



# Patient involvement in research



PACER webinar

2:00 – 3:00 pm Tuesday 10<sup>th</sup> July 2018

Kids Research, The Children's Hospital at Westmead, NSW 2145

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# “Nothing about us with out us”

**INVOLVE** defines public involvement as “research being carried out ‘**with**’ or ‘**by**’ members of the public rather than ‘**to**’, ‘**about**’ or ‘**for**’ them”. <http://www.invo.org.uk/>



# Definitions

## **Patient**

Patient, caregiver or family member with lived experience of a condition

## **Involvement**

Sustained and meaningful contribution to the research process as more than a research subject or participant

## **Engagement**

Establishment of a relationship between patients and researchers → the first step of involvement.

# Challenges (why we don't)



I don't know how



It's too expensive



I don't have time



We are the experts



No one else does it



What difference  
does it make?

# Why should we involve patients in research?



Recommended by global organisations



World Health  
Organization



To get published



To get funded



Australian Government

National Health and  
Medical Research Council



To improve translation to practice and policy

N|H|M|R|C

# Why should we involve patients in research?

Patient involvement adds value across the spectrum of planning, policy, and **research** *(NHMRC, WHO, etc)*

Patients are experts of their experience and have unique knowledge of living with a condition. Involvement in research increases the quality of care. *(Canadian Institutes of Health Research etc)*

Ethically – it is the right thing to do!

# Benefits for researchers?



- ▶ Reduce waste through aligning research priorities
- ▶ Improve communication with patients (*consent, results*)
- ▶ Improve recruitment and retention (*acceptability/feasibility*)
- ▶ Ethics approval
- ▶ Public support, confidence and wider dissemination



# Benefits for patients

- ▶ Increased knowledge about their condition
- ▶ Opportunities to meet other patients and health professionals
- ▶ Driving research that is relevant and meaningful to them
- ▶ Greater understanding of research – developing trust
- ▶ Better translation of research into delivery of better health outcomes





# How can we involve patients?



- ▶ Patient roles
- ▶ Levels of involvement
- ▶ Stages of involvement

# Patient roles

Cancer Australia describe five different types of involvement for consumers:

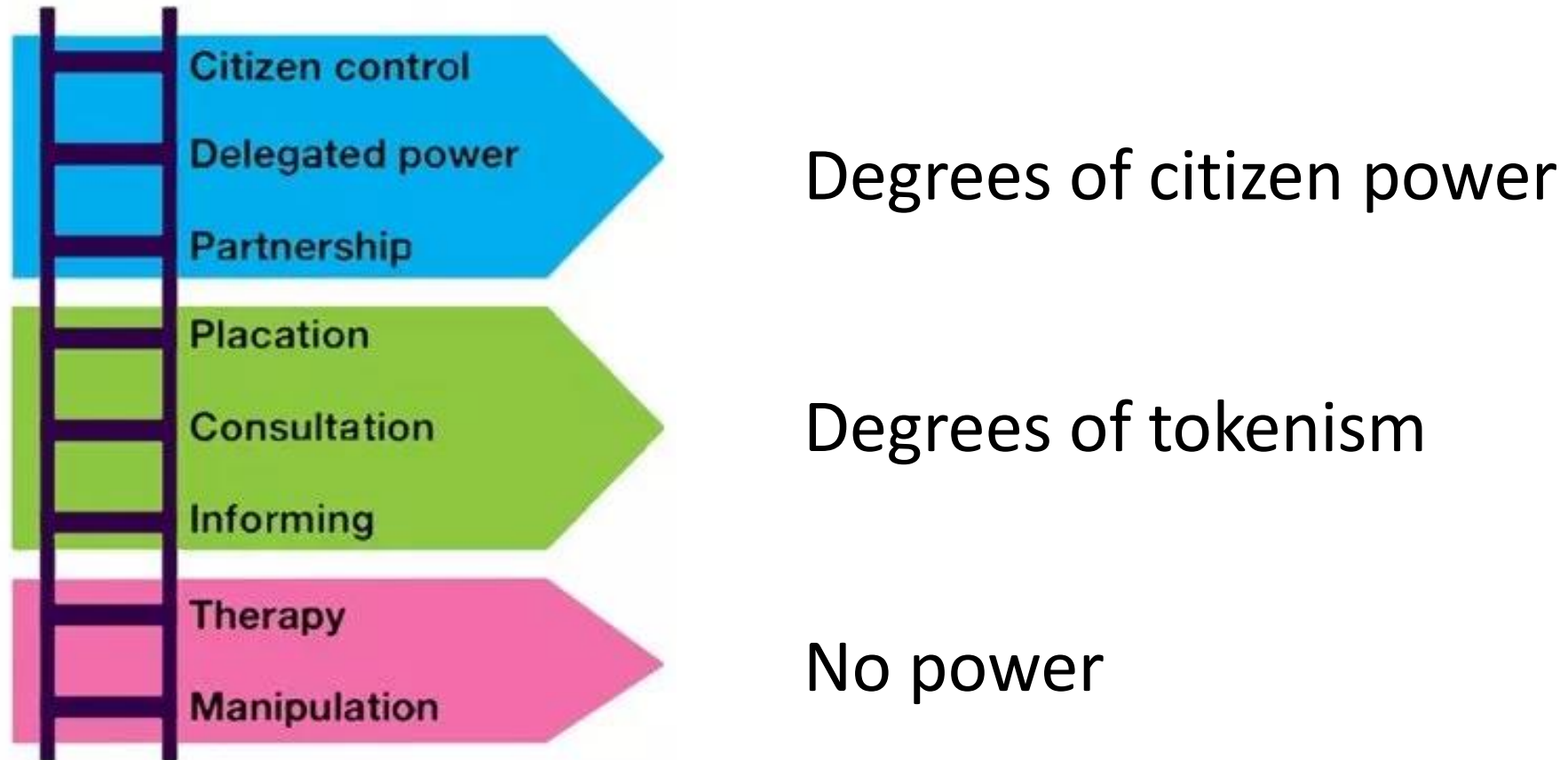
1. **Personal engagement:** More broadly patients can engage and inform researchers through personal perspectives, story-telling, surveys, focus groups and targeted groups
2. **Advocate:** They can advocate on behalf of other patients to represent broad views and experiences of a range of people affected by a certain condition
3. **Advisor:** They can give advice based on their experience to influence decision-making
4. **Expert:** They may be recognized as an expert for their condition
5. **Partner:** They can be valued equally to researchers as partners who can contribute significant knowledge

