Patient and clinician perspectives on electronic patient-reported outcome measures in the management of advanced CKD

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Patient and clinician perspectives on electronic patient-reported outcome measures (ePROMs) in the management of advanced CKD: a qualitative study

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Abstract

Rationale and Objective: Chronic kidney disease (CKD) can significantly affect patients' health-related quality of life (HRQOL). Electronic patient-reported outcome measures (ePROMs) may capture symptoms and HRQOL, and assist in the management of CKD. This study explored patient and clinician views on the use of a renal ePROM system.

Study Design: Qualitative study.

Setting & Participants: Twelve patients with stage 4 or 5 CKD (pre-dialysis); 22 clinicians (6 CKD community nurses, 1 clinical psychologist, 10 nephrologists, 3 specialist registrars and 2 renal surgeons) in the United Kingdom.

Analytical Approach: Semi-structured interviews and focus group discussion during which patients received electronic versions of the Kidney Disease Quality of Life-36 (KDQOL-36) or the Integrated Patient Outcome Scale-Renal (IPOS-Renal) to exemplify the type of content that could be included in an ePROM. Thematic analysis of interview transcripts.

Results: Four themes were identified: (i) general opinions of PROMs; (ii) potential benefits and applications of an ePROM system; (iii) practical considerations for the implementation of ePROMs; and (iv) concerns, barriers and facilitators. Patients were willing to complete ePROMs on a regular basis as part of their care despite clinician concerns about patient burden. Patients assessed the questionnaires favourably. Clinicians suggested that the extent of adoption of renal ePROM systems in routine clinical settings should be based on evidence of significant impact on patient outcomes. Clinicians were concerned that an ePROM system may raise patient expectations to unrealistic levels and expose clinicians to the risk of litigation. Patients and clinicians identified potential benefits, highlighted issues and concerns that need to be addressed to ensure the successful implementation of the renal ePROM system.

Limitations: Transferability of the findings may be limited as only English-speaking participants were recruited to the study.

Conclusions: A renal ePROM system may play a supportive role in the routine clinical management of patients with advanced CKD if the concerns of clinicians and patients can be sufficiently addressed.

INDEX WORDS: Chronic kidney disease; CKD; renal disease; chronic renal failure; interview; focus group; qualitative research; health-related quality of life; HRQOL; QOL; patient-reported outcome; PRO; electronic patient-reported outcome measures; ePROM.

Plain language summary

Patients with advanced chronic kidney disease often experience clusters of symptoms and impaired health-related quality of life (HRQOL) as their kidney function deteriorates. Remote electronic monitoring of patients' symptoms may facilitate communication between patients and the clinical team, and allow early interventions to manage symptoms; potentially delaying deterioration in kidney function and improving HRQOL. To ensure that our ePROM system met stakeholder needs we interviewed patients and clinicians to seek their opinions regarding system design as well as barriers and facilitators to implementation. Clinicians and patients were supportive of the proposed system suggesting that a renal ePROM system may play a supportive role in the clinical management of patients with advanced kidney disease.

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Introduction

Patients with chronic kidney disease (CKD) commonly report 'clusters' of non-specific symptoms such as pain, fatigue and pruritus[7 8] , which may adversely affect their physical, emotional and psychological well-being[9] and significantly impair health-related quality of life (HRQOL).[10]

While 'hard' parameters such as estimated glomerular filtration rate (eGFR) are established routine indicators of health status,[11] these may not fully capture the impact of disease on patients' symptoms and HRQOL.[6 12 13] Thus, there has been a growing move towards patient-led provision of HRQL and symptom data using validated self-reported questionnaires known as patient-reported outcome measures (PROMs).[6 14] In recent years, there has been increasing interest in the use of PROMs in routine renal practice.[15 16]

With rapid information technology developments , collection of electronic PROMs (ePROMs) via digital platforms – e.g. personal computers, smartphones and tablets[6] – is increasingly common. This 'real-time' data could assist with timely tailoring of treatment to individual patient needs and may reduce unnecessary clinical appointments in stable patients.[6 18] In addition, the use of ePROMs may promote patient-centred care by aiding identification of health-related issues of priority to patients, facilitating patient-clinician communication and shared-decision making.[6 19-21]

The aim of this qualitative study was to explore the perspectives of patients and clinicians on the use of a renal ePROM being developed by the Centre for Patient Reported Outcomes Research, University of Birmingham and University Hospitals Birmingham NHS Foundation Trust (UHB), in the UK. The objective was to gain valuable insights to inform the design, implementation and delivery of such a system within routine clinical practice.

