EVERY VOICE, EVERY PATIENT: SYMPTOM BURDEN AND QUALITY OF LIFE AMONG ADULTS RECEIVING DIALYSIS IN THE AUSTRALIAN SWIFT STUDY

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Renal Society of Australasia, Christchurch, 2026



THE UNIVERSITY OF SYDNEY
NHMRC Clinical Trials Centre
ANZ DATA
Kidney Health Australia
BEAT CKD
BETTER EVIDENCE AND TRANSLATION IN CHRONIC KIDNEY DISEASE
Griffith UNIVERSITY Queensland, Australia

Dialysis Symptoms Are A Global Phenomena



Symptoms are global and ubiquitous



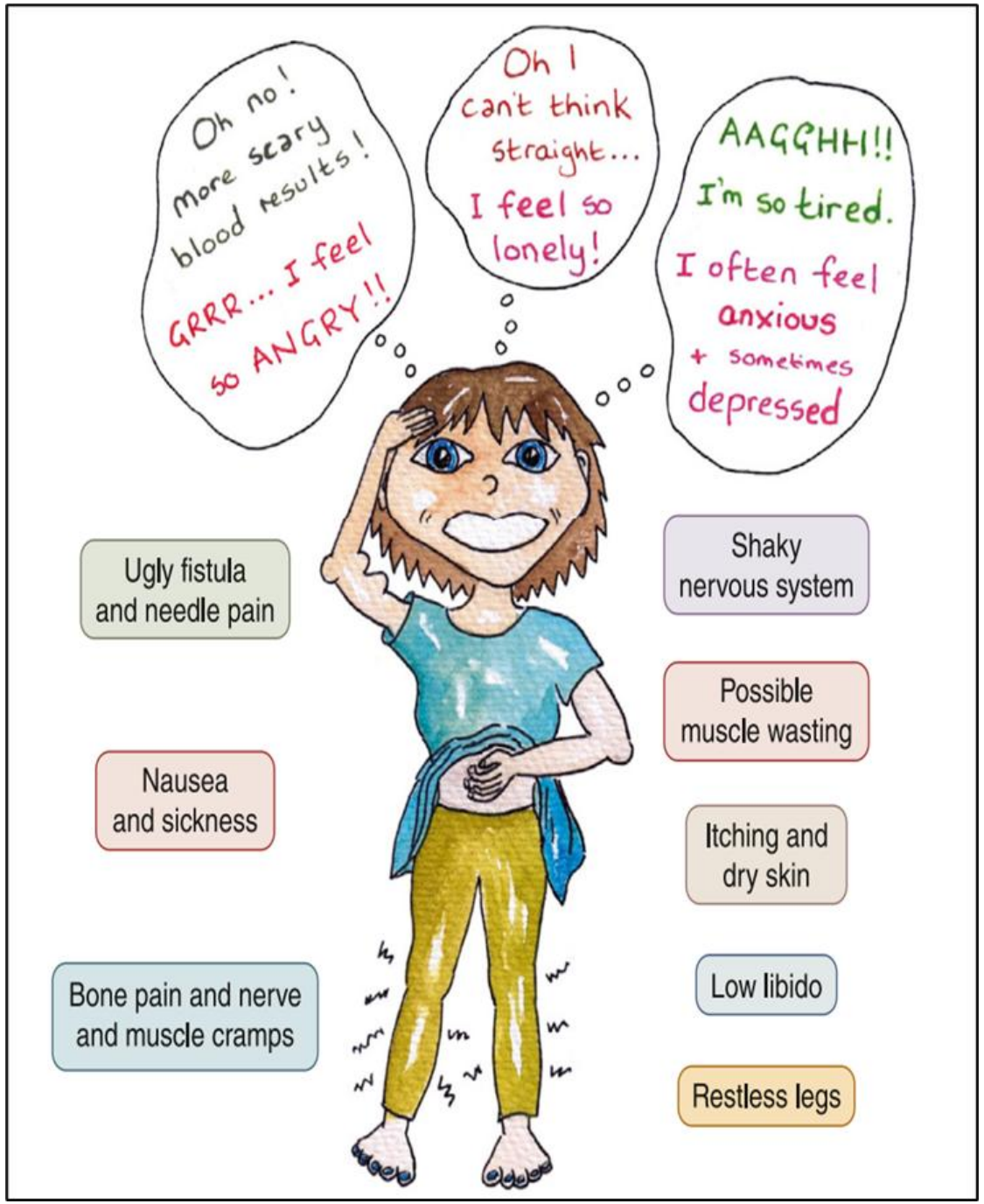












PEOPLE ON DIALYSIS SUFFER FROM A HIGH SYMPTOM BURDEN

KI REPORTS
KIReports.org

The Role of Nephrology Nurses in Symptom Management – Reflections on the Kidney Disease: Improving Global Outcomes Controversies Conference on Symptom-Based Complications in Dialysis Care

