

The background features a circular arrangement of stylized, semi-transparent illustrations of medical professionals and patients. At the top, a male doctor in a white coat and tie stands with his hands on his hips. To his right, a female nurse in a white uniform stands with her hands on her hips. Further right, a male patient in a blue shirt and dark trousers stands with his hands on his hips. At the bottom, a female doctor in a white coat and tie stands with her hands on her hips. To her left, a male patient in a blue shirt and dark trousers stands with his hands on his hips. In the center, a female patient in a blue dress stands with her hands on her hips. The entire scene is set against a dark, textured background with a circular pattern of light gray lines.

# ELECTRONIC PATIENT-REPORTED OUTCOME MEASURES FOR SYMPTOM MANAGEMENT IN aCKD

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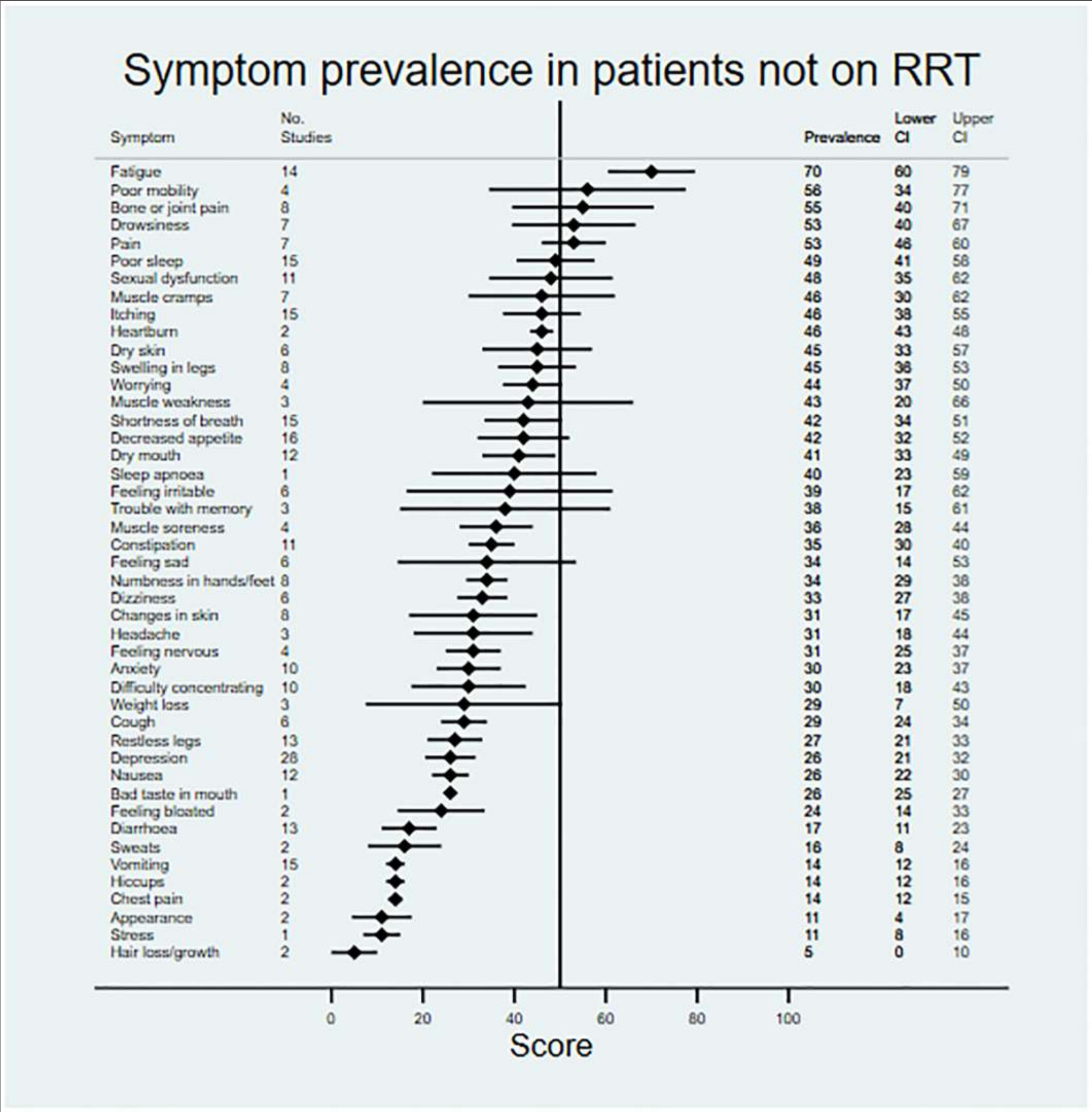
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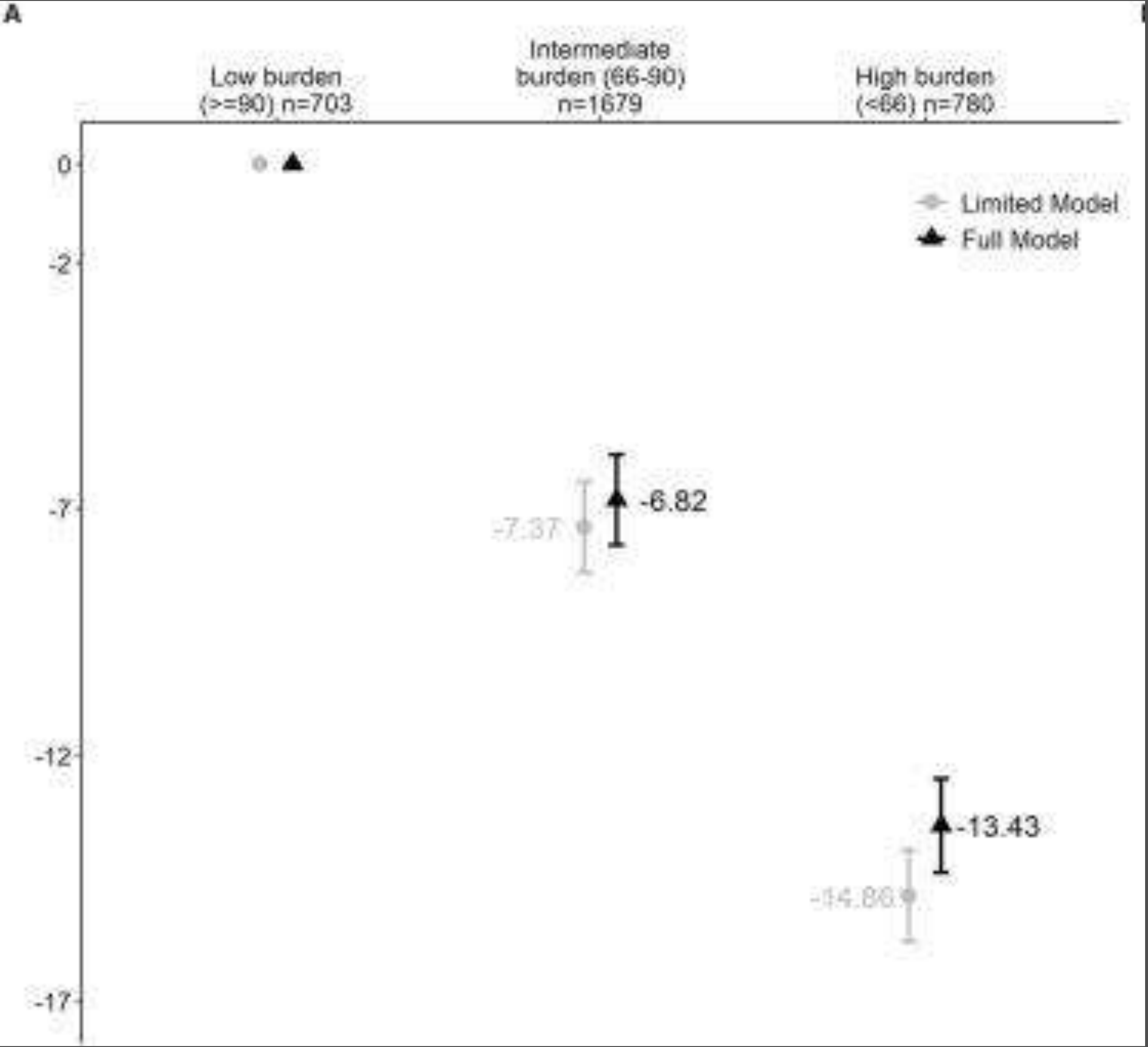
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# SYMPTOM BURDEN IN aCKD IS HIGH AND IMPACTFUL