Methods

Participant selection

Participants at the host site (UHB) were recruited and data collected and analysed simultaneously between August 2017 and May 2018 according to the published protocol (ethical approval [13/02/2017] ref: 17/WM/0010).[30] Consenting, English-speaking, adult patients with stage 4 and 5 CKD (pre-dialysis) were purposively recruited as we hypothesised that a cohort, with high symptom burden and risk of rapid progression to end-stage renal disease (ESRD), would benefit most from the ePROM system.[30] A third of patients were recruited from minority ethnic groups to reflect the diversity of the patient catchment area, as highlighted in the recent Renal Impairment In Secondary Care (RIISC) cohort study where 32% of the patients were from minority ethnic backgrounds.[31] UHB Renal clinicians were recruited through a combination of purposive and snowball sampling:[32] where clinicians known to the research team were contacted directly and those who agreed to be interviewed were asked to suggest other potentially eligible colleagues.

Data collection

All participants were provided information sheets which explained the study aim/objectives and also outlined the UHB ePROM system under development (Figures S1 - S3). They had the opportunity to ask questions before signing the consent forms prior to any interview/focus group.

All interviewees were provided with advance copies of the Kidney Disease Quality of Life-36 (KDQOL-36) and Integrated Patient Outcome Scale-Renal (IPOS-Renal) questionnaires to aid discussion. These questionnaires were selected, following review of the literature[33 34] and discussions with the project patient advisory group, to provide participants with an idea of the type of content that could be included in the ePROM system. The KDQOL-36 has strong

evidence for internal consistency and moderate evidence for construct validity[33] while the IPOS-Renal was reported to have good evidence for test-retest reliability, internal consistency, and construct validity.[34] Interviews/focus groups were conducted in accordance with relevant topic guides, developed based on findings from existing literature and discussions within the research team (Boxes 1 & 2). OLA conducted audio-recorded semi-structured face-to-face or telephone interviews with patients according to their preference. A focus group and semi-structured interviews were held with clinicians. Focus groups were not conducted with patients as it was felt some might have found it distressing to discuss their condition within a group setting.[35]

Data analysis

Thematic data analysis was conducted by OLA[36] alongside data collection, providing an opportunity to refine the topic guide in response to findings.[37] Initial coding was reviewed by DK and MC prior to further analysis supported by the Nvivo 11 Plus software package by QSR International. As data analysis progressed, OLA grouped the codes into categories, subthemes and themes. These were regularly discussed with members of the research team and modified where deemed appropriate. Data collection and analysis continued until data saturation was achieved for both participant groups.[39 40] At this point, no new concept-relevant information was elicited from analysing additional interview data.[41 42] Saturation tables, which documented the initial and subsequent occurrences of codes, were used to assess data saturation.[41]

Results

Study participants

Participant characteristics are summarized in Tables 1-2 and interview characteristics/saturation data in Table 3. Focus group members were predominantly female nurses. For this reason, we invited medical doctors for interviews and targeted male doctors in order to minimise the potential risk of non-response bias and increase the diversity of our sample. Examination of the saturation data (Supplementary tables S1 & S2) throughout the study suggested that (i) saturation was reached at the 10th patient and 12th clinician interviews (ii) there were no appreciable differences in the views held by nurses and doctors, and (iii) no gender differences in the views held by participants.

Themes

Four themes were identified in the interviews/focus group: (i) general opinions of PROMs; (ii) potential benefits and applications of ePROMs; (iii) Practical considerations; and (iv) concerns, barriers and facilitators. Themes and sub-themes are presented below, illustrative quotations are provided in Table 4 and supplementary Table S3. Figure 1 illustrates the conceptual relationships between the themes. Specific comments KDQOL-36 and the IPOS-Renal questionnaires are provided in supplementary file S4.

General opinions of PROMs

The role of PROMs in healthcare (clinician-generated)

Most clinicians welcomed the idea of incorporating symptoms/HRQOL assessment into clinical practice as they believed that clinical parameters may not fully capture the impact of CKD on patients nor reflect outcomes regarded as important by patients (q1). Some clinicians felt that the use of ePROMs would play an important role in the continued digitisation of healthcare (q2).

Knowledge and experience of PROMs (clinician-generated)

Knowledge and experience of PROMs varied among clinicians. Only four doctors stated that they had used PROMs for research and only one stated that they had used a PROM for routine clinical practice. Majority of clinicians expressed a keen interest PROMs research and the findings of this present study (q3).