*National Framework for Consumer Involvement in Cancer Control, Cancer Australia 2011:*

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

# Levels of involvement

## Arnstein's ladder of Public Participation



# Levels of involvement

*Provide information, seek  
feedback, build awareness,  
improve knowledge*

*Work equally with health  
professionals, administrators,  
researchers, policy makers*

*Set priorities,  
lead major activities*



Researcher Led

Partnership

Consumer Led

# The research cycle

**Setting priorities and selecting research questions** → Identifying and prioritising topics so research answers patient-relevant questions (Stevens 2003)

**Designing the study** → Improving information sheets and consent forms (Marsden 2004) – breast cancer trial, involving patients in the design of the trial

**Collecting the data** → Increasing trial recruitment and identifying trials likely to recruit poorly (Terry 2007)

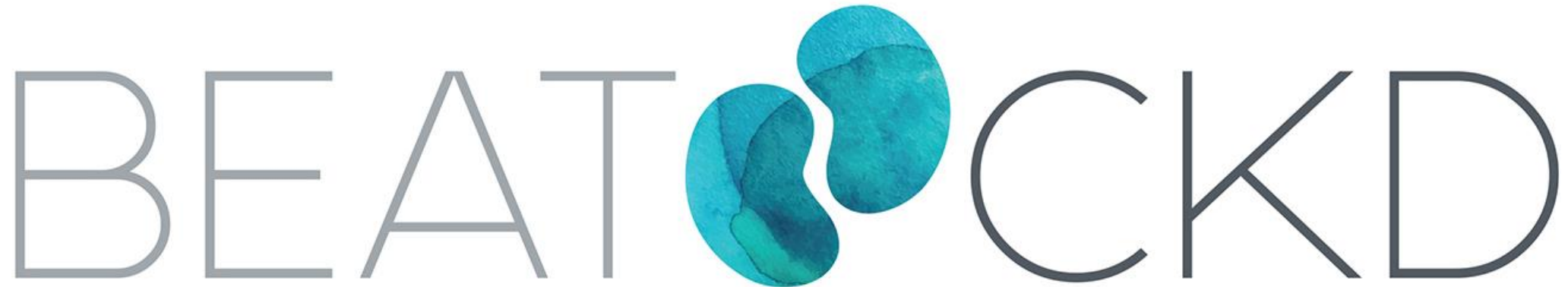
**Analysing the data** → Interpreting the results of trials (Hanley 2001) - their lived experience may shed a different light on how the data could be interpreted

**Disseminating the findings** → we can work with patients to produce plain language summaries of our findings which can widen dissemination (Stevens 2003)

**Implementing the results in a real world setting** → Ensuring outcome measures are relevant and feasible (Ali 2006)

**Evaluating the impact** → Evaluation study of the Standardised Outcomes in Nephrology (SONG) Initiative Nominal Group Technique Focus Groups (Survey, Gutman, unpublished) Patients can provide useful and practical feedback on how we can improve our methods

# Principles and strategies for involving patients in research in chronic kidney disease: National workshops report



BETTER EVIDENCE AND TRANSLATION IN CHRONIC KIDNEY DISEASE



# Background

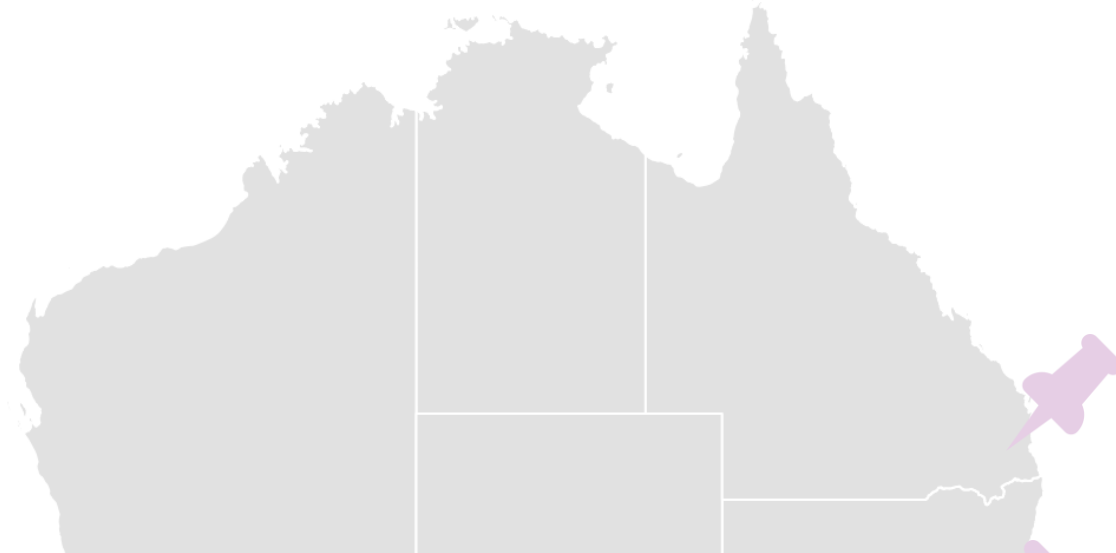
- ▶ Involvement recommended and benefits recognized
- ▶ Limited evidence on 'best-practice'
- ▶ Context of CKD
  - Lifelong, mortality x100, poor QoL, relentless symptom burden
  - Many critical treatment decisions over lifetime
  - Involvement needed
- ▶ Despite current efforts (INVOLVE, JLA, Can-SOLVE) involving patients remains challenging for researchers
- ▶ We asked patients and health professionals 'why?'



# Methods

## Data collection

- ▶ 3 workshops (n=17 breakout groups) in Sydney (n=6), Adelaide (n=5) and Brisbane (n=6) with patients and HPs
- ▶ Participants were invited to attend through BEAT-CKD Investigator networks and KHA
- ▶ In total 148 people attended including 105 patients and carers



# Results



“Once the patient is happy and healthy and everything is in good order, then they’ll be able to go on and do research”

*Patient, Female, Sydney*

“The power of people’s lived experience is immense”

*Health professional, Male, Brisbane*

“It’s about spinning it around and not talking about the clinical stuff. It’s talking about the patient reasons of why it’s important – what’s in it for the patient”

*Health professional, Female, Brisbane*

“If we could piggyback onto that diabetes research, I think that might raise a lot of public awareness”

*Patient, Female, Adelaide*

“The organisation has got to have a strategy to involve those people, and some funds to maintain that... You’ve got a lot of people interested in participating in research. It’s like confetti. Throw it up in the air, and unless you’ve got a net to catch it...”

