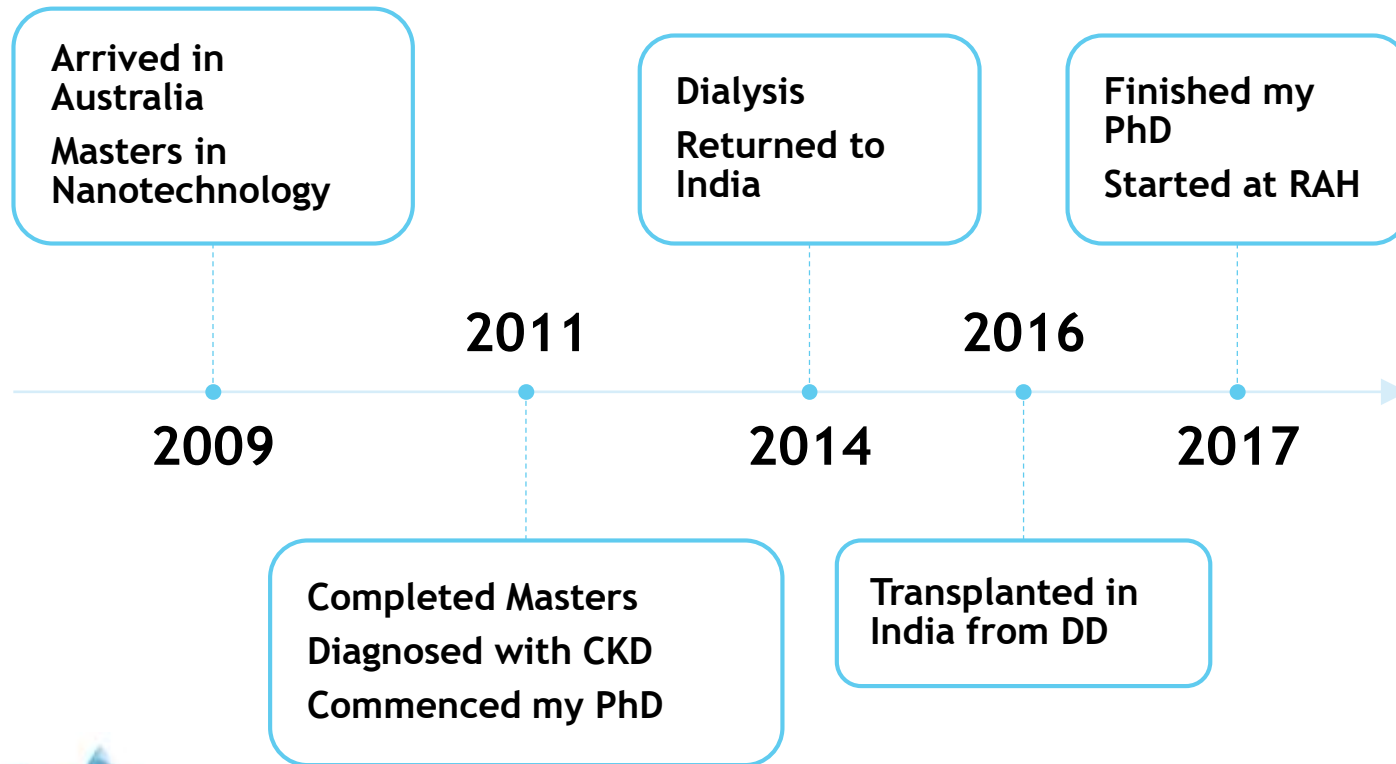


Consumer Engagement Activities at ANZDATA Registry

Dr. Shyamsundar Muthuramalingam
Project Officer - Consumer Engagement

55th ANZSN Online Annual Scientific Meeting,
Wednesday, 2nd December 2020

My Chronic Kidney Disease journey



Definitions

Patient/consumer

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

Involvement

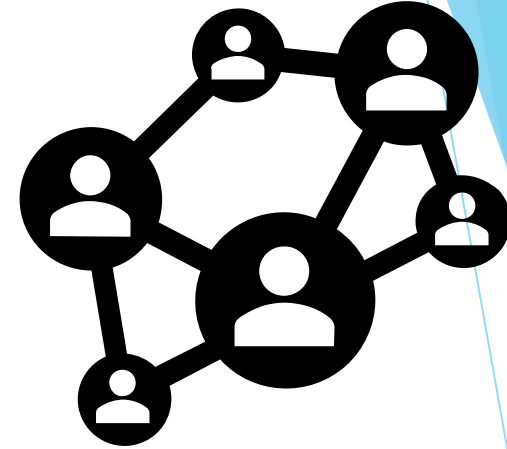
Sustained and meaningful contribution to the research process as more than a research subject or participant

