

Development and usability testing of an electronic patient-reported outcome measure (ePROM) system for patients with advanced chronic kidney disease

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1 **Development and usability testing of an electronic patient-reported outcome**
2 **measure (ePROM) system for patients with advanced chronic kidney disease**
3

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32 **Abstract**

33 **Background:** Chronic kidney disease (CKD) is a long-term medical condition
34 associated with symptoms which may negatively impact on patients' health-related
35 quality of life (HRQOL). Patient-reported outcome (PRO) measures or
36 questionnaires may be used to capture symptoms/HRQOL experienced by patients
37 with advanced CKD.

38 **Method:** Two PRO questionnaires were electronically adapted and incorporated in
39 an electronic system developed at University Hospitals Birmingham NHS Foundation
40 Trust (UHB), Birmingham. Usability testing was conducted with patients with
41 advanced CKD. Qualitative methodology was used to elicit participants' views.

42 **Results:** Participants had a mean age of 64.3 years (range: 36 - 87 years). All
43 owned electronic devices and had access to the internet. The mean time required to
44 complete the two electronic questionnaires was 15.9 minutes (range = 8-34
45 minutes). Patients who had difficulties with the system were those who had the least
46 experience of using the internet and electronic devices. The average usability and
47 satisfaction score was 4.6 (5-point scale).

48 **Conclusions:** Our study suggests that individuals with advanced CKD may find the
49 Renal ePROM system acceptable and easy to use. The use of the Renal ePROM
50 may complement clinician-reported outcomes and assist with the management of
51 patients with advanced CKD.

52

53 **Keywords:** usability testing; user testing; eHealth; electronic patient reported
54 outcome measures; electronic system; chronic kidney disease; ePROM

55 Introduction

56 Chronic kidney disease (CKD) is a long-term medical condition associated with
57 symptoms such as fatigue, pain and pruritus which may negatively impact on
58 patients' health-related quality of life (HRQOL).[1-3] While the use of clinician-
59 reported outcomes is essential in the management of patients with CKD, relying
60 exclusively on these clinical parameters may underestimate the impact of the
61 disease and its treatment on patients' HRQOL.[4, 5] A patient-reported outcome
62 (PRO) is defined as "any report of the status of a patient's health condition that
63 comes directly from the patient, without interpretation of the patient's response by a
64 clinician or anyone else." [6, 7] Self-reported questionnaires, known as patient-
65 reported outcome measures (PROMs), are standardized instruments designed to
66 capture PRO information.[6, 7] PROM data could complement clinical parameters
67 and inform the management of patients with advanced CKD.[4, 8]

68 Traditionally, PROMs have been administered using a paper-based format.[9]
69 However, in recent years, there has been a widespread interest in adapting and
70 developing PROMs for electronic administration via telephone (interactive voice
71 response) or screen-text devices [10] such as desktop and laptop computers, tablets
72 and smartphones.

73 The use of electronic PROMs (ePROMs) may facilitate the remote monitoring of
74 patients' symptoms/HRQOL and provide clinicians the opportunity to initiate timely
75 interventions to delay disease progression.[11-13] Additional benefits may include: a
76 lower administrative burden, increased acceptance rates, prevention of secondary
77 data entry errors, and lower incidence of missing data.[9, 10, 14]

78 In Denmark, the generic ePROM system, AmbuFlex, has been successfully
79 implemented for tailoring the care of various patient groups including patients with
80 renal failure [15, 16] while the Advanced Symptom Management System (ASyMS)
81 and the eRAPID system have been successfully used in the UK to monitor the side
82 effects of chemotherapy.[17, 18]

83 It is essential that the usability of an ePROM system is formally assessed during
84 development to ensure it is fit for purpose.[10, 19] The International Organization for
85 Standardization (ISO) defines usability as "The extent to which a product can be
86 used by specified users to achieve specified goals with effectiveness, efficiency, and
87 satisfaction in a specified context of use." [20] According to ISO, effectiveness
88 describes the ability of users to complete pre-determined tasks during a usability test
89 while efficiency refers to the level of resource required to perform these tasks.[20]
90 Satisfaction relates to the subjective views of users based on their test
91 experience.[20]

