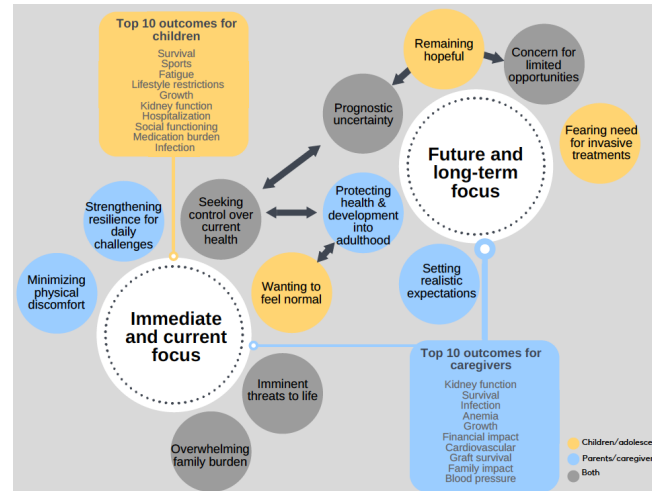


# Better and equitable evidence and translation for people with chronic kidney disease



**Jonathan Craig**

I want to acknowledge the countless patients, caregivers, clinical and research colleagues who have generously imparted their wisdom on their lived experience, and how research can truly be transformational for people with CKD



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## Na Marni (welcome)

We acknowledge the traditional owners of the lands Flinders University teaches and researches across (Arrernte, Boandik, Dagoman, Erawirung, Jawoyn, Kurna, Larrakia, Ngarrindjeri, Ngadjuri, Peramangk, Ramindjeri, Waramungu, Wardaman and Yolngu) and honour their Elders past and present.

*“Always was... always will be”*

Image: Long Way Home – A celebration of 21 years of Yunggoorendi First Nations Centre (2011)



