

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

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# Accepted Manuscript

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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.

+ Register now

Problems logging in?

@ Email  
myhealthsupport@uhb.nhs.uk

Online  
Visit the help section

Delivering the best in care

ISV Entrust

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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 <sup>a</sup>	
<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 <sup>b</sup>	6
Occasionally <sup>c</sup>	1
Rarely <sup>d</sup>	1

258 <sup>a</sup> Mean: 64.3 years, range: 36 - 87 years

259 <sup>b</sup> Often: 4 – 7 days per week

260 <sup>c</sup> Occasional: 1 - ≤ 3 days per week

261 <sup>d</sup> 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 - ≤ 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 <sup>a</sup> & rare <sup>b</sup> ( <i>n</i> = 2)
mean time	KDQOL-36	10.0 (± 1.6)	8.5 (± 1.1)	14.5 (± 5.5)
Mean time	IPOS-Renal	5.9 (± 1.2)	4.7 (± 0.4)	9.5 (± 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 <sup>a</sup> Participant 4

288 <sup>b</sup> 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)
<b>Average usability and satisfaction score</b>	<b>4.6 (<math>\pm</math> 0.1)</b>

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"> <li>• "Simple, straightforward and easy to use" (Participant 1)</li> <li>• "It is quite good really. It is easy enough" (Participant 2)</li> <li>• "Completing this was easy. On a regular basis it will be convenient to use a smartphone." (Participant 3)</li> <li>• "Easy to use." (Participant 4)</li> <li>• "Clear and easy to understand. It didn't appear to have any trick questions." (Participant 5)</li> <li>• "Clear and easy" (Participant 6)</li> <li>• "The questions were straightforward." (Participant 7)</li> <li>• "Nothing complicated...its controlling the mouse...(laughs).." (Participant 8)</li> </ul>
Issues (Participants)	<ul style="list-style-type: none"> <li>• "The print is a bit small. That thing (<i>mouse</i>) is a bit fiddly to use" (Participant 4)</li> <li>• "It (<i>the fonts</i>) could have been a bit bigger because you have got plenty of room on it" (Participant 2)</li> <li>• "Can't see the options after a while" (please see the first observation below). (Participant 6)</li> </ul>
Observations	
Interviewer	<ul style="list-style-type: none"> <li>• 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</li> </ul>

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  $\geq 50$   
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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**Appendix**

<b>List of tasks</b>	
<b>Task</b>	<b>Description</b>
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.