Engagement

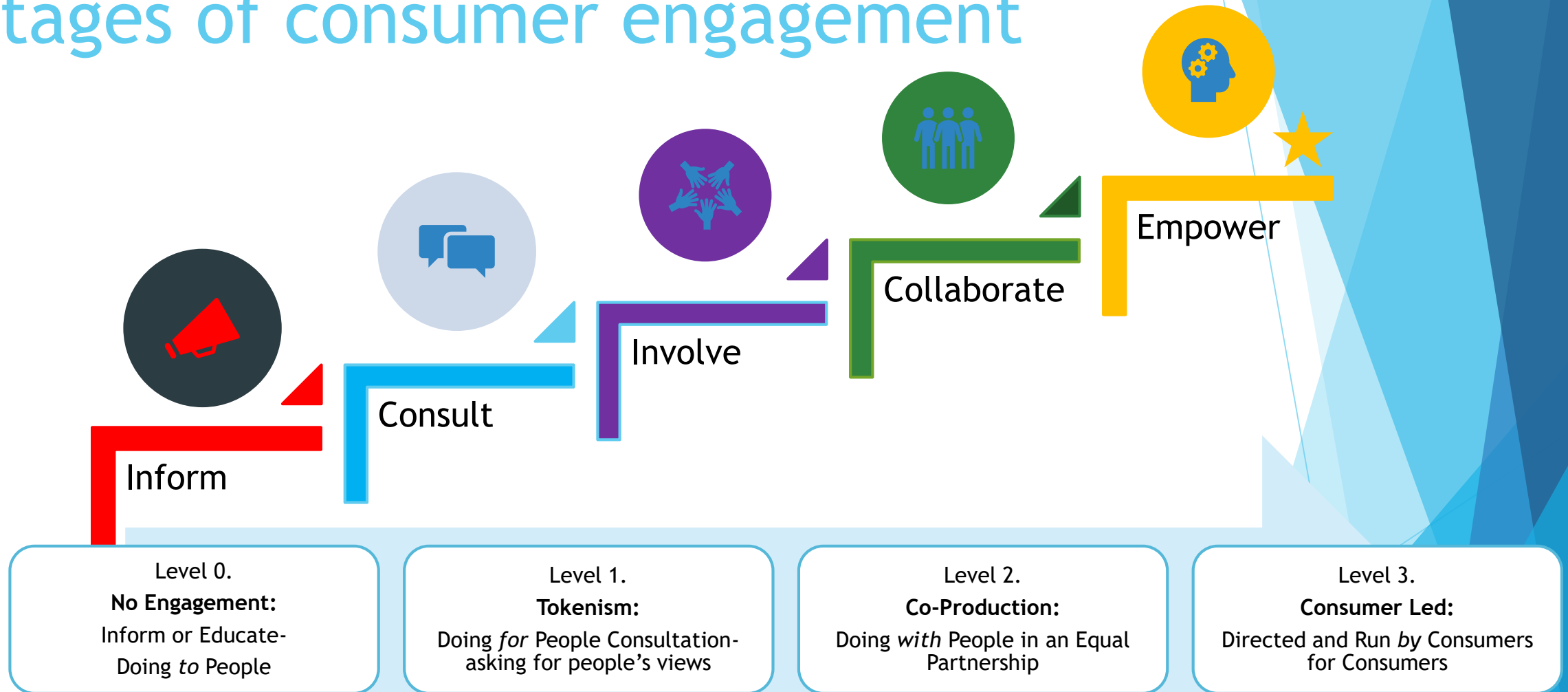
Establishment of a relationship between patients and researchers → the first step of involvement.

“Nothing about us, without us”

The NHMRC recognizes that involving consumers adds value to health and medical research, and that they have a right and responsibility to do so.



Stages of consumer engagement



References:

1. SAHMRI Consumer and Community Engagement Framework (2014)
2. Gaps in understanding and practice around consumer involvement in mental health research by **Dr Katherine H Gill**, Chair of the Consumer-Led Research Network.

Consumer Involvement Projects

Consumer co-produced outputs from ANZDATA reports

- ▶ Development of 1-page infographic summary of key data from 41st Annual Report 2018 (2017 data) and 42nd Annual Report 2019 (2018 data)
- ▶ Development of video version of consumer 1-page
- ▶ Plain language summary of the 42nd ANZDATA Annual report

Consumer Surveys and reference groups

- ▶ **Consumer Perspective Surveys**

A national survey on Consumer perspectives of **PREGNANCY COUNSELLING** and **EDUCATION** in Australian women with kidney disease

- ▶ **Consumer Reference group**

A data linkage study on incidence and outcomes of cardiothoracic surgery in patients with acute kidney injury and end stage kidney disease