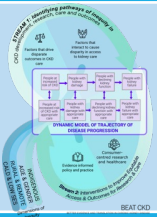
# Outline



Epidemiology and impact of CKD



Evidence ecosystem in CKD



Opportunities and challenges



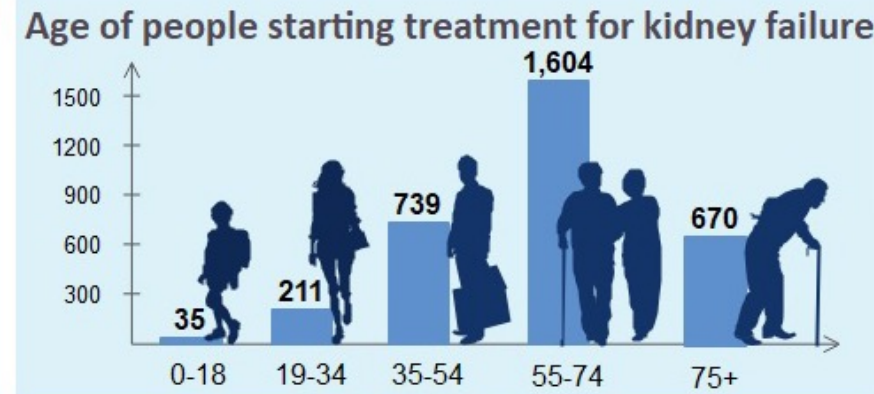
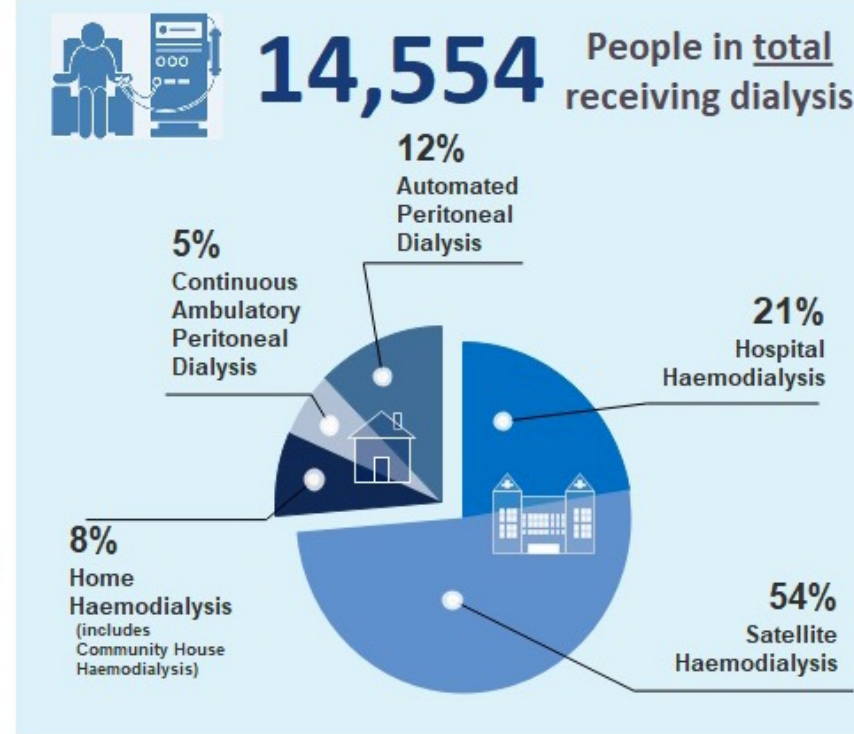
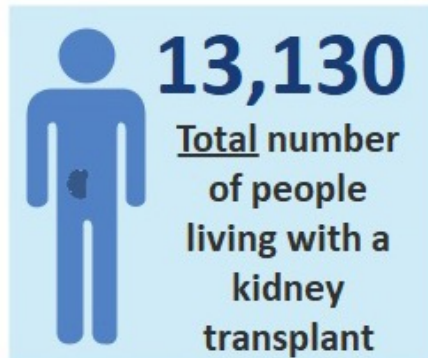
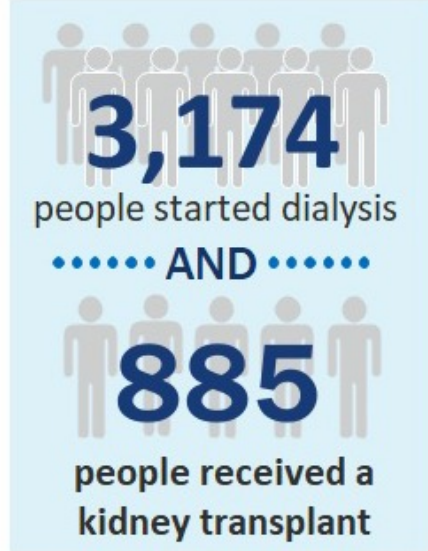
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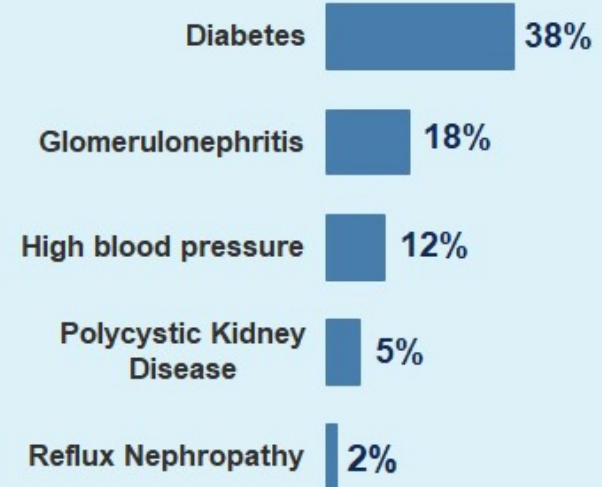
# By the numbers

CKD 10% of Australians

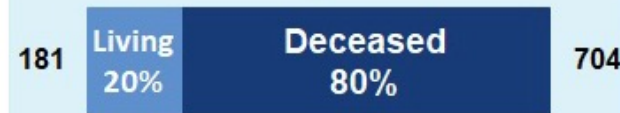
## Dialysis and Kidney Transplantation in Australia 2020 Summary



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



### Sources of kidney donation in 2020



Developed with members of the BEAT-CKD Consumer Advisory Board and National Kidney Consumer Council Research Network



# And the experience...

- Mortality 15% per year
- Dialysis 3x/week for 4-5 hours leaving people washed out
- Management and not cure
- Unemployment, social isolation, pervasive impacts upon caregivers and family members
- Uncertainty, complications and hospitalisations
- Utility values of 0.6



*Being alive, is important. Most of us don't like it. It's sad. You have to experience surgeries, doctors, and other medical related things. You have to experience pain, one of us feels sick, most of us feel worried, scared. Life participation is most important because without it, you can't do anything.*



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# THE INVERSE CARE LAW

The Lancet · Saturday 27 February 1971

JULIAN TUDOR HART

*Glyncorrwg Health Centre, Port Talbot, Glamorgan, Wales*

**Summary** The availability of good medical care tends to vary inversely with the need for it in the population served. This inverse care law

CKD, like all chronic conditions, is a disease of inequity.

