

## Patients' and Clinicians' Perspectives on the Acceptability of Completing Digital Quality of Life Questionnaires During Routine Haemodialysis Clinics: A Mixed-Methods Study

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### Abstract

Advanced chronic kidney disease is a serious and common medical condition with significant treatment choices incurring varying high treatment burdens. Better understanding on how to best collect quality of life (QoL) in this unique situation may help guide critical decisions. This study investigates the acceptability of digital QoL questionnaires completed during routine haemodialysis sessions. Qualitative data was collected from patient (n=23) and clinical researcher (n=2) interviews alongside analysis of data from questionnaires completed by patients (n=101) during a 6-week validation study. Interviews refined the content and format of digital QoL questionnaires and provided novel insights regarding how patients assessed and completed QoL questions. This study suggests collecting QoL data using digital tablet technology during routine haemodialysis clinics is both feasible and acceptable to patients and has provided novel insights that are not routinely available with traditional methods.

### Keywords:

Advanced Chronic Kidney Disease, Quality of Life Measures, Digital Questionnaires.

### Introduction

Chronic kidney disease (CKD) is a serious and common medical condition, with up to 18% of the population over 60 in the UK affected by some degree of diminished renal function (CKD stages 1–5) [1]. End-stage (ECKD, stage 5) is itself a further independent risk factor for other morbidities, including cardiovascular diseases, anxiety and de-pression and premature mortality [2–4]. ECKD necessitates renal replacement therapy (RRT), such as haemodialysis. The ensuing high treatment burdens for patients has consistently been associated with a substantial decrease in long-term quality of life (QoL) [4–6].

Haemodialysis (HD) is a life-prolonging medical procedure and involves the mechanical, external filtration of the patient's blood to remove excess fluid and waste products from the blood; a task which is normally conducted by the kidneys when functioning normally. This treatment is typically performed three times a week, each HD session lasting four to five hours. However there are key decisions regarding the way that the HD machine is connected to patients (vascular access) with several different options that each have widely differing short-term

and long-term consequences. A better understanding of patients' views on vascular access and the impact on QoL is therefore critical to inform and optimize the care of ECKD patients [7]. However there is no data on how vascular access impacts day to day QoL. Indeed capturing this data itself may pose additional complications that patients may be mid-treatment, and physically limited by the vascular access.

In this study, we sought to investigate the acceptability of administering tablet-based QoL questionnaires during routine, haemodialysis sessions in the largest health-board of Scotland, NHS Greater Glasgow and Clyde (NHSGGC). Three QoL questionnaires were used: EQ5D5L [8], SF36 [9], alongside a vascular-access specific quality of life measure, VASQoL, which was purposely developed and evaluated by the study authors [7,10]. This study used a mixed-methods design, combining qualitative interviews with patients and clinicians involved in the capture of QoL data in clinics, as well as the data analysis of questionnaires' completion rates and time for completion.

### Methods

#### Ethics & Participants

Ethical approval for this study was provided by the University of Strathclyde ethics committee and by an NHS Ethics committee (19/LO/2005). Patients with CKD stage 5 and listed for creation of vascular access, who underwent regular haemodialysis and patients who had an access related clinical event and the ability to give informed consent were recruited for a VASQoL validation study between August and October 2020 [10]. As part of that process and to understand the practicality of the timing and technology involved, patients were approached by clinical researchers (renal consultants) and written informed consent obtained.

#### Data Collection

The study was completed in three stages: (1) patient interviews to inform the design of the VASQoL questionnaire [7], (2) validation of VASQoL measure and (3) clinician interviews. Patients used a digital tablet and purposely developed App [11] and were asked to complete the EQ5D5L [8] and SF36 [9] questionnaires alongside the VASQoL [7,10] during regular dialysis sessions at the hospital, over a 6-week period. VASQoL and EQ5D5L questionnaires were completed on 4 occasions over a

6 week period (weeks 1, 2, 4 and 6) while the SF36 questionnaire was completed twice (weeks 1 and 6). During the study, two clinical researchers supported the delivery of tablet-based questionnaires to patients. All three stages are discussed further in the following sections.