Cautious optimism (clinician-generated)

Although majority of clinicians acknowledged the importance of assessing HRQOL, some believed that PROMs were of limited benefit in routine clinical practice (q4). They perceived PROMs as a useful adjunct to traditional clinical management but insufficient on their own for obtaining research funding or changing health policy (q5).

Criticism of PROMs (clinician-generated)

One doctor argued that PROMs do not capture HRQOL as they are: (i) incapable of measuring the gap between patient health experience and aspirations; and (ii) not truly ‘patient-reported’ as the questions are not generated by the individual patient and so may not be important to them (q6). The individual went on to speculate that PROMs gained

prominence due to time pressures and reluctance or inability of clinicians to communicate effectively with patients (q7).

Comparison with history taking (clinician-generated)

Some doctors compared the administration of PROMs with traditional history taking, maintaining that the latter remains the model for patient-clinician interactions. They described PROMs as a structured way of asking the same questions they would ask during a clinical consultation (q8). The key difference was that "you *[the doctor]* ask them a series of questions that *you* select". In other words, the questions asked during a clinical consultation are questions the doctor deems important.

Potential benefits and applications of ePROMs

Potential benefits (patient and clinician-generated)

Patients and clinicians asserted that employing an ePROM system could improve or open lines of communication between patients and clinicians as well as providing clinicians with an insight into patient experiences and care priorities (q9). They believed that ePROMs could generate early warnings of deterioration in patients' condition and detect psychological distress in patients (q10, 11).

Patients with stable CKD suggested that the use of an ePROM system could potentially reduce the frequency of their hospital appointments and in turn the need to take time off work (q12). Clinicians agreed with patients on this point with the proviso that such patients were made aware of the symptoms of deterioration and had mandatory laboratory tests done (q13). Some patients felt this would facilitate self-monitoring and management; aspects of care they believed were currently neglected (q14). Patients and clinicians believed that the regular

completion of an ePROM would raise the level of CKD awareness and self-reflection among patients (q14, 15).

Some clinicians proposed that ePROM use could help focus clinical consultations on issues prioritised by patients and reduce time pressures (q16).

Determinants of benefits (patient and clinician-generated)

Clinicians concluded that the utility of an ePROM system would depend on the manner and purpose of its use, the consultation style of individual doctors, and the personalities of patients (q17). They felt that ePROMs may facilitate communication with patients and promote rapport in situations where the clinician was unfamiliar with the patient (q18).

Potential Applications (clinician-generated)

Clinicians suggested ePROM systems could assist with the remote monitoring of patient symptoms and response to treatments, and provide additional information to review during the regular Multidisciplinary Team (MDT) meetings (q19, 20). They believed ePROMs could play a vital role in the conservative/palliative management of patients where symptoms/HRQOL is the focus rather than clinical outcomes (q21).

Practical considerations

Administration of ePROMs (patient and clinician-generated)

While there was no consensus on the optimal frequency of administration, patients and clinicians generally felt that it would become burdensome if an ePROM was administered more frequently than on a monthly basis. Some participants reasoned that the frequency of administration would depend on disease trajectory in individual patients with stable patients requiring less frequent administration. However, they pointed out that deteriorating patients,

who may require closer monitoring, might be unwilling to complete ePROMs due to the burden of illness (q22, 23). There were suggestions that patients could complete an ad-hoc ePROM if they felt unwell rather than wait for the next fixed time interval (q24). Some participants felt the frequency could coincide with patients' follow-up so that clinicians have the results to review before hospital appointments. Patients and clinicians agreed that the best time to complete an ePROM was at home prior to a clinical appointment away from the pressures of busy clinics and interference from medical staff (q25). The general opinion of patients and clinicians was that everyone involved in a patient's care, including the patient, should have access to ePROM data (q26).

Participants pointed out that some patients might not be able or willing to complete ePROMs due to age, computer literacy, access to the internet and electronic devices, and language difficulties. While most patients expressed a strong preference for ePROMs, a few preferred paper questionnaires but were willing to complete ePROMs (q27). Some participants speculated that family members who assist patients with the completion of ePROMs may influence the results obtained (q28).

Feedback (patient and clinician-generated)

Patients felt that receiving feedback on their ePROM reports would help them understand and monitor their condition better, while clinicians would like feedback on the effectiveness of their response to ePROMs data (q29, 30).

