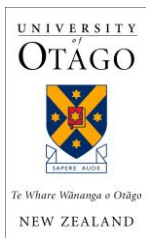


# Symptom Monitoring With Feedback Trial (SWIFT)

Professor Suetonia Palmer, University of Otago  
Christchurch  
(in collaboration with Waitematā DHB, NHMRC  
Clinical Trials Centre and ANZDATA Registry)

28 November 2019  
Kidney Health New Zealand 40<sup>th</sup> Anniversary Annual  
General Meeting  
Wellington, New Zealand





2800 New Zealanders receive maintenance dialysis



Māori and Pacific patients experience a 6-12-fold higher rate of starting dialysis

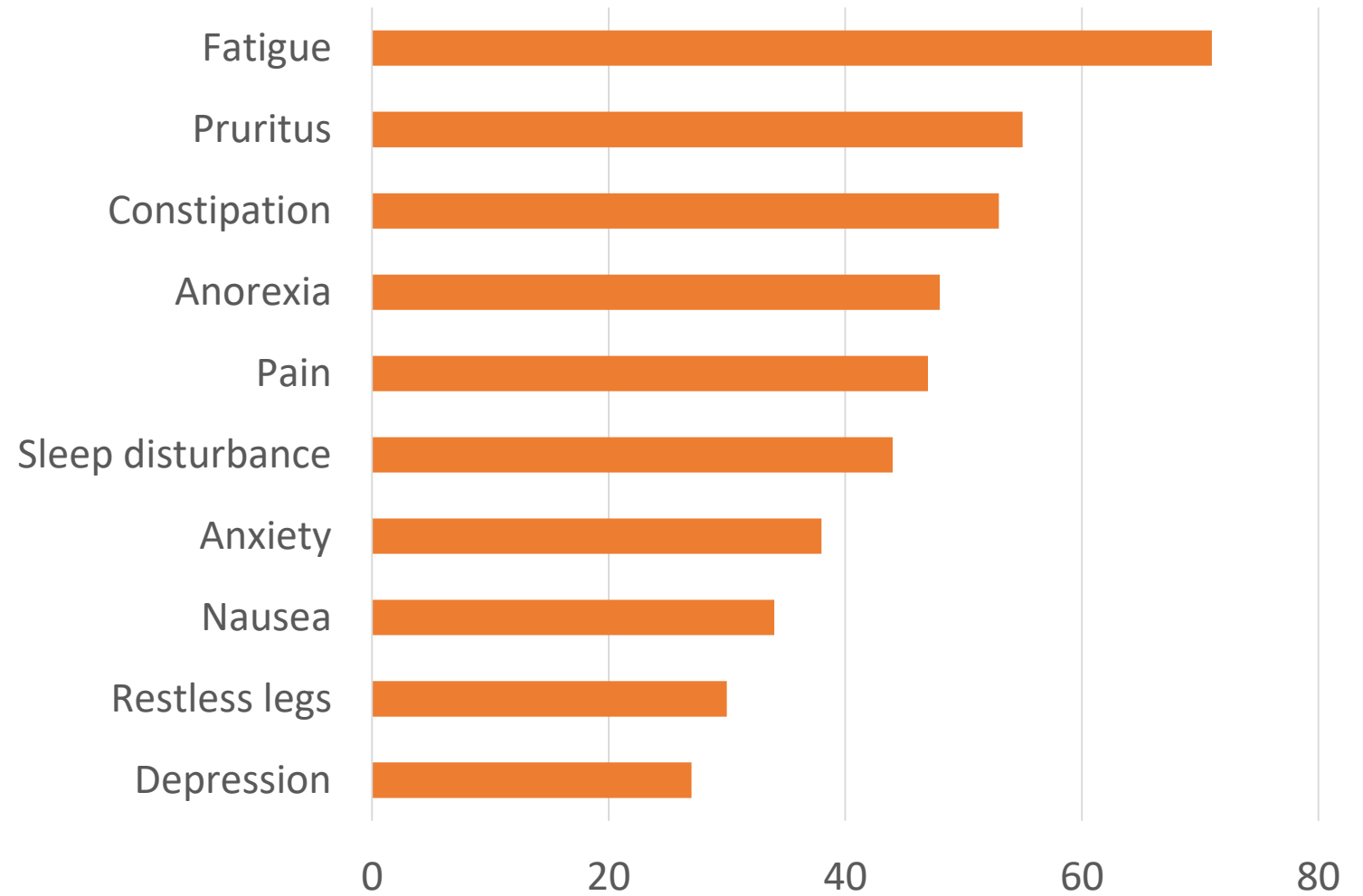


Dialysis is more costly (to patients and health system) than the most expensive cancer therapies