Marques Shek Nam Ng[1], Edwina A. Brown[2], Michael Cheung[3], Ana Elizabeth Figueiredo[4], Helen Hurst[5], Jennifer M. King[3], Rajnish Mehrotra[6], Lillian Pryor[7], Rachael C. Walker[8], Betty Ann Wasylynuk[9] and Paul N. Bennett[10]

A/Prof Pantellis Sarafidis – EDTNA Athens 22nd Sept 2023



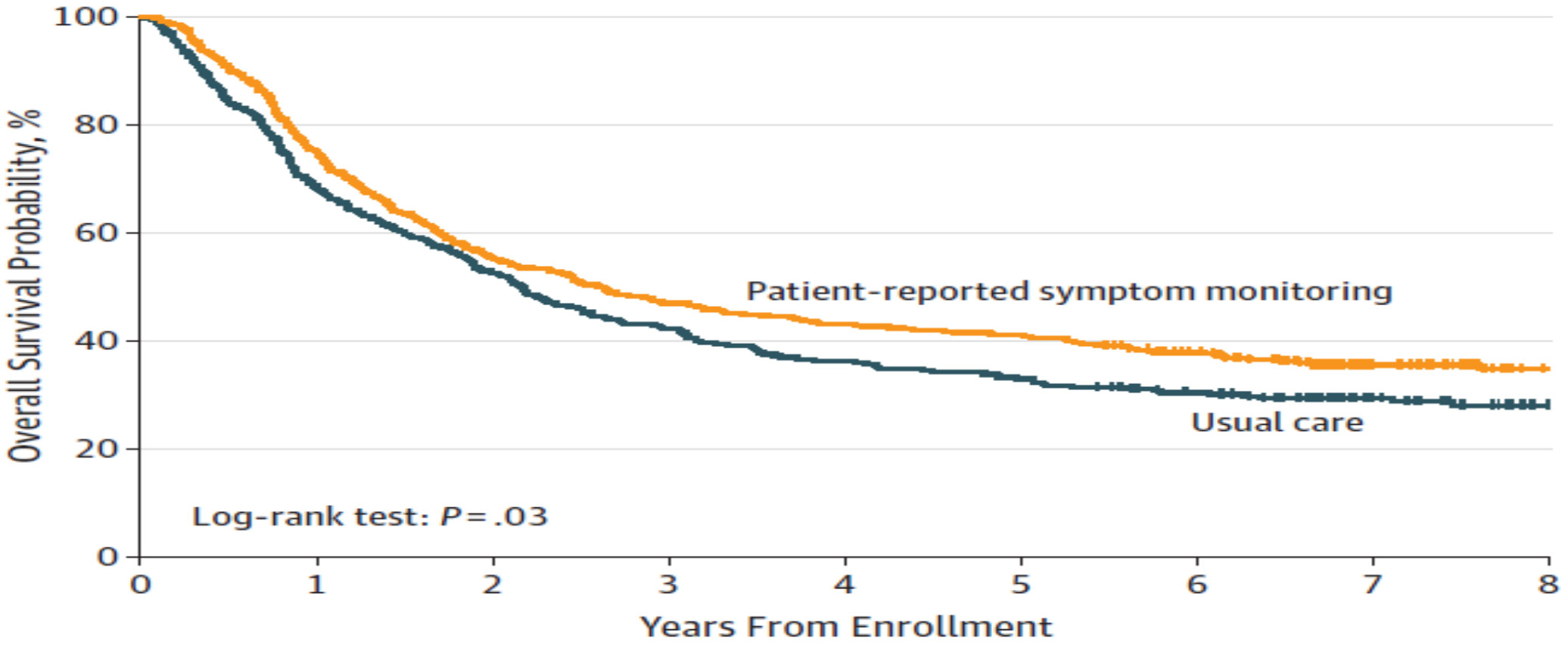
Nephrologists think that everything is much better than what is reality. Nurses (and renal physiologists) know the reality that patients do have symptoms and life isn't so good a lot of the time.

Research Question

Does regular symptom monitoring with feedback result in improved QOL for people on haemodialysis?



IN CANCER THERAPY IT IMPROVES SURVIVAL



rted	441	331	244	207	190	181	148	65	33
nitoring	325	223	171	137	118	107	89	50	27

Basch E et al 2017 JAMA

RESEARCH QUESTIONNAIRES

Quality of Life – EQ5D
Dialysis Symptoms - IPOS Renal



QUALITY OF LIFE - EQ-5D-5L

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

Q1. MOBILITY

MOBILITY

- ○ 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

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

Q2. SELF-CARE

SELF-CARE

- ○ I have no problems washing or dressing myself
- ○ I have slight problems washing or dressing myself
- ○ I have moderate problems washing or dressing myself
- ○ I have severe problems washing or dressing myself
- ○ I am unable to wash or dress myself

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

Q3. USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)

USUAL ACTIVITIES

- ○ I have no problems doing my usual activities
- ○ I have slight problems doing my usual activities
- ○ I have moderate problems doing my usual activities
- ○ I have severe problems doing my usual activities
- ○ I am unable to do my usual activities