Fletcher et al 2022 PLoS Med  
doi: 10.1371/journal.pmed.1003954

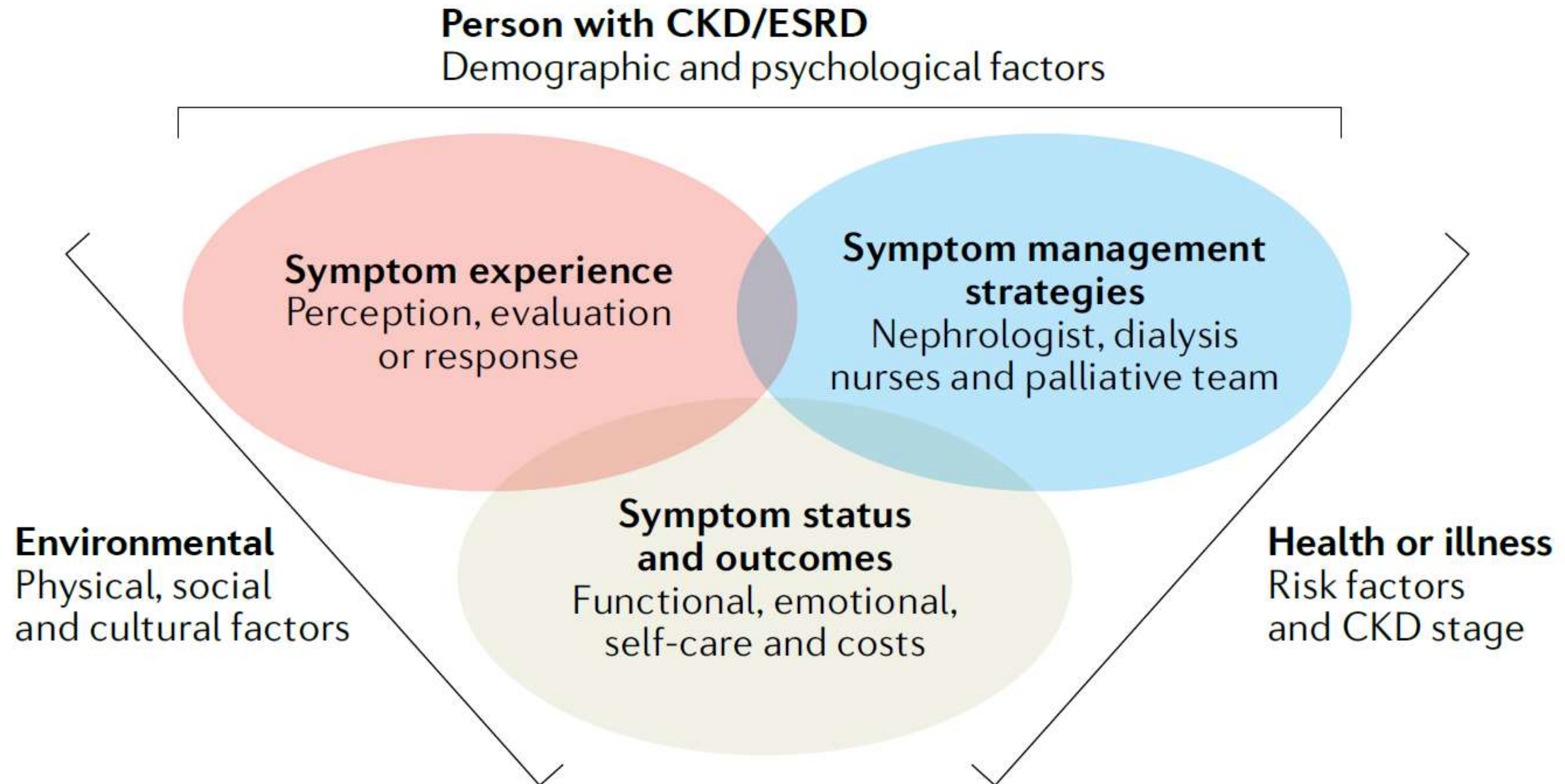


Speyer et al 2024 AJKD  
doi: 10.1053/j.ajkd.2024.06.011



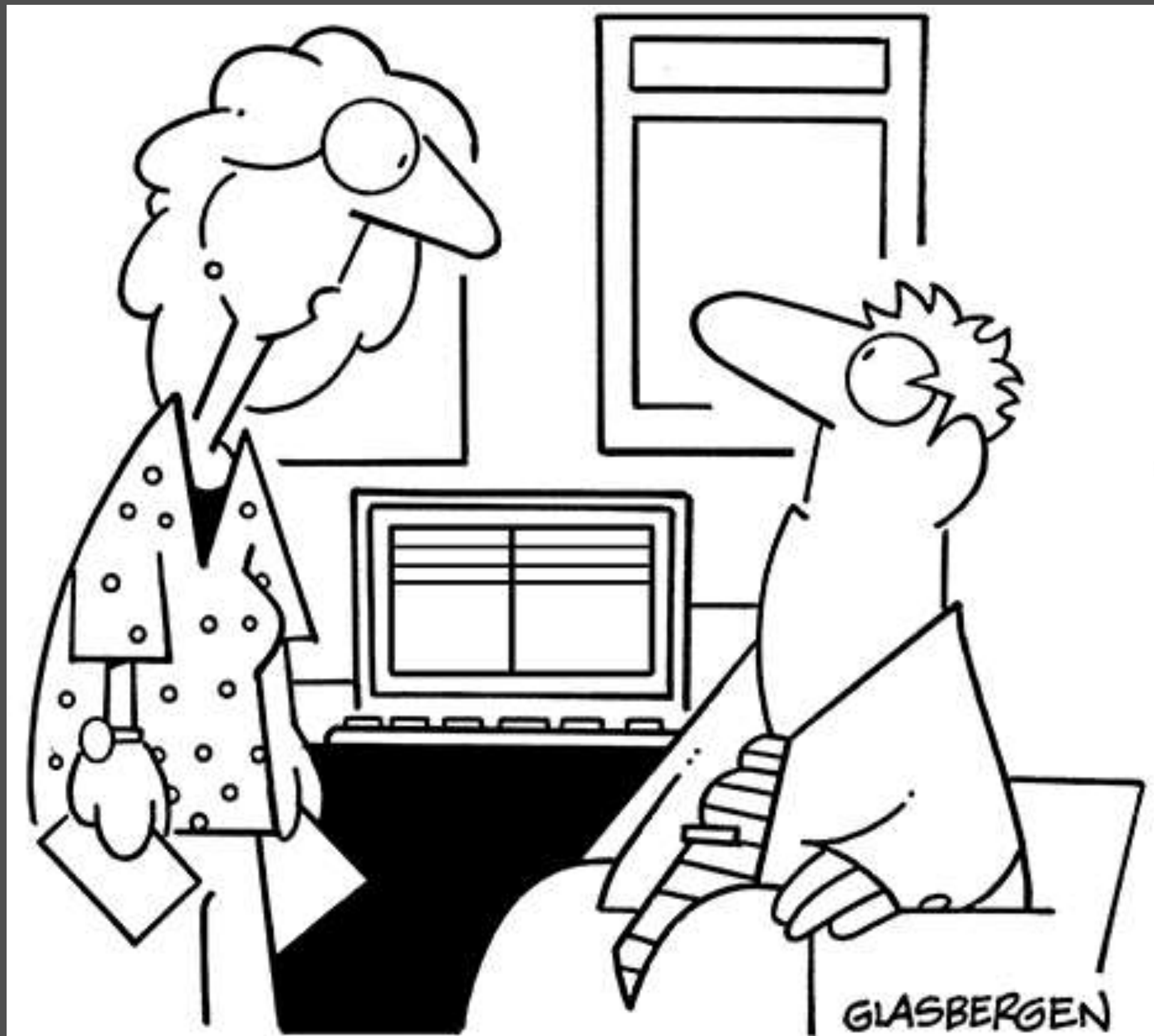
# CKD SYMPTOM MANAGEMENT

## b UCSF symptom management theory





# SYMPTOMS MAY NOT ALWAYS BE DISCUSSED IN CLINIC



"The doctor will be in shortly to type on the computer and update your chart. If he has time, he will ask how you're feeling and take a look at your rash."



Flythe et al 2018 NDT  
doi: 10.1093/ndt/gfy069

Aresi et al 2019 J Pain Symptom Manage  
doi: 10.1016/j.jpainsymman.2019.06.010

# ELECTRONIC PATIENT-REPORTED OUTCOMES (ePROMS)

*Electronic Patient-Reported Outcome Measures*  
(ePROMs) are online questionnaires that capture patients' perspectives of health, illness, and the effects of health care interventions in a reliable, valid, acceptable and feasible way.



