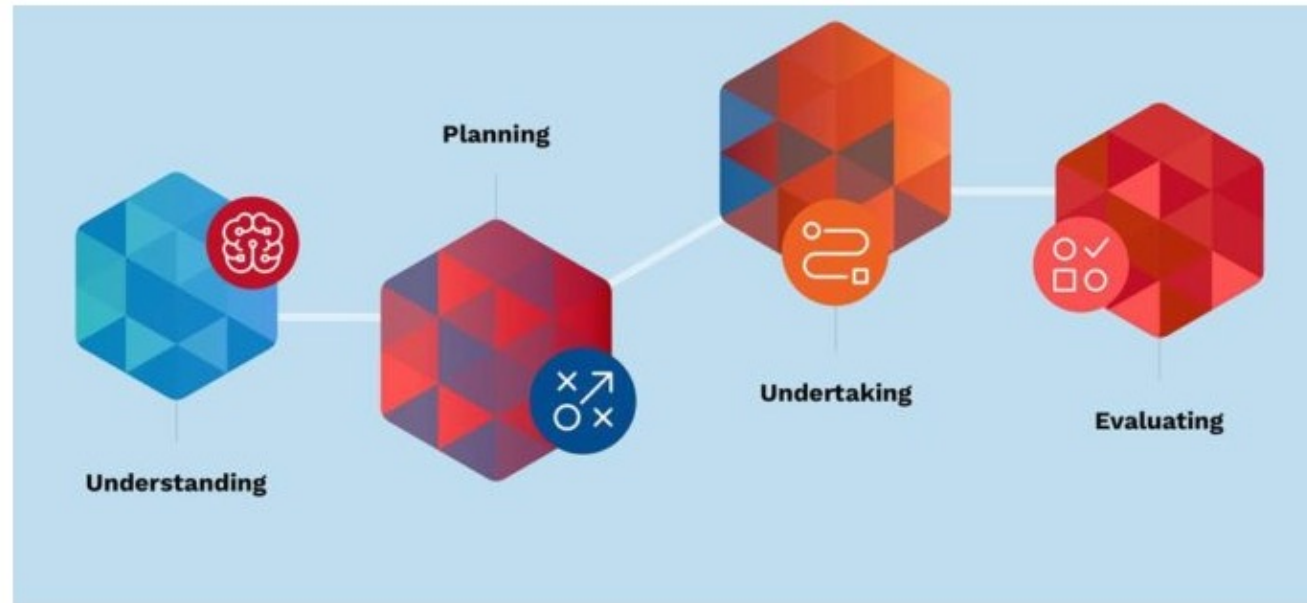
- Phase 1** – Commitment
- Phase 2** – Planning and Preparation
- Phase 3** – Managing for Success
- Phase 4** – Evaluating the Involvement
- Phase 5** – Concluding the Involvement

# Tools and resources 2

## Consumer Involvement Toolkit



Australian  
Clinical  
Trials  
Alliance



# (Your) potential roles CCI

**Supporter** – agrees with, advocates for.... asks why not?

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**Enabler** – Supporter plus, active role in operations for CCI

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**Leader** – Strategic enabler; has sense of accountability; committed and systematic process





# Take aways:

CCI doesn't have to be complex

- Be clear on why you are doing CCI
- Consider appropriate levels of CCI and why patients would want to be
- Consider the environment, recognition and eth patient role (avoid tokenism)
- Plan, but be flexible and manage expectations

# Resources

- Cambridge Clinical Trials Case Study - <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-018-0104-4>
- The Statement on Consumer and Community Involvement in Health and Medical Research (2016) NHMRC <https://www.nhmrc.gov.au/about-us/publications/statement-consumer-and-community-involvementhealth-and-medical-research>
- WAHTN Involving Consumers in Health Medical Research Handbook [https://wahtn.org/wp-content/uploads/2021/09/WAHTN-CCI-Handbook\\_29092021.pdf](https://wahtn.org/wp-content/uploads/2021/09/WAHTN-CCI-Handbook_29092021.pdf)
- Australia Clinical Trials Alliance Consumer and Community Involvement Tool Kit <https://involvementtoolkit.clinicaltrialsalliance.org.au>
- Consumer and Community Involvement in Health and Medical Research: An Australia-wide Audit [https://www.wahtn.org/wp-content/uploads/2019/03/AHRA-CCI\\_Final-Report\\_Full\\_Dec2018.pdf](https://www.wahtn.org/wp-content/uploads/2019/03/AHRA-CCI_Final-Report_Full_Dec2018.pdf)
- South Australian Health and Medical Research Institute (SAHMRI) Framework [https://www.sahmri.org/m/downloads/20140606\\_Health\\_Consumers\\_in\\_Research\\_Report\\_FINAL.pdf](https://www.sahmri.org/m/downloads/20140606_Health_Consumers_in_Research_Report_FINAL.pdf)
- South Australian Health and Medical Research Institute (SAHMRI) Value Statement <https://healthtranslationsa.org.au/wp-content/uploads/2020/11/The-value-of-CCI-report-v2.pdf>
- Cancer Australia: National Framework for Consumer Involvement in Cancer Control [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)
- Miller et al (2017), Integrating consumer engagement in health and medical research – an Australian framework <https://health-policy-systems.biomedcentral.com/articles/10.1186/s12961-017-0171-2>