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

Q4. PAIN / DISCOMFORT

PAIN

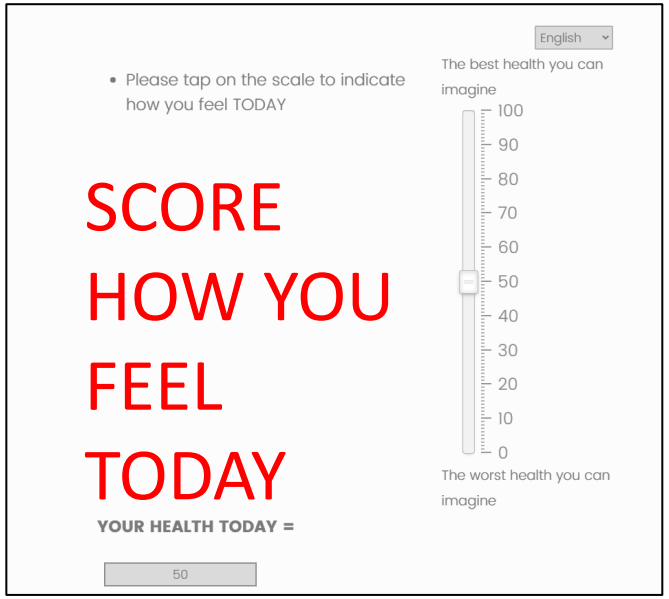
- ○ I have no pain or discomfort
- ○ I have slight pain or discomfort
- ○ I have moderate pain or discomfort
- ○ I have severe pain or discomfort
- ○ I have extreme pain or discomfort

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

Q5. ANXIETY / DEPRESSION

ANXIETY DEPRESSION

- ○ I am not anxious or depressed
- ○ I am slightly anxious or depressed
- ○ I am moderately anxious or depressed
- ○ I am severely anxious or depressed
- ○ I am extremely anxious or depressed



SYMPTOMS - IPOS RENAL SYMPTOM QUESTIONS

Q2. Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick the box that best describes how it has affected you over the past week?

	Not at all	Slightly	Moderately	Severely	Overwhelmingly
Pain	○	○	○	○	○
Shortness of breath	○	○	○	○	○
Weakness or lack of energy	○	○	○	○	○
Nausea (feeling like you are going to be sick)	○	○	○	○	○
Vomiting (being sick)	○	○	○	○	○
Poor appetite	○	○	○	○	○
Constipation	○	○	○	○	○
Sore or dry mouth	○	○	○	○	○
Drowsiness	○	○	○	○	○
Poor mobility	○	○	○	○	○
Itching	○	○	○	○	○
Difficulty Sleeping	○	○	○	○	○
Restless legs or difficulty keeping legs still	○	○	○	○	○
Changes in skin	○	○	○	○	○
Diarrhoea	○	○	○	○	○

SURVEYS - SONG-HD FATIGUE

SONG-HD Fatigue (Standard Outcomes in Nephrology - Haemodialysis Fatigue)

- 3 questions only across 1 screen about fatigue.
- Check box responses from “Not at all” to “Severely”.

In the past week:

	Not at all	A little	Quite a bit	Severely
1. Did you feel tired?	○	○	○	○
2. Did you lack energy?	○	○	○	○
3. Did fatigue limit your usual activities?	○	○	○	○