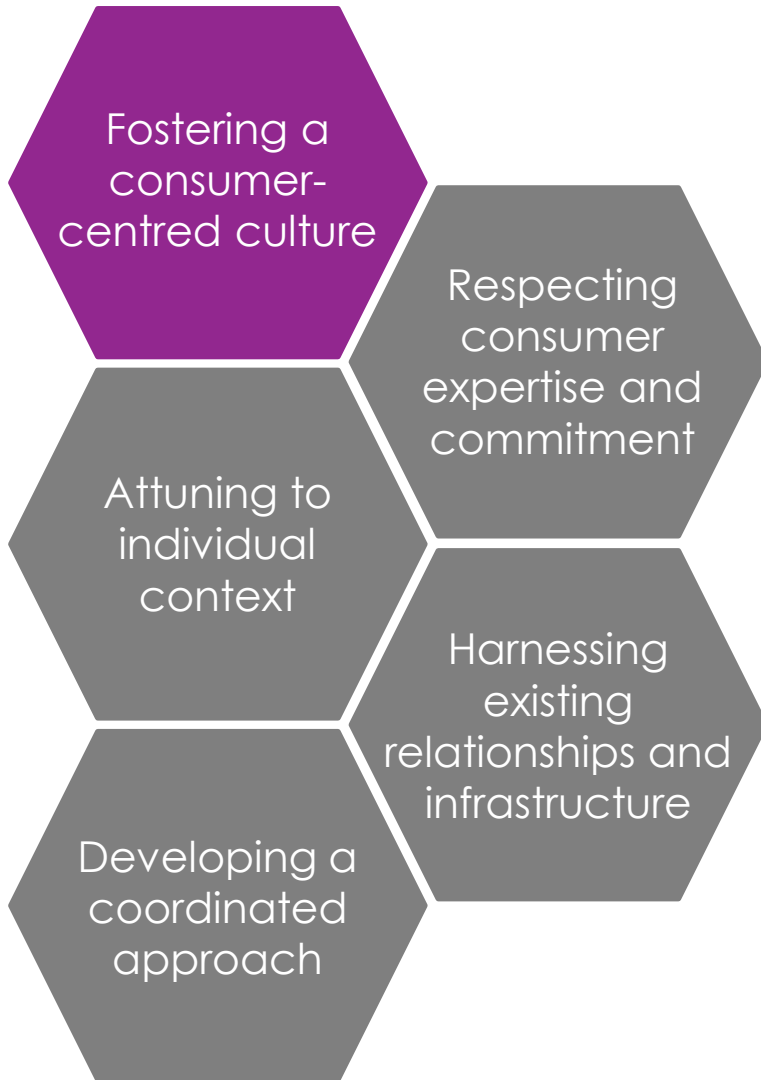
*Health professional, Male, Brisbane*

# Themes

## Building a community

From a “sanitised approach” to a “friendly, relaxed atmosphere”

*Patient, Male, Adelaide*



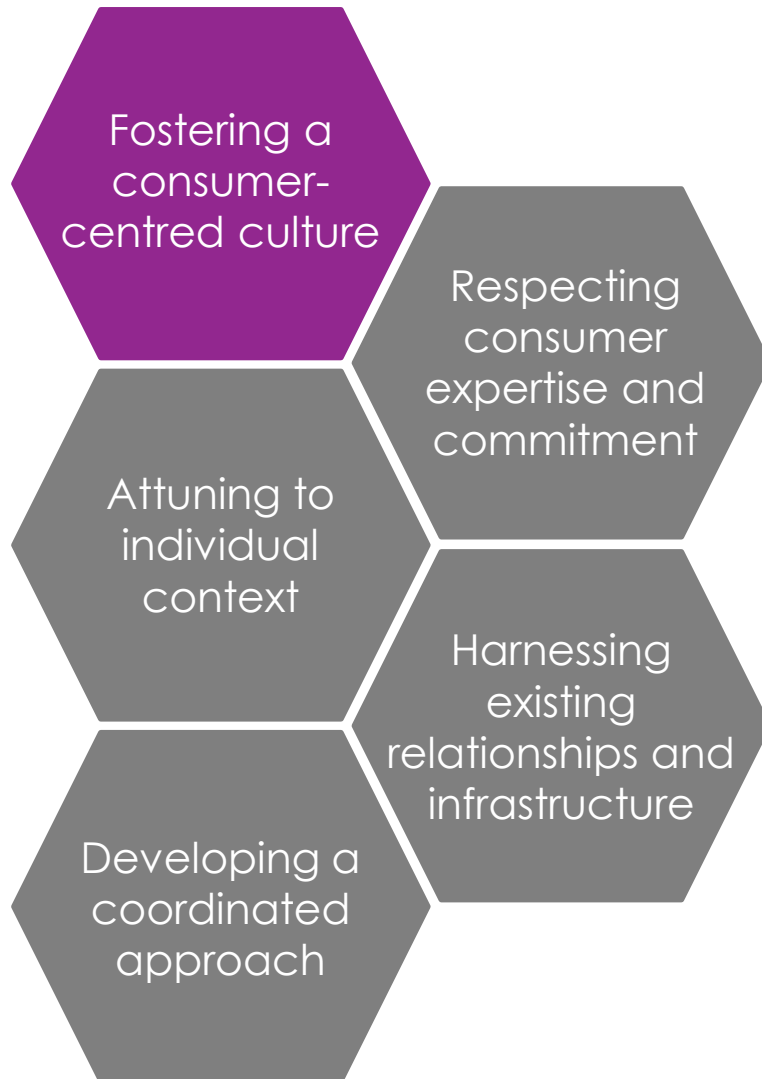
# Themes

**Building a community**

**Facilitating knowledge exchange and translation**

“Knowledge is power”