Interpretation of ePROM data (clinician-generated)

Many clinicians discussed the interpretation of ePROMs data giving examples of how they would interpret responses to certain questions (q31). A clinician mentioned the difficulty with interpreting and understanding the clinical significance of summary scores and score changes, particularly if clinicians were unfamiliar with PROMs (q32).

Presentation of ePROM data (clinician-generated)

Clinicians believed that ePROMs data should be provided within the electronic health care record to encourage clinician uptake. They suggested pictorial representation specifically; graphical and colour-coded 'traffic light' formats which were seen as quick and easy to review. A 'traffic light' format could have the additional benefit of providing triggers or alerts if there was a significant change in a patient's condition (q33-35).

Concerns, potential barriers and facilitators

Concerns (patient and clinician-generated)

One patient was convinced that patients generally 'want to keep the doctor happy' and so may provide very positive responses which they believe will please their doctor and protect their existing relationship (q36). This was echoed by some doctors who stressed the importance of patients completing their ePROMs in the absence of their doctor to ensure that they provide 'truthful' responses.

Although patients identified data security and patient confidentiality as potential issues, they did not appear unduly concerned by them (q37).

Clinicians worried about the potential burden on very ill patients who may struggle to complete ePROMs (q38). One clinician argued that improving patient's HRQOL (e.g. reduced frequency of dialysis) might worsen patients' clinical parameters which would have a negative effect on the monthly assessment of clinicians' performance (q39). There were concerns that ePROMs might generate more work for clinicians and lead to an increase in psychological/psychiatric referrals (q40, 41). Some clinicians worried about charges of clinical negligence and the risk of litigation if ePROM results were not acted upon and patients experience adverse outcomes (q42).

Some clinicians suggested that an increased focus on patients' emotions and psychological wellbeing through the use of ePROMs could lead to the medicalization of what they believed to be normal reactions to illness (q43). Some feared that using ePROMs may unwittingly raise patients' expectations beyond what they considered to be achievable (q44).

Potential barriers (patient and clinician-generated)

A lack of interest in the ePROM system, a dislike of information technology, limited capabilities or access to the internet/electronic devices were identified by patients as potential barriers (q45).

Some patients speculated that individuals with relatively stable disease would be less inclined to complete an ePROM on a regular basis (q46). This contradicted the suggestion by patients with lived experience of 'stable' CKD that they would rather complete an ePROM report on a regular basis than take time off work to attend clinic appointments (q12).

Clinicians felt that the current 'alert fatigue' as a result of numerous alerts being provided in Clinical Portal may cause clinicians to ignore ePROM results and alerts (q47). Some believed that clinician discomfort broaching issues outside of physical symptoms may be a potential barrier (q48). The perception was that there are tight limits to what is achievable; limited financial resources and time pressures during clinical consultations were considered potential barriers (q49, 50).

Potential facilitators (patient and clinician-generated)

Patients felt that the provision of explanations of the significance of questions and results would encourage them to complete ePROMs on a regular basis (q51).

Clinicians believed that evidence of impact on patient outcomes would be the strongest facilitator for the adoption of ePROMs. It was acknowledged that such hard evidence would

take time to generate but anecdotal or preliminary evidence would suffice in the meantime (q52).

The provision of clear guidelines on how to interpret ePROM results and address issues raised was also suggested as a facilitator (q53, 54). Nurses asserted that buy-in by doctors and their involvement in the design and implementation process was crucial (q55). Easy access to ePROMs results and providing patients with paper option were also cited as potential facilitators (q56, 57).

Discussion

This study explores the views of patients and clinicians on the use of an ePROM system in the clinical management of patients with advanced CKD. Consistent with previous literature, patients welcomed the idea of completing ePROMs on a regular basis as part of their care.[43] They believed ePROMs could help clinicians manage their care more efficiently and effectively. A notable finding was the interest expressed by some patients in using ePROM data to improve their knowledge of CKD to facilitate self-monitoring and management.