92 When assessing these three aspects of usability, consideration needs to be given to
93 the context of use.[21-23] Participant characteristics such as age and health status
94 would therefore determine the specific methods to employ and the metrics to
95 measure during a usability study.[21-23] Patients with CKD tend to be older
96 adults[24, 25] who may have age-related physical and cognitive limitations.[26, 27]
97 They may also experience a number of debilitating CKD-related symptoms such as
98 fatigue and cognitive impairment which could significantly affect their ability to use an
99 ePROM system.[28, 29] These age and health-related issues need to be taken into
100 account when designing and testing an ePROM system for this patient group. It is
101 also crucial that patients iteratively [30] assess the usability of the system so that

102 usability issues may be detected and addressed prior to full-scale implementation
103 [31] in order to reduce attrition rates.[26, 32, 33]

104

105 **Development of the Renal ePROM**

106

107 At the start of this project, a systematic review of PROMs used in patients with CKD
108 was conducted. The review found evidence to support the use of the 80-item kidney
109 disease quality of life-short form (KDQOL-SF) [34] and the 36-item kidney disease
110 quality of life-36 (KDQOL-36).[35] However, very few studies validated these two
111 measures in our target population (stages 4 and 5 CKD).[35, 36] The review also
112 identified the IPOS-Renal (11 items), [37] which was undergoing validation at the
113 time.

114 A patient advisory group evaluated the acceptability, burdensomeness and
115 relevance of the KDQOL-SF, KDQOL-36 and the IPOS-Renal. The patients
116 expressed a preference for the KDQOL-36 and IPOS-Renal as they were brief and
117 easy to understand.[38] Their preference for shorter, and therefore less burdensome,
118 questionnaires is understandable given that patients with advanced CKD often suffer
119 from fatigue and lack of energy, [1, 3] which may make completing longer
120 questionnaires KDQOL-SF on a regular basis a significant challenge. Therefore, we
121 adapted the KDQOL-36 and the IPOS-Renal for the renal ePROM system. In order
122 to comply with the questionnaire developers' terms of use, we had to keep the user
123 interface as similar as possible to the original paper versions. However, we still
124 followed a number of recommendations for web-design for elderly users [39] and the
125 interface was designed to be simple and straightforward to minimise patient burden.
126 For example, we avoided the need for pull down menus, double clicking and kept the

127 number of pages to click through to a minimum, as ability to precisely position the
128 computer cursor has been shown to diminish with age.[26, 39, 40] Older individuals
129 may also have issues with visual acuity, contrast sensitivity and colour
130 discrimination.[41] Therefore the colour palette was restricted and the text for the
131 questionnaires was presented on a neutral background using black Arial font, which
132 is an easy to read sans-serif font (See Fig 1).

133 The electronic adaptation was performed by a senior .Net developer from the
134 Application Development team, University Hospitals Birmingham NHS Foundation
135 Trust (UHB) using the DataCollector application developed in-house (See Figs. 1 -
136 3).[38] The DataCollector has two sections - the 'back end' of the application is the
137 administrative section which is used to create and manage questionnaires while the
138 'front end' is the user section which enables patients and/or staff to answer
139 questionnaires. The DataCollector was developed using Microsoft.Net technology,
140 mainly ASP.Net Webforms, C#, Entity framework and SQL Server. Bootstrap
141 framework was used to make the 'front end' as responsive as possible to enhance its
142 performance on electronic devices and on most of the main web browsers. The
143 DataCollector was embedded in myhealth@QEHB, a secure electronic patient portal
144 also developed by the Application Development and Informatics team (See Figure
145 3).[42]

146

KDQOL-36

This survey asks for your views about your health. This information will help you keep track of how you feel and how well you are able to do your usual activities.

In general, would you say your health is: (Select one box that best describes your answer).

- Excellent
- Very good
- Good
- Fair
- Poor

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Climbing several flights of stairs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

147

148 Fig. 1. Screenshot of the electronic KDQOL-36 questionnaire.

149

Once you have completed this questionnaire, please click SAVE & NEXT to proceed

Save to edit later

Save and Next

Submit

Cancel

150

151 Fig. 2. Screenshot of the progress buttons.

152

153

154

HB My Health: Authorisation

ps://www.myhealth.uhb.nhs.uk/login.aspx

myhealth@QEHB
unlocking your own health records

Queen Elizabeth Hospital Birmingham NHS
Part of University Hospitals Birmingham NHS Foundation Trust

Register Log in Help

Registered users can use this page to log in. If you have not yet registered to use myhealth@QEHB, please visit the registration page.