Symptom monitoring With Feedback Trial (SWIFT)

INVESTIGATOR TEAM: RACHAEL L. MORTON (CHIEF INVESTIGATOR), LAVERN M. GREENHAM, ANDREA K. VIECELLI, PAUL N. BENNETT, SHILPA JESUDASON, CHRIS BROWN, **WILLIAM HANDKE (CONSUMER REPRESENTATIVE)**, REBECCA MISTER, PORTIA WESTALL, JOHN R SIMES, MATTHEW D. JOSE, RAJESH RAJ, PETER CHOI, PETER MOUNT, LILIANA LARANJO, SUETONIA C. PALMER, ANDREW SALMON, ALLISON TONG¹⁵, DAVID HARRIS, CARMEL HAWLEY, DAVID W. JOHNSON, STEPHEN P. MCDONALD

FUNDING

This trial is funded through an NHMRC Project Grant #1159051; KHA Project Grant KHA2018-RM; NHMRC TRIP Fellowship #1150989 RM; and the BEAT-CKD NHMRC Program Grant #1159051.




THE UNIVERSITY OF
SYDNEY





Results from the Pilot

Example pamphlet given to SWIFT participants to disseminate results of Pilot Study. Co-Designed with Consumer partner




SWIFT– The Symptom monitoring With Feedback Trial


Results from the Pilot Study

What is SWIFT and what did we do?


The SWIFT team wanted to find out if feeding back patients' symptom information (like tiredness, pain and itching) to nurses and kidney doctors could lead to improvements in patients' overall wellness.




4 haemodialysis units- 3 in SA & 1 in QLD



226 adult haemodialysis patients




Surveys completed on electronic tablets




Patients, nurses & kidney doctors interviewed for feedback on the study

What did we discover from the Pilot study?



Patients felt collecting symptom information was valuable








Patients found the tablets easy to use

What's next?

The main SWIFT study will start in September 2020 and we hope to involve at least 160 haemodialysis units across Australia and New Zealand, with about 3000 patients

Thank You to all who participated

For more information email: swift@anzdata.org.au or call ANZDATA SWIFT Trial Coordinator: Lavern Greenham on 08 8128 4264



Consumer Researcher Co-Design



Photo of stakeholder engagement at the Home Therapies Conference - PROMs session with Nicki Scholes-Robertson, Rachael Morton, Bill Handke, Jennie Handke and Guy Higgins

Process for involving consumers in development of ANZDATA outputs

- ▶ **EOI to BEAT-CKD Consumer Advisory Board**
 - ▶ Consumer group (5 people - transplant recipients, carer, person receiving dialysis)
- ▶ 2 x electronic meetings to devise content and layout of infographic, before meetings:
 - ▶ Example infographics
 - ▶ List of key data points to consider for inclusion
 - ▶ Draft versions of infographic for review
 - ▶ Send consumer things to consider/provide feedback on ahead meetings



ANZDATA Registry 2019 – Areas for Consumer Input

If you would like to know more about what is in this ANZDATA table, please contact:

Emily Duncanson emily@anzdata.org.au (08) 8128 4769 or Kathryn Dansie kathryn@anzdata.org.au (08) 8128 4766

Research topic/project	What type of input and what will I be doing?			How much of my time will it take up?
	Planning & doing research	Reviewing & giving advice to researchers	Helping to communicate research and findings	(Estimates over the next 12 months) (ANZDATA meetings will be available face-to-face for SA board members, others will be able to join via tele/videoconference)
ANZDATA Annual Report (2018) Funding: Australian Organ and Tissue Authority (Australian Government)	Providing advice on what areas should be analysed/included in the ANZDATA report	Co-writing a consumer version of the ANZDATA annual report, contributing ideas to: <ul style="list-style-type: none"> • What information/ANZDATA data do consumers want to know about? • Selecting language, layout and presentation of this information for a report suitable for consumers, including infographics and pictures to show the data 	Contributing ideas of how to share these reports and results with consumers/the public	<ul style="list-style-type: none"> • 3-4 x 1-hour meetings • ~ 2 hours total to make edits on drafts of consumer report via computer/e-mail in between meetings • Phone/e-mail communication throughout with ANZDATA researchers to discuss your ideas if you need/wish
ANZDATA Key Highlights Brochure (2018) Funding: Australian Organ and Tissue Authority (Australian Government)	Involvement in: <ul style="list-style-type: none"> • Deciding what topics/areas of analysis should be included in the brochure 	Advising the ANZDATA staff: <ul style="list-style-type: none"> • How this information can best be displayed in the brochure so that it is clear and easily understood • What layout, pictures, graphs, language should be used in the brochure 	Assisting with ideas of how to share the brochure with consumers/the public	<ul style="list-style-type: none"> • 3-4 x 1-hour meetings • ~ 2 hours total to make edits on drafts of consumer report via computer/e-mail in between meetings • Phone/e-mail communication throughout with ANZDATA researchers to discuss your ideas if you need/wish