[christopher.williams1@health.nsw.gov.au](mailto:christopher.williams1@health.nsw.gov.au)

# Resources

## Planning

- Quick tools to figure out *your* 'why' (in what components) you want/need CCI: Cancer Australia checklist: [https://consumerinvolvement.canceraustralia.gov.au/sites/default/files/doc-lib/accessible/researchers/r4.0-15\\_checklist\\_researchers.pdf](https://consumerinvolvement.canceraustralia.gov.au/sites/default/files/doc-lib/accessible/researchers/r4.0-15_checklist_researchers.pdf) AND Western Australia Health Translation Network Handbook (resource 7): [https://consumerinvolvement.canceraustralia.gov.au/sites/default/files/doc-lib/accessible/researchers/r4.0-15\\_checklist\\_researchers.pdf](https://consumerinvolvement.canceraustralia.gov.au/sites/default/files/doc-lib/accessible/researchers/r4.0-15_checklist_researchers.pdf)
- General considerations. Telethon Kids [https://www.telethonkids.org.au/globalassets/media/images/pagessections/research/help-shape-our-research/purple\\_planning\\_book\\_271015.pdf](https://www.telethonkids.org.au/globalassets/media/images/pagessections/research/help-shape-our-research/purple_planning_book_271015.pdf) AND Barriers and Enablers [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/)

## Terms of Reference

- Writing terms of references: <https://hic.org.au/writing-terms-of-reference-for-consumer-committees/> and [https://consumerinvolvement.canceraustralia.gov.au/sites/default/files/doc-lib/accessible/service\\_managers/m\\_4\\_1-14-a\\_12\\_guide\\_writingtermsofreference\\_2\\_2.pdf](https://consumerinvolvement.canceraustralia.gov.au/sites/default/files/doc-lib/accessible/service_managers/m_4_1-14-a_12_guide_writingtermsofreference_2_2.pdf)

## Budget

- Deciding whether you should pay your CCI partner: <https://hic.org.au/should-money-come-into-it-a-tool-for-deciding-whether-to-pay-patient-engagement-participants/>
- Preparing a budget: Cost calculator: <https://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/>
- Reimbursement guidelines: Monash <https://monashpartners.org.au/wp-content/uploads/2020/05/Remuneration-Guidelines-1.pdf>; Health Consumers NSW <https://www.hcnsw.org.au/for-health-consumer-organisations/remuneration-and-reimbursement-of-health-consumers/>; To board/committees: <https://www.vic.gov.au/guidelines-appointment-remuneration>

## Funding sources (other than LHD)

- [Philanthropy Australia](#)
- [Our Community](#)
- [Grant Guru](#)
- Local Government Area Council!

# Resources

## Recruiting

- NSW Regional Health Partners role description template: <https://nswregionalhealthpartners.org.au/wp-content/uploads/2021/12/Position-Description.pdf>
- Common Forums: Health Consumers NSW, Consumers Health Forum of Australia,

## Training and orientation

- Common barriers and enablers here: [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/)
- Communicating with people with a disability: [http://www.daru.org.au/wp/wp-content/uploads/2013/05/Inclusive-Consultation-and-Communication-with-People-with-a-Disability\\_04.pdf](http://www.daru.org.au/wp/wp-content/uploads/2013/05/Inclusive-Consultation-and-Communication-with-People-with-a-Disability_04.pdf)

## 'Doing'

- International Association for Public Participation Spectrum: <https://iap2.org.au/resources/spectrum/>
- Selecting methods <https://dpmc.govt.nz/sites/default/files/2020-10/policy-project-community-engagement-selecting-methods.pdf> OR <https://involve.org.uk/sites/default/files/field/attachemnt/People-and-Participation.pdf>

## Communication

- National Safety and Quality Healthcare Service Standards Health Literacy: <https://www.safetyandquality.gov.au/standards/nsqhs-standards/partnering-consumers-standard/health-literacy>
- Written - general info: <https://www.sahealth.sa.gov.au/wps/wcm/connect/fcb907004e455125ab8eaf8ba24f3db9/HLT-AssessingReability-T7-PHCS-SQ20130118.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE-fcb907004e455125ab8eaf8ba24f3db9-nKKxi3l>
- Written - Flesch Kincaid Grade and Simple Measure of Gobbledygook (SMOG) assessments: <https://readable.com/readability/smog-index/>

## Evaluation

- Standards: <https://www.safetyandquality.gov.au/sites/default/files/migrated/User-Guide-for-Measuring-and-Evaluating-Partnering-with-Consumers.pdf>
- General guides and available tools: <https://www.ourcommunity.com.au/files/books/MeasuringWhatMattersBooklet.pdf> ; [https://ahra.org.au/wp-content/uploads/2021/10/AHRA\\_CCI\\_Measuring\\_Impact\\_web.pdf](https://ahra.org.au/wp-content/uploads/2021/10/AHRA_CCI_Measuring_Impact_web.pdf); <http://www.evaluationtoolbox.net.au/>



# RR-CLaN

*Rural Research Collaborative Learning Network*

The Rural Research Collaborative Learning Network is proud to present:

## How to read and interpret a systematic review

Wednesday 3rd May 2023

Time: To be confirmed



**RR-CLaN**

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**Thank you for  
attending!**

**How did we do?**



**We would really appreciate if you could take a couple of  
minutes to complete the evaluation survey**