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SYDNEY

# PROMs and PREM<sup>s</sup> in ANZ renal units: who's measuring what for whom and why?

Associate Professor Rachael Morton  
NHMRC Clinical Trials Centre,  
The University of Sydney,

Adelaide, 21 February 2018



# Outline

- ▶ What are PROMs and PREMs?
- ▶ Results of the ANZDATA PROMs unit survey
- ▶ A proposal for a registry-based randomised trial

# Patient Reported Outcomes Measures (PROMs)

- ▶ Patient-reported outcome measures (PROMs) are a method to better understand outcomes that matter to patients
- ▶ Include any metric assessing health, illness or health care benefits from the patient's perspective; usually a questionnaire, such as a quality of life or symptom questionnaire
- ▶ PROMs are used for several different purposes including informing patient care, promoting patient engagement in treatment, benchmarking, audit and quality assurance
- ▶ Patient reported experience measures (PREMs), include satisfaction with care

# Aims

- ▶ To understand current practices for measurement of PROMs in renal care in Australian and New Zealand renal units
- ▶ To gauge interest in an ANZDATA Registry PROMs trial

# Methods

- ▶ Unit survey developed by ANZDATA PROMs working group
  - ▶ Define scope and purpose
  - ▶ Consultation with UKRR, Canadian RR, National and State PROMs registry initiatives (e.g. NZ, SA, VIC, NSW)
- ▶ V1.8 emailed to Heads of Units and cc'ed to ANZDATA unit contacts
- ▶ 2 week data collection period, then telephone follow up (June - August 2017)

# ANZDATA PROMs Survey

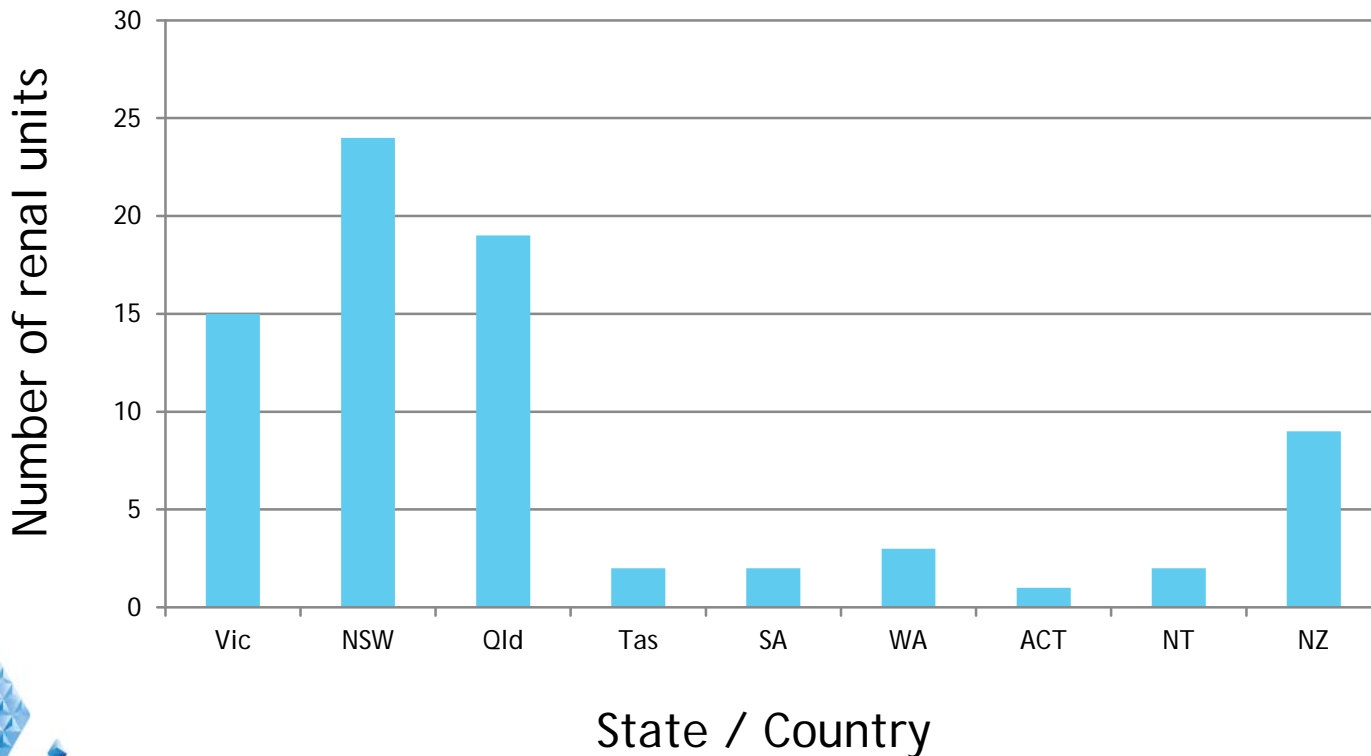
## Questions:

1. Name of renal unit
2. Position of respondent
3. Does your renal unit collect any patient reported outcomes measures (PROMs) including quality of life for specific groups with kidney disease as a part of routine clinical practice? *(Please select all that apply)*
  - a. None
  - b. Chronic Kidney Disease Stage 1-5
  - c. In-centre or Satellite Haemodialysis
  - d. Home Haemodialysis
  - e. Peritoneal Dialysis
  - f. Kidney Transplantation
  - g. Supportive Care
  - h. Other eg. all admitted patients *(Please specify)*
4. If yes, what is the main purpose/use for collecting PROMs? *(Please select all that apply)*
  - a. Health service mandates collection
  - b. Auditing clinical practice
  - c. Directly informs clinical care