Although, as reported by other studies, most patients expressed a preference for ePROMs over paper questionnaires,[28 46] patients and clinicians stressed the need to provide a paper option for patients unable/unwilling to complete ePROMs. Studies have shown that response rates can be optimised when electronic and paper formats are provided and reminders are utilised.[18 47 48]

Whilst all the clinicians interviewed had research experience, their overall clinician knowledge and experience of PROMs in clinical research or routine practice was limited. Whilst most clinicians agreed on the potential benefits of ePROMs, they were cautious about

their real life performance in practice. The consensus was that renal ePROM systems could become a vital adjunct in the clinical management of patients, providing there was compelling evidence of their usefulness. This demonstration of value has been recommended as an important facilitator for the adoption of ePROM systems.[49] Clinicians in the study believed there was little evidence to support the use of PROMs in routine renal practice. However, this is not the case, as recent research suggests that ePROMs may detect clinically relevant changes in patients receiving dialysis.[6 50] In Denmark the use of an ePROM system (Ambuflex), led to a 50% decrease in follow-up hospital visits.[47] In other areas, a recent ePROM trial demonstrated improved survival, HRQOL, and reduction in hospitalization in patients with cancer undergoing chemotherapy.[12]

Some clinicians were concerned that ePROMs could potentially raise patient expectations beyond what is achievable in daily practice. However, most of the patients interviewed understood, through first-hand experience, the chronic and progressive nature of their condition, and the challenges facing the health system. Some clinicians were concerned that evaluating psychological domains in patients might lead to a 'medicalization' of what *they* consider as normal responses to illness. The assumption that clinicians are able to distinguish between 'normal' and 'abnormal' responses has been questioned;[51] patients often see different doctors at each clinic appointment and so may be unable to forge relationships that could enable the detection of deviations from 'normal' responses.[51] Some clinicians felt that the evaluation of these domains would be helpful as they believed that renal doctors were either unskilled at detecting and addressing psychological problems or reluctant to explore these issues due to factors such as time constraints and personal discomfort. While medicalization of normal emotional responses may be an unintended consequence of evaluating patients' emotional and psychological status, this may be unlikely if appropriate thresholds are set for the ePROM system and suitable training provided.[52 53] Moreover, it has

been shown that the emotional self-awareness gained from self-monitoring may reduce depression in patients.[54]

Clinicians pondered the issue of providing appropriate response to ePROMs data particularly results relating to psychological domains. While making referrals to appropriate specialists appeared as the obvious solution, some felt this could lead to excessive referrals being made. This is a valid concern as a substantial increase in referrals would place greater burden on limited resources. However, this may be unlikely if appropriate thresholds are set. Others worried about the potential risk of litigation if ePROMs data is not acted on and patients suffer unforeseen adverse outcomes such as suicide. The worry about litigation and charges of medical negligence is an important consideration which may influence clinician adoption of the ePROM system. The risk of litigation could be minimised if prior to full system implementation appropriate care protocols are developed for clinicians and patients are provided information for emergency situations. Unsurprisingly, clinicians requested clear guidance on meaning of and the appropriate response to ePROMs data as recommended in literature.[55 56]

In order to be fit for purpose the ePROM system needs to be efficient, effective and satisfactory for stakeholders.[58 59] If appropriately addressed, these study findings could assist with the design and implementation of the renal ePROM system, improve its usability, facilitate stakeholder adoption.[60] Although the study focuses on ePROMs, majority of the key findings are applicable to the use of PROMs in routine clinical practice regardless of format. While we have selected the KDQOL-36 and IPOS-Renal for this project, there are other renal-specific PROMs in use such as the CHOICE Health Experience Questionnaire (CHEQ) and the Edmonton Symptom Assessment System (ESAS).[33]

Patients with stages 4 and 5 (pre-dialysis) CKD were interviewed as they represented our target population for the intervention. Further research is necessary to see if similar views are held by patients with stages 1-3 CKD, or patients receiving renal replacement therapy for ESRD. In addition, this study was conducted during the early stages of system development therefore, participant opinions may differ post-implementation and may not reflect those held in settings where ePROMs are already implemented. While the focus group was all-female and the majority were nurses, their opinions on the key issues were confirmed by the mostly male doctors interviewed. We therefore believe that the composition of the focus group does not affect the transferability of our findings in terms of gender and clinician profession.

At present, there is limited information on the use of ePROM systems in the routine renal practice and the majority of the articles we came across described systems at development or pilot stages.[43] The RePROM system being developed by researchers at the Centre for Patient Reported Outcome Research (CPROR), UHB, and Birmingham Clinical Trials Unit (BCTU) has a focus on patient symptoms. Recruitment has commenced for a randomised pilot trial of usual care supplemented with the RePROM system in patients with advanced CKD.[61]

The use of a renal ePROM system has the potential to enhance routine clinical practice by facilitating patient engagement and involvement in their care and providing clinicians with timely information which may guide clinical management. The rapid developments in information technology may also assist with the integration of ePROM data with other routinely collected electronic health data, thus facilitating its impact.[62] However, patients and clinicians need to be involved at every stage in the development of ePROM systems. Patient and clinician views should be sought, considered and appropriately utilised in other to facilitate their subsequent engagement with ePROM interventions. The degree of patient and clinician engagement may crucially influence the usefulness of ePROMs post-implementation.