*Patient, Female, Brisbane*



# Themes

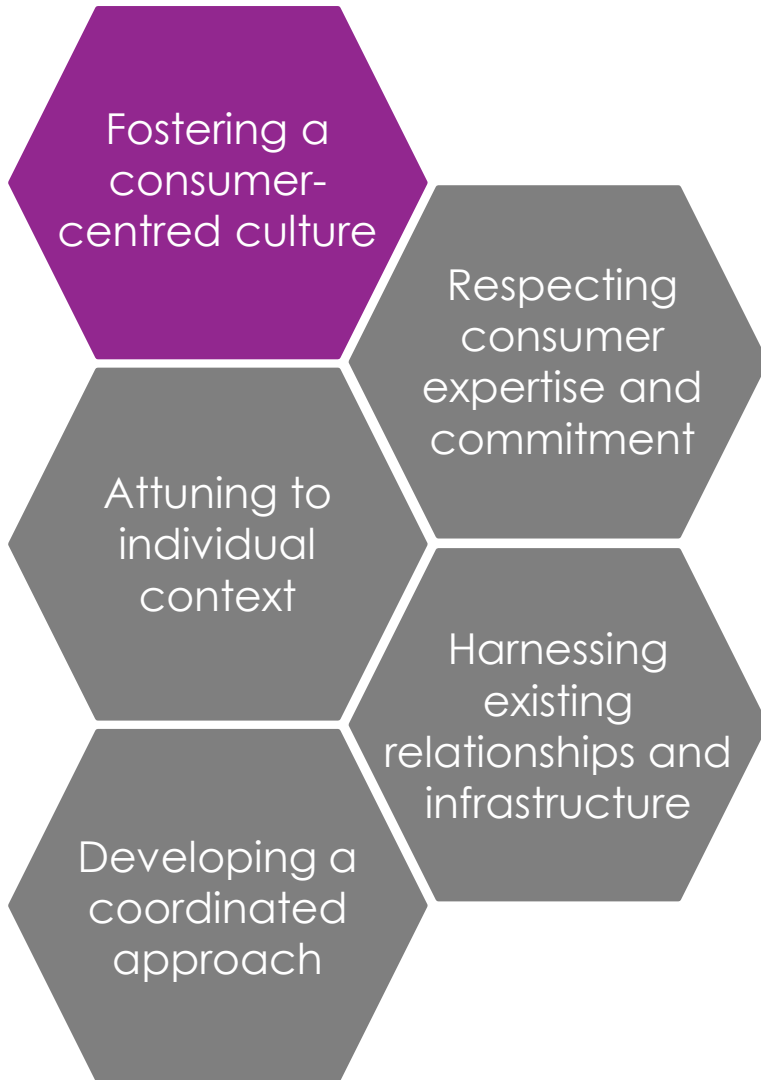
**Building a community**

**Facilitating knowledge exchange and translation**

**Providing an opportunity to 'give back'**

“Why would someone participate? It's because they want to help other people.”

*Male, Patient, Adelaide*



# Themes

**Building a community**

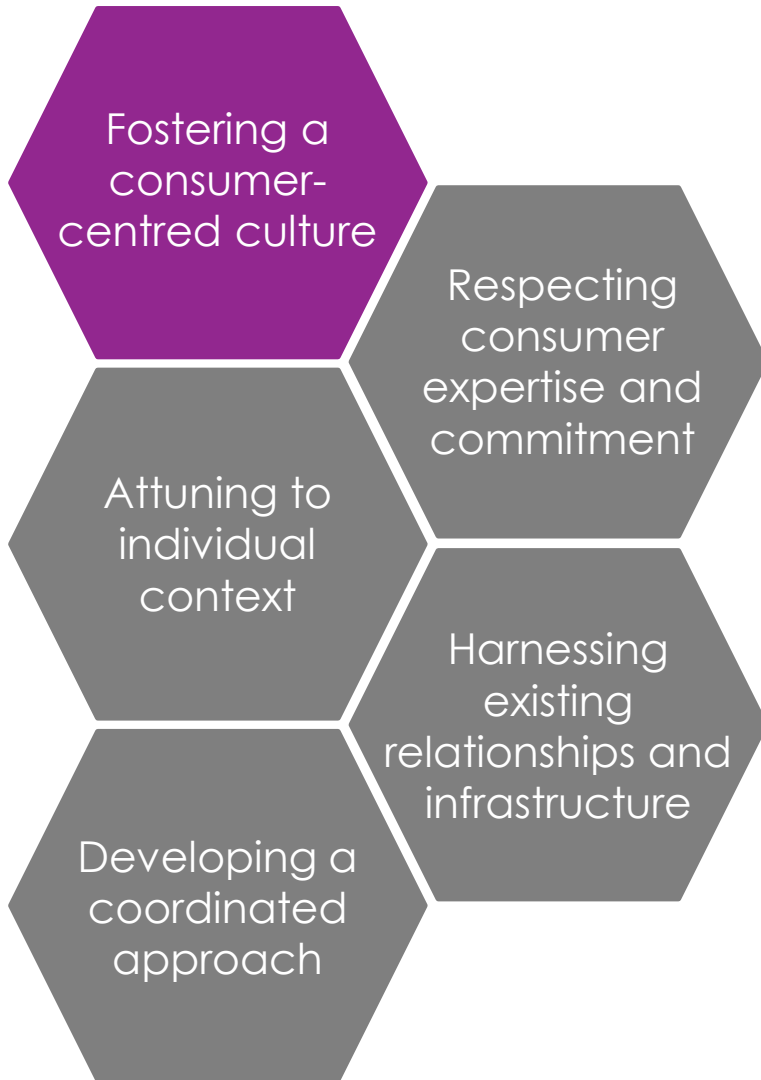
**Facilitating knowledge exchange and translation**

**Providing an opportunity to ‘give back’**

**Empowering health ownership**

“I believe in the power we have as consumers to change what’s important to us.”