“Much of the burden of dialysis is hidden” – SWIFT NZ patient partner

Over half of  
dialysis patients  
are affected by  
severe symptoms  
which often occur  
in clusters



# SONG-HD



## 1 CORE OUTCOMES

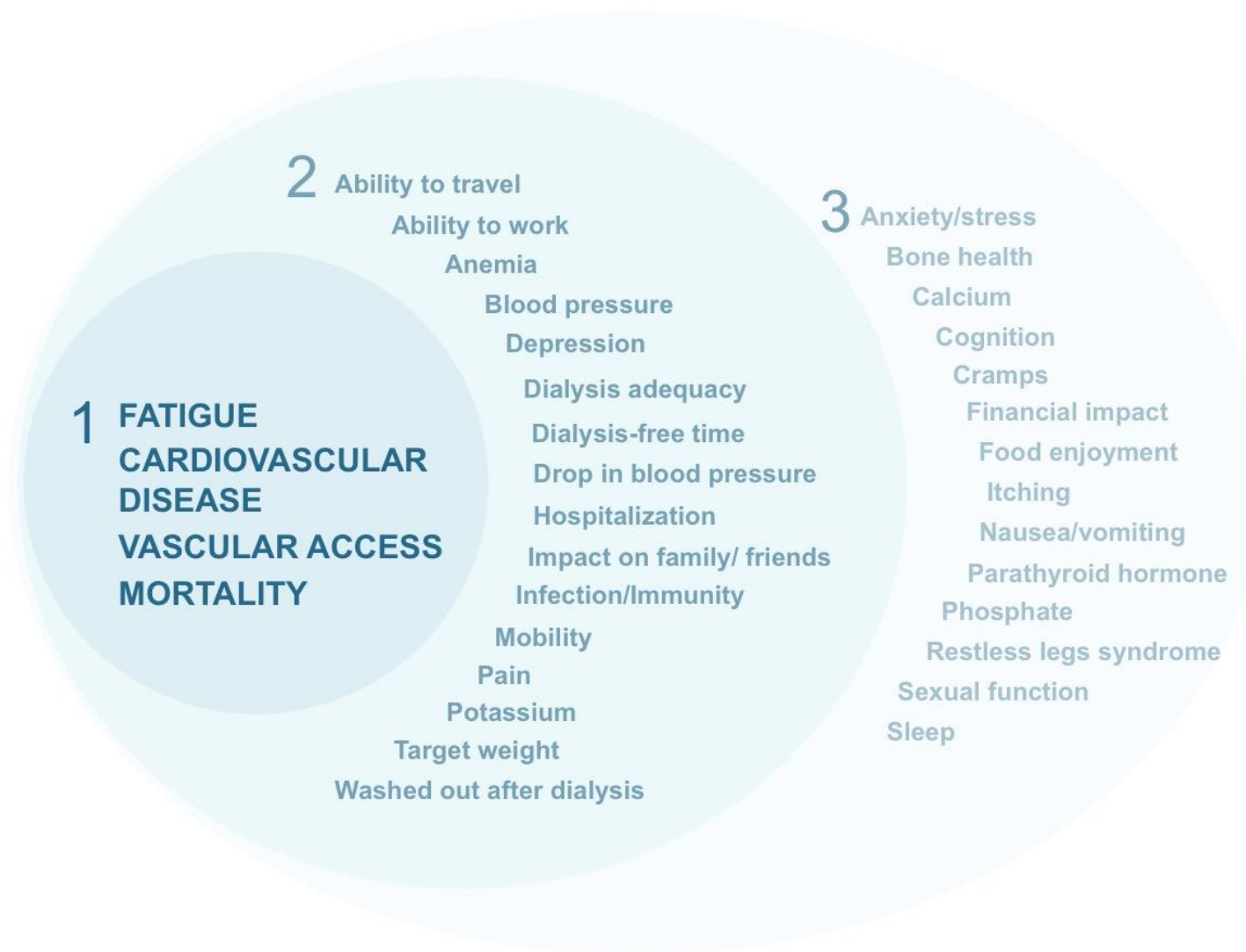
Critically important  
to all stakeholder groups  
Report in all trials