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155

156 Fig. 3. Screenshot of the myhealth@QEHB login page.

157

158 **Methods**

159

160 This usability study was designed and conducted according to the study protocol,
161 [38] following guidelines and recommendations provided by the International Society
162 for Pharmacoeconomics and Outcomes Research (ISPOR), [10, 19] and the United
163 States Department of Health and Human Service.[43] The study was approved by
164 the West Midlands Edgbaston Research Ethics Committee (Reference 17/WM/0010)
165 and received Health Research Authority (HRA) approval on 24 February 2017.
166 Project authorisation was granted by UHB Research and Design (R & D) in April
167 2017 (RRK6050).

168 **Study participants**

169

170 Eight adult patients with advanced CKD stages 4 & 5 who are at risk of rapid clinical
171 deterioration to renal failure [38] were recruited from the UHB nephrology service
172 between May and July 2017. We targeted this group of patients as we hypothesised
173 that they are likely to benefit the most from using the ePROM system which may
174 help delay disease progression. Patients with acute kidney injury were excluded
175 because their underlying medical condition may not be CKD. Patients who have
176 debilitating co-morbidities or are judged by their clinicians to be severely unwell were
177 also excluded as it would be unethical to subject them to the demands of the study.
178 The research team is currently working on a separate project focused on patients
179 receiving dialysis whose lived experiences and care needs differ from those of
180 advanced CKD patients.

181

182

183

184 Recruitment process

185

186 A research nurse from the Renal services at UHB screened patient records and
187 approached eligible patients in clinic.[38] The nurse informed these patients about
188 the study, provided them information sheets and responded to their queries. The
189 patients were contacted by the nurse after 48 hours to ascertain that they had read
190 the information sheet and wished to participate in the study. The research nurse
191 gave the interviewer (OLA), in person, the contact details of patients who expressed
192 an interest in the study and verbally agreed to OLA contacting them. OLA
193 telephoned these patients, confirmed their wish to participate in the study, answered
194 further queries, and arranged a mutually suitable date and time for the testing.
195 Written informed consent was obtained from all the participants and study data was
196 anonymised.

197

198 Testing procedure

199 The interviewer (OLA) conducted one-to-one test sessions with participants at the
200 Institute of Translational Medicine (ITM) using the demonstration version of the
201 Renal ePROM system. Participants completed the questionnaires using desktop
202 computers and received as little assistance as possible while OLA noted verbal and
203 non-verbal cues. Family members were allowed to sit in on the test sessions as we
204 are aware that in real life home settings, they may be present when patients
205 complete their ePROMs.

206 At the start of the sessions, OLA presented the participants with an *a priori* scenario.
207 Participants were asked to assume they were reporting their health status between
208 clinic appointments from home. They were told to recall and report their health over

209 the past 4 weeks for the KDQOL-36 and within the last week for the IPOS-Renal.
210 Each participant had 11 tasks to complete during the test session (See Appendix).
211 Participants were asked during their session to assume that they needed a break, for
212 whatever reasons, before continuing their test session. They were told they needed
213 to save their responses up to that point or lose them as the system would time out
214 during the break. Patients were also told just after commencing the IPOS-Renal to
215 assume they had made an error on the preceding KDQOL-36 and needed to go back
216 to the questionnaire to correct it. The purpose of this scenario was to provide a
217 defined context for the test sessions, assess the intuitiveness of the system and the
218 functionality of the progress buttons.

219 In order to assess efficiency, the time taken to complete each questionnaire was
220 recorded for each participant. The number of errors per participant and the amount
221 and nature of assistance required during the test sessions were also recorded in
222 order to assess effectiveness. Non-critical errors were regarded as errors
223 participants successfully addressed themselves following instructions from the
224 interviewer. Critical errors were those that required the interviewer to take over and
225 rectify such as the accidental closure of questionnaire page.

226 The sessions were followed by brief audio-recorded interviews during which
227 participants were asked specific questions on their views and opinions of the
228 ePROM system, the issues or difficulties they encountered during their test session
229 and their access to and use of electronic devices/internet. These interviews were
230 scheduled to last no more than 10 minutes in order to minimise participant burden.

