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

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32 Abstract

Background: Chronic kidney disease (CKD) is a long-term medical condition 33 associated with symptoms which may negatively impact on patients' health-related 34 35 quality of life (HRQOL). Patient-reported outcome (PRO) measures or questionnaires may be used to capture symptoms/HRQOL experienced by patients 36 with advanced CKD. 37 Method: Two PRO questionnaires were electronically adapted and incorporated in 38 an electronic system developed at University Hospitals Birmingham NHS Foundation 39 Trust (UHB), Birmingham. Usability testing was conducted with patients with 40 advanced CKD. Qualitative methodology was used to elicit participants' views. 41 Results: Participants had a mean age of 64.3 years (range: 36 - 87 years). All 42 owned electronic devices and had access to the internet. The mean time required to 43 complete the two electronic questionnaires was 15.9 minutes (range = 8-34 44 minutes). Patients who had difficulties with the system were those who had the least 45 experience of using the internet and electronic devices. The average usability and 46 satisfaction score was 4.6 (5-point scale). 47 **Conclusions:** Our study suggests that individuals with advanced CKD may find the 48 Renal ePROM system acceptable and easy to use. The use of the Renal ePROM 49 may complement clinician-reported outcomes and assist with the management of 50 patients with advanced CKD. 51

52

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

55 Introduction

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

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

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

In Denmark, the generic ePROM system, AmbuFlex, has been successfully 78 implemented for tailoring the care of various patient groups including patients with 79 renal failure [15, 16] while the Advanced Symptom Management System (ASyMS) 80 and the eRAPID system have been successfully used in the UK to monitor the side 81 effects of chemotherapy.[17, 18] 82 It is essential that the usability of an ePROM system is formally assessed during 83 development to ensure it is fit for purpose.[10, 19] The International Organization for 84 Standardization (ISO) defines usability as "The extent to which a product can be 85 used by specified users to achieve specified goals with effectiveness, efficiency, and 86 87 satisfaction in a specified context of use."[20] According to ISO, effectiveness describes the ability of users to complete pre-determined tasks during a usability test 88 while efficiency refers to the level of resource required to perform these tasks.[20] 89 Satisfaction relates to the subjective views of users based on their test 90

91 experience.[20]

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

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

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105 Development of the Renal ePROM

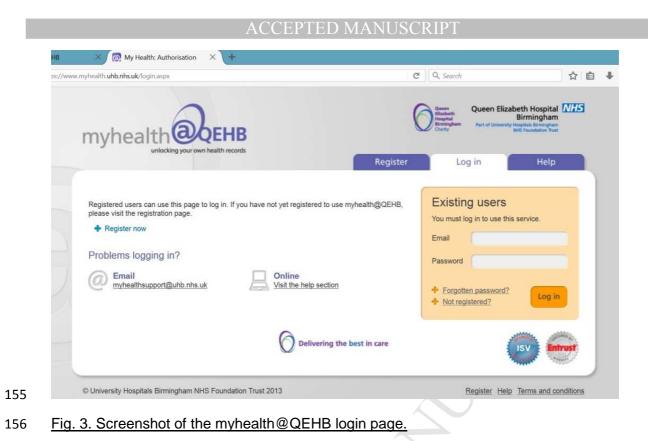
At the start of this project, a systematic review of PROMs used in patients with CKD was conducted. The review found evidence to support the use of the 80-item kidney disease quality of life-short form (KDQOL-SF) [34] and the 36-item kidney disease quality of life-36 (KDQOL-36).[35] However, very few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