Some groups are

- more likely to get CKD, and progress faster
- less likely to receive appropriate care
- less likely to be engaged in transformative research



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# Dimensions of inequity in CKD

## PROGRESS framework

### First Nations peoples

- Risk of kidney failure 10-15x/higher in 40-60 year old people
- ¼ likelihood of receiving a transplant (12% vs 45%)

### Rural and remote

- Less likely to receive specialist care, out of pocket expenses greater, higher mortality and hospitalization

### Women

- 2.5x more likely to be a living donor, ½ likelihood of receiving a kidney





# Outline



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Opportunities and challenges





AUSTRALASIAN  
**KIDNEY  
TRIALS  
NETWORK**

**1. Identification and  
prioritisation of evidence  
gaps**

**Australasian  
Kidney Trials  
Network**  
reliable  
comparative  
effectiveness

**2. Evaluation of  
promising  
interventions**

**Cochrane Kidney  
and Transplant**  
evidence in real time



**Cochrane**  
Kidney and Transplant

**3. Global evidence  
synthesis**

**4. Implementation  
into practice and  
policy**

**ANZ  
DATA**  
AUSTRALIA &  
NEW ZEALAND  
DIALYSIS & TRANSPLANT  
REGISTRY

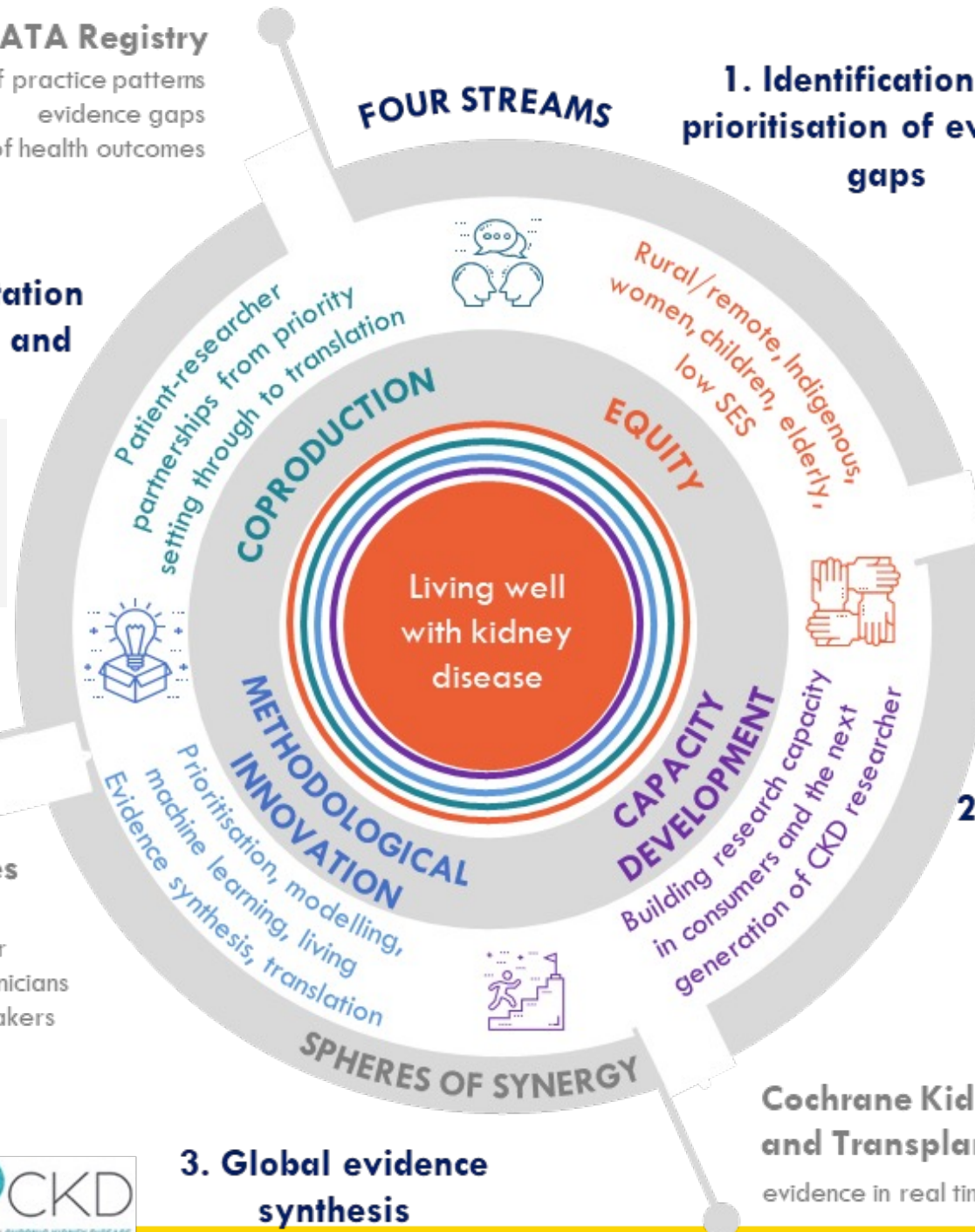


**CARI  
Guidelines**

knowledge  
translation for  
consumers, clinicians  
and policy makers

**ANZDATA Registry**

evaluation of practice patterns  
evidence gaps  
prediction of health outcomes



**BEAT CKD**  
BETTER EVIDENCE AND TRANSLATION IN CHRONIC KIDNEY DISEASE



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Registry trials (BEST Fluids)



Updated guidelines (Uric acid lowering)



Systematic reviews informing RCTs

Living guidelines (diabetes, cardiovascular disease)



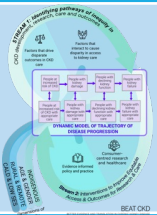
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# The “glue/fix” in the evidence ecosystem – consumer voices



Shared  
membership of  
advisory groups

+

SONG  
STANDARDISED OUTCOMES IN NEPHROLOGY



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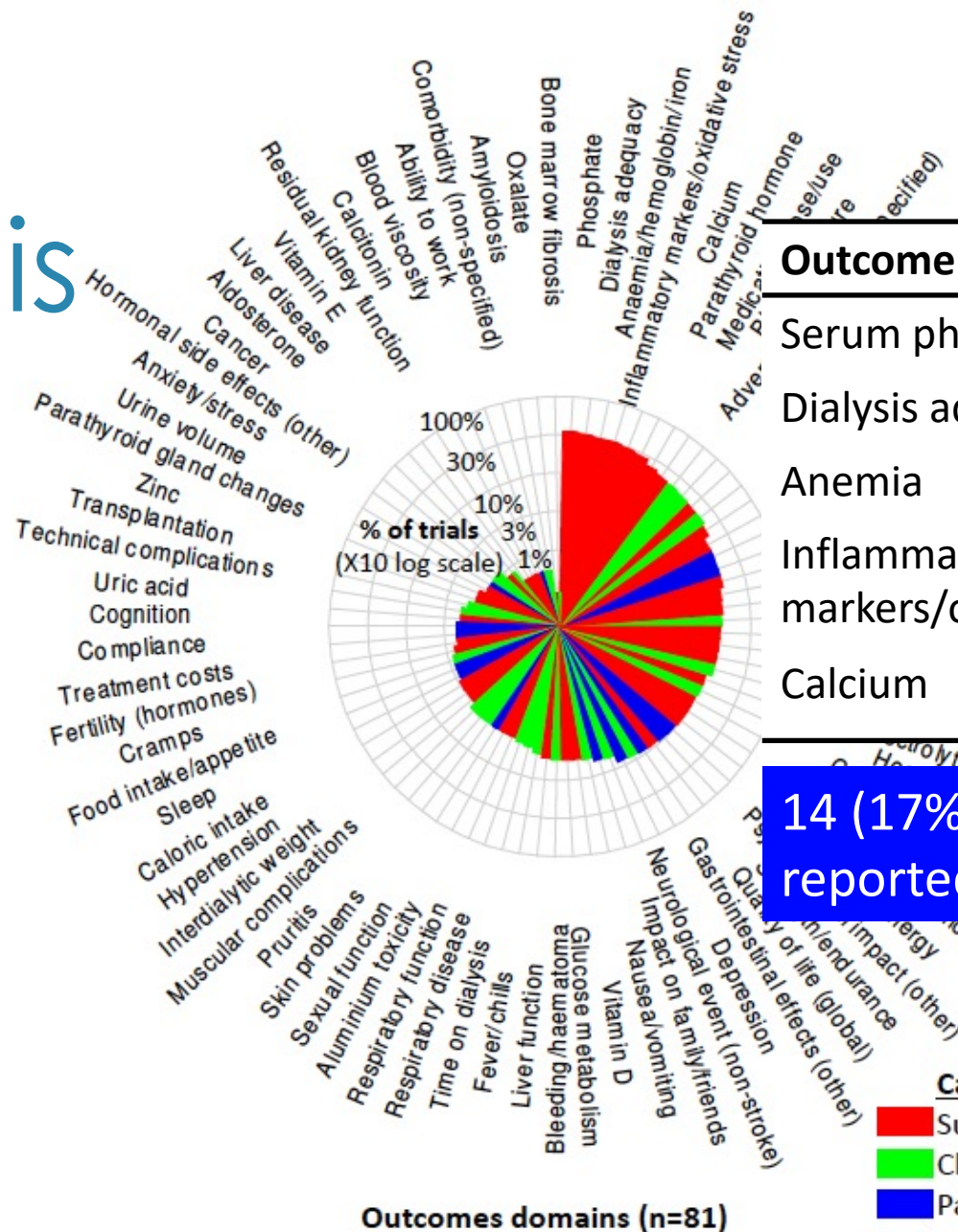
# Trials in haemodialysis

139 different measures for phosphate



Trials that don't address problems of relevance to end-users of research cannot inform decisions.