Supplementary materials

S1. Patient saturation table

S2. Clinician saturation table

S3. Supplementary table

S4. Comments on selected questionnaires

Figure S1. Login page

Figure S2. Electronic KDQOL-36 questionnaire

Figure S3. Progress buttons for the ePROM system

Article Information

Contributions

This study was conceived and designed by OLA, MC, DK, PC, TM, MD and NWA. AS moderated the focus group. OLA conducted the interviews and analysed the transcripts. OLA, MC, DK, PC, TM, CM reviewed the data analysis. Each author contributed important intellectual content during manuscript drafting or revision and accepts accountability for the overall work by ensuring that questions pertaining to the accuracy or integrity of any portion of the work are appropriately investigated and resolved.

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Box 1. Topic guide for patient interviews

- Was the purpose for the study clear from reading the patient information sheets?
- Do you think the study will benefit patients? If so why and how?
- Views on the content of the questionnaire(s)
    1. What do you think of the lengths?
    2. Are the questions easy to understand? Are the questions (and their response options) worded in a way that would be easily understood by patients? How easy do you think it is to complete the questionnaires?
    3. Do individual questionnaires cover all aspects that might be important to patients with advanced CKD, or are any elements missing?
    4. Are there questions that might be seen as unacceptable? If so why?
- How often would you be prepared to complete the questionnaire(s) as part of your care? Do you think that patients with advanced CKD would be willing to complete the questionnaire on a regular basis in-between their clinic appointments? If so, how frequently do you think they would be willing to do so?
- How would you prefer to complete the questionnaires - by PC, smartphone, tablet, telephone voice recognition or paper completion?
- What might discourage you from completing the questionnaires?
- What might encourage you to complete the questionnaires?
- Do you think the benefits you mentioned earlier are sufficient to motivate other patients to fill the questionnaire on a regular basis?
- If not mentioned, ask if feedback is desired. What kind of feedback would you prefer?
- Are there any issues about completing these questionnaires that worry you?
- Any final comments?

Box 2. Topic guide for clinician focus group and interviews

- What are your thoughts on the use of ePROMs in the management of CKD patients?
- Do you think the use of ePROMs will benefit patients? If so why and how? If not why?
- Do you think that patients with advanced CKD would be willing to complete the questionnaire on a regular basis in-between their clinic appointments?
- How often would you like patients to complete questionnaires like these?
- How would you like the data to be displayed?
- Are there any issues about using these questionnaires that you would like to mention?
- What factors may improve the use of ePROM data by clinicians?
- What factors may discourage the use of ePROM data by clinicians?
- Is there anything else anyone would like to say on the use of PROMs for the management of patients with CKD?
- Views on KDQOL-36 and IPOS-Renal
    5. What are your thoughts on the lengths of questionnaires?
    6. What are your opinions of the wording of the questions and their response options?
    7. What about the scope of the questionnaires? Do individual questionnaires cover all aspects that might be important to patients with advanced CKD, or are any elements missing?
    8. Are there questions that might be seen as unacceptable to patients? If so which questions and why?

Table 1. Patient characteristics (n = 12)	
Variable	n
Age (years)	
below 50	1
50 and over	11
Gender	
Female	5
Ethnicity	
British-White	7
British-Asian	4
Irish-White	1
Occupation	
Retired	7
Employed (Part-time & full time)	4
Unemployed	1

n – Sample size

Table 2. Clinician characteristics	
Focus group (n = 8)	
Variable	n
Gender	
Female	8
Ethnicity	
White	6
Asian	1
Black	1
Occupation	
CKD community nurses	6
Clinical psychologist	1
Nephrologist	1
Interviews (n = 14)	
Variable	n
Gender	
Female	6
Ethnicity	
White	11
Asian	3
Position	
Specialist registrars	3
Renal surgeons	2
Nephrologists	9

n – Sample size

CKD – chronic kidney disease

Table 3. Description of interviews and saturation tables	
Interviews	
Number of patient participants (number invited) Reasons for non-participation	12 (15) • Involvement in other research studies • Lack of time due to numerous clinical appointments • Lack of interest in research
Duration of patient interviews (minutes) Range Mean ± S.D	 22 - 64 37.4 ± 15.2
Number of focus group participants (number invited) Reason for non-participation	8 (14) Competing clinical commitments
Duration of focus group (minutes)	45
Number of interviews with doctors (number invited) Reason for non-participation	14 (17) Competing clinical commitments
Duration of interviews with doctors (minutes) Range Mean ± S.D	 21 - 59 32.8 ± 10.8
Saturation tables	
Patient saturation table Number of codes generated Point of data saturation	 77 10th interview
Clinician saturation table Total number of codes generated Number of codes identified in focus group Percentage of codes from focus group that recurred in subsequent interviews with doctors (%) Point of data saturation	 141 56 86* 12th interview