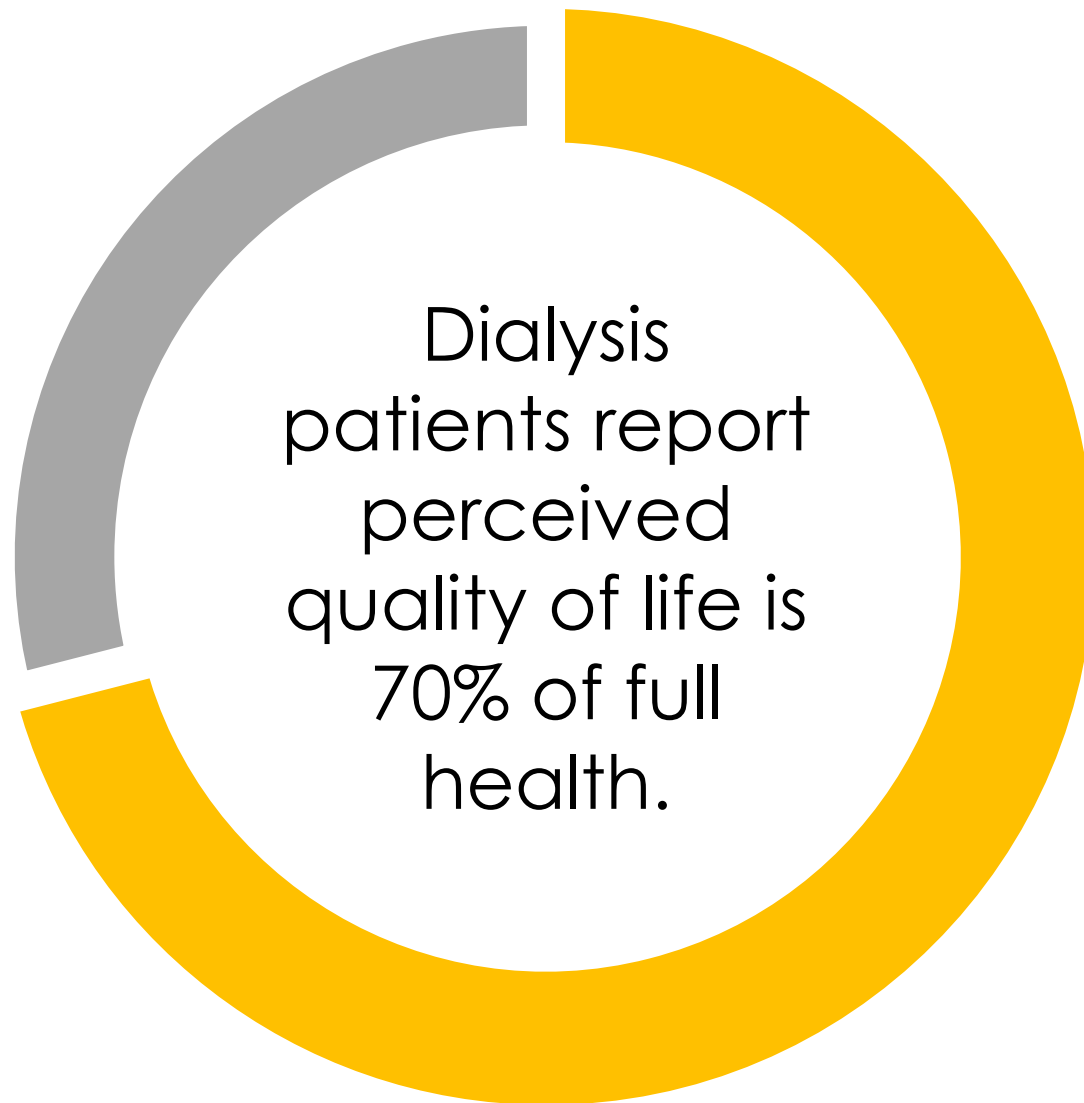
## 2 MIDDLE TIER

Critically important to  
some stakeholder groups  
Report in some trials

## 3 OUTER TIER

Important to some or  
all stakeholder groups  
Consider for trials





# New Zealand Nephrology

## 12th Annual Report

Reporting on treatment practices and patient outcomes of dialysis and kidney transplantation in Aotearoa New Zealand in 2017