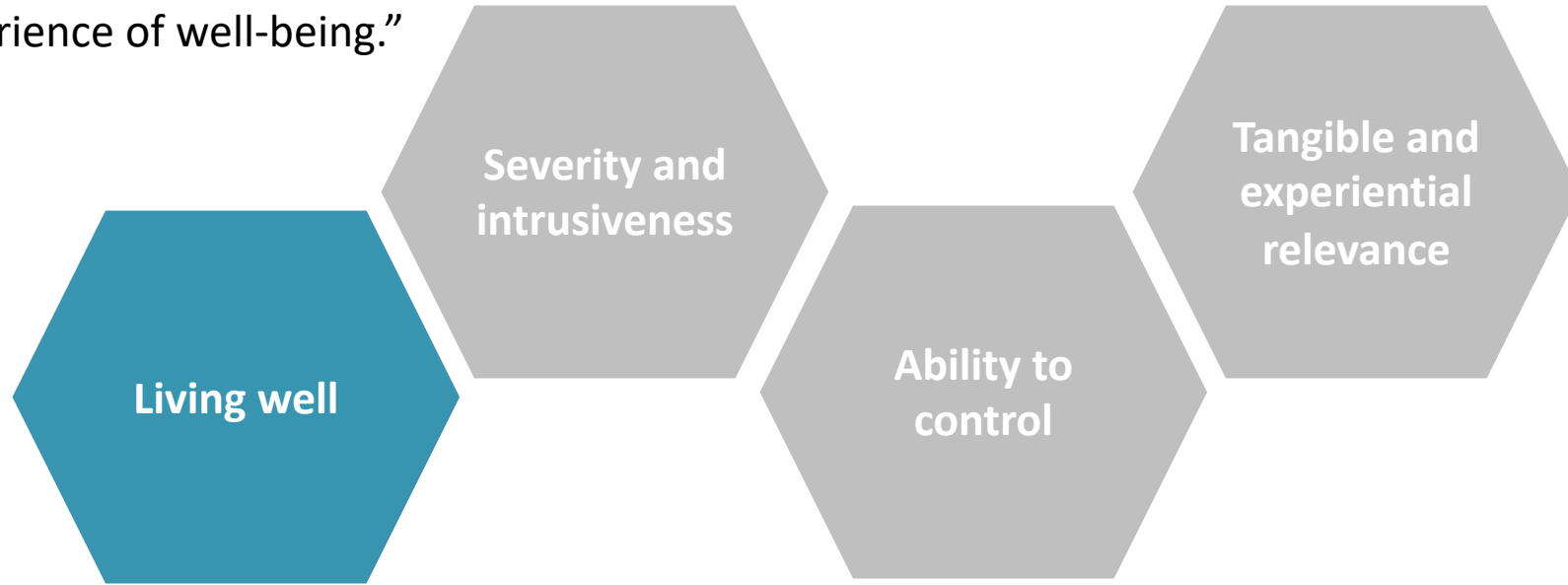
**362 trials:** 20% trials report mortality; 12% report CVD, 9% report QoL



Outcome	N (%)
Serum phosphate	125 (35%)
Dialysis adequacy	120 (33%)
Anemia	115 (32%)
Inflammatory markers/oxidative stress	114 (31%)
Calcium	109 (30%)