*Patient, Female, Brisbane*



# Themes

**Building a community**

**Facilitating knowledge exchange and translation**

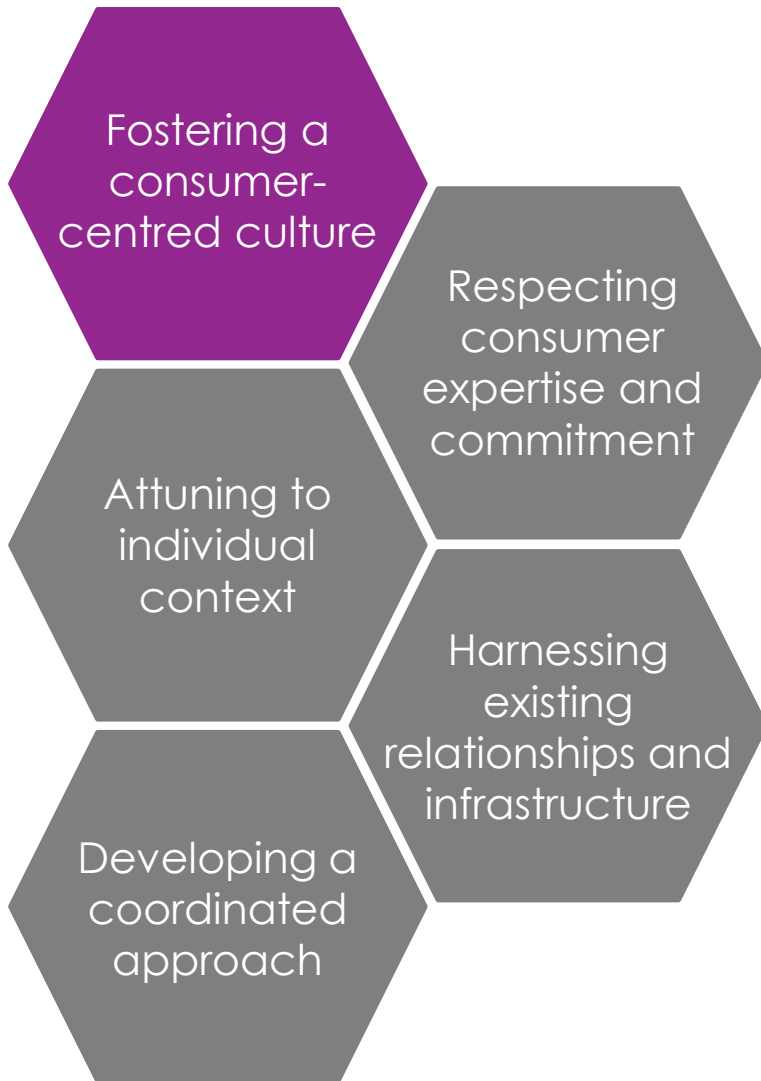
**Providing an opportunity to ‘give back’**

**Empowering health ownership**

**Allaying scepticism and suspicion**

“Sometimes the grant allocations are a bit contrary to what the patient might have picked. Sometimes there’s no patient on the selection committee.”

*Patient, Female, Sydney*





# Themes

## Clarifying expectations and responsibilities

“One of the things that happens poorly is the explanation upfront...because research can be kind of mystical, but it can also be really hands on and grounded if you explain it correctly.”

*Health Professional, Female, Adelaide*



# Themes

**Clarifying expectations and responsibilities**

**Equipping for meaningful involvement**

“I was a bit horrified that they had a consumer involved and he pulled out because it was too technical...you simplify, you train...don't just go 'oh, it didn't work'.”

*Patient, Female, Sydney*



# Themes

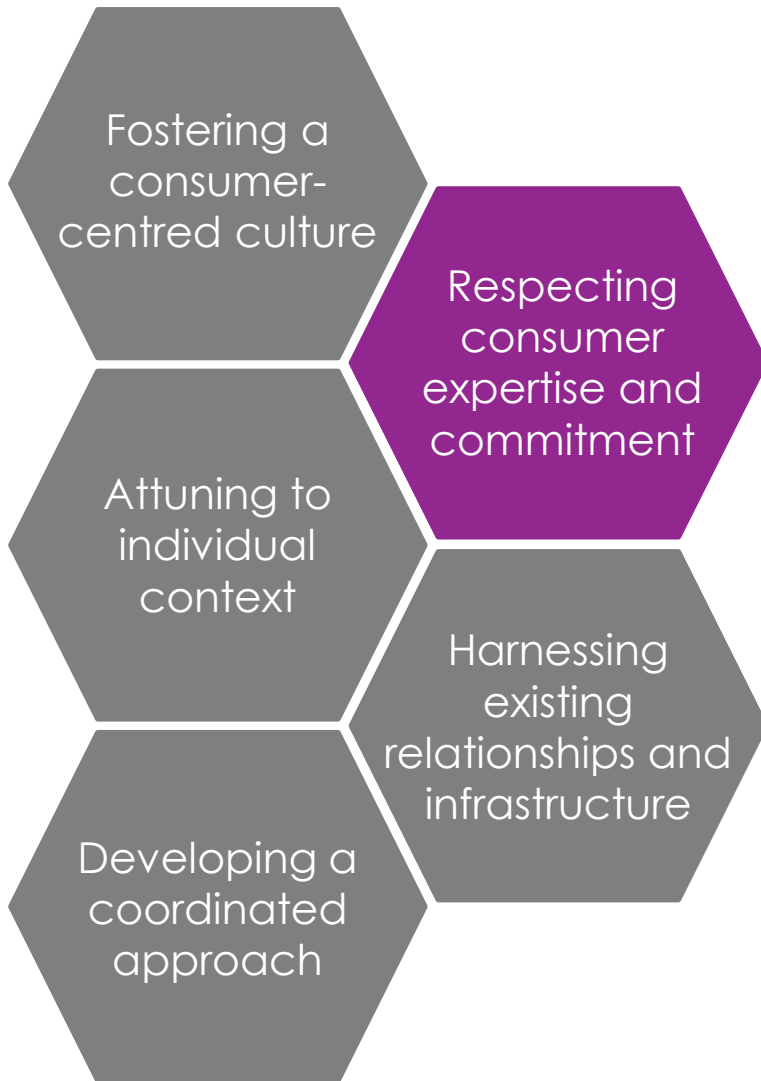
**Clarifying expectations and responsibilities**

**Equipping for meaningful involvement**

**Valuing unique and diverse experiential knowledge**

“You do bring in knowledge that they don’t have...the reason people ask the wrong question is because they don’t have the experience of living with it.”

*Patient, Male, Sydney*



# Themes

**Clarifying expectations and responsibilities**

**Equipping for meaningful involvement**

**Valuing unique and diverse experiential knowledge**

**Keeping in the loop with results and impact**

“I can't tell you how many trials throughout my kidney journey I've been involved in, and they've taken a lot of information from me, but I've never heard back about what the outcomes are...as a consumer that makes me disengage.”