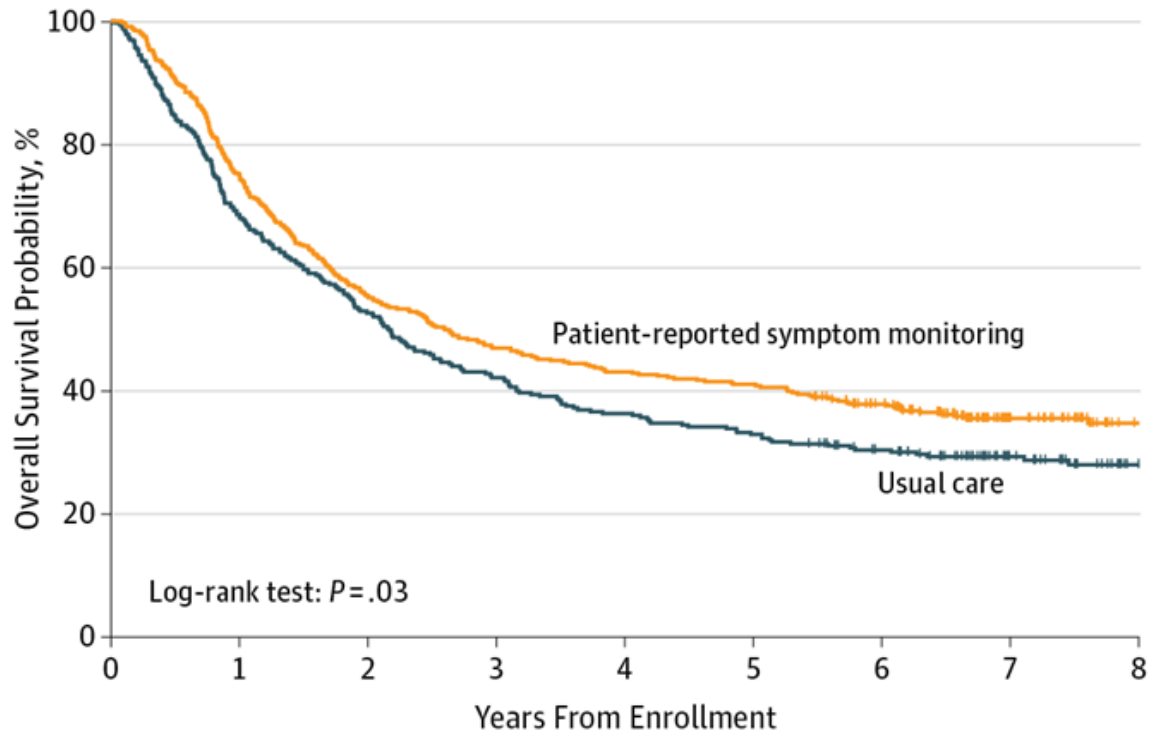


Patient-reported outcome measures (such as quality of life and symptom severity) are missing from New Zealand ANZDATA registry databases and reports.

“Clinical services need to recognize the illness experience, including the invisibility, intangibility and disconnectedness, and address this through specific interventions focused on improving clinical assessment, communication and education, alongside peer and professional support”.

Bristowe K, et al Annals of Palliative Medicine 2019;8(2).





No. at risk									
Patient-reported symptom monitoring	441	331	244	207	190	181	148	65	33
Usual care	325	223	171	137	118	107	89	50	27

Symptom monitoring in patients with metastatic cancers increased survival. One potential mechanism is early responsiveness to patient symptoms preventing downstream adverse consequences. Nurses responded to symptom alerts with symptom counseling, supportive medications, chemotherapy dose modifications and new referrals.



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

- Patient

“Things like sleep, or whether someone can go to work or someone’s quality of life, or their mental well-being we’re just starting to measure. Patients probably could have told us 50 years ago that we should be measuring these things, but they weren’t asked.”