**ANZ
DATA**

AUSTRALIA &
NEW ZEALAND
DIALYSIS & TRANSPLANT
REGISTRY

The Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) records the incidence, prevalence and outcomes of dialysis and transplant treatment for patients with end-stage kidney disease

COLLECTS

- Data on chronic dialysis and transplantation
- Indicators of clinical process
- Outcome Data

REPORTS

- Outcome of treatment
- Individual Hospital activity
- Australian and New Zealand data

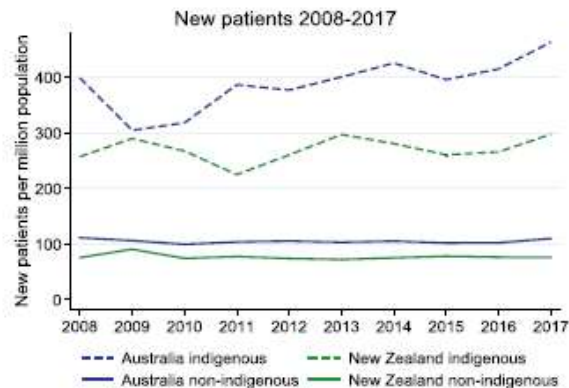
PROVIDES

For widespread use of its data for Quality Assurance, Audits, Surveys, Service Planning and Research Projects

2018 Summary - data to 31 December 2017

INTRODUCTION

This brochure provides an introduction to ANZDATA and includes data collected to the end of 2017 and reported in the 2018 Annual Report. The ANZDATA Registry collects information on renal replacement therapy (dialysis and transplantation) for end-stage kidney disease in Australia and New Zealand. Much more information can be found at our website, including our Annual Report, data forms and dictionaries, list of publications and guidelines for requesting data.



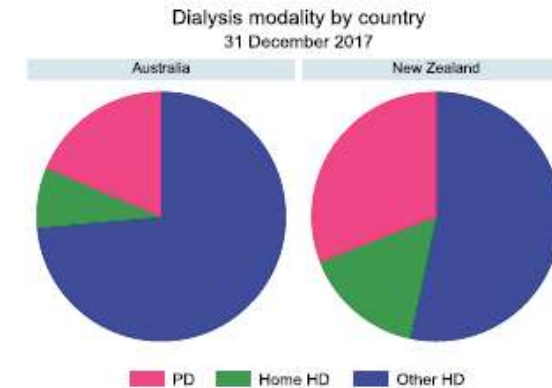
NEW PATIENTS

There were 3056 patients who commenced treatment for end-stage kidney disease in Australia in 2017, a rate of 124 per million population. In New Zealand, the number of new patients commencing renal replacement treatment was 615, a rate of 128 per million of population. Rates of treated end-stage kidney disease are substantially higher in Indigenous than non-Indigenous populations in both Australia and New Zealand.

PREVALENT PATIENTS

Australia Total	24,738 (1006)
No. Functioning Transplants	11,687 (475)
No. Dialysis Patients	13,051 (531)
Proportion Home Haemodialysis	8%
Proportion Facility Haemodialysis	74%
Proportion Peritoneal Dialysis	19%
New Zealand Total	4,658 (972)
No. Functioning Transplants	1,890 (394)
No. Dialysis Patients	2,768 (577)
Proportion Home Haemodialysis	16%
Proportion Facility Haemodialysis	53%
Proportion Peritoneal Dialysis	31%

At the end of 2017 there were almost 25,000 patients receiving renal replacement therapy in Australia and around 4,700 in NZ.