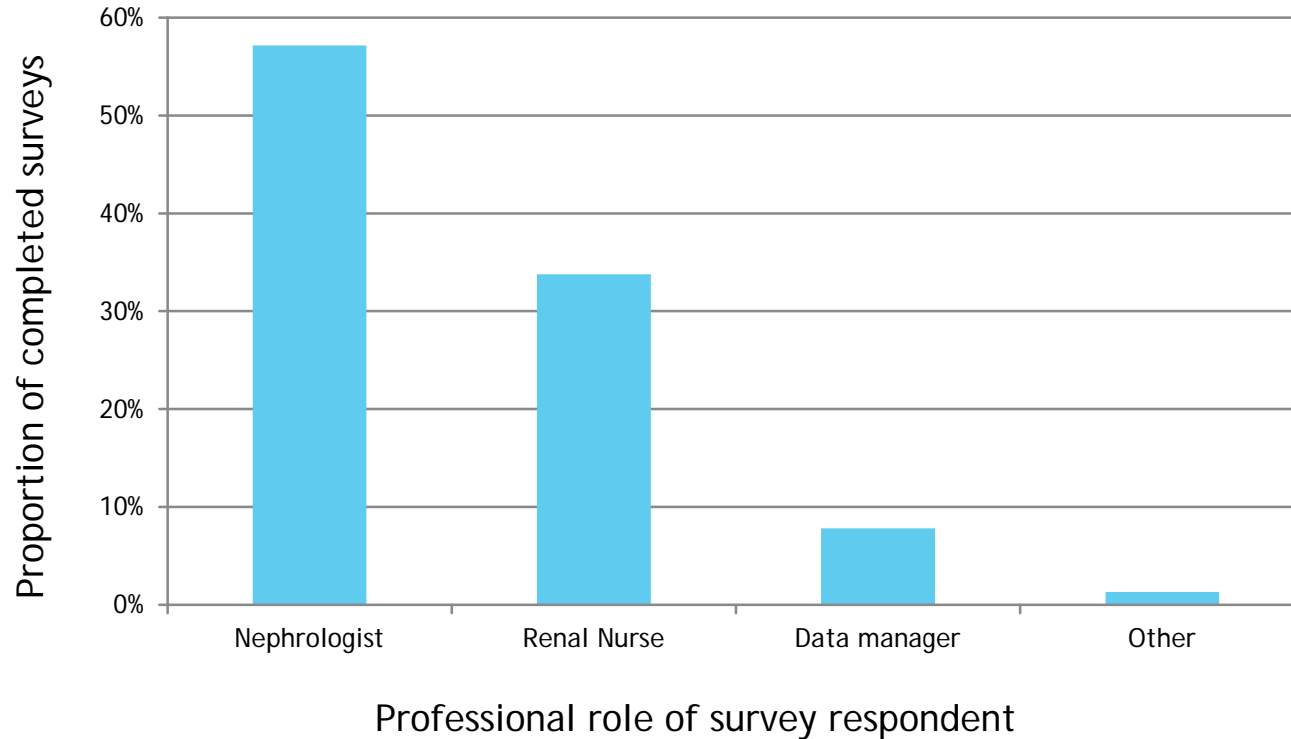
Version 1.8  
15 Questions  
<5 minutes to complete