231 Participants were also asked 4 questions designed to rate their satisfaction with the
232 system and its usability on a 5-point scale (1 representing poor/never and 5

233 representing excellent/yes). The 10-item System Usability Scale (SUS) [22] and
234 other usability scales were considered, but in the end we concluded that a much
235 shorter set of four questions would be less burdensome for participants who also had
236 to complete the 46-item ePROM questionnaire.

237 **Moderating technique**

238 A combination of Concurrent Think Aloud (CTA) and Retrospective Probing (RP)
239 moderating techniques were used.[44] Participants were encouraged to vocalise
240 their thoughts *during* the test sessions and had brief interviews *after* their
241 session.[44] Combining these two techniques made it possible to gather 'real time'
242 feedback which were subsequently explored during the interviews.[43]

243 **Data Analysis**

244
245 Continuous variables such as age and time required for completion of ePROMs were
246 presented as means. Participant ratings for the four usability questions were used to
247 calculate a mean score. Categorical variables such as errors (critical and non-
248 critical) were presented as percentages (%). Participants' comments during the
249 interviews were extracted as quotes and categorised under 'general impressions'
250 and 'issues'. These categories of comments were presented in a table along with the
251 interviewer's observations.

252

253 **Results**

254

255 Table 1 presents the participant demographics. The eight participants had a mean
 256 age of 64.3 years (range: 36 - 87 years).

257

Table 1. Patient demographics (n = 8)	
Variable	n
Age ^a	
<50	1
≥50	7
Gender	
Female	4
Ethnicity	
British-White	5
British-Asian	2
Irish-White	1
Occupation	
Retired	6
Employed	1
Unemployed	1
Computer/internet usage	
Often ^b	6
Occasionally ^c	1
Rarely ^d	1

258 ^a Mean: 64.3 years, range: 36 - 87 years259 ^b Often: 4 – 7 days per week260 ^c Occasional: 1 - ≤ 3 days per week261 ^d Rare: <1 day a week

262

263

264 Assessment of efficiency

265 Table 2 presents the time requirements by the participants. The mean time required
 266 to complete the two questionnaires was 15.9 minutes (range = 8 - 34 minutes). The
 267 mean time required to complete the KDQOL-36 was 10 minutes (range = 5 - 20
 268 minutes) while the mean time to complete the IPOS-Renal was 5.9 minutes (range =
 269 3 - 14 minutes).

270 Participants were divided into two groups solely for the purpose of analyzing the
 271 data. Group 1 consisted of the six participants that used the internet/electronic
 272 devices often (4 – 7 days per week), while Group 2 comprised of the one occasional
 273 user (1 - \leq 3 days per week) and the one rare user (<1 day a week). Participants in
 274 Group 1 required a mean time of 8.5 minutes to complete the electronic KDQOL-36
 275 while those in Group 2 took a mean time of 14.5 minutes. The participant who rarely
 276 used the internet/electronic devices took the longest time to complete both
 277 questionnaires.

278

279 Assessment of effectiveness

280 There were five non-critical errors and one critical error. The five non-critical errors
 281 were due to omissions and participants addressed these themselves after being told
 282 by the interviewer to scroll up the questionnaires and check for omissions. The
 283 critical error which was recorded for participant 8 required the interviewer to take
 284 over the mouse and locate the cursor before the participant could progress with the
 285 tasks. A list of the tasks is provided in the Appendix.

Table 2. Time requirements (mean and standard deviation) and error information

		All participants (<i>n</i> = 8)	Group 1* Often (<i>n</i> = 6)	Group 2* Occasional ^a & rare ^b (<i>n</i> = 2)
mean time	KDQOL-36	10.0 (\pm 1.6)	8.5 (\pm 1.1)	14.5 (\pm 5.5)
Mean time	IPOS-Renal	5.9 (\pm 1.2)	4.7 (\pm 0.4)	9.5 (\pm 4.5)

Total mean time	15.9 (\pm 2.8)	13.2 (\pm 1.5)	24.0 (\pm 5.0)
Non-critical errors	5 (5.7%)	3 (4.5%)	2 (9.1%)
Critical errors	1 (1.1%)	0 (0.0%)	1 (4.5%)

286 * Grouping based on frequency of computer/internet use

287 ^a Participant 4

288 ^b Participant 8

289

290 Assessment of satisfaction and opinions of the renal ePROM system

291 Table 3 presents participants' rating of the usability and their satisfaction with the
 292 Renal ePROM. The mean scores for individual questions were high and the average
 293 usability and satisfaction score was 4.6 (5-point scale).