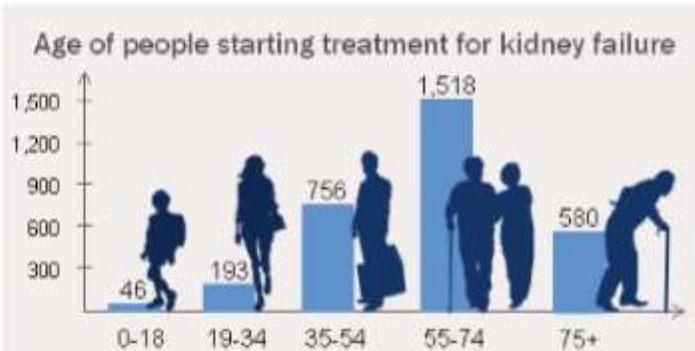
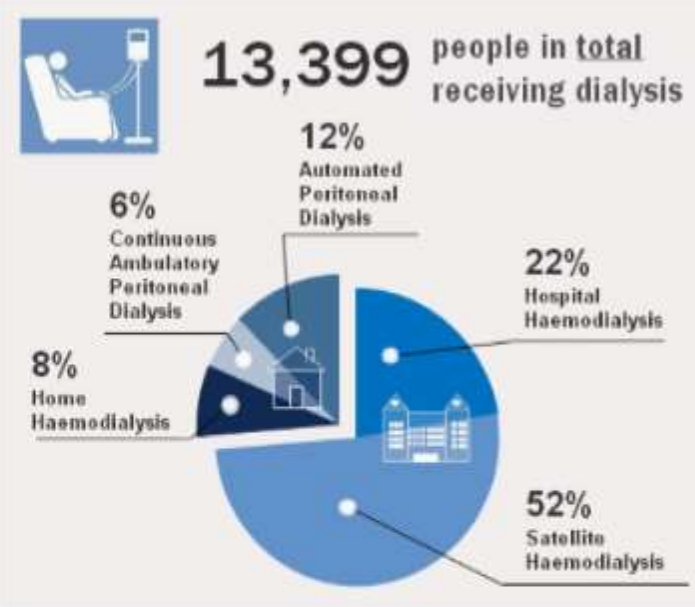
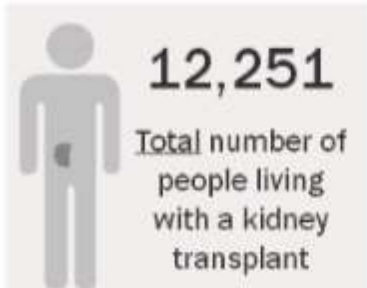


Australia and New Zealand have a strong focus on home dialysis, with 26% of Australian and 47% of New Zealand dialysis patients receiving dialysis at home.

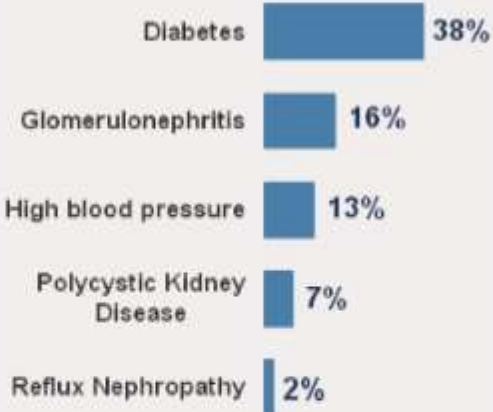
Consumer Infographics 2018



Dialysis and Kidney Transplantation in Australia 2018 in summary



Causes of kidney disease among people who received a transplant or started dialysis



Sources of kidney donation in 2018



Developed with members of the
BEAT-CKD Consumer Advisory Board



42nd ANNUAL REPORT 2019

SUMMARY FOR PATIENTS AND THE PUBLIC

*A lay summary of adult data for kidney
transplant and dialysis in Australia and
New Zealand, up to 31st December 2018*