# Results - survey responses (n=77)

100%

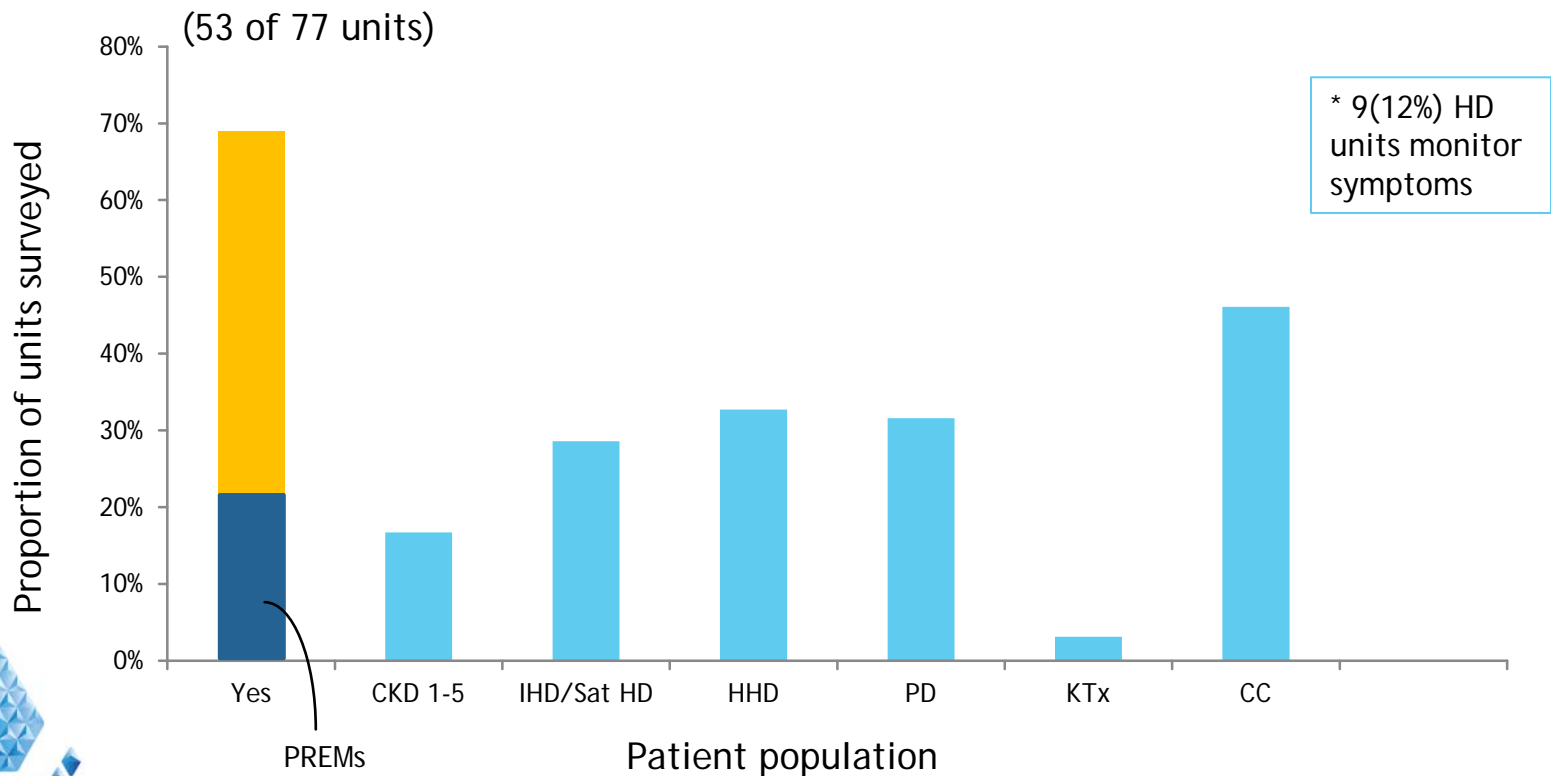


# Results - Survey respondents

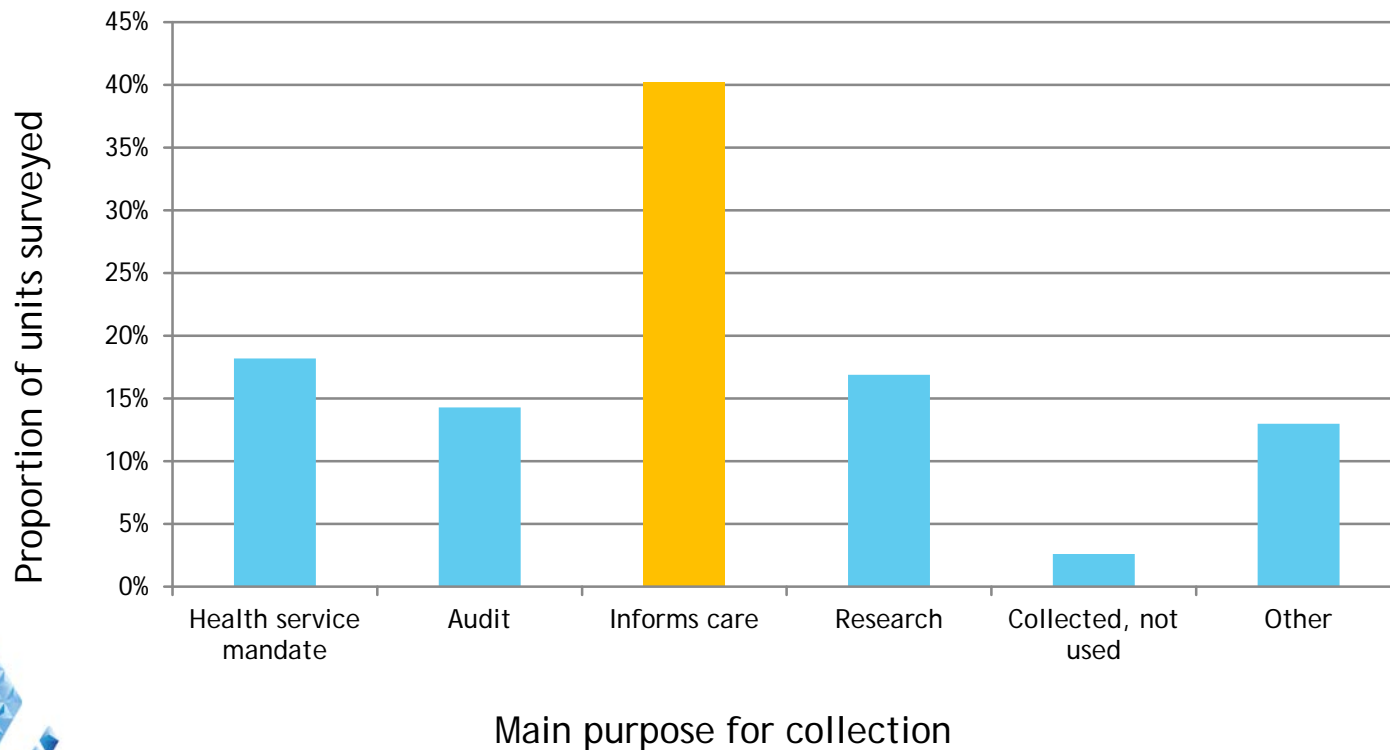




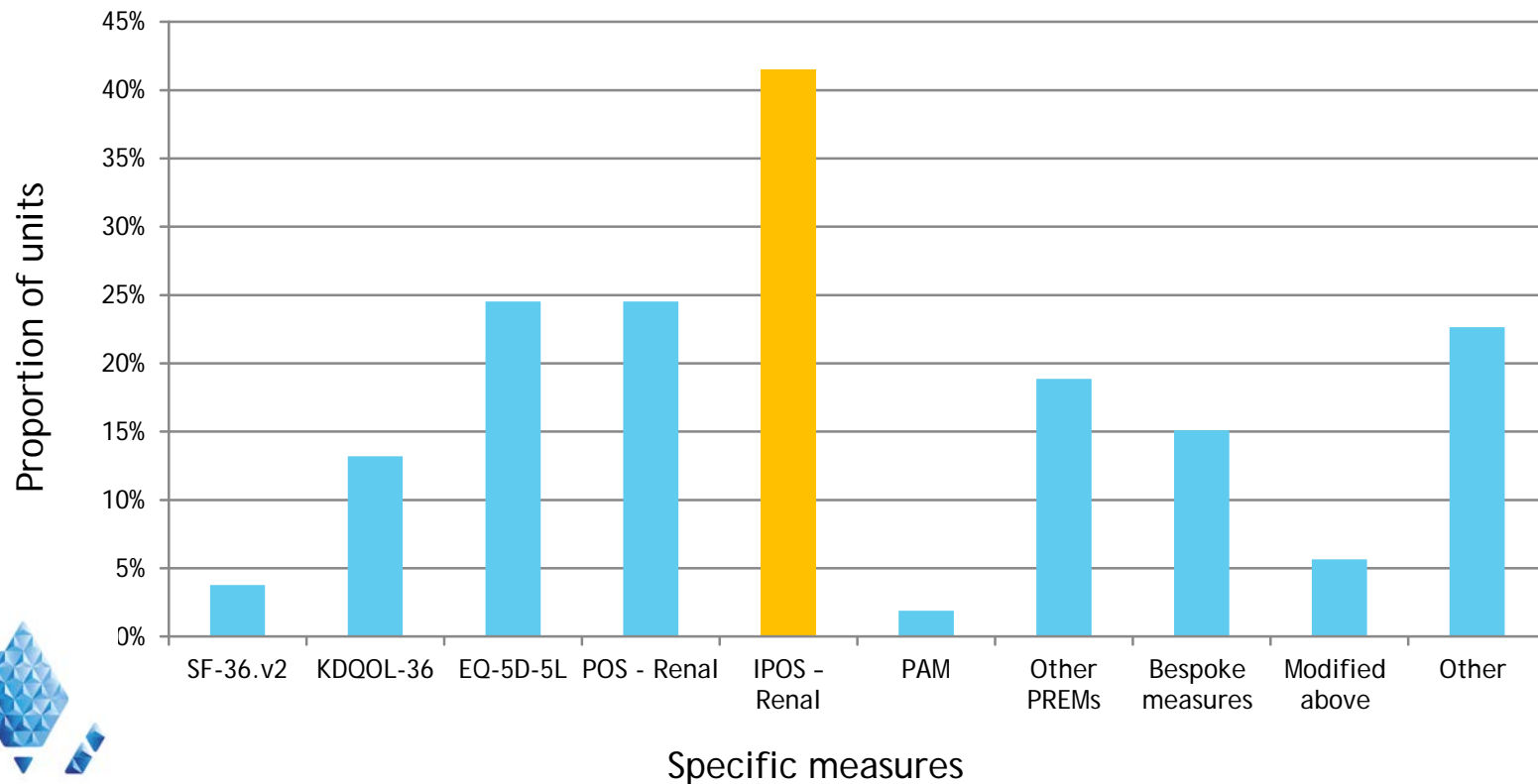