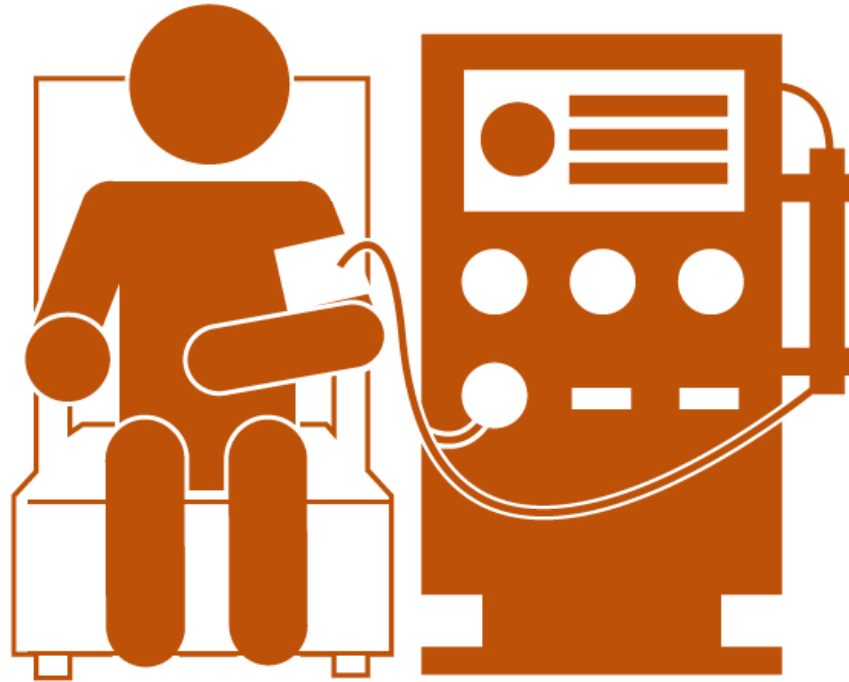
- Nephrologist

# Symptom monitoring with feedback trial (SWIFT)

This large simple trial is asking “does monitoring of symptoms for people treated with haemodialysis and feedback of the symptom information to the dialysis health care team improve patient quality of life”



Trial Registration: ACTRN12618001976279



SWIFT will include 650 adults 18 years or older who are treated with haemodialysis at one of 7 DHBs in New Zealand (involving 19 dialysis units).

## In the **INTERVENTION** dialysis units

Patients will be asked to fill out a survey asking about symptoms every 3 months



The survey results will be sent to dialysis teams. Doctors will be given guidance on symptom management and encouraged to talk about symptoms.



## In the **CONTROL** dialysis units

Patients will receive their usual care but without filling in the symptom survey (they will still be asked about their quality of life)



Dialysis teams will continue to provide their usual care without receiving any symptom feedback.

Restart Survey



Draft

Place Bookmark



Under each heading, please select **ONE** box that best describes your health **TODAY**.

#### Q1. MOBILITY

Please select **ONE** box that best describes your health **TODAY**.

- ☐ I have no problems in walking about
- ☐ I have slight problems in walking about
- ☐ I have moderate problems in walking about
- ☐ I have severe problems in walking about
- ☐ I am unable to walk about

← Previous

Next →



Under each heading, please select **ONE** box that best describes your health **TODAY**.

#### Q1. MOBILITY

Please select **ONE** box that best describes your health **TODAY**.

- ☐ I have no problems in walking about
- ☐ I have slight problems in walking about
- ☐ I have moderate problems in walking about

At the start, and at 6 months and 1 year, we will ask ALL patients about their quality of life to evaluate whether measuring their symptoms and giving feedback to clinical teams made any difference (a 7-point change in the quality of life measure).



# Critical and important outcomes

- Health-related quality of life (on a visual scale from 0-100)
- Severity of symptoms
- Withdrawal from dialysis
- Overall survival
- Health service utilization (outpatient visits, pharmacy use, GP care, emergency attendances)
- Equity





Currently under funding consideration by the Health Research Council of New Zealand



Partnership with NHMRC Clinical Trials unit, the ANZDATA Registry, consumers and 7 District health Boards



Embedded in ANZDATA Registry



Video/voice support for language diverse patients

“Māori patients with CKD experience marginalization within the NZ healthcare system due to delayed diagnosis, focus on individuals rather than family, multigenerational fear of dialysis, and awareness that clinicians do not fully account for cultural considerations and values during decision making.”