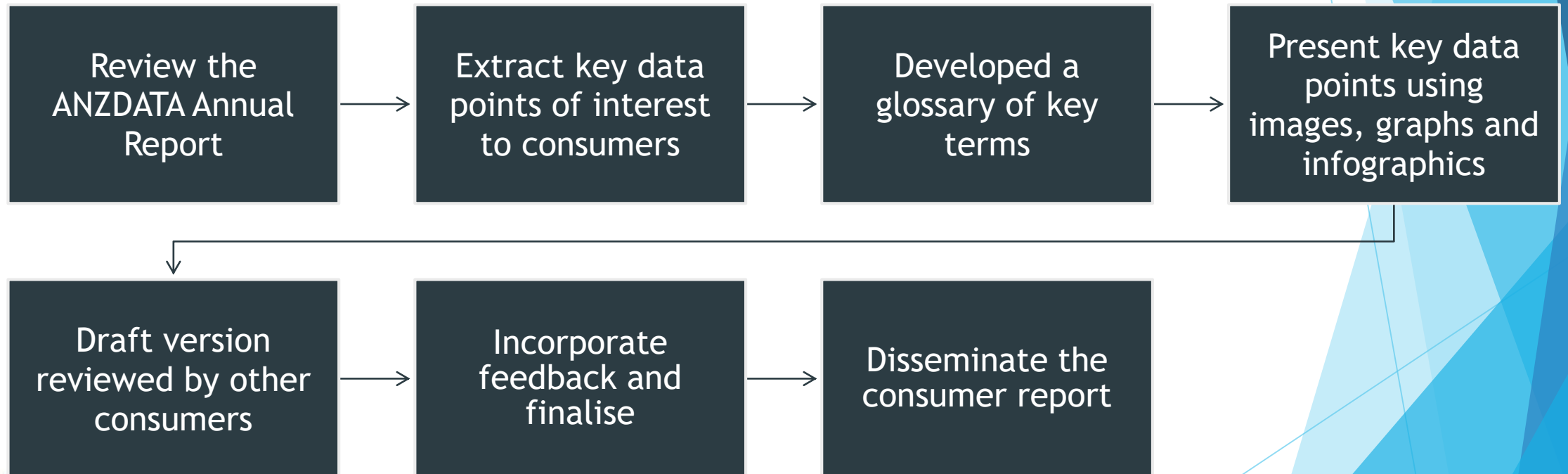
A MUST Report



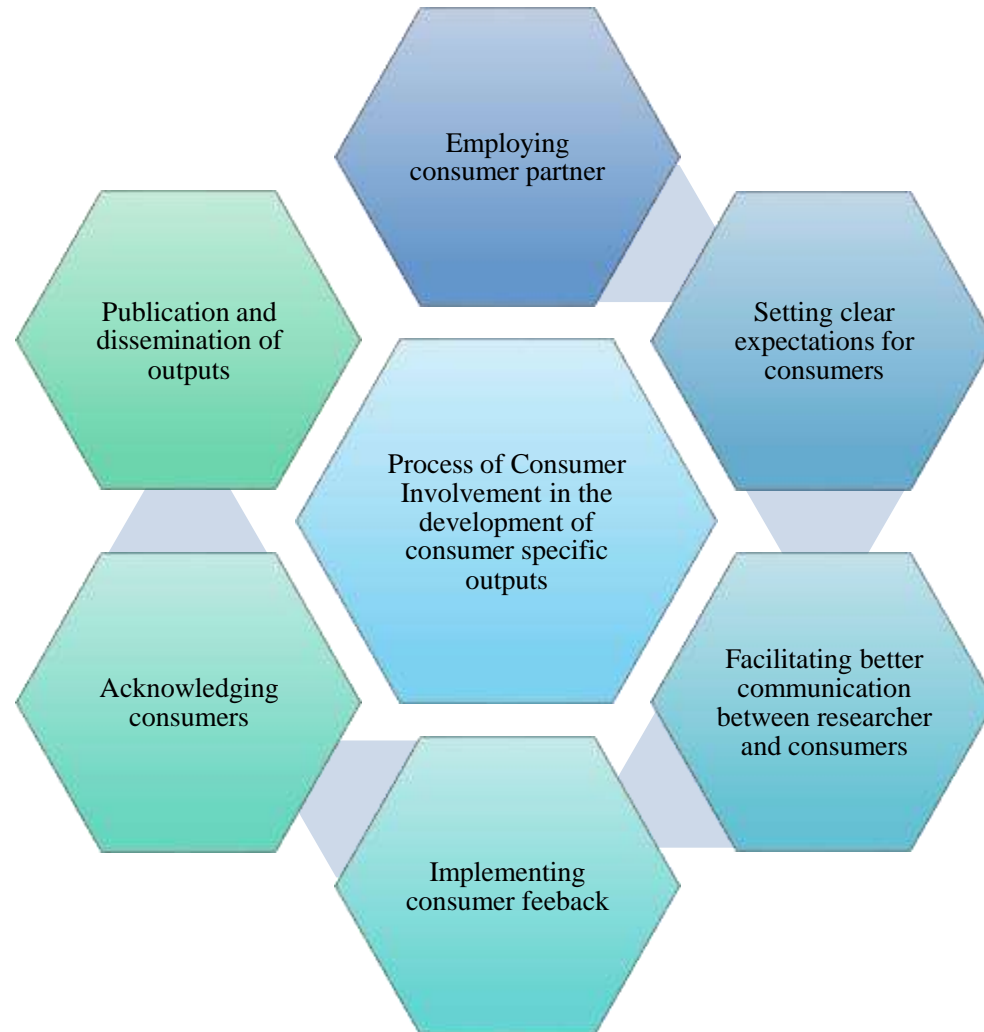
M- Make an impact
U- User friendly
S- Specific
T- Template



Process flow for developing a consumer version of ANZDATA report



Six crucial determinants of consumer involvement for the coproduction of consumer specific outputs



National Kidney Consumer Research Network (“The Network”)