# Does your renal unit collect any PROMs or PREMs for specific groups with kidney disease as a part of *routine* clinical practice?



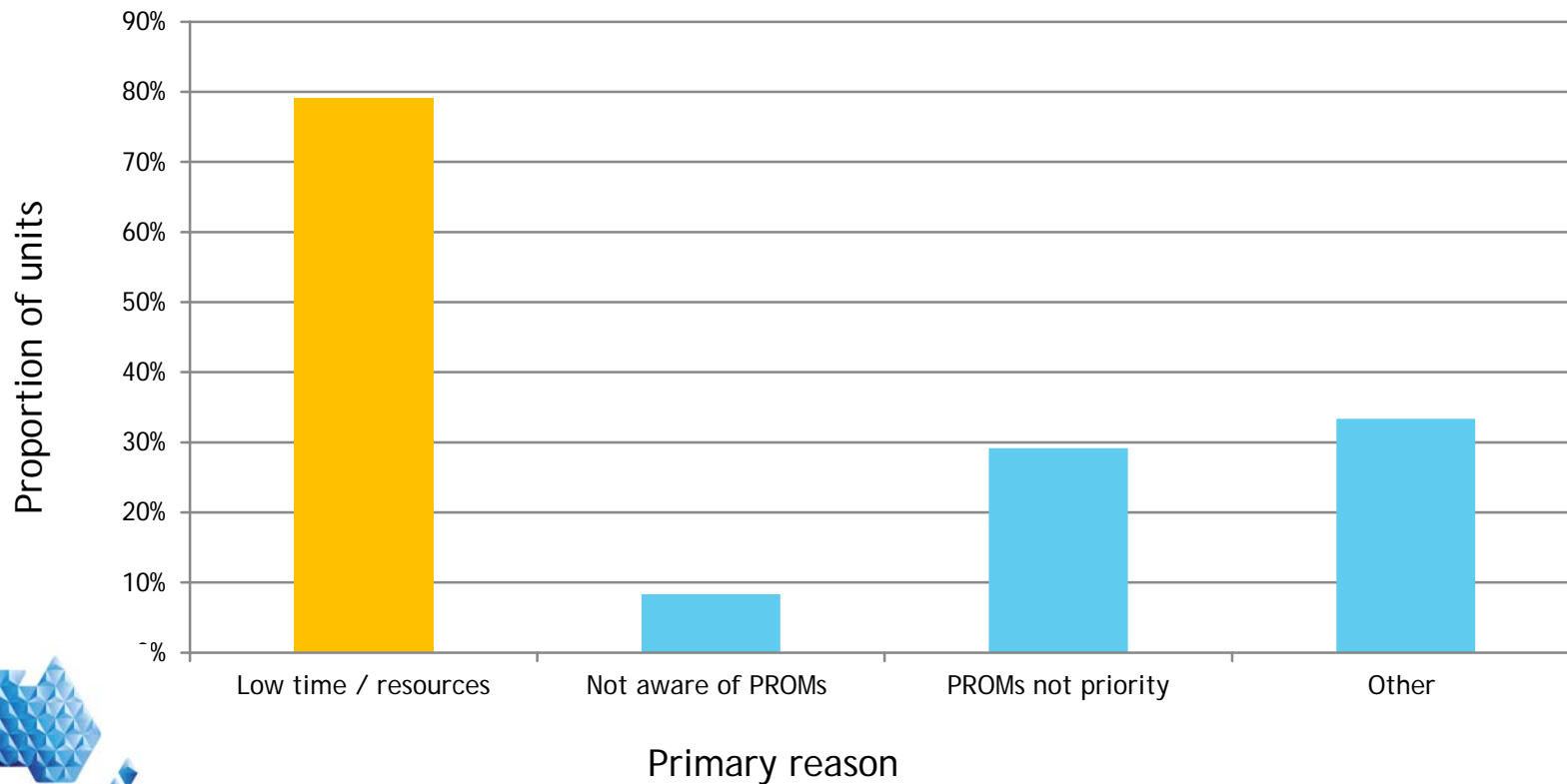
# What is the main purpose for collecting PROMs?