Table 3. Usability and satisfaction with Renal ePROM (mean and standard deviation)

Question	Average score (5-point scale)
Ease of use and navigation	4.6 (\pm 0.2)
Satisfaction with content	4.5 (\pm 0.2)
Satisfaction with visual display	4.5 (\pm 0.3)
Likelihood of using again or recommending to others	4.9 (\pm 0.1)
Average usability and satisfaction score	4.6 (\pm 0.1)

294

295 Table 4 presents the participants' comments and OLA's observations. The interviews
 296 lasted on average 5 minutes (range of 4 – 10 minutes). The general impression of
 297 the Renal ePROM was positive with all the participants commenting on its simplicity
 298 and ease of use. Two participants recommended an increase in font sizes.

299 The scenario given to the participants helped OLA assess how intuitive the Renal
 300 ePROM was and the functionality of the progress buttons. The progress buttons

301 were fully functional and all the participants correctly identified the 'previous' button
 302 to go back to the KDQOL-36 questionnaire. When invited to take a break all except
 303 one participant (participant 8) identified the correct button to 'save and continue
 304 later'.

Table 4. Participants' comments and interviewer's observations

Comments	
Overall impression of the Renal ePROM V1 (Participants)	<ul style="list-style-type: none"> • "Simple, straightforward and easy to use" (Participant 1) • "It is quite good really. It is easy enough" (Participant 2) • "Completing this was easy. On a regular basis it will be convenient to use a smartphone." (Participant 3) • "Easy to use." (Participant 4) • "Clear and easy to understand. It didn't appear to have any trick questions." (Participant 5) • "Clear and easy" (Participant 6) • "The questions were straightforward." (Participant 7) • "Nothing complicated...its controlling the mouse...(laughs).." (Participant 8)
Issues (Participants)	<ul style="list-style-type: none"> • "The print is a bit small. That thing (<i>mouse</i>) is a bit fiddly to use" (Participant 4) • "It (<i>the fonts</i>) could have been a bit bigger because you have got plenty of room on it" (Participant 2) • "Can't see the options after a while" (please see the first observation below). (Participant 6)
Observations	
Interviewer	<ul style="list-style-type: none"> • Beyond a certain point, the descriptions for the response options do not remain visible at the top for the group of KDQOL-36 questions that were set in a matrix format. The participants needed

to scroll up to see the descriptions. This was an issue for those who struggled to use the mouse (Participants 4, 8).

- Five participants (Participants 1, 4, 5, 7, 8) unintentionally omitted questions and assumed the progress buttons were not functioning when they could not proceed. The interviewer had to tell them to scroll up and check for omissions.
- Three of the participants (one frequent user (Participant 1), the occasional user (Participant 4) and the rare user (Participant 8) had varying levels of dexterity issues controlling the mouse. Two of them were able to scroll up and down the pages without assistance but with some difficulty while the third (rare user) had more difficulty controlling the cursor and needed the interviewer to locate the cursor on two occasions in order to continue with the tasks.
- Participant 7, who was accompanied by their partner, paused significantly when answering questions on burden to family, sex life (KDQOL-36) and feelings of depression (IPOS-Renal).

305

306

307

308 **Discussion**

309

310 *Summary of main findings*

311 This article reports the usability testing of the Renal ePROM system in a group of
312 patients with advance CKD. Our study suggests that patients with advanced CKD
313 may find the Renal ePROM system easy to use and acceptable for reporting their
314 symptoms remotely. Error levels were relatively low and mostly due to non-critical
315 omissions. Overall, the system was found to be efficient and effective despite the few
316 issues identified.