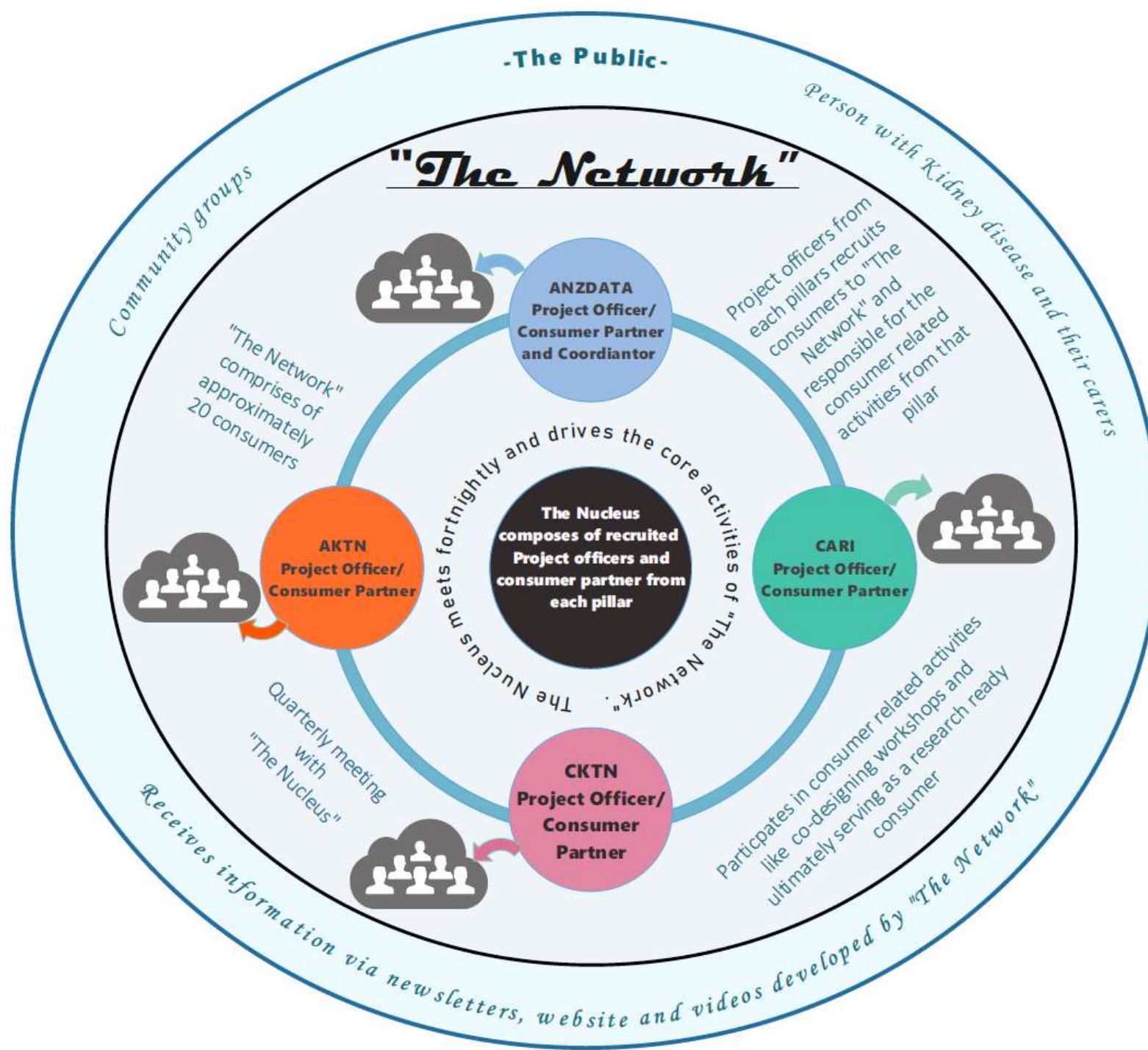


- ▶ Grant provided under Public Health and Chronic Disease program
- ▶ Aligns with Kidney Health Australia National Strategic Action Plan
- ▶ From May 2020 - December 2023
- ▶ Build upon existing activities of the participants, the current BEAT-CKD Consumer Advisory Board and its pillars

National Kidney Consumer Research Network (“The Network”)



Key objectives	
Establish	A National Kidney Consumer Research Network (~20 consumers)
Provide	Pathways for consumers to co-produce research across participating programs, from priority-setting through to implementation.
Develop	Education and training materials on consumer engagement for both consumers and researchers.
Support	Provide dedicated mentorship and support to fellow consumers.
Convene	Workshops providing information about current research and involvement opportunities.



Where to start?

Explaining the project – a summary or ‘3-minute thesis’

- Key milestones of the project (long-term and in next 12 months)?
- What type of consumer input/involvement do I think would be useful?
- Is there a specific perspective I am looking for? Or not?
- Is there particular knowledge/skills that are essential for this role?

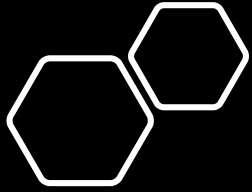
Defining roles & responsibilities for consumers

- What are the specific tasks and discussions you'd like consumer involvement in?
- How much of their time will it take up?
- Frequency, length and mode of meetings?
- Tasks/reviewing materials outside of meetings?