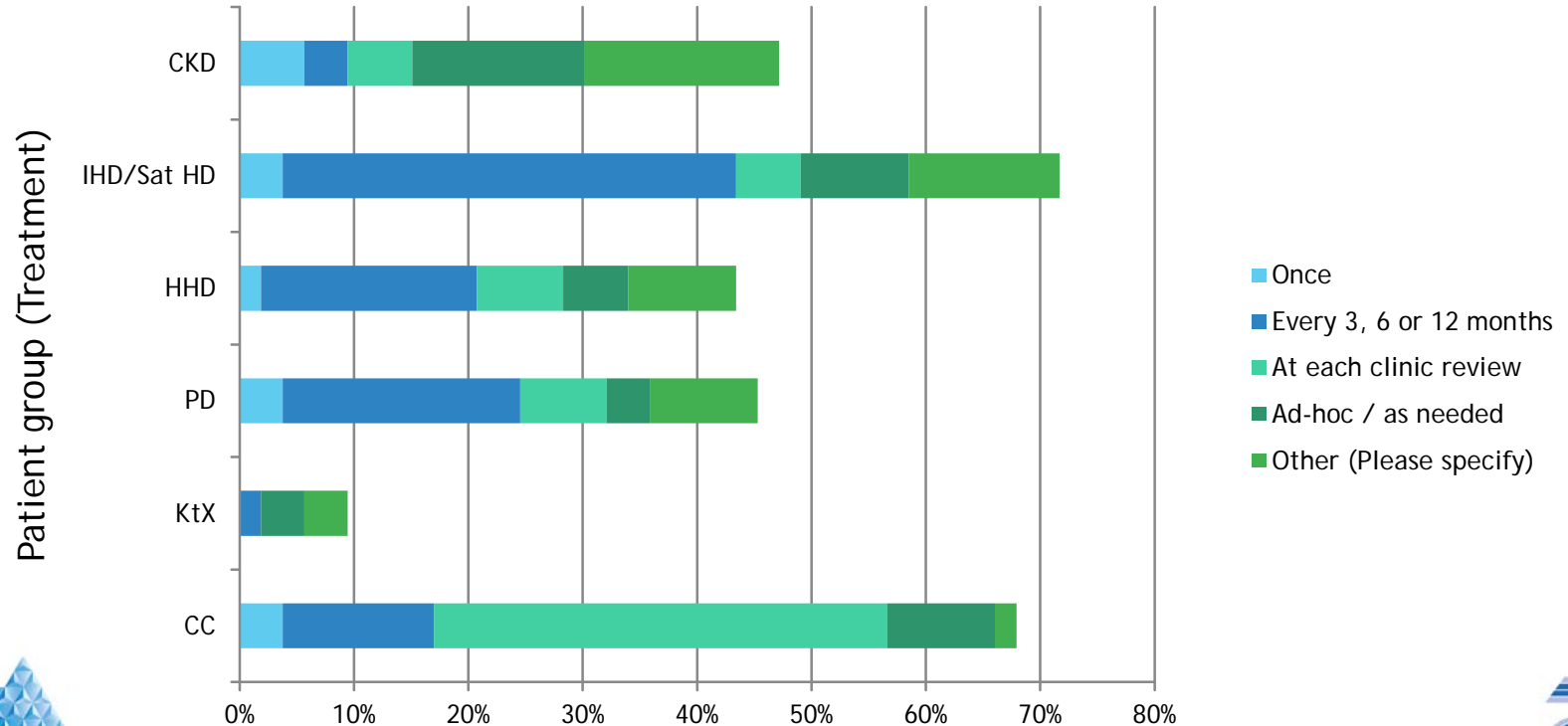
# Which questionnaires or measures does your renal unit use?