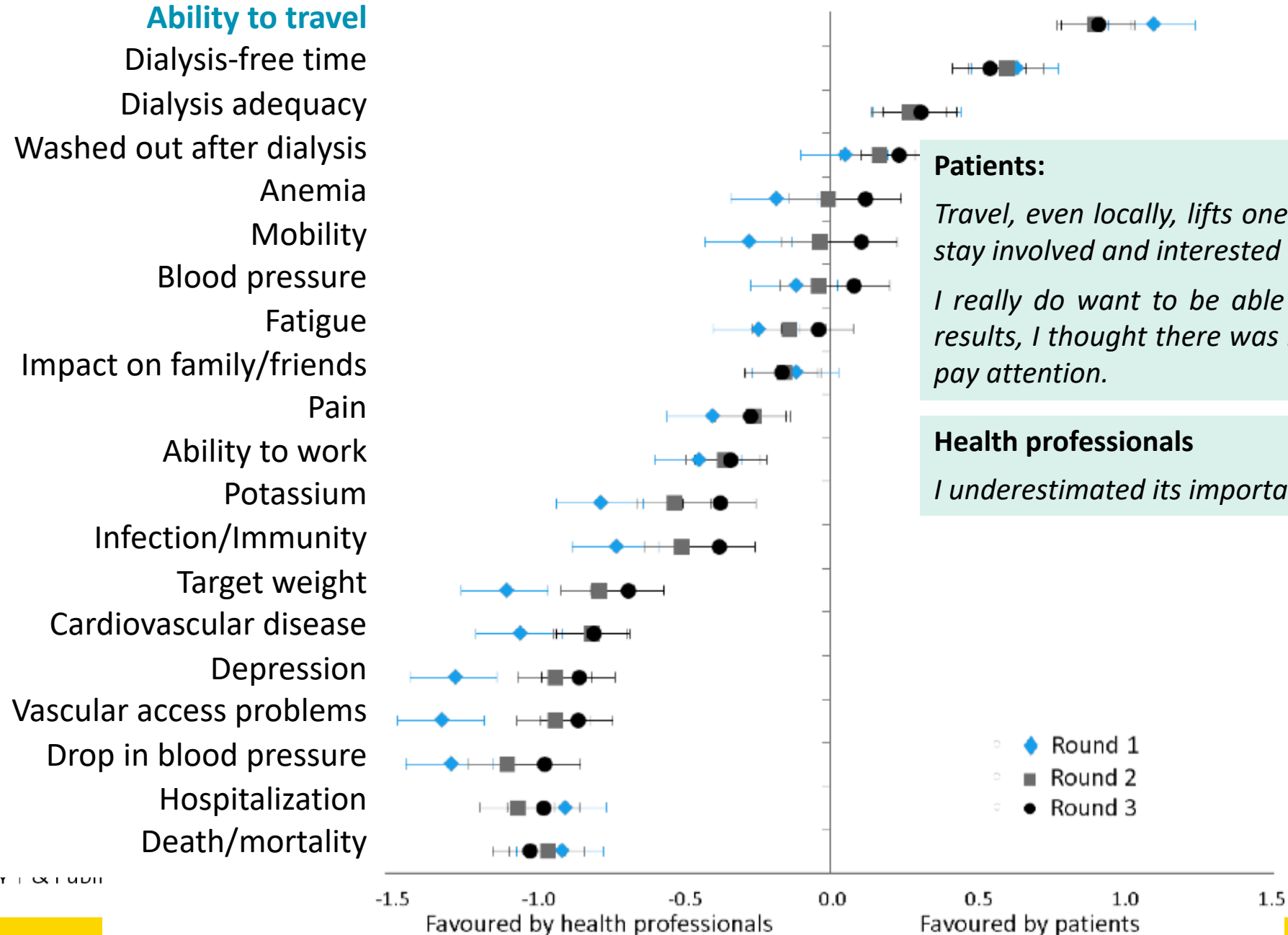
14 (17%) domains were patient-reported

“You could have half a dozen measurements that hold important implications [phosphate, potassium, calcium], but they have no day to day implications... none whatsoever... for our physical or our experience of well-being.”





# Mean difference in rating between patients/caregivers and health professionals



# The SONG Initiative

To establish core outcomes for research (trials) across CKD

**Core outcome set:** an agreed standardised set of outcomes that should be measured and reported, as a minimum, in all clinical trials in specific areas of health.

- Included on the basis of importance *(important to patients for decision-making)* even if there is no difference



# The SONG Initiative

To establish core outcomes for research (trials) across CKD



SONG-HD  
Haemodialysis



SONG-KIDS  
Children and adolescents



SONG-TX  
Kidney transplantation



SONG-PD  
Peritoneal dialysis



SONG-GD  
Glomerular disease



SONG-PKD  
Polycystic kidney disease



SONG-CKD  
Chronic kidney disease



GET INVOLVED



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# The SONG Initiative

To establish core outcomes for research (trials) across CKD



SONG-HD  
Haemodialysis

~

10 000



SONG-KIDS  
Children and adolescents



SONG-TX  
Kidney transplantation



SONG-PD  
Peritoneal dialysis



SONG-GD  
Glomerular disease



SONG-PKD  
Polycystic kidney disease



SONG-CKD  
Chronic kidney disease



GET INVOLVED

**More than 5000 patients/caregivers &**  
5000 health professionals  
100 countries



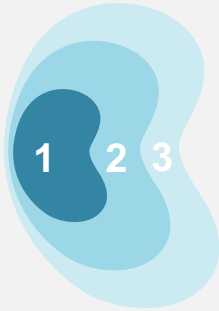
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**Each stream (HD, Tx, PD, PKD, Kids, GD, CKD) has involved n > 1000 from ~ 70 countries**