317 *Findings in relation to existing literature*

318 The opinion of study participants' that the renal ePROM system is acceptable and
319 easy to use is in keeping with reports from well-designed ePROM-related usability
320 studies.[45-48] Participant perception is very important as it has been demonstrated
321 that perceived ease of use of an information technology (IT) system or product, by
322 the end user, has a direct effect on its perceived usefulness and subsequent
323 usage.[45, 49]

324 Our study participants had a mean age of 64.3 years which is approximately the
325 mean age of our target population.[25, 50, 51] All except one participant were ≥ 50
326 years old and five of them reported a similar usage of the internet/electronic devices
327 as the 36-year-old participant. Their computer literacy levels also matched the
328 current levels expected for individuals within this age group.[52] Our study confirms
329 the finding by Gatto et al. that individuals aged 55 and over possess significantly
330 higher levels of computer literacy with each passing decade as people take their IT
331 skills into retirement.[52] Although we had a mixture of male and female participants,

332 there were no indications that gender had an effect on their usability experiences.
333 We did not observe any gender differences in access or use of the internet/electronic
334 devices which is in keeping with findings in literature.[52, 53]
335 Participants required a mean time of 10 minutes to complete the electronic version of
336 the KDQOL-36 which is lower than the mean time of 15 minutes participants required
337 to complete the paper format in the study by Thaweethamcharoen et al.[54] It was
338 not surprising that the participants who recorded the longest completion times also
339 had the least experience of using computers as reported by previous studies.[10, 55,
340 56] However, their completion times may reduce over time as Erharter et al.[57]
341 showed that with regular use, the time required by patients' to complete an ePROM
342 may reduce by as much as 30%.[57]

343 *Implications for ePROM developers, programmers and healthcare professionals*

344 The omissions by the participants may be due to eyesight issues (the participants
345 wore glasses) or cognitive impairment which may be age-related [26, 27, 41] or
346 associated with advanced CKD.[28, 29] The font size (12pt) might have been a
347 contributing factor [39, 41, 58] as it was suggested by two of the participants that we
348 increase the font sizes. Programmers and usability moderators should therefore
349 inquire directly about the suitability of font sizes during usability tests. The dexterity
350 issues observed in the occasional and rare users could be due to their limited
351 experience of using the internet and computer. It could also be due to age-related
352 joint problems such as arthritis.[27, 39, 40] These patients might have found it easier
353 to use a touch screen tablet instead of a mouse controlled desktop.[39, 40]
354 Programmers and usability moderators should ensure that various electronic
355 platforms are tested at some point during the development of an ePROM system.

356 It was interesting to note that when asked about their use of the internet, virtually all
357 the participants initially replied 'not often or rarely' but when probed further, all except
358 two visited websites such as YouTube and used social media websites and
359 applications such as Facebook, Twitter, WhatsApp on a regular basis. This suggests
360 that some individuals may unwittingly under-report their engagement with information
361 technology as they do not consider the use of online entertainment or social media
362 as 'surfing' the internet. Developers need to be cognisant of this perception of
363 information technology when designing ePROM systems for this age group as it
364 could determine how it is perceived and adopted.[45, 49]

365 The noticeable hesitation by a participant during their test session, which was
366 attended by their partner, raises the issue of external influences on the information
367 patients may provide especially if completing the Renal ePROM at home. Various
368 studies have shown positive and negative influences of the family and friends on the
369 actions of patients living with chronic illnesses.[59-63] There is also a tendency for
370 proxy reports of a patient's health status or function to be worse than self-
371 reports.[64-67] While these influences cannot be removed entirely, healthcare
372 professionals can minimise them by educating patients and their families on the
373 importance of self-completion.

374 Some patients may consider certain questions very personal or may feel
375 uncomfortable or embarrassed admitting that they have problems in some domains
376 of HRQOL. Bataclan and Dial [68] reported significant amounts of missing data for
377 questions relating to sexual function which shows reluctance among patients to
378 answer certain questions.[68] Therefore, healthcare professionals need to be aware

379 of these important but potentially sensitive issues and devise practical ways of
380 addressing them.

381 *Limitation of the study*

382 The key limitation of this study is that test sessions were conducted on-site in an
383 interviewer-controlled setting. There is a possibility that participants' usability
384 performance and experience may be different at home without the instructions and
385 prompts given by the interviewer.