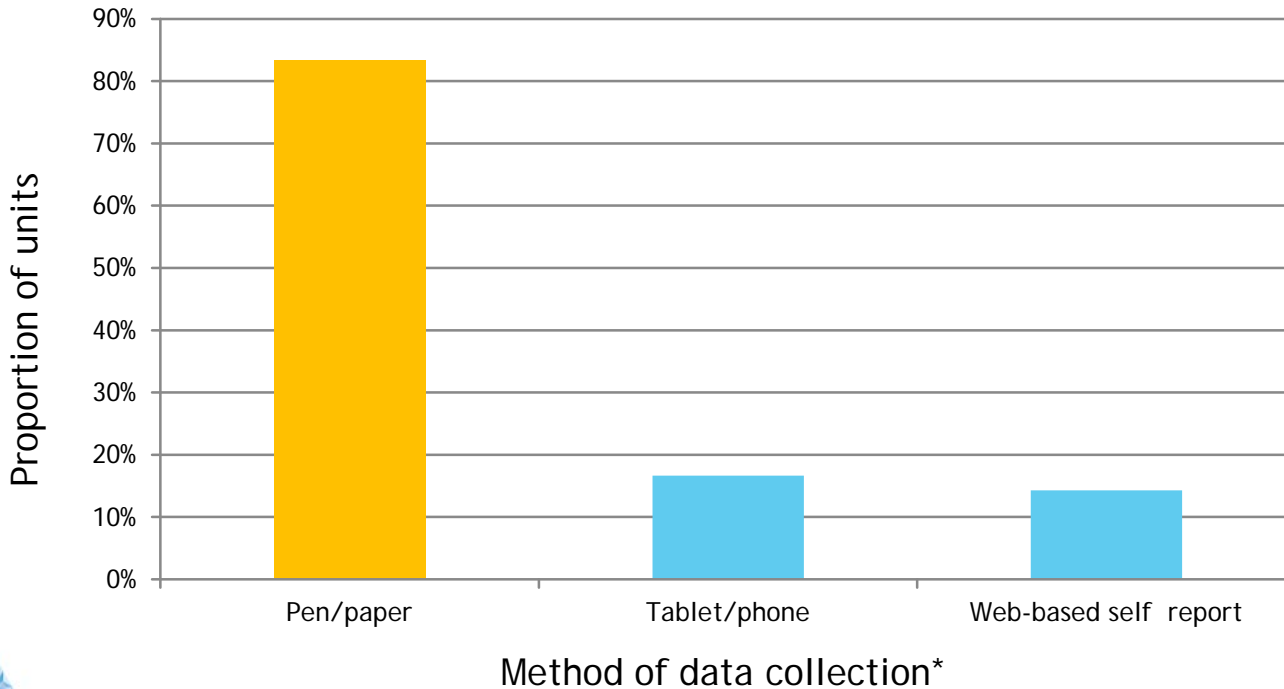
# If not collected, what was the main reason?