S.D - Standard deviation

* - non-recurring codes from the focus group pertained to discussions about the importance of involving doctors in the ePROMs project

Table 4. Illustrative Quotations by Theme and sub-themes	
Sub-themes	**Illustrative Quotations**
	General opinion of PROMs
The role of PROMs in healthcare	"It would be great if we could start incorporating more quality of life aspect..it is an aspect partly neglected at the moment." (Doctor 8, q1) "It's the natural direction of healthcare." (Doctor 3, q2)
Knowledge of PROMs	"I'm definitely looking forward to seeing the outcomes of the research." (Doctor 8, q3)
Cautious optimism	"So things like level of kidney function, etc, and age, they feel at the moment more like hard risk factors. Whereas quality of life at the moment doesn't feel like a hard risk factor that I can really latch on to and use that to stratify a patient's risk." (Doctor 8, q4) "I'm not sure on its own we would be able to use to change policy or to get funding or permission for various interventions but it's an extremely useful adjunct." (Doctor 11, q5)
Criticism of PROMs	"I agree with the concept that quality of life is a reflection of the gap between where you are and where you want to be. Those questionnaires don't ask that…It's just not individualised….they're not coming up with it themselves. In that sense, it's not patient reported." (Doctor 5, q6) "You sit the patient and you say, 'How are you?' and you remain silent and the patient will tell you everything you need in two minutes. I wonder whether the whole business of PROMs has arisen through time pressure and a reluctance to do exactly that..." (Doctor 5, q7)
Comparison with history taking	"When I was trained in medicine that's not the way that you have clinical consultations. Basically history and examinations and that's still maintained as a model. I suppose you could say it is a bit like a questionnaire because it's a formulaic you have in your mind." (Doctor 3, q8)
	Potential benefits and applications of ePROMs
Potential benefits	"It raises issues the clinician, or the patient has never felt that they can broach before and that is the heart of clinical care..." (Doctor 6, q9) "I'm hoping that if the PROMs comes in it would raise alerts and that it would flag up if anything was wrong...." (Patient 8, q10) "..,the advantage is you might more systematically detect or detect sooner physical or psychological symptoms." (Doctor 3 q11) "…if I can do these sort of interviews at home I don't have to take time off work. It makes things easier for everybody." (Patient 2, q12) "I think to cut down clinic and distance for patients you know." (Doctor 4, q13)

	"I'm looking after my own health by doing it...it's nice to know how you're getting on....or things I should be changing? …" (Patient 8, q14) "I think it will make them more reflective." (Doctor 5, q15) "It helps them decide what they like to discuss…having the patient narrow it down, might help you in clinic as well then." (FG, q16)
Determinants of benefits	"I think the utility depends on what it's used for… people operate, perform differently, have a different style in clinic" (Doctor 3, q17) "If you're seeing someone regularly…I'm not sure that there is as much utility because you develop that feel for the patient." (Doctor 9, q18)
Potential applications	"Using more global assessments of patient wellbeing is often a very useful marker of whether a treatment is working….or at least to capture other benefits of our interventions that can't be succinctly summarise in a blood test." (Doctor 11, q19) "I think these questionnaires might be part of the wider multidisciplinary management of patients with complex diseases." (Doctor 9, q20) "Another area where it would be especially useful would be in conservative management of chronic kidney disease or palliative care in which the focus really is on managing the symptoms of their chronic kidney disease." (Doctor 8, q21)
	Practical considerations
Administration of ePROMs	"...it depends how I feel. I suppose if you're at stage four or five, you wouldn't really want something that's monthly." (Patient 11, q22) "If you've got advanced CKD, you probably don't want to be filling in a questionnaire every 6 weeks. If they're reasonably stable, they should be okay filling out a questionnaire every 3 to 6 months. I think it depends on the patient...on the nature of the disease." (Doctor 9, q23) "I suppose the other way to look at this would be to say, 'Okay, if you feel less well, maybe you should complete this questionnaire'…. rather than being very didactic and say every two months, every six months or every four months." (Doctor 9, q24) "I think filling it in before they come (but bringing it with them) so they're not rushed." (Doctor 7, q25) "I think generally the medical people that are looking after me so my GP, my consultant and anyone else..." (Patient 10, q26) "Probably my tablet or my phone 'cause it's quick and handy to just pick up, isn't it? Yeah, rather than a paper or a laptop." (Patient 8, q27) "It might be interpreted by someone else which would, create a bit of a struggle transferring what the patients actually think." (Doctor 5, q28)
Feedback	"I want an explanation so that I understand what's going on. I don't see the point in doing it and me telling you how I'm feeling unless I get some sort of feedback from it as to why that's happening to me." (Patient 4, q29) "...some sort of absolute feedback for the clinician so they know where they are is probably going to be useful." (Doctor 9, q30)
Interpretation of ePROMs	"… If they're struggling to climb several flights of stairs, that might mean fluid overloaded…" (FG, q31)