Methods

Timeline



Baseline

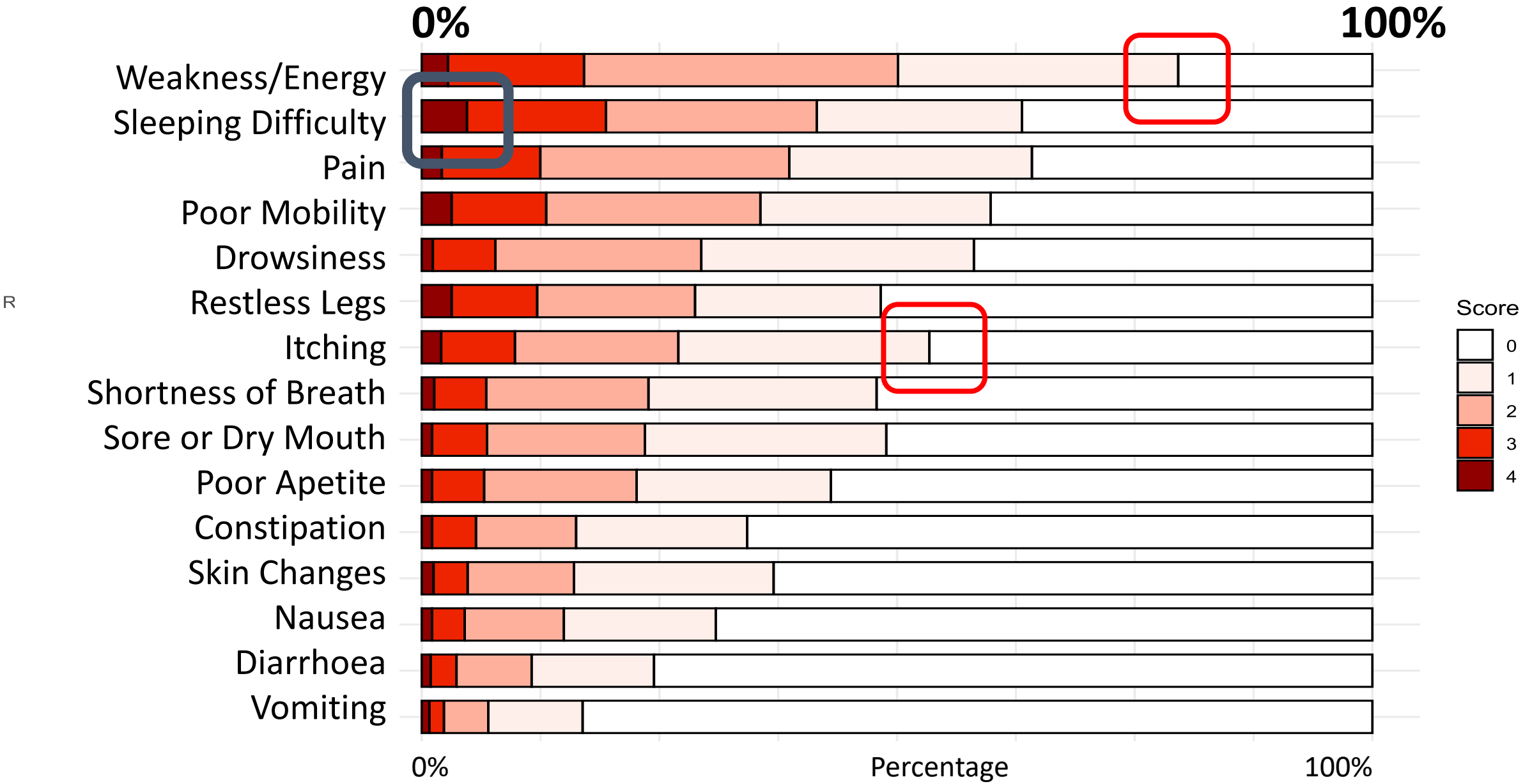


3 months

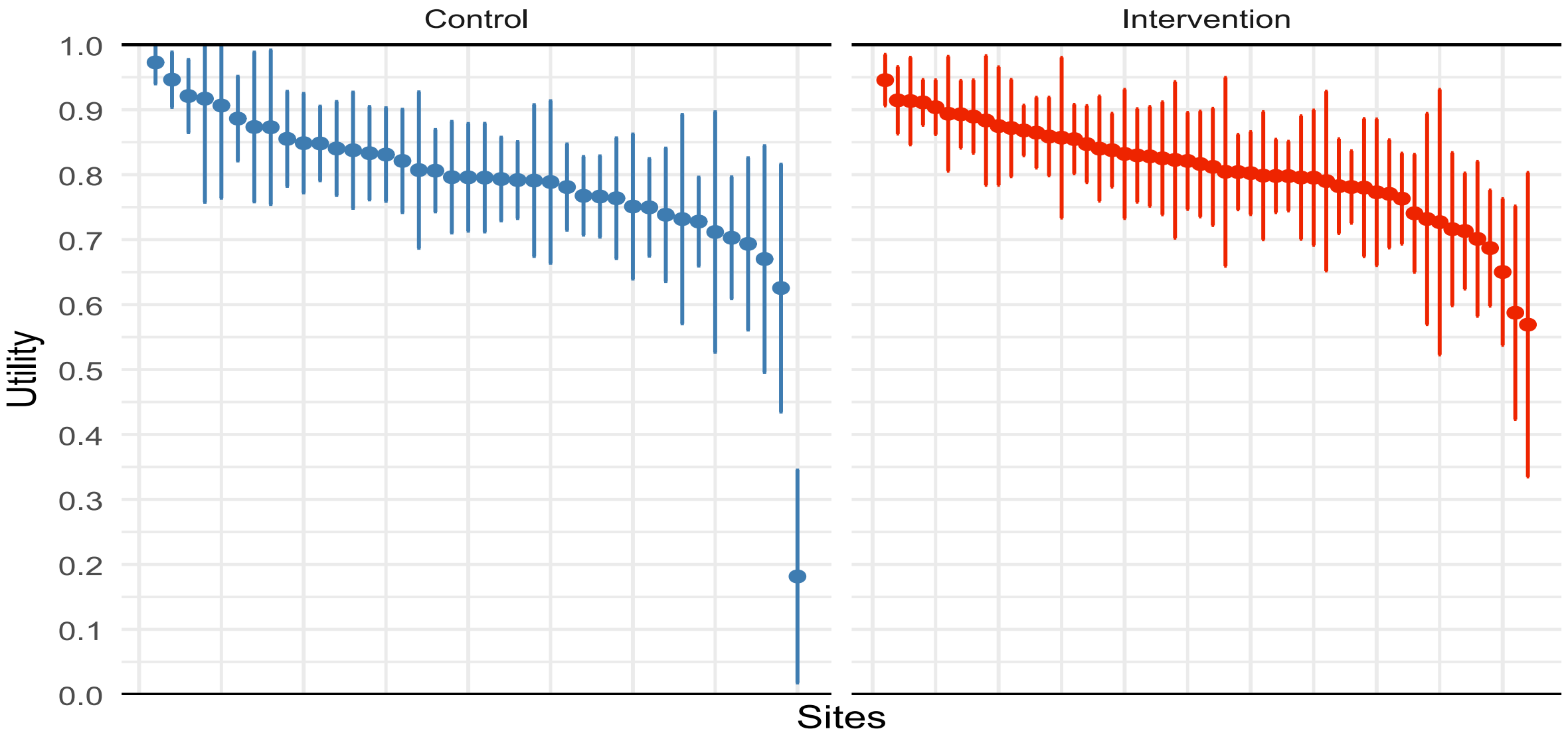


6 months

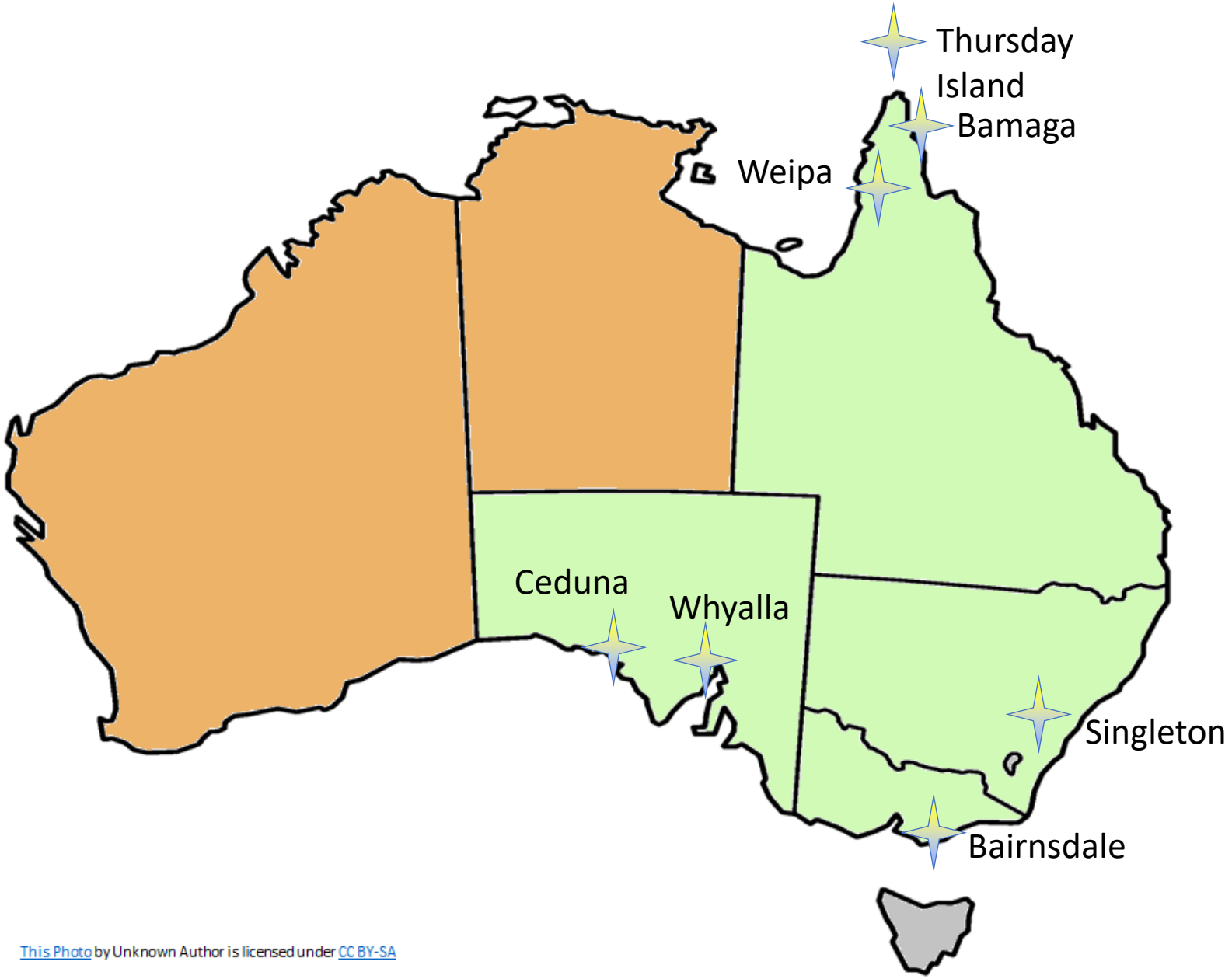
RESULTS - BASELINE SYMPTOMS (1378 INTERVENTION GROUP)



BASELINE QUALITY OF LIFE INDEX (N=92 DIALYSIS CENTRES)



RURAL AND REMOTE TRIAL PARTICIPATION



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Results – Is This Representative of Australia?