# EXAMPLES OF AVAILABLE ePROMS

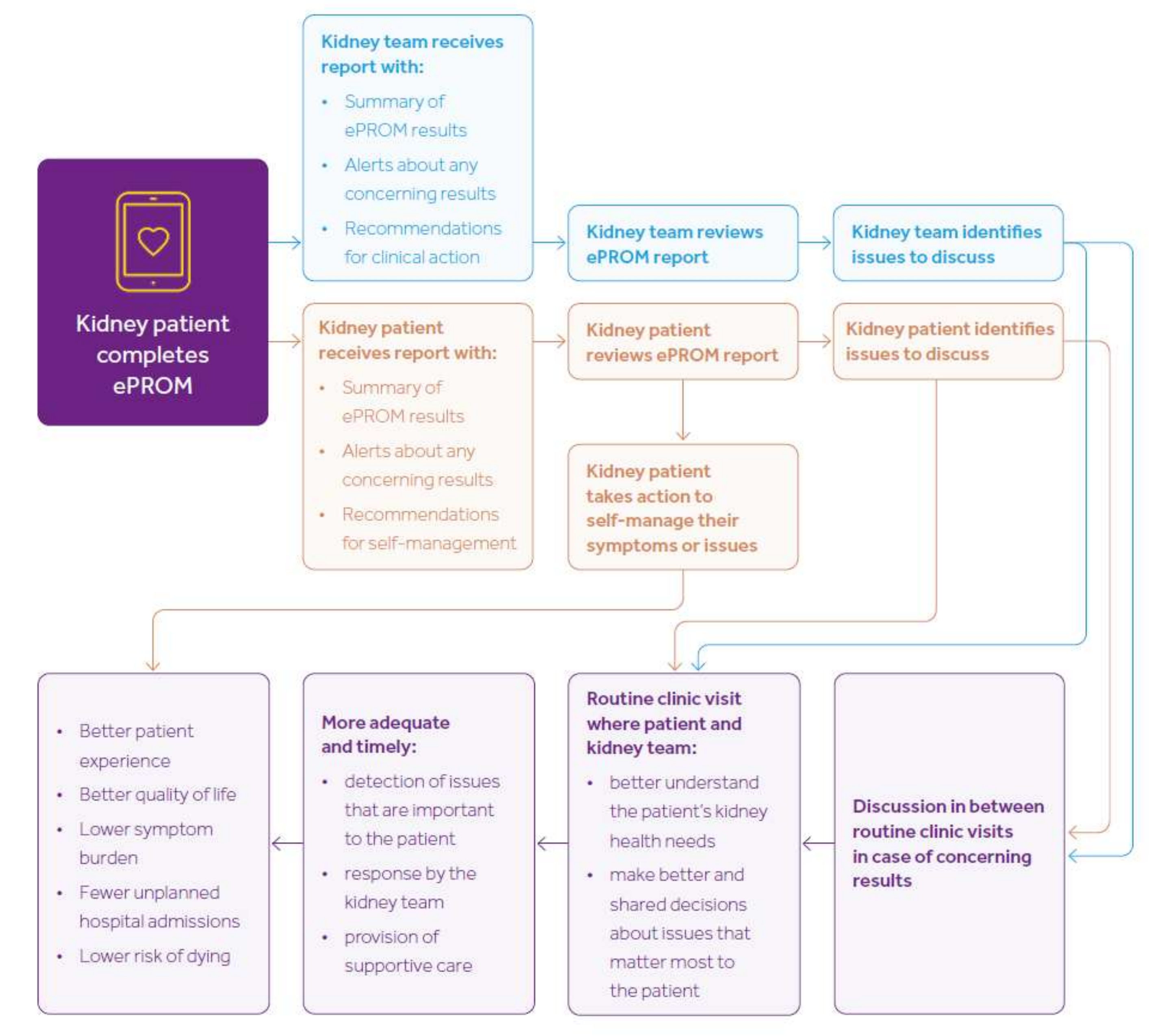
Table 3 | Tools for symptom appraisal in CKD

Type of tool	Name of tool	Details
Generic instruments	PROMIS-57	57 questions across seven quality-of-life domains (physical function, anxiety, depression, fatigue, pain, sleep and social functioning)
	Memorial Symptom Assessment Scale	Instrument designed to assess physical and emotional symptoms experienced by diverse types of cancer patients
	Rotterdam Symptom Checklist	Tool originally developed to measure the symptoms reported by cancer patients participating in clinical research
	Symptom Distress Scale	Measures constructs of symptom distress (degree of discomfort from the specific symptom as reported by the patient)
Disease-specific instruments	Kidney Disease Quality of Life Instrument (KDQOL)	134-item instrument, designed to assess quality-of-life aspects for individuals on dialysis
	Dialysis Symptom Index	30-item survey that assesses physical and emotional symptoms and their severity
	Edmonton Symptom Assessment Revised: Renal	Modified from the original tool to specifically assess the physical and emotional symptoms of patients on dialysis
	Integrated Palliative Care Outcome Scale Renal	11-item survey that combines the common symptoms experienced by patients with additional items (such as information needs, family anxiety, and so on)

CKD, chronic kidney disease; PROMIS-57, Patient Reported Outcomes Measurement Information System-57.