# How often were PROMs collected for each patient group?

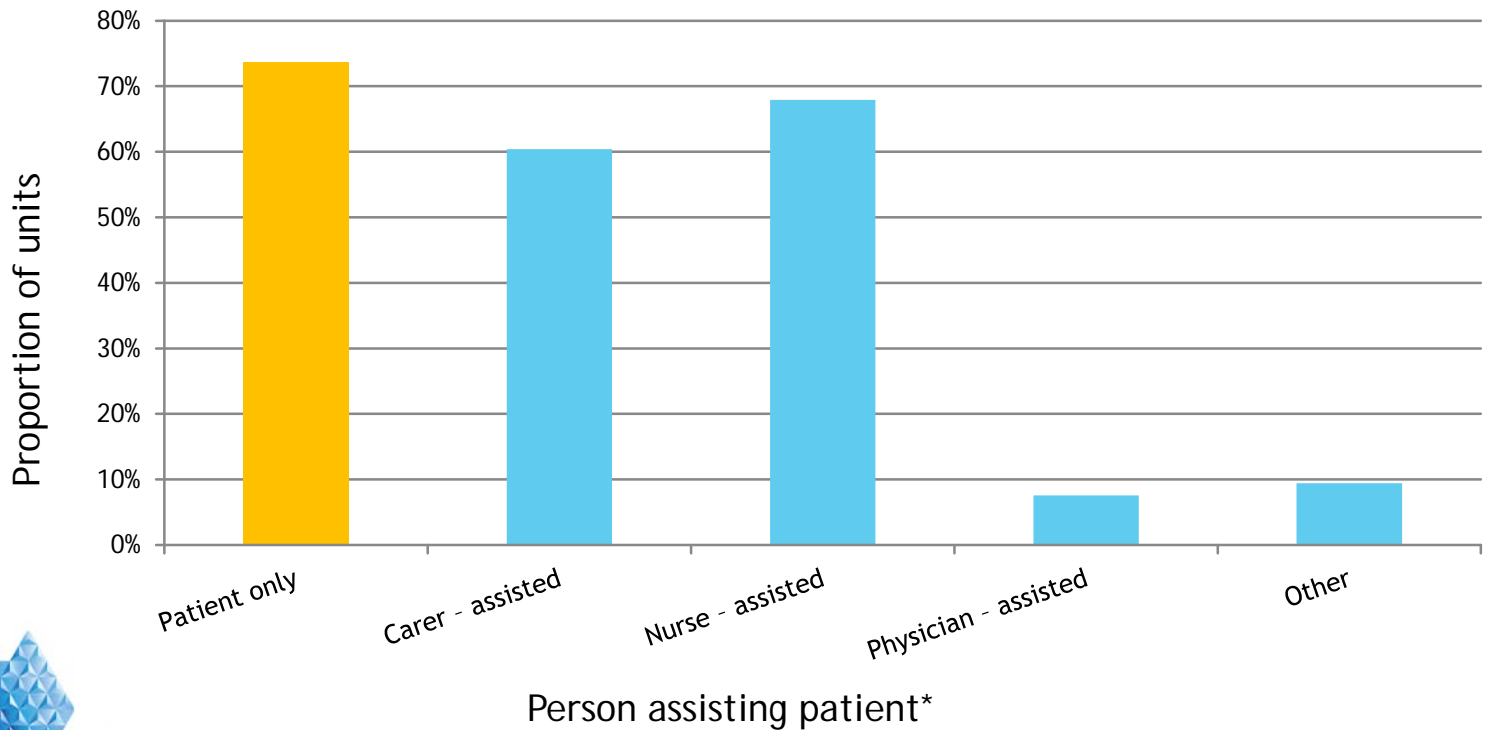


# How were PROMs collected?



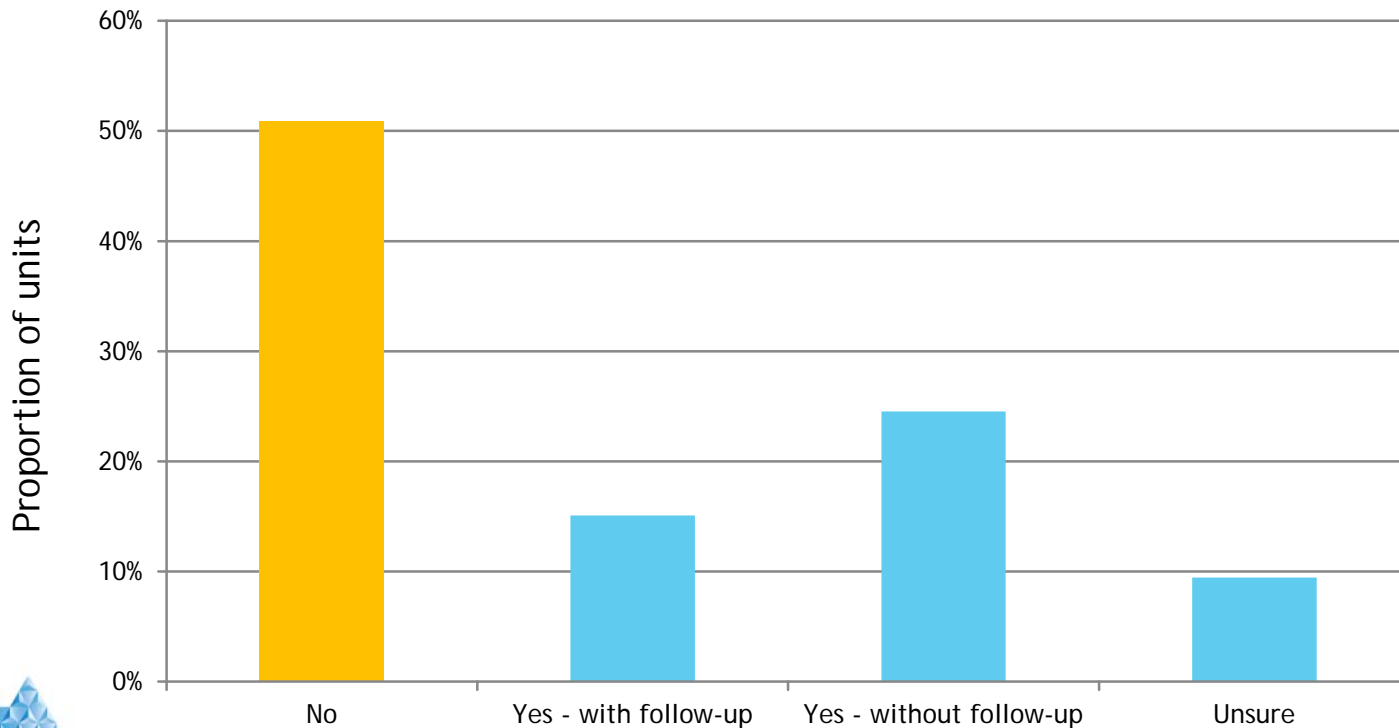
*\*Multiple methods possible*

# Who assists PROMs data collection?



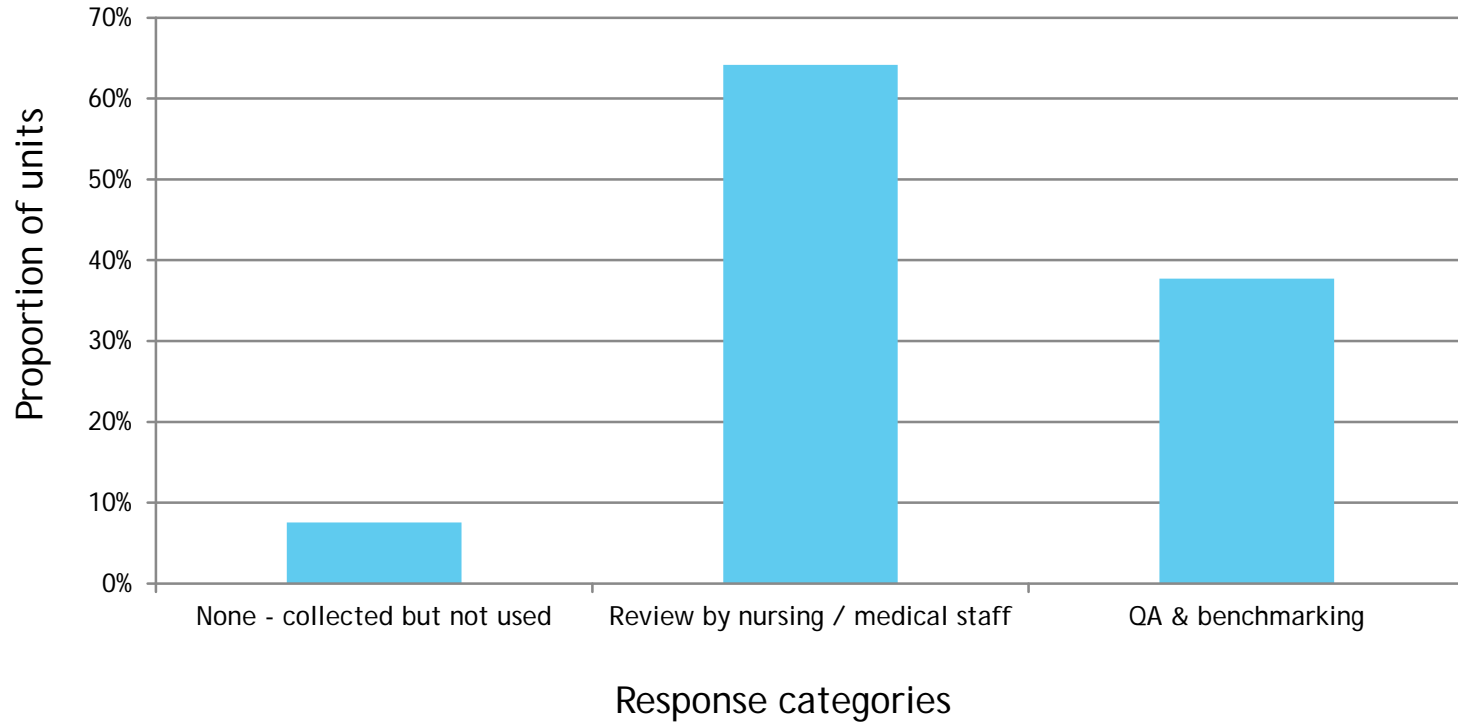
*\*Multiple categories possible*

# Is PROMs data audited by hospital/network?

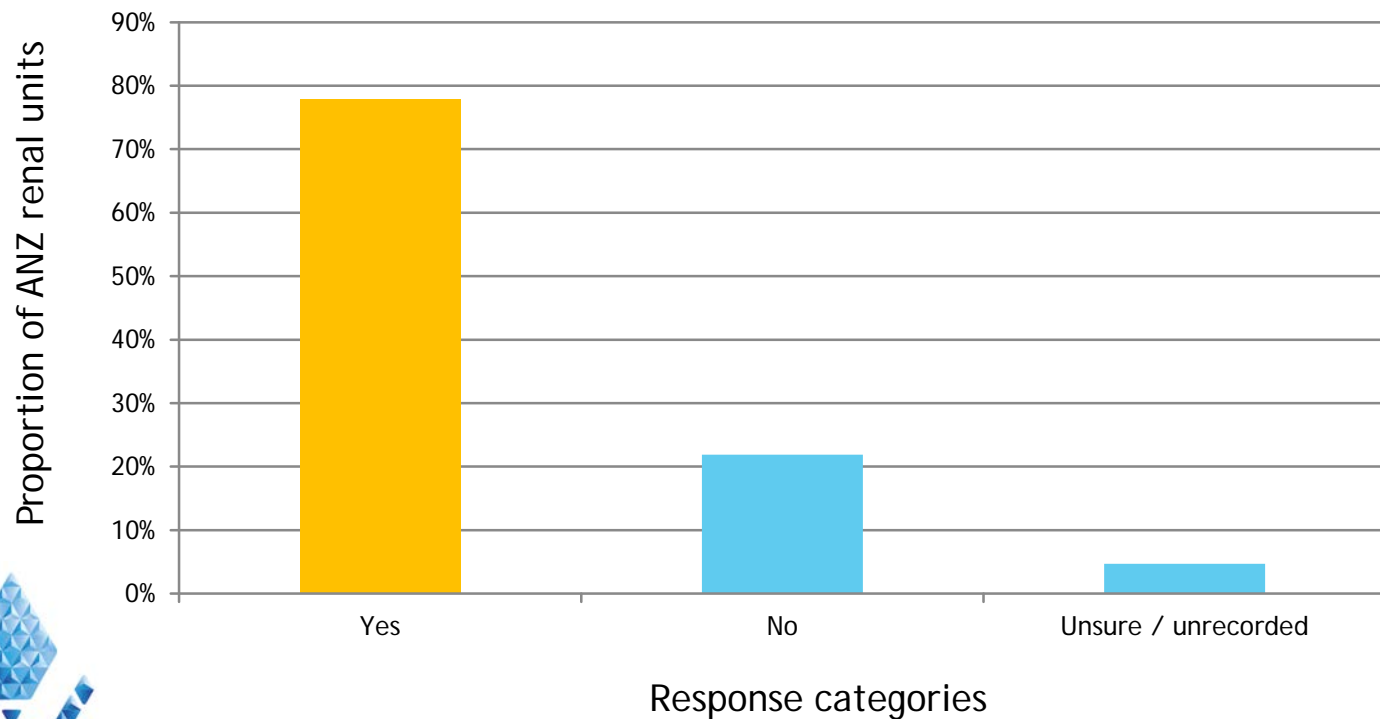




# Action taken based on PROMs



# Interest in participating in an ANZDATA PROMs Trial?



# Survey – Main points

- ▶ 53 of 77 (69%) of units routinely collect some form of PROMs/PREMs
- ▶ Units not collecting PROMs cited insufficient time / resources
- ▶ Of those collecting, IPOS-Renal (symptom checklist), mostly used for patients receiving Conservative care, and used to inform clinical practice
- ▶ There is strong interest in an ANZDATA PROMs trial

# Next steps

- ▶ Working Group will consider all quantitative and qualitative data from the surveys
- ▶ Determine whether PROMs could be used for QA/benchmarking, or to inform clinical care
- ▶ Registry-based trial (SWIFT)
- ▶ Apply for funding to support PROMs project manager, database extension, data collection methods

# Acknowledgements:

## ANZDATA PROMs Working Group members

- ▶ Rachael Morton (Chair)
- ▶ Neil Boudville, Kathryn Dansie, Matthew Jose, Nicole Lioufas (Advanced trainee), Marie Ludlow, Stephen McDonald, Suetonia Palmer, Rajesh Raj, Andy Salmon, Matthew Sypeck (ANZDATA fellow), Allison Tong

# A little pause for questions

- ▶ [Rachael.morton@ctc.usyd.edu.au](mailto:Rachael.morton@ctc.usyd.edu.au)
- ▶ [Kathryn.Dansie@anzdata.com](mailto:Kathryn.Dansie@anzdata.com)