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

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

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

In general, would you say your health is: (Select one box that best describes your answer).			how you feel and how well you are able to do your usual ac	
Once you have completed this questionnaire, please click SAVE & NEXT to proceed	In general, would you say your health is: (Selec	ct one box that best describe	s your answer).	
Ves, limited a lot Ves, limited a little No, not limited a Moderate activities, such as moving a table, pushing a o o Climbing several flights of stairs o o Fig. 1. Screeenshot of the electronic KDQOL-36 questionnaire. Once you have completed this questionnaire, please click SAVE & NEXT to proceed Save to edit later Save and Next Submit Cancel	 Very good Good Fair 			
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf Climbing several flights of stairs O Fig. 1. Screeenshot of the electronic KDQOL-36 questionnaire. Fig. 1. Screeenshot of the electronic KDQOL-36 questionnaire. Once you have completed this questionnaire, please click SAVE & NEXT to proceed Save to edit later Save to edit later Save and Next Submit: Cancel	The following items are about activities you m	ight do during a typical day.	Does your health now limit you in these activi	ties? If so, how muc
vacuum cleaner, bowling, or playing golf Climbing several flights of stairs		Yes, limited a lot	Yes, limited a little	No, not limited at a
Fig. 1. Screenshot of the electronic KDQOL-36 questionnaire. Once you have completed this questionnaire, please click SAVE & NEXT to proceed Save to edit later Save and Next Submit Cancel		0	0	0
Fig. 1. Screenshot of the electronic KDQOL-36 questionnaire. Once you have completed this questionnaire, please click SAVE & NEXT to proceed Save to edit later Save and Next Submit Cancel	Climbing several flights of stairs	0	0	0
Once you have completed this questionnaire, please click SAVE & NEXT to proceed Save to edit later Save and Next Cancel				
Save to edit later Save and Next Submit Cancel	-ig. 1. Screenshot of the elect	ronic KDQOL-36	questionnaire.	
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	Once you have completed this	questionnaire, pleas	e click SAVE & NEXT to proceed	
	Once you have completed this	questionnaire, pleas	e click SAVE & NEXT to proceed	
Fig. 2. Screenshot of the progress buttons.				
rig. z. screenshot of the progress buttons.				
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	Save to edit later Save and	l Next Submit		
	Save to edit later Save and	l Next Submit		
	Save to edit later Save and	l Next Submit		
	Save to edit later Save and	l Next Submit		



158 Methods

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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

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

181

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Recruitment process 184

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

197

Testing procedure 198

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

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

the past 4 weeks for the KDQOL-36 and within the last week for the IPOS-Renal. 209 Each participant had 11 tasks to complete during the test session (See Appendix). 210 Participants were asked during their session to assume that they needed a break, for 211 whatever reasons, before continuing their test session. They were told they needed 212 to save their responses up to that point or lose them as the system would time out 213 during the break. Patients were also told just after commencing the IPOS-Renal to 214 assume they had made an error on the preceding KDQOL-36 and needed to go back 215 216 to the questionnaire to correct it. The purpose of this scenario was to provide a defined context for the test sessions, assess the intuitiveness of the system and the 217 functionality of the progress buttons. 218 In order to assess efficiency, the time taken to complete each questionnaire was 219 recorded for each participant. The number of errors per participant and the amount 220 and nature of assistance required during the test sessions were also recorded in 221 order to assess effectiveness. Non-critical errors were regarded as errors 222 participants successfully addressed themselves following instructions from the 223 interviewer. Critical errors were those that required the interviewer to take over and 224 rectify such as the accidental closure of questionnaire page. 225

The sessions were followed by brief audio-recorded interviews during which participants were asked specific questions on their views and opinions of the ePROM system, the issues or difficulties they encountered during their test session and their access to and use of electronic devices/internet. These interviews were scheduled to last no more than 10 minutes in order to minimise participant burden. Participants were also asked 4 questions designed to rate their satisfaction with the system and its usability on a 5-point scale (1 representing poor/never and 5

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

237 Moderating technique

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

243 Data Analysis

244

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

253 **Results**

254

- Table 1 presents the participant demographics. The eight participants had a mean
- age of 64.3 years (range: 36 87 years).
- 257

Table 1. Patient demograph	hics (n = 8)
Variable	n
Age ^a	
<50	1
<u>></u> 50	7
Gender	
Female	4
Ethnicity	
British-White	5
British-Asian	2
Irish-White	_1
Occupation	
Retired	6
Employed	
Unemployed	1
Computer/internet usage	
Often ^b	6
Occasionally ^c	
Rarely ^d	

- ^a Mean: 64.3 years, range: 36 87 years
- 259 ^b Often: 4 7 days per week
- 260 ^c Occasional: $1 \leq 3$ days per week 261 ^d Rare: <1 day a week
- 261 ^d Rare: <1 day a we

263

264 Assessment of efficiency

Table 2 presents the time requirements by the participants. The mean time required

to complete the two questionnaires was 15.9 minutes (range = 8 - 34 minutes). The

- 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

by the interviewer to scroll up the questionnaires and check for omissions. The

critical error which was recorded for participant 8 required the interviewer to take

over the mouse and locate the cursor before the participant could progress with the

tasks. A list of the tasks is provided in the Appendix.