Highlights, Challenges and Lessons

- ▶ Communication- Keeping consumers in the loop
- ▶ Change in the consumer engagement perspective, from insiders looking out to outsiders looking in

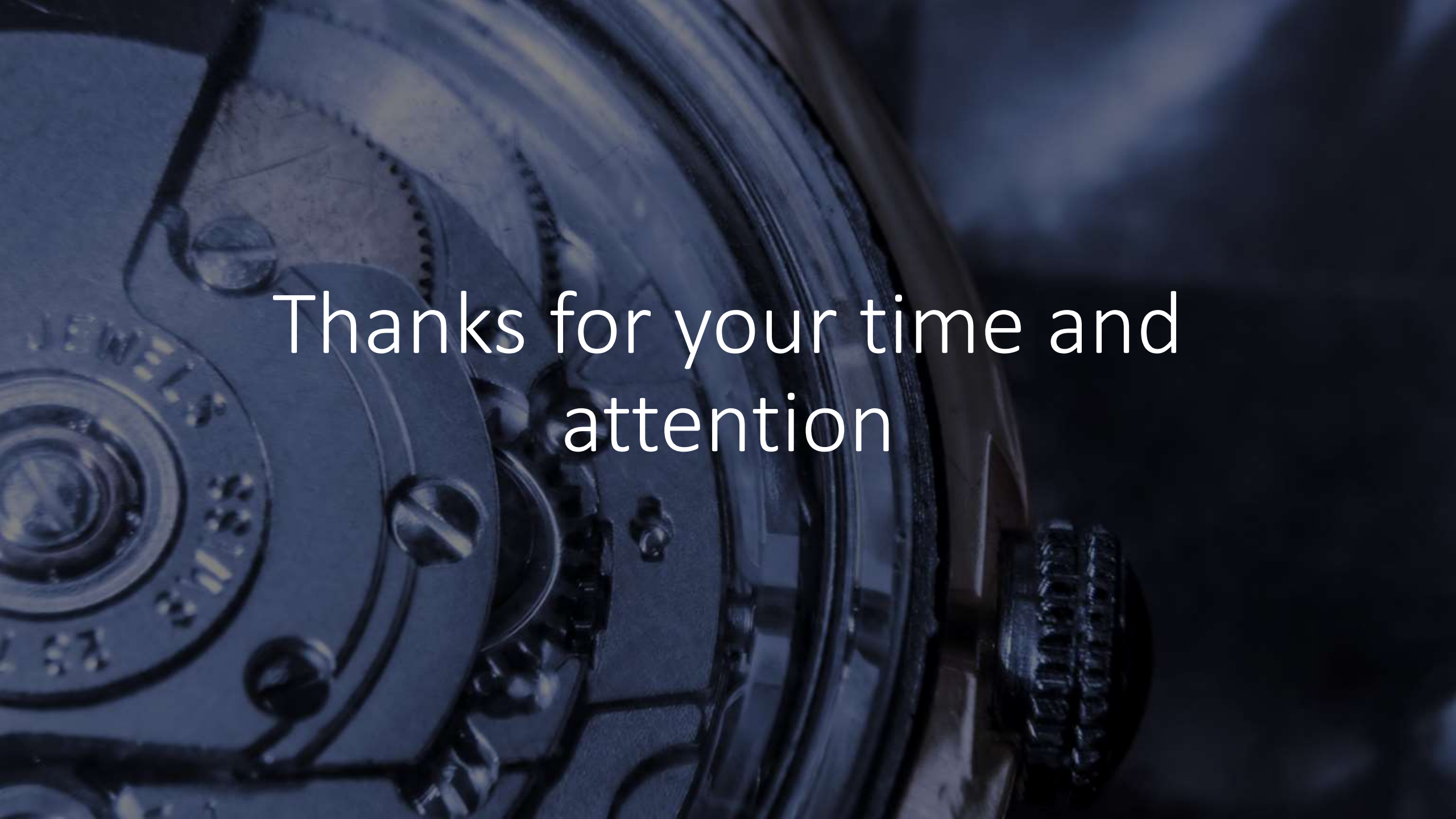




Acknowledgement

- Prof. Stephen McDonald
- A/Prof. Shilpa Jesudason,
- Ms. Emily Duncanson,
- ANZDATA Registry Staff
- BEAT-CKD Consumer Advisory Board



A close-up photograph of a mechanical watch movement, showing various gears, screws, and components. The image has a strong blue color cast. The text "Thanks for your time and attention" is overlaid in white, centered on the right side of the image. The watch movement is partially visible on the left and bottom, with a crown on the right side.

Thanks for your time and
attention