*92 clusters [centres]
4 states: QLD, NSW, VIC, SA

	SWIFT (n=2412)* May 2021–Jul 2025		ANZDATA (n=9633) Dec 2024		Difference (SWIFT-ANZDATA)	p-value
Characteristic	**n**	**(%)**	**n**	**(%)**		
Age, median (min, max)	68	17-99	67	18-97	+1 year	0.002
Sex, females	905	38	3688	38	0%	1.00
First Nations	186	8	881	9	-1%	0.12
Country of birth, Australia	1557	65	5886	61	+4%	0.0003
Others (S&E Europe, Oceania, S.E Asia)	855	35	3747	39	-4%	
SES, Lowest 2 deciles	640	27	2688	28	-1%	0.33
Highest 2 deciles	337	14	1306	14	0%	1.00
Comorbidities:						
CAD (yes + suspected)	1120	46	4360	45	+1%	0.38
PVD and/or CVD (yes + suspected)	962	40	3916	41	-1%	0.37
T2 Diabetes (yes + suspected)	1296	54	4771	50	+4%	0.0004

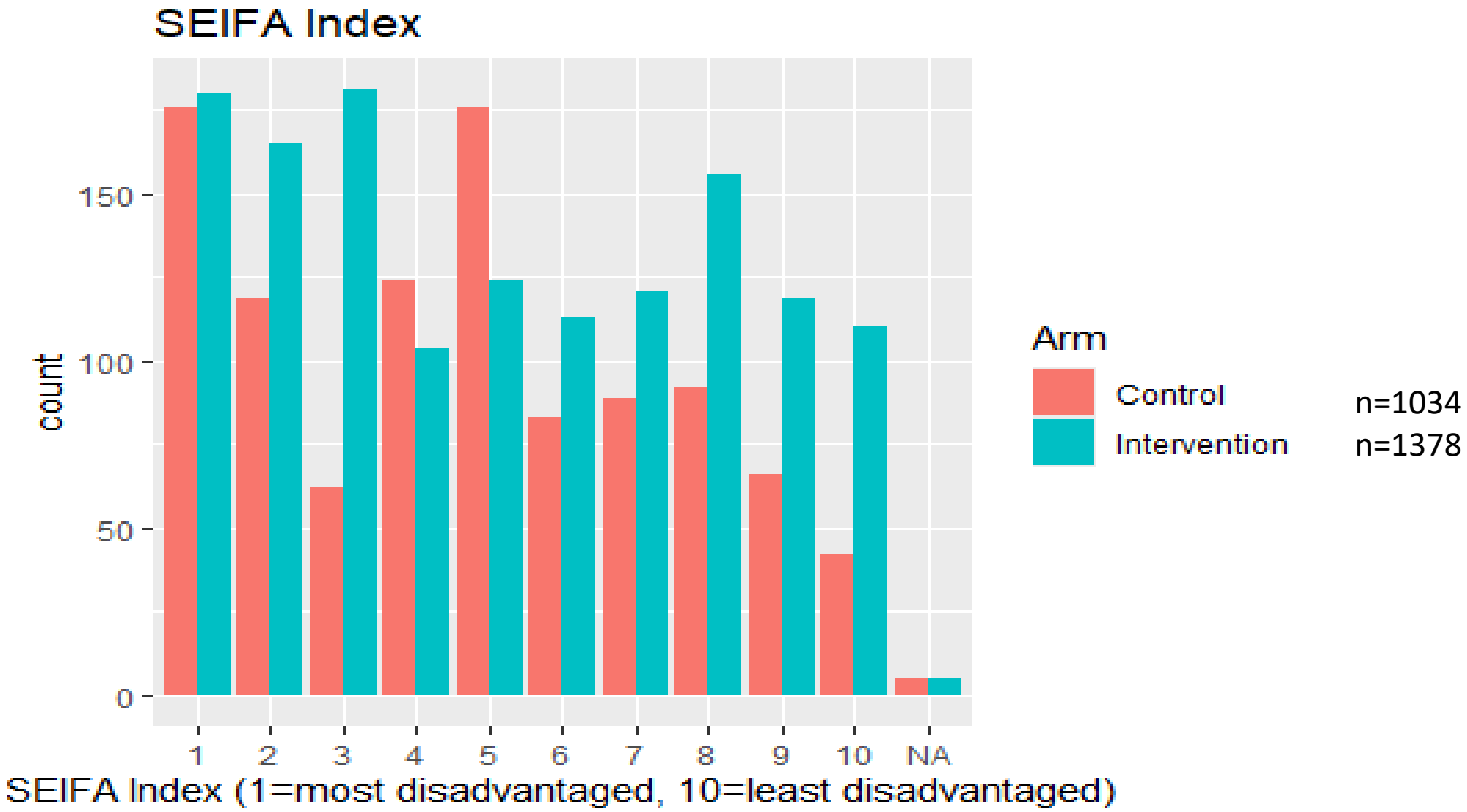
PARTICIPATING DIALYSIS CENTRE CHARACTERISTICS