SWIFT interview study



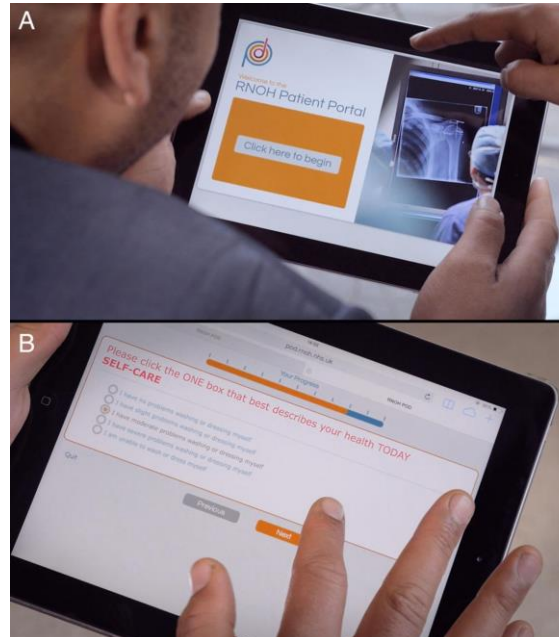
In-depth interviews with 25-30 Māori patients about perspectives of what is important when considering quality of life while treated with dialysis. Analysis using qualitative thematic synthesis.

# Why SWIFT is so important.

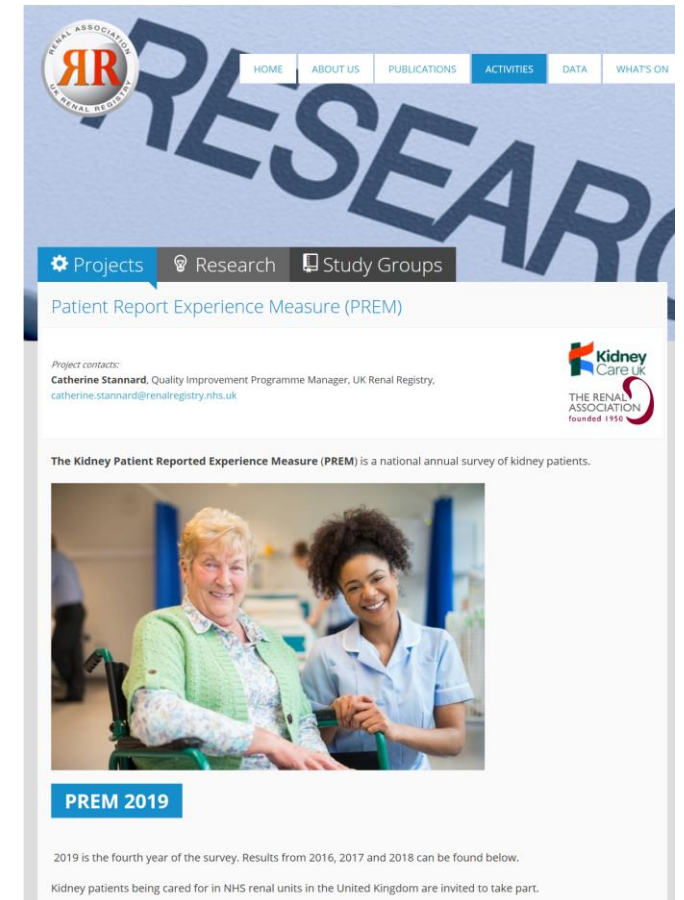
Involving dialysis teams and patients in research using highly efficient methods to reduce their burden



Measure and report patient symptoms and quality of life as part of our routine clinical quality improvement process (using direct-to-database technology)



Build infrastructure and capacity for expanded patient-reporting of outcomes and experiences.



# Acknowledgements

Patient partners (Rikki McGregor, Jonnie Maguire, Jenny Ili)

NHMRC Clinical Trials Centre

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Coinvestigators (Prof David Tipene-Leach, Associate Professor Rachael Walker, Associate Professor Rachael Morton, Michael Collins)

ANZDATA team (Kathryn Dansie)

Kidney Health Australia and Kidney Health New Zealand

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