*Patient, Female, Brisbane*

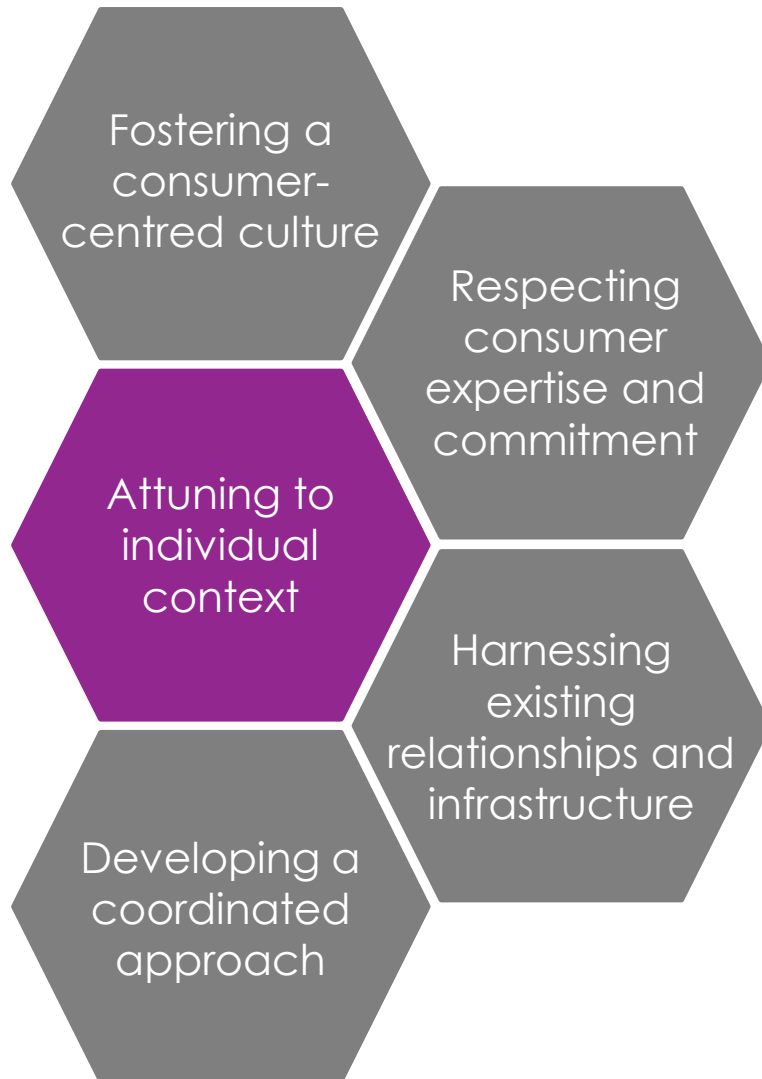


# Themes

## A preference based multi-pronged approach to engagement

“It’s horses for courses, isn’t it? That’s the challenge of communicating.”

*Patient, Male, Adelaide*



# Themes

**A preference based multi-pronged approach to engagement**

**Reducing the burden of involvement**

“For me it depends on how much is involved, how much commitment, whether you need to take a day off work.”

*Patient, Female, Sydney*



# Themes

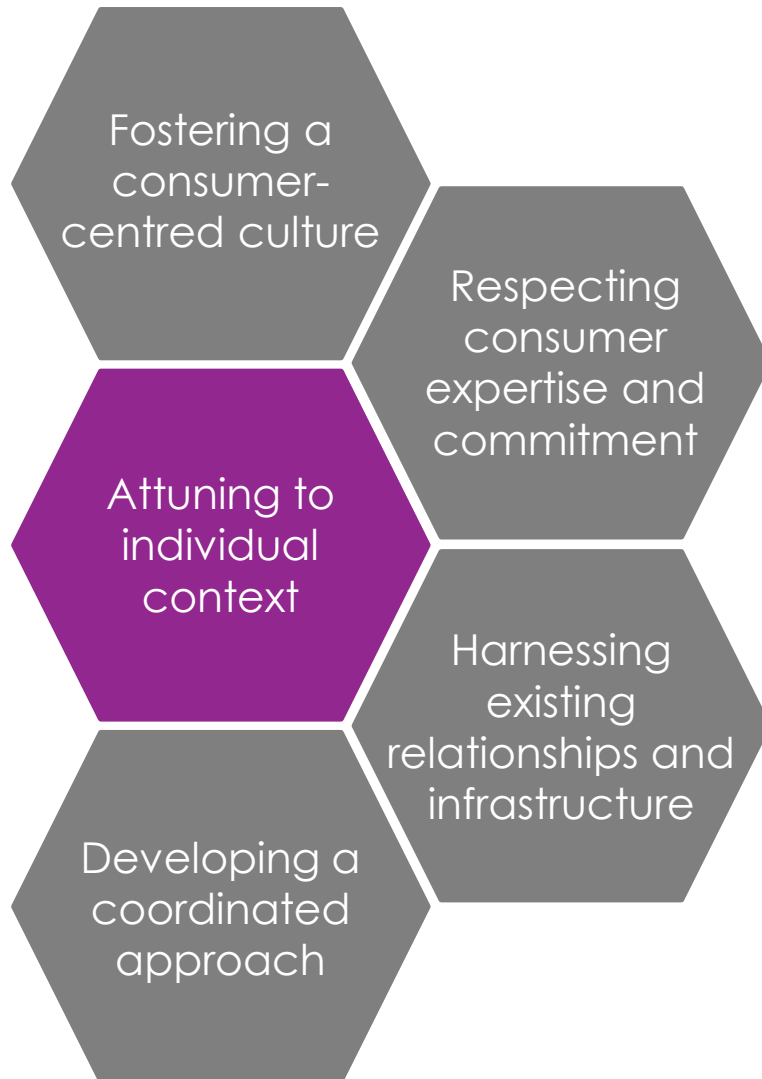
**A preference based multi-pronged approach to engagement**

**Reducing the burden of involvement**

**Being sensitive to the patient journey**

“They’ve got to have some sort of knowledge of when they hit you up for it. Not when you’re at your worst.”

*Patient, Female, Brisbane*





# Themes

## Partnering with trusted clinicians

“Every kidney patient who goes and sees a nephrologist or a kidney doctor, I think the kidney specialist can play a bigger role than they do about talking to the patient about research and getting yourself involved.”

*Patient, Male, Brisbane*



# Themes

**Partnering with trusted clinicians**

**Increasing exposure in clinical settings**

“There’s a TV in the waiting area. Instead of running commercials, you just run adds for your research.”