# SONG-HD

Hemodialysis



## 1 CORE OUTCOMES

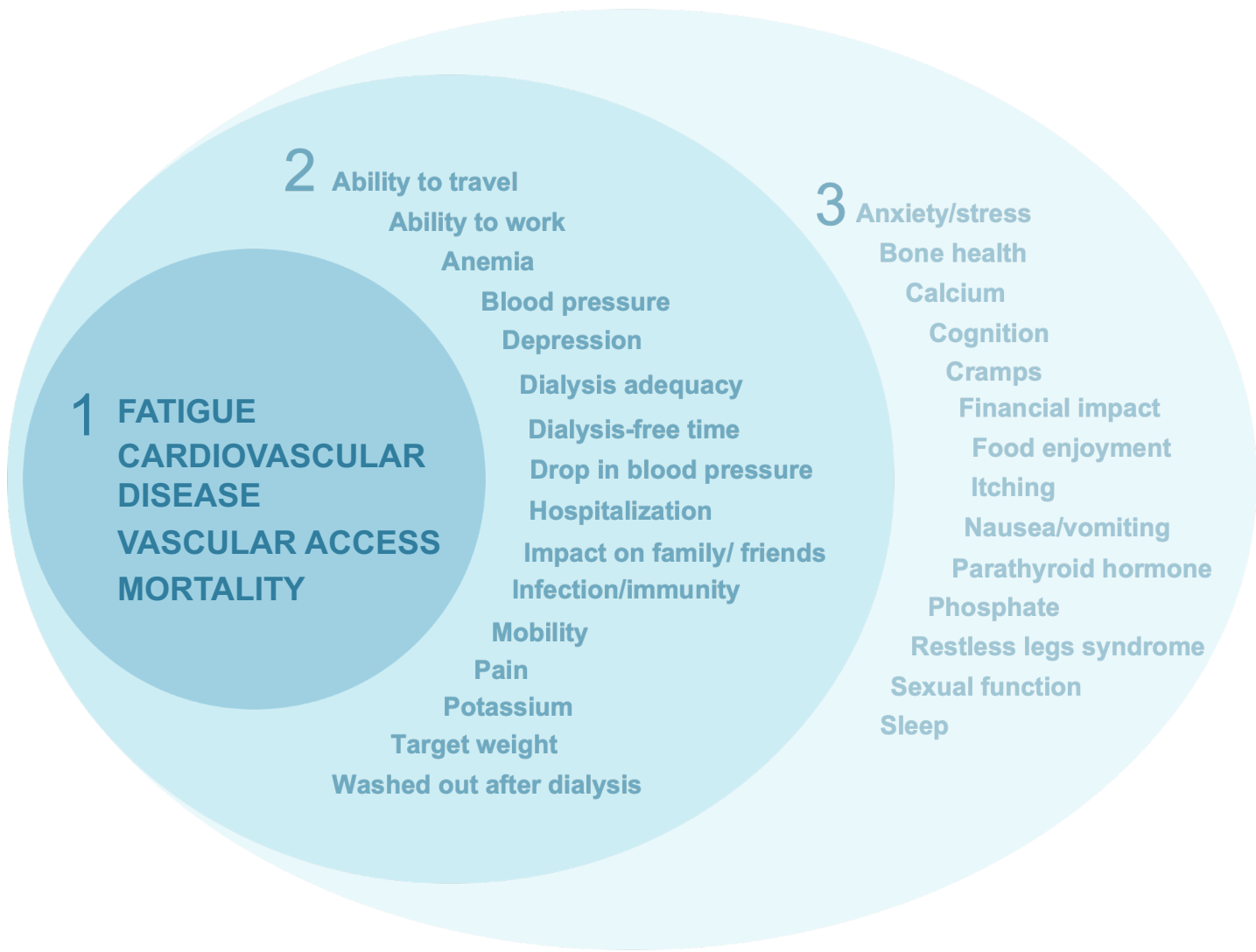
Critically important  
to all stakeholder groups  
Report in all trials