386 *Other issues*

387 There is an on-going debate about sample sizes for usability testing.[69-73] The
388 current recommendation by ISPOR is 5 to 10 participants for simple ePROM
389 systems.[10] Given that the patient-facing side of the ePROM system was designed
390 to be as simple and as straightforward as possible, a sample size of eight
391 participants was deemed adequate and exceeds the minimum number of five
392 recommended for this type of test.[10, 69-73] A number of published usability studies
393 have also successfully used sample sizes similar to ours.[74-76]

394 While we did not use the SUS for this study, it should be noted that there are clear
395 parallels between the four questions and the SUS scale. For instance the first
396 question of our scale which addressed the ease of use and navigation is closely
397 related to questions 2 & 3 from the SUS scale ("I found the system unnecessarily
398 complex" and "I thought the system was easy to use"). Gray et al. decided not to use
399 an existing scale opting for a more qualitative approach in their usability study.[76]
400 Cornet et al. suggested that qualitative methods might actually provide better results in
401 older adults.[26] The SUS and other usability scales will be considered for use in a

402 future pilot study with a much larger sample size, where their statistical potential
403 could be maximised.

404 *Planned modifications to the ePROM system*

405 The findings from this test will be used to improve the system. Therefore, we will
406 increase the font sizes to make the questionnaires easier to read. The descriptions
407 for the response options will be redesigned as a floating panel which will remain
408 visible as users scroll down the questionnaires. This will reduce the need for scrolling
409 the page. An alert will be incorporated into the system to inform users about
410 omissions and their specific locations if possible. As stated in the study protocol, [38]
411 the system will be optimised for use on touch-screen tablets and mobile phones. All
412 the versions will be tested in the next cycle and after implementation, patients will be
413 able to use the digital platform of their choice. The final version will be tested
414 remotely (participants' homes) via the personal health record system at UHB. A full
415 validation study will be conducted later to ascertain the reliability and validity of the
416 ePROMs in our target patient group.

417 A/B testing will be conducted for future system upgrades, to compare the upgrade
418 version with the current version, following published guidelines.[77] A much larger
419 patient sample will be utilised to adequately power the statistical analysis of the test
420 data.[78] The results from this large scale analysis will provide valuable insights on
421 user preferences and behaviour which will be used to further improve the
422 system.[77]

423 *Conclusion*

424 Although the digital divide between older and younger populations is decreasing,[79]
425 older individuals have a tendency to discontinue the use of health information

426 technology.[80] In order to minimise post implementation attrition rates, we have
427 involved patients from our target population in the design and development of the
428 ePROM system.[32] We have also conducted this usability test with patients, who
429 represent our target users [33] in order to assess the acceptability and usability of
430 the Renal ePROM system.[10, 19]

431 As access and use of the internet and electronic devices increase, the use of
432 ePROMs could assist clinicians with the monitoring of HRQOL/symptoms of
433 deterioration in patients with CKD.[13] This may provide clinicians the opportunity to
434 intervene early and possibly delay disease progression. It also has the potential to
435 facilitate patient-clinician communication and enhance patient-centred care.[11, 13]

436

437 Authors' Contributions

438 MC is the guarantor. The study was conceived and designed by OLA, MC, DK, PC
439 and TM. RA, OLA, DK worked on the electronic adaptation of the PROMs. MD and
440 NWA recruited the participants for the study. OLA conducted the usability testing and
441 interviews. OLA analysed the data and drafted the manuscript. The manuscript was
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458 Conflict of interest statement

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Appendix

List of tasks	
Task	Description
1	"Choose 'Main Questionnaire' from the 'Application' menu."
2	"Click Submit."
3	"Can you see the section 'New Available'? Please click the link 'Your Health Today'."
4	"Please answer the questions."
5	"Imagine you now need to stop for a bit. What do you do? Find the 'save to edit later' button and click."
6	"From the menu page, can you find the saved questionnaire? Click the saved questionnaire."
7	"Please complete the questionnaire."
8	"Proceed to the next questionnaire."
9	"Please complete the questionnaire."
10	"Click the submit button please."
11	"Can you see a page saying 'Success'? Please logout."

647

Highlights

- A renal ePROM system may assist clinicians with the management of patients with advanced chronic kidney disease.
- Usability testing is crucial during the development of an ePROM system for older patients with chronic medical conditions.
- Patients with advanced CKD may find the system acceptable for reporting their symptoms and health-related quality of life.
- Some individuals may experience dexterity issues and family members may influence the use of the system real life.
- Individuals within this age group may unwittingly under-report their engagement with information technology.