	"I think with a lot of these questionnaires, when the numbers change, you don't quite know what that means in real life." (Doctor 6, q32)
Presentation of ePROMs	"…. I think having a separate tab where you can view it probably useful." (Doctor 9, q33) "…a graph, could be a bar chart, the score against time or something, something visual that's easy, quick to see." (Doctor 3, q34) "...we need trigger points don't we? ...nstead of sifting through quite a lot of information, a traffic light system or something." (FG, q35)
	Concerns, potential barriers and facilitators
Concerns	"They want to keep the doctor happy.....let's be true it's 1 but to keep the doctor happy I'm going to say 4.5…." (Patient 5, q36) "...so much of our details are online these days... *[shrugs shoulders]* I don't think that really bothers me *[laughter]*..." (Patient 4, q37) "They do but they feel obliged some of them…They do feel obliged…" (FG, q38) "If I want to make my numbers better and make my patients live longer I dialyse them more. If you look at the one thing that impairs their quality of life in the questionnaire it's having more dialysis." (Doctor 2, q39) "…I mean I think we are at risk of just generating more work for ourselves." (Doctor 10, q40) "The potential is that we could then be making lots psychology referrals or getting lots and lots of outpatient psychiatry referrals." (FG, q41) "..once you start to collect this information…if somebody committed suicide and have ticked certain boxes, if you're standing up in a Coroner's Court, how do you justify that you haven't done anything about it, it starts to raise ethical issues…(FG, q42) "…I would like to see this used to focus on very practical issues that can be dealt with in a clinic environment but I wouldn't want to see this phenomenon of medicalising what is really a spectrum of sort of normal response to stress…." (Doctor 10, q43) "There is a danger of raising expectations....." (Doctor 2, q44)
Potential barriers	"The biggest problem is people who don't like computers, don't have one or don't understand them but have one." (Patient 1, q45) "...as long as you're feeling well, you might not be inclined to do it...." (Patient 4, q46) "There are lots of alerts already in PICS and it's well known that people get alert fatigue and just click ignore, ignore …" (FG, q47) "Clinicians feel comfortable asking about physical health and probably less comfortable asking about mental health." (Doctor 3, q48) "The resources available to any of us to try and address and support people psychologically are quite limited." (Doctor 3, q49) "The limitation is going to be time for consultation." (Doctor 3, q50)
Potential facilitators	"I think what would help is if there was an explanation as to why you're filling that….in fairly basic language." (Patient 4, q51)

	"I want there to be some evidence at the very least, even anecdotal evidence to begin with until full evidence, you can't just magic up evidence like that, it's a process and it needs some anecdotal evidence that filling in this questionnaire has helped Patient X, Y, Z." (Doctor 2, q52) "I think there needs to be some clear guidelines or clear advice about what constitutes an abnormal result…." (Doctor 9, q53) "Simplicity and then expert suggestions of what I can be doing might be useful." (Doctor 2, q54) "I think it will be really exciting to be honest, if there was enough buy into it. I think you probably need to look at the Consultants as well include them, in this sort of discussion…..." (FG, q55) "I think it needs to be easy to access." (Doctor 9, q56) "Some of them won't prefer to use computers, so I think it would be useful for the patient to have a choice." (Patient 1, q57)

FG – Focus group participant (clinician)

PICS - Prescribing Information and Communications System

Figures

Figure 1. Thematic schema