*92 clusters [centres] 4 states: QLD, NSW, VIC, SA ^ >10 pts per centre

Characteristic	SWIFT (n=92)* May 2021–Jul 2025 %	ANZDATA (n=236)^ Dec 2024 %
Rural	46	46
Metropolitan	54	54
Size (large >100 dx patients)	5	3
Public	61	86
Private	39	14

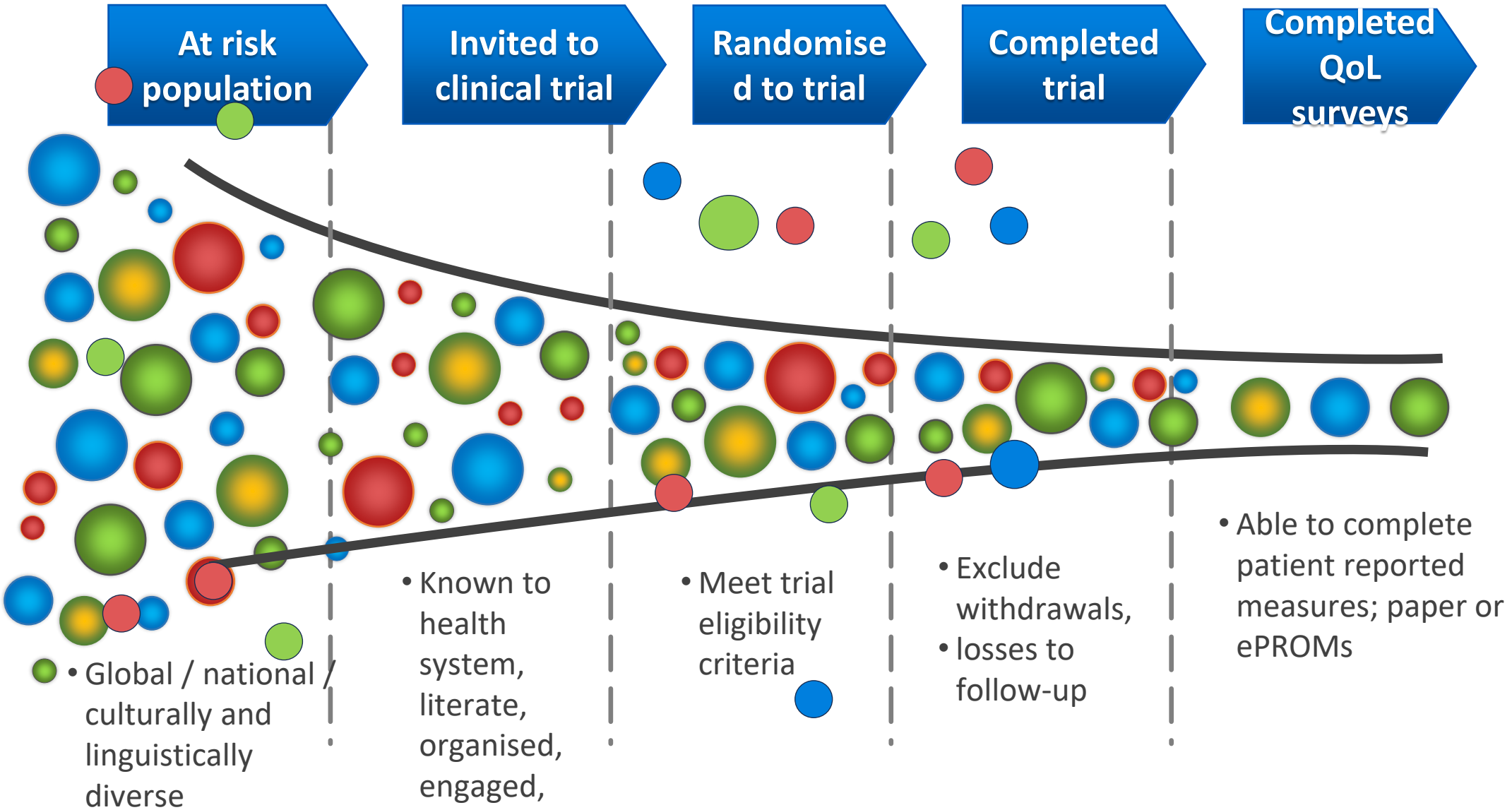
First RCT; ATP supported

SOCIO-ECONOMIC STATUS OF SWIFT PARTICIPANTS



n=1034
n=1378

SELECTION BIAS IN TRADITIONAL CLINICAL TRIALS



In SWIFT we had a more representative participant population

Trial strategies to facilitate representative recruitment included:

- consumer co-design
- few exclusion criteria
- encouragement of >90% of eligible patients in each haemodialysis unit participating
- translation of trial documents in 7 languages
- finger-sign consent on tablets
- on-site research support for electronic patient-reported outcomes data collection





أنت مدعو للمشاركة في دراسة بحثية باسم "تجربة مراقبة

Quý vị được mời tham gia vào một nghiên cứu có tên 'Thử nghiệm theo dõi triệu chứng kèm phản hồi'





Back To Research Question

Does regular symptom monitoring with feedback result in improved QOL for people on haemodialysis?