*Patient, Male, Brisbane*



# Themes

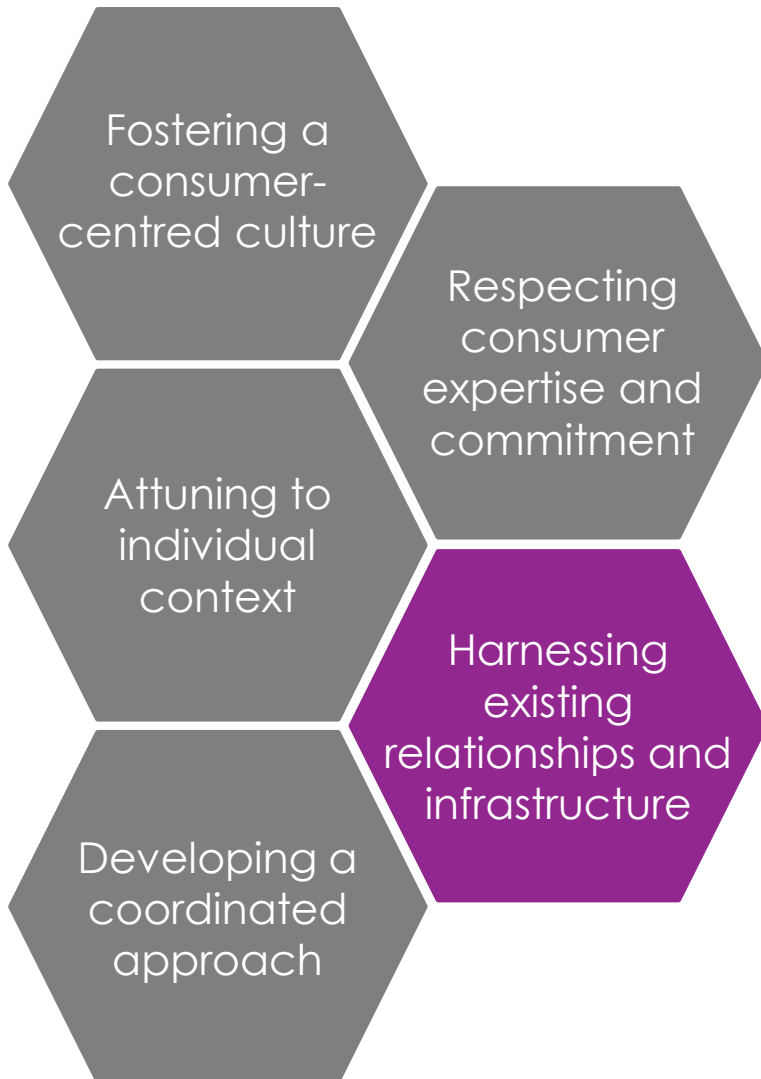
**Partnering with trusted clinicians**

**Increasing exposure in clinical settings**

**Mentoring patient to patient**

“I found [patient’s] talk very helpful because he’s been through it. The more you hear about the process, the more you start to think, yeah, I could probably cope with that.”

*Patient, Male, Sydney*



# Themes

**Partnering with trusted clinicians**

**Increasing exposure in clinical settings**

**Mentoring patient to patient**

**Extending reach through established networks**

“[KHA] were set up in the foyer, kidney health week, we’ll take your blood pressure. I said ‘people, you’re in the wrong spot. People who come to the hospital already know they’ve got high blood pressure. You should be outside Bunnings’.”

*Patient, Male, Brisbane*

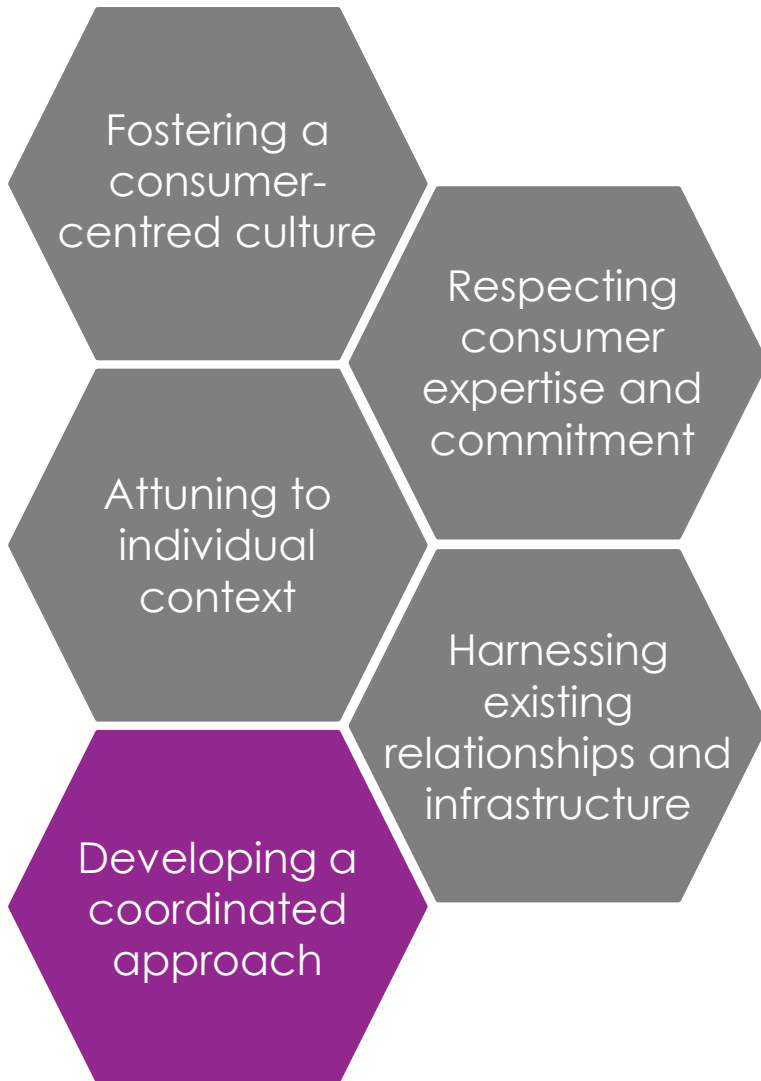


# Themes

## Power in the collective and united voice

“There doesn’t seem to be one umbrella organisation that’s driving communication to the consumer... There are so many of them [organisations] that it’s diluting the power of the communication.”