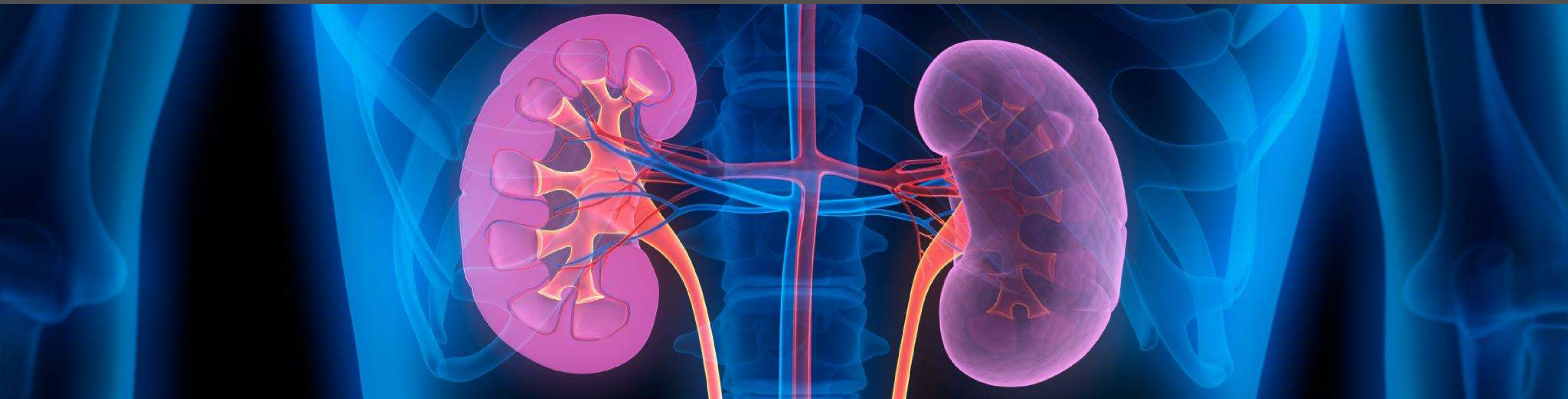
# HOW ePROMS CAN IMPROVE aCKD CARE AND OUTCOMES





# THE USE OF AN ELECTRONIC PATIENT-REPORTED OUTCOME MEASURE (ePROM) IN THE MANAGEMENT OF PATIENTS WITH ADVANCED CHRONIC KIDNEY DISEASE (CKD) – THE REPROM PILOT TRIAL

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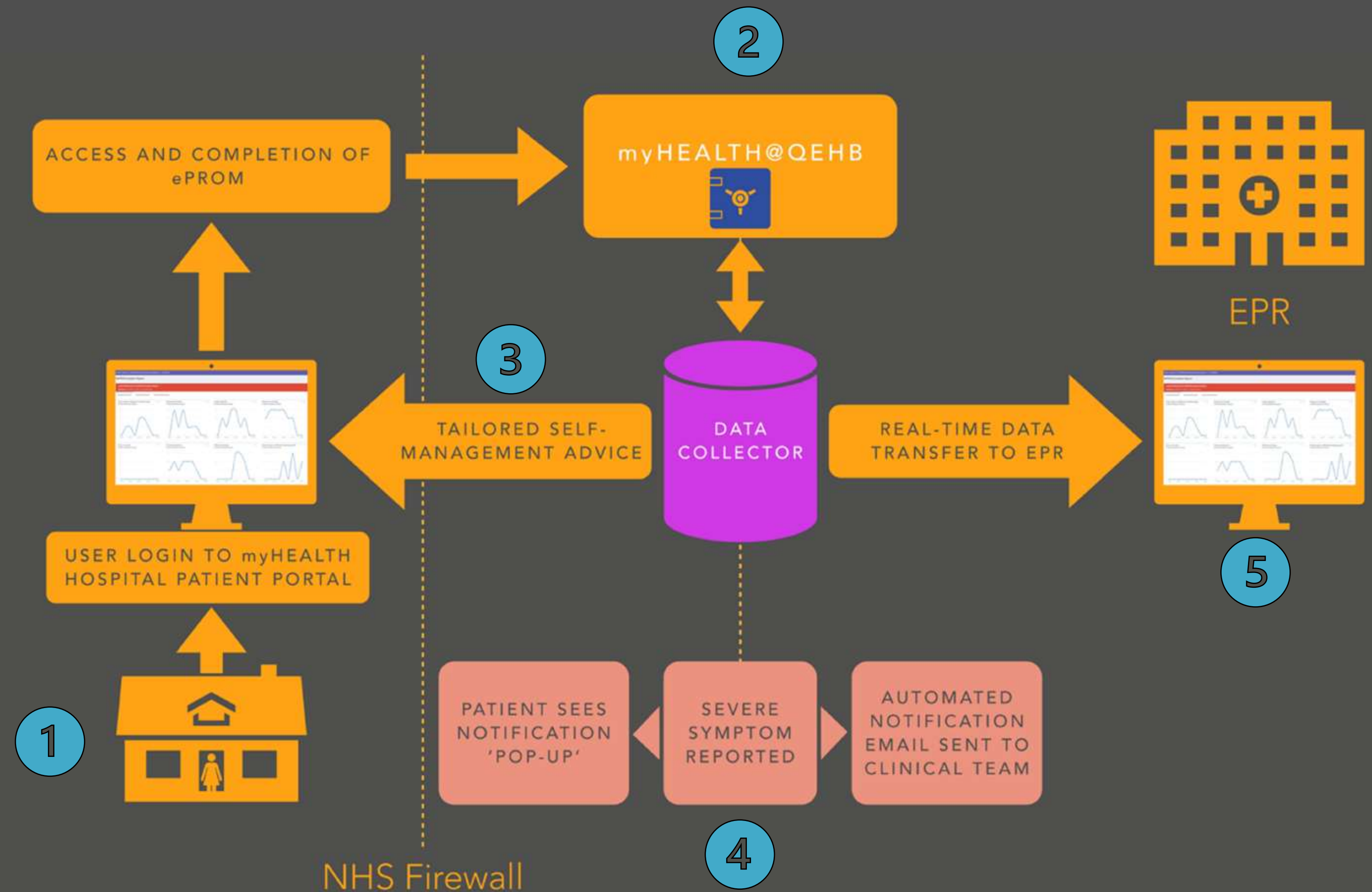
UNIVERSITY OF  
BIRMINGHAM