## 2 MIDDLE TIER

Critically important to  
some stakeholder groups  
Report in some trials

## 3 OUTER TIER

Important to some or  
all stakeholder groups  
Consider for trials





# Implementation

**Funding agencies**

NIHR, NIH

**Trials**

SPIRIT, ISRCTN, AKTN

**Journals**

CKT, NDT

**Regulators**

NHS, EMA, FDA, EMA/ESOT

**Guidelines**

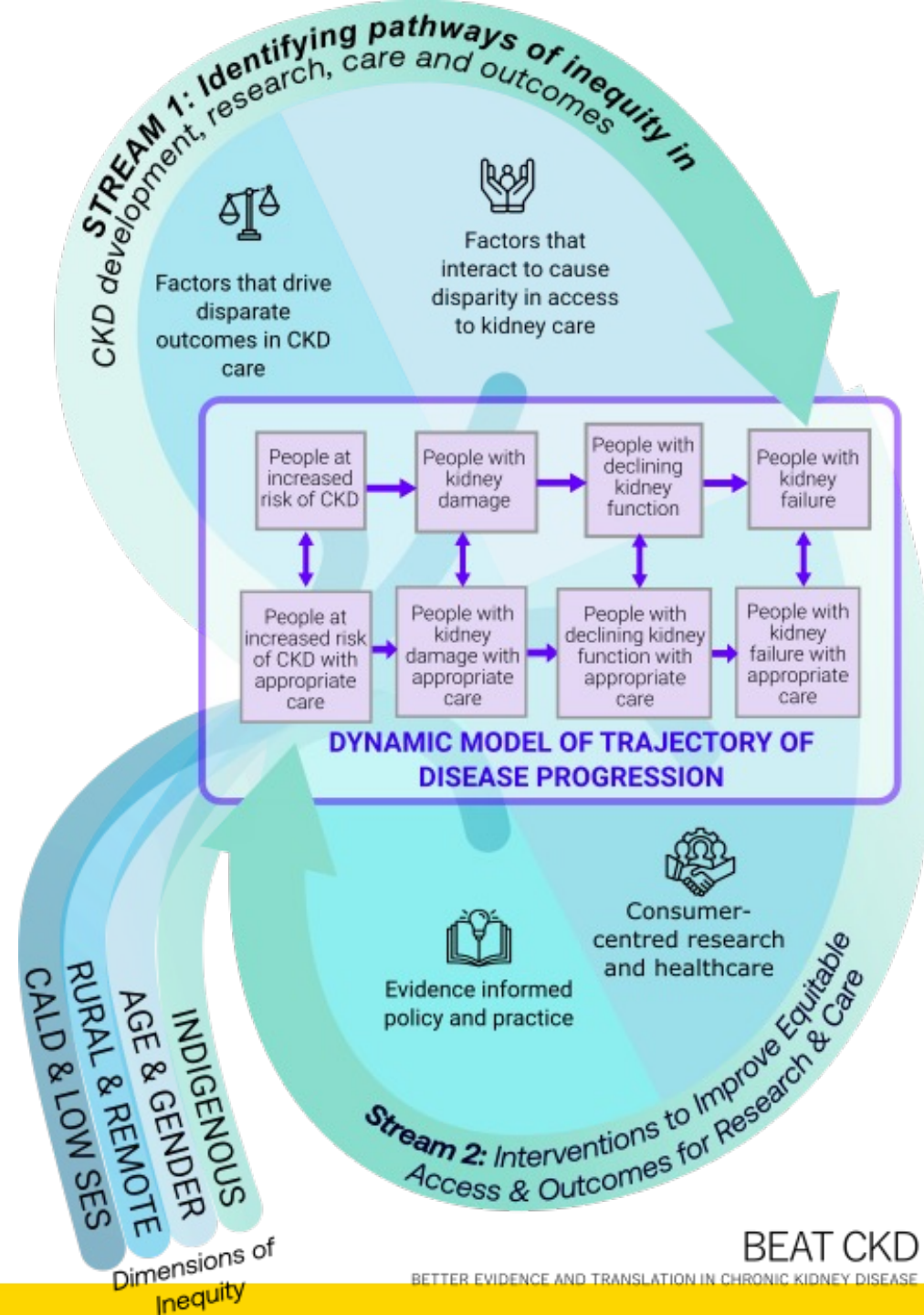
KDIGO, CARI (Cochrane)





# Next steps, some examples

- Systems dynamic model for care
- NIKKT – transplantation for Aboriginal and/or Torres Strait Islander people
- SONG-Equity
- Patient navigators to improve access, care and outcomes
- Less frequent dialysis trial
- “Equity” lens across all research



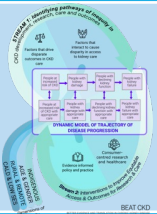
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