Table 2. Time require	ments (mean and s	standard deviation	and error information
	All participants $(n = 8)$		
	` ,	Group 1*	Group 2*
		Often (<i>n</i> = 6)	Occasional ^a & rare ^b $(n = 2)$
mean time KDQOL- 36	10.0 (<u>+</u> 1.6)	8.5 (<u>+</u> 1.1)	14.5 (<u>+</u> 5.5)
Mean time IPOS- Renal	5.9 (<u>+</u> 1.2)	4.7 (<u>+</u> 0.4)	9.5 (<u>+</u> 4.5)

Total mean time	15.9 (<u>+</u> 2.8)	13.2 (<u>+</u> 1.5)	24.0 (<u>+</u> 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

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

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 (<u>+</u> 0.2)
Satisfaction with content	4.5 (<u>+</u> 0.2)
Satisfaction with visual display	4.5 (<u>+</u> 0.3)
Likelihood of using again or recommending to others	4.9 (<u>+</u> 0.1)
Average usability and satisfaction score 4.6 (+ 0.1)	

294

Table 4 presents the participants' comments and OLA's observations. The interviews
lasted on average 5 minutes (range of 4 – 10 minutes). The general impression of
the Renal ePROM was positive with all the participants commenting on its simplicity
and ease of use. Two participants recommended an increase in font sizes.
The scenario given to the participants helped OLA assess how intuitive the Renal
ePROM was and the functionality of the progress buttons. The progress buttons

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

Table 4. Participants' comments and interviewer's observations				
Comments				
Overall impression of the Renal ePROM V1 (Participants)	 "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 complicatedits controlling the mouse(laughs)" (Participant 8) 			
Issues (Participants)	 "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	• 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

308 **Discussion**

309

310 Summary of main findings

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

317 Findings in relation to existing literature

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

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

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

devices which is in keeping with findings in literature.[52, 53]

Participants required a mean time of 10 minutes to complete the electronic version of 335 the KDQOL-36 which is lower than the mean time of 15 minutes participants required 336 to complete the paper format in the study by Thaweethamcharoen et al.[54] It was 337 not surprising that the participants who recorded the longest completion times also 338 339 had the least experience of using computers as reported by previous studies.[10, 55, 56] However, their completion times may reduce over time as Erharter et al.[57] 340 showed that with regular use, the time required by patients' to complete an ePROM 341 may reduce by as much as 30%.[57] 342

343 Implications for ePROM developers, programmers and healthcare professionals

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

It was interesting to note that when asked about their use of the internet, virtually all 356 the participants initially replied 'not often or rarely' but when probed further, all except 357 two visited websites such as YouTube and used social media websites and 358 applications such as Facebook, Twitter, WhatsApp on a regular basis. This suggests 359 that some individuals may unwittingly under-report their engagement with information 360 technology as they do not consider the use of online entertainment or social media 361 as 'surfing' the internet. Developers need to be cognisant of this perception of 362 information technology when designing ePROM systems for this age group as it 363 could determine how it is perceived and adopted.[45, 49] 364 The noticeable hesitation by a participant during their test session, which was 365 attended by their partner, raises the issue of external influences on the information 366 patients may provide especially if completing the Renal ePROM at home. Various 367 studies have shown positive and negative influences of the family and friends on the 368 actions of patients living with chronic illnesses.[59-63] There is also a tendency for 369 proxy reports of a patient's health status or function to be worse than self-370 reports.[64-67] While these influences cannot be removed entirely, healthcare 371 professionals can minimise them by educating patients and their families on the 372 importance of self-completion. 373

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

of these important but potentially sensitive issues and devise practical ways ofaddressing them.

381 Limitation of the study

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

386 Other issues

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

have also successfully used sample sizes similar to ours.[74-76]

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

future pilot study with a much larger sample size, where their statistical potentialcould be maximised.

404 Planned modifications to the ePROM system

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

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

423 Conclusion

Although the digital divide between older and younger populations is decreasing,[79]
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 involved patients from our target population in the design and development of the 427 ePROM system.[32] We have also conducted this usability test with patients, who 428 429 represent our target users [33] in order to assess the acceptability and usability of the Renal ePROM system.[10, 19] 430 As access and use of the internet and electronic devices increase, the use of 431 ePROMs could assist clinicians with the monitoring of HRQOL/symptoms of 432 deterioration in patients with CKD.[13] This may provide clinicians the opportunity to 433 intervene early and possibly delay disease progression. It also has the potential to 434 facilitate patient-clinician communication and enhance patient-centred care.[11, 13] 435

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 442 reviewed and the final draft approved by all authors.

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458 **Conflict of interest statement**

459 None declared

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644

646 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."	

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.