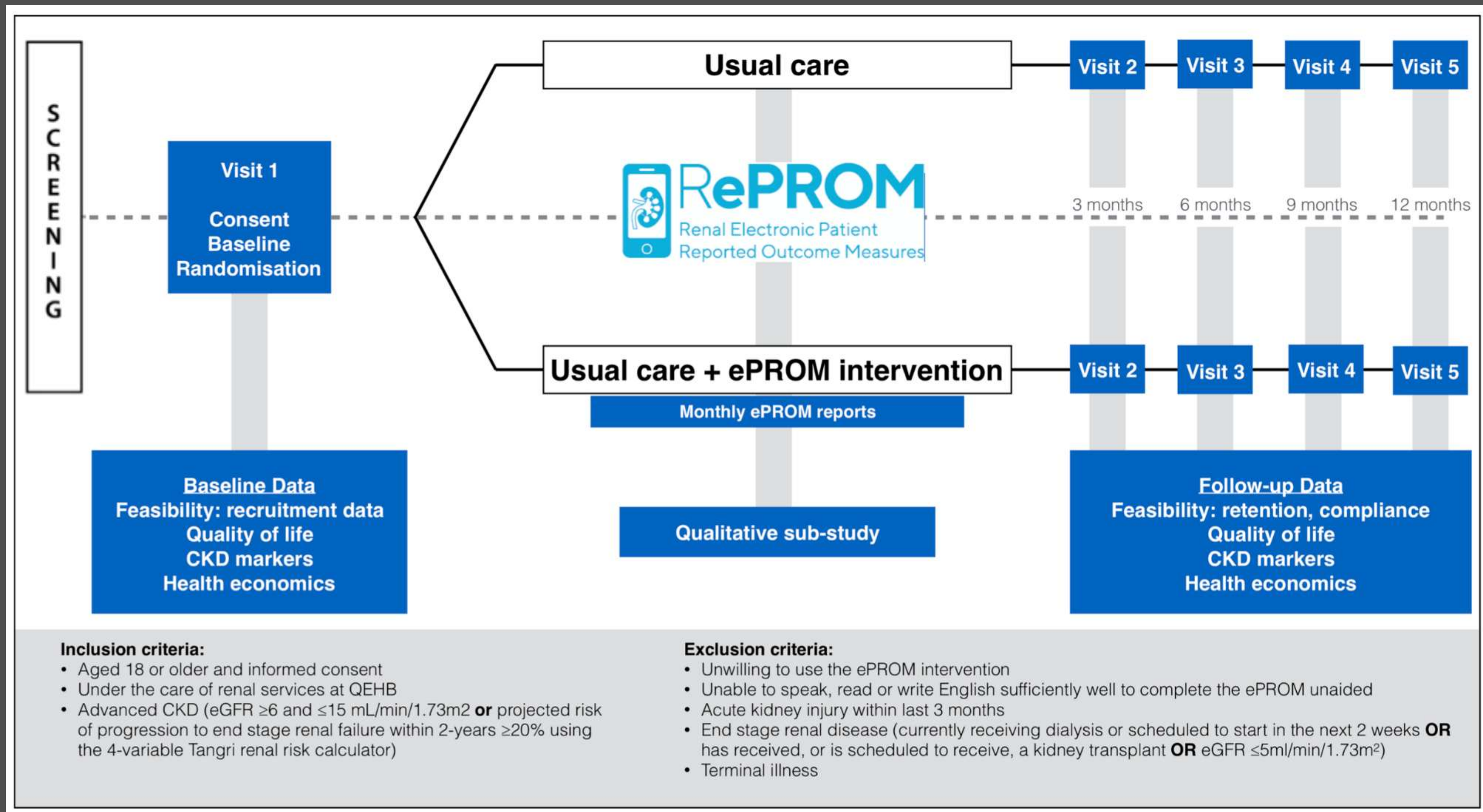
# BACKGROUND

- Advanced CKD: costly condition, significant patient burden, reduced quality of life, increased morbidity, mortality.
- Patients at risk of deterioration between clinics.
- Research question: how can we better monitor patient symptoms between hospital visits?