Currently analysing all data.

Trial will be completed in July 2026. Results plan to be presented at the American Society of Nephrology Kidney Week October 2026 with presentations at next RSA and ANZSN Meetings

Discussion & Conclusions

- People on dialysis suffer significant symptom burden
- Our SWIFT results highlight fatigue, insomnia and pain as most prevalent symptoms in adults receiving haemodialysis
- The SWIFT study is the largest haemodialysis trial in Australia, with participants nationally representative for age, sex, First Nations, comorbid conditions
- SWIFT will assist us in understanding what effect asking and feeding back symptoms has on patient's quality of life

Acknowledgements & Contact details

- Patients participating in the trial
- The SWIFT and ANZDATA Investigator team members, CTC operations staff
- Nursing and medical staff supporting recruitment and trial conduct
- Funders: NHMRC, Kidney Health Australia, University of Sydney

For more information:
rachael.morton@sydney.edu.au

Publications

Protocol:

Feasibility trial:

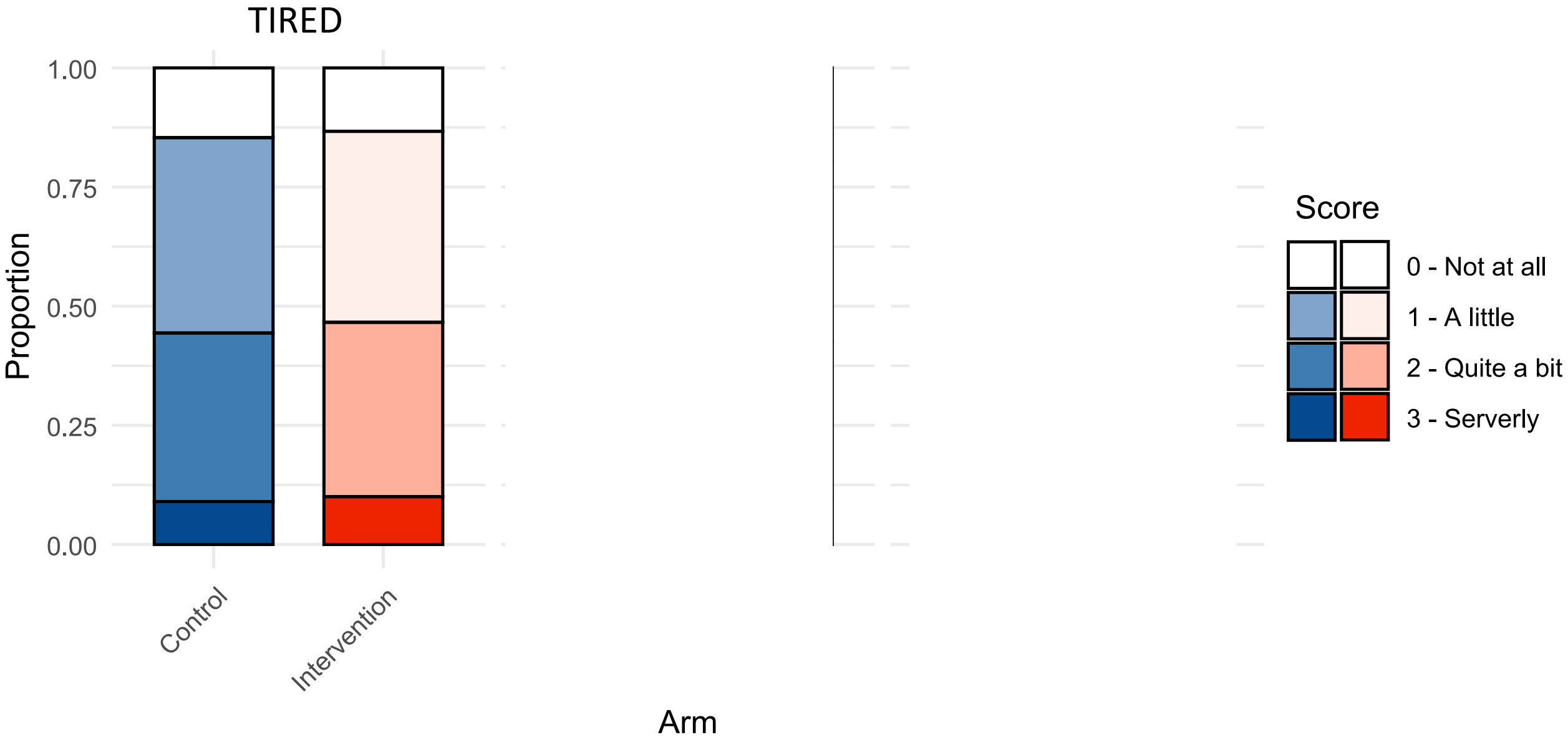
SWIFT Pilot:



THANK YOU

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Results - Baseline SONG-HD Fatigue Scores (n=2412)



BASELINE EQ-5D-5L QUALITY OF LIFE SCORES (N=2412)