*Patient, Male, Adelaide*



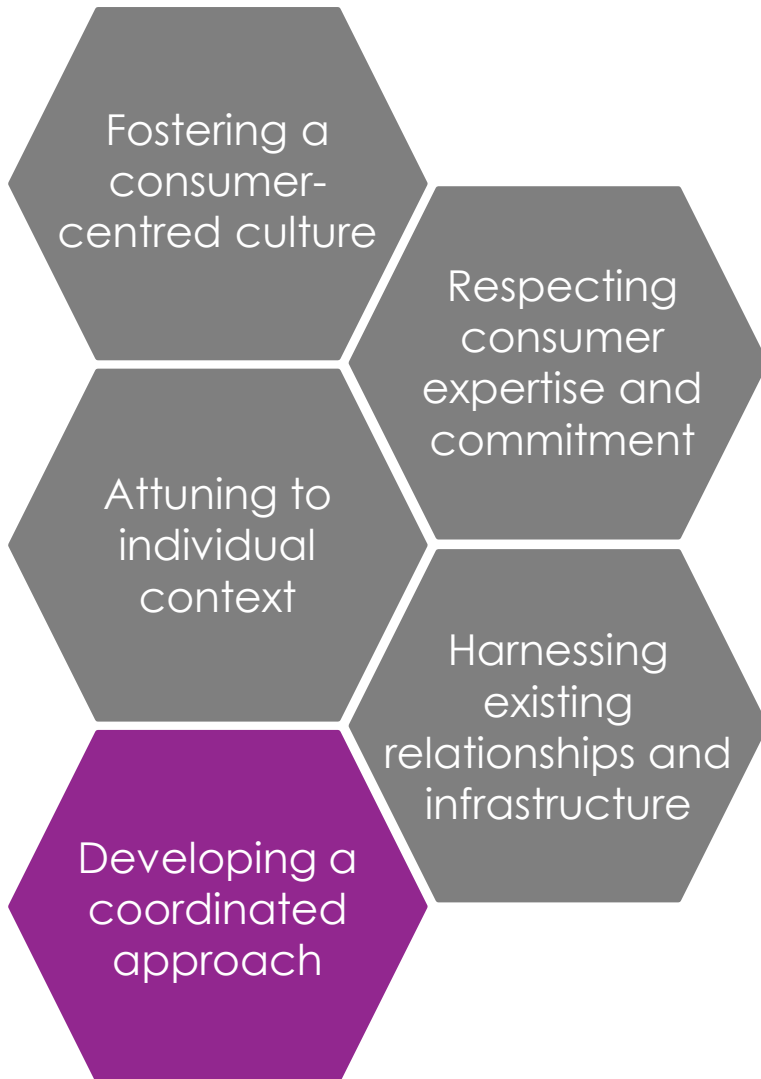
# Themes

**Power in the collective and united voice**

**Systematic approach for equitable inclusion**

“A register of everybody [patients] with a description of what stage they’re at...A Tinder trial site.”

*Patient, Female, Adelaide*



# Themes

**Power in the collective and united voice**

**Systematic approach for equitable inclusion**

**Streamlining access to opportunities and trustworthy information**

“If you had a one stop shop ...If there could be a tailored site where kidney-specific things could be put. Perhaps research results, or trials or whatever. Something that ordinary people can understand.”

*Patient, Female, Brisbane*







Fostering a  
consumer-  
centred culture

Respecting  
consumer  
expertise and  
commitment

Attuning to  
individual  
context

Harnessing  
existing  
relationships and  
infrastructure



Developing a coordinated approach

# Discussion

- ▶ Can we replicate trust built with clinicians in one-on-one interactions in a platform that can reach more people? (More systematic/inclusive)
- ▶ Do we need to re-evaluate data privacy → patients have the right to be notified about opportunities to shape their health (are our policies to protect their privacy depriving them of opportunities for involvement?)
- ▶ We need to make research opportunities more relevant and personal to patients – what's in it for them?

## Next steps

- ▶ Establishing Consumer Advisory Board to direct patient involvement across the spectrum of BEAT-CKD research activities
- ▶ Planning and delivering patient sessions at ANZSN ASM 2018
- ▶ Evaluate!

# Establishing a consumer advisory board

- ▶ Circulated EOI to BEAT-CKD networks
- ▶ 37 consumers submitted applications
- ▶ Decided to take an inclusive approach
- ▶ Held 'first' meeting over 3 sessions with combination face-to-face, videoconference and teleconference (recorded)
- ▶ Discussed:
  - How members want to run the board
  - Program planning for ANZSN patient sessions
- ▶ Follow up with survey to ensure inclusiveness/comprehensiveness

# References

1. Chu LF, Utengen A, Kadry B, et al. “Nothing about us without us”—patient partnership in medical conferences. *BMJ*. 2016;354:i3883.
2. Hayes H, Buckland S, Tarpey M. Briefing notes for researchers: public involvement in NHS, public health and social care research. INVOLVE: Eastleigh. 2012
3. Statement on Consumer and Community Involvement in Health and Medical Research. National Health and Medical Research Council; 2016.
4. Cancer Australia and Cancer Voices Australia, 2011. National Framework for Consumer Involvement in Cancer Control. Cancer Australia, Canberra, ACT.
5. Arnstein SR. A ladder of citizen participation. *J Am Inst Plann*. 1969 Jul 1;35(4):216-24.
6. Stevens T, Wilde D, Hunt J, Ahmedzai SH. Overcoming the challenges to consumer involvement in cancer research. *Health Expect*. 2003 Mar;6(1):81-8.
7. Marsden J, Bradburn J, Consumers’ Advisory Group for Clinical Trials (CAG-CT), Lynda Jackson Macmillan Centre. Patient and clinician collaboration in the design of a national randomized breast cancer trial. *Health Expect*. 2004 Mar;7(1):6-17.
8. Hanley B, Truesdale A, King A, Elbourne D, Chalmers I. Involving consumers in designing, conducting, and interpreting randomised controlled trials: questionnaire survey. *BMJ*. 2001 Mar 3;322(7285):519-23.
9. Ali K, Roffe C, Crome P. What patients want: consumer involvement in the design of a randomized controlled trial of routine oxygen supplementation after acute stroke. *Stroke*. 2006 Mar 1;37(3):865-71.
10. Crocker JC, Boylan AM, Bostock J, et al. Is it worth it? Patient and public views on the impact of their involvement in health research and its assessment: a UK-based qualitative interview study. *Health Expect*. 2017;20:519-28.
11. Domecq JP, Prutsky G, Elraiyah T, et al. Patient engagement in research: a systematic review. *BMC Health Serv Res*. 2014;14:89.
12. McKenzie A, Alpers K, Heyworth J, et al. Consumer and community involvement in health and medical research: evaluation by online survey of Australian training workshops for researchers. *Res Involv Engagem*. 2016;2(1):16.
13. Robinson BM, Zhang J, Morgenstern H, et al. Worldwide, mortality risk is high soon after initiation of hemodialysis. *Kidney Int*. 2014;85:158-65.
14. Wyld M, Morton RL, Hayen A, et al. A systematic review and meta-analysis of utility-based quality of life in chronic kidney disease treatments. *PLoS Med*. 2012;9:e1001307.
15. Whitstock MT. Seeking evidence from medical research consumers as part of the medical research process could improve the uptake of research evidence. *J Eval Clin Pract*. 2003;9:213-24.

# Acknowledgements

## My Supervisors



A/Professor Allison Tong



Professor Jonathan Craig



Dr Shilpa Jesudason