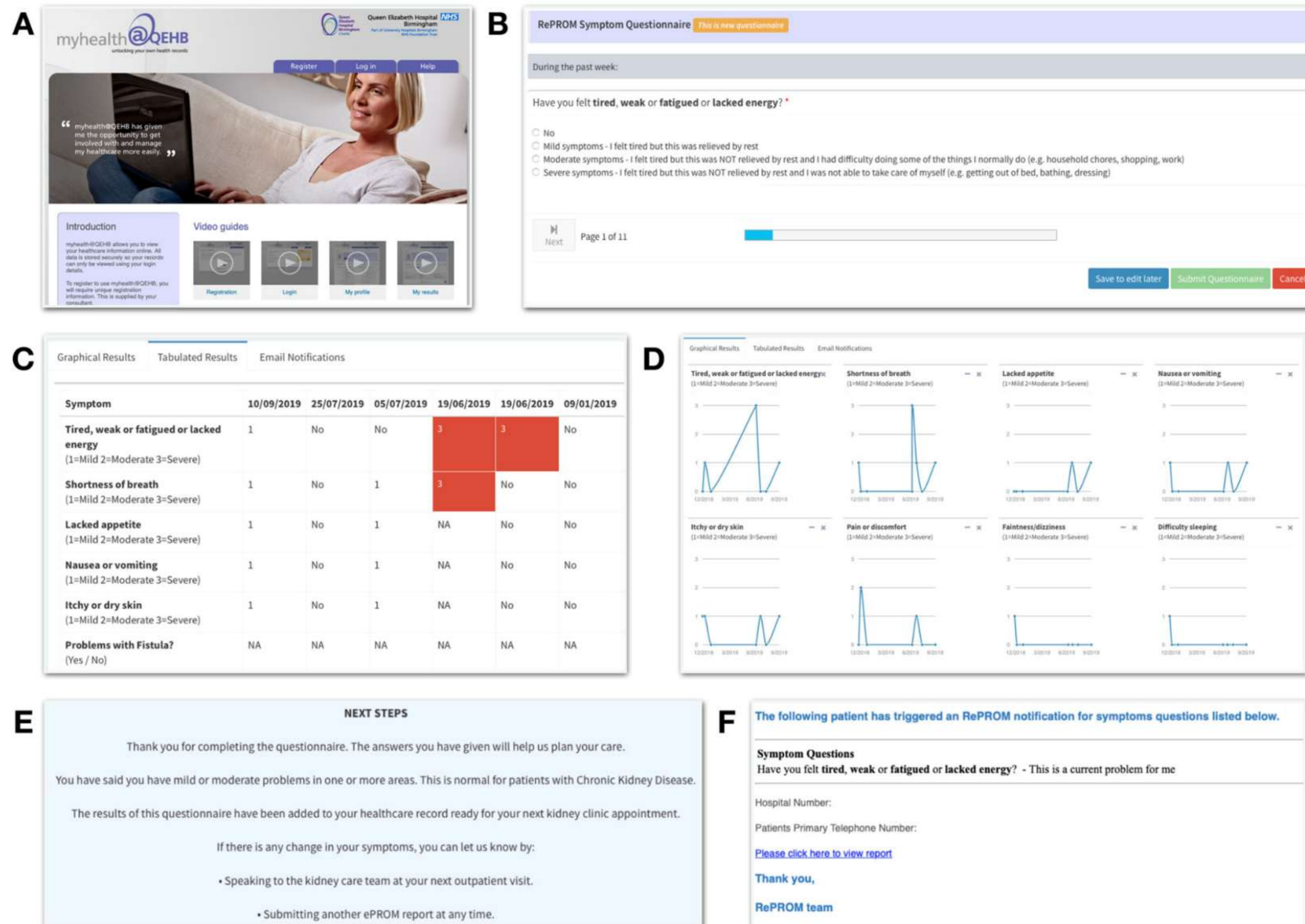




# PILOT TRIAL DESIGN







**Fig. 2** RePROM system example screenshots (dummy data). **a** myHealth home screen; **b** RePROM question page; **c** tabulated raw questionnaire data and **d** graphical display of longitudinal ePROM data, patient/clinician view identical; **e** tailored advice provided to patients upon submission of a questionnaire; **f** example of automated email notification sent to the kidney care team in response to a patient report of severe and current fatigue



# RESULTS

n = 52 patients randomised: 79% of target sample size (66); recruitment rate (of approached) = 31%; monthly rate = 4.3.

## Case Report Form (CRF) returns.

Timepoint	CRF	Expected	Received (%)
Baseline	Consent	52	52 (100)
Baseline	CRF	52	52 (100)
Baseline	EQ5D-5L	52	52 (100)
3 Month	CRF	47	47 (100)
3 Month	EQ5D-5L	47	45 (96)
6 Month	CRF	41	41 (100)
6 Month	EQ5D-5L	41	41 (100)
9 Month	CRF	29	29 (100)
9 Month	EQ5D-5L	29	29 (100)
12 Month	CRF	18	18 (100)
12 Month	EQ5D-5L	18	18 (100)

EuroQol five-level five-dimension PRO measure, EQ5D-5L.

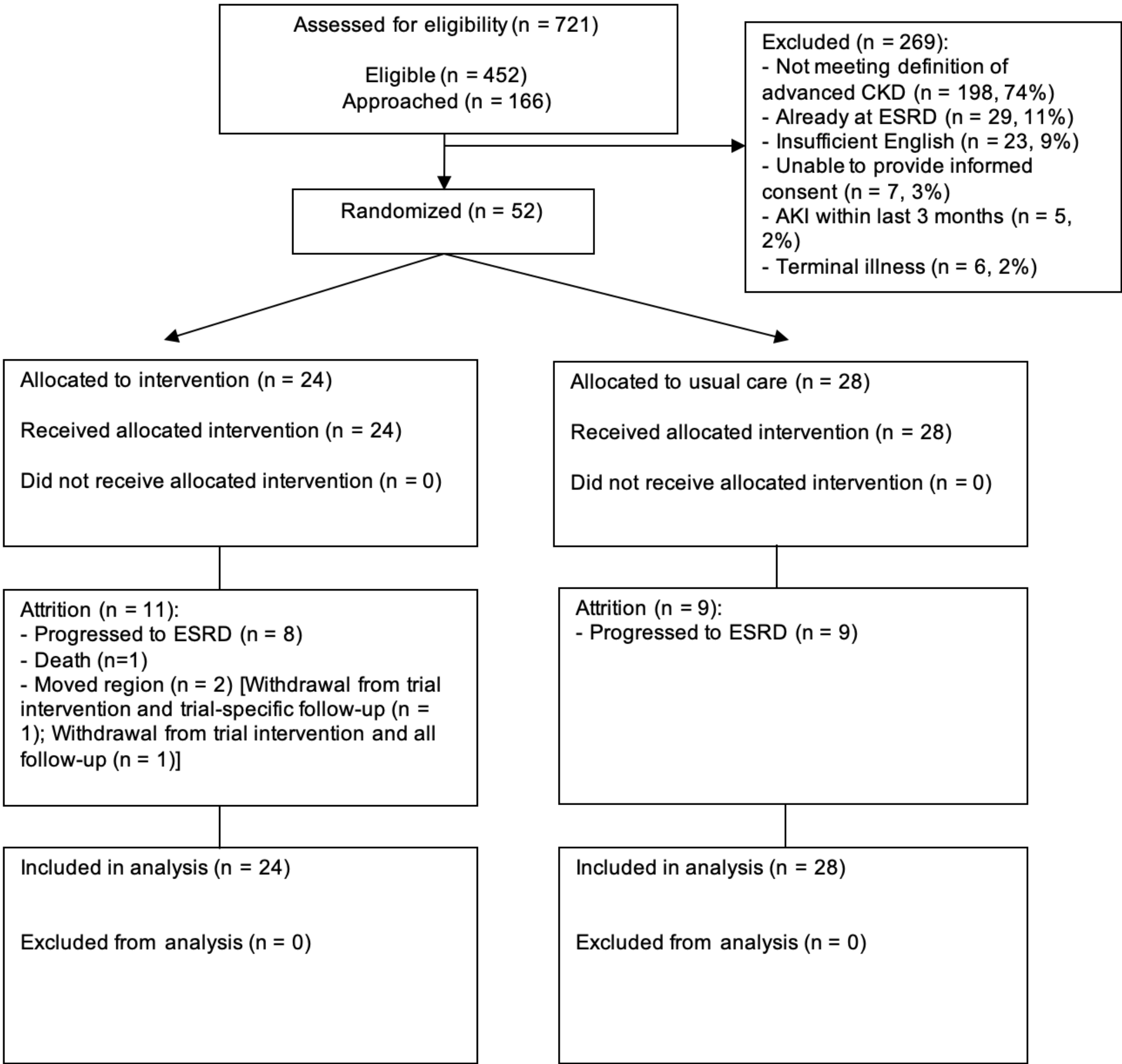
<1% missing CRFs

Enrolment

Allocation

Follow-up

Analysis





# RESULTS

Total number of expected ePROM questionnaires	Total received (% , 95%CI))	Proportion of patients submitting ePROM questionnaires >90 days (95%CI)	Proportion of patients submitting ePROM questionnaires >180 days (95%CI)	Proportion of patients submitting ePROM questionnaires >270 days (95%CI)
230	169 (73, 67-79)	74% (52-90)	65% (41-85)	46% (19-75)

## ePROM intervention: reporting pattern by symptom.

		Number of symptoms reported			
	Number of times reported	Mild (%)	Moderate (%)	Severe (%)	Proportion of total symptoms reported (N = 579)
Fatigue	135	69 (51)	60 (44)	6 (4)	23%
Shortness of breath	109	88 (81)	17 (16)	4 (4)	19%
Itchy/Dry skin	102	53 (52)	42 (41)	7 (7)	18%
Pain	87	54 (62)	29 (33)	4 (5)	15%
Lack of appetite	57	35 (61)	22 (39)	0 (0)	10%
Ankle swelling	21	11 (52)	9 (43)	1 (5)	4%
Nausea	20	13 (65)	7 (35)	0 (0)	3%
Difficulty sleeping	17	7 (41)	9 (53)	1 (6)	3%
Faintness/dizziness	11	6 (55)	5 (45)	0 (0)	2%
Restless legs or difficulty keeping legs still	10	7 (70)	3 (30)	0 (0)	2%
Diarrhoea	10	5 (50)	5 (50)	0 (0)	2%
Problems with fistula	0	0 (0)	0 (0)	0 (0)	0%
TOTALS	579	348 (60)	208 (36)	23 (4)	

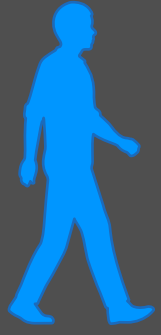
In total, n= 16 symptom ‘notifications’ from n = 5 patients.  
Median time taken to resolve = 10mins

## ePROM intervention: notification pattern by symptom.

	Number of notifications triggered for severe + current symptoms (%)
Itchy/Dry skin	6 (38)
Fatigue	4 (25)
Shortness of breath	2 (13)
Pain	2 (13)
Difficulty sleeping	1 (6)
Ankle swelling	1 (6)



# QUALITATIVE FINDINGS



## Patients with CKD

"...I was very impressed that what I had put on the form obviously had been noticed and had been picked up. And was discussed with me at clinic and I thought that was one of the big positives of the form itself." [Patient]

"...it prompted you to give the QE a ring and discuss it... you know like feeling worse and feeling tired or whatever, just to ring up and speak to somebody cause sometimes you don't... you just carry on till your next appointment. So, it made you think about it." [Patient]

"...it's nice to know that, you know... if anything is going wrong then I can get help more or less straightaway." [Patient]



## Health Care Professionals

"...RePROM... often highlighted things that were completely off the radar... it meant that you knew in advance and you were able to get straight into it, rather than it being the kind of thing that they casually mention as they're leaving the room. So, you have a bit more time to explore things in a bit more detail I think." [HCP]."

"...now our capacity to see patients face-to-face has reduced by about 75% because of the need for social distancing. So actually... something like RePROM is more important than ever because that does give patients a bit more of an ability to... to contact us and tell us things that they were worried about in between their reviews." [HCP]



# CONCLUSIONS

- Feasibility:
  - Prelim evidence of proof of concept in renal disease population: clinician response to ePROM data leading to amelioration of patient symptoms and lower levels of healthcare utilisation.
  - Satisfactory recruitment and consent rate. Clinicians willing to randomise.
  - Extremely low levels of missing data.
  - Intervention: good patient acceptance and adherence. Low clinical workload.



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- Sonja O’Brien
- Gary Price
- Keeley Sharpe
- Rav Verdi
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A background illustration featuring several stylized human figures in various poses, connected by a network of thin, light-colored lines. The figures are rendered in a simple, sketch-like style with muted colors. The overall composition suggests a collaborative or interconnected environment.

WANT TO LEARN MORE?

JOIN OUR WORKSHOP THIS AFTERNOON

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