### Qualitative Data

A subset of patients took part in the semi-structured interviews, which lasted on average 45 minutes. Interviews were conducted in-person by one clinical researcher involved in the study. Patients were asked to complete all three QoL measures using the App on a tablet device. They were then interviewed in relation to the VASQoL questionnaire, with a focus on their interpretation of each question. Interviews were audio recorded and transcribed for qualitative thematic analysis [12].

In addition, the two clinical researchers who administered the questionnaires were interviewed themselves by the first author after the completion of quantitative data collection, in order to gain an understanding of their observations of patients' interactions with each QoL questionnaire during dialysis treatment. These interviews were conducted remotely over Zoom, audio recorded and subsequently transcribed for analysis as mentioned above.

### Quantitative Data

Quantitative data was collected during the 6-week validation phase of the study, with patients completing the QoL measures at required intervals during routine haemodialysis treatment. A clinical researcher was responsible for delivering the tablet device and App to the patients and were available if assistance was required.

When a questionnaire was started, a timestamp was automatically recorded by the digital App [11]. Upon selection of a response for a question, a timestamp was recorded for that question and recorded alongside the provided response. If the patient revised and edited their response, the timestamp was updated. When completed, this data was securely transferred and stored within an SQL database hosted by the University of Strathclyde, alongside an anonymous identifier unique to each patient.

Anonymized patient demographic data was later merged through data linkage. Using the timestamps collected, the order of completion and length of time spent on each question was then calculated. To investigate each questionnaire, patients who did not complete the questionnaire at required intervals were filtered from the dataset, leaving only those who completed the SF36 twice and the EQ5D5L and VASQoL four times. From these filtered datasets, data was separated into intervals e.g., the EQ5D5L dataset was split into datasets for entries in weeks 1, 2, 4 and 6. This allowed comparison between intervals, such as calculating the difference in completion time between intervals.

## Results

### Patient Characteristics

A total of 101 patients participated in the VASQoL study [10]. 55 were male (46 female) with a mean age of  $59 \pm 16$  years (range 21 and 88 years, Table 1). A subset of  $n=23$  patients participated in the qualitative interviews described in the next sections.

### Understanding and Interpretation

The interviews focused on confirming the patient's understanding of what each question was trying to elicit, often referring to the use of language. While it appeared most questions were easily understood, there were some instances where patients had difficulty in interpreting the question or required further information.

Table 1 – Patient Characteristics

	Total	SF36	EQ5D5L	VASQoL
<b>Sex n (% of total)</b>				
Male	55 (54)	50 (57)	43 (59)	36 (57)
Female	46 (46)	38 (43)	30 (41)	27 (42)
<b>Age in Years</b>				
Mean (SD)	59 (16)	59 (16)	60 (15)	59 (17)
Range	21-88			
<b>Age Group</b>				
< 65 years	58	48	40	38
65+ years	43	40	33	25
<b>Scottish Index of Multiple Deprivation (SIMD)</b>				
1 (Most deprived)	39	32	25	22
2	18	16	13	12
3	11	10	9	8
4	17	15	13	10
5 (Least deprived)	16	15	13	11

### Emotionally Loaded / Difficult Questions

While all 23 patients expressed positive relationships with staff or confidence in their ability to communicate and participate in care decisions, some suggested that some people could have reservations.

*P1: Yes, but I think maybe, have you been asked about your care, that kind of thing maybe. Some people probably come in and maybe they don't want to ask, maybe they are afraid or frightened.*

Patients were also at times unsure whether some of the questions should be interpreted in the context of their clinical treatment or their personal life in general. Even though some questions were more generic than others, the "confines of dialysis" still affected how they responded as part of the reality of their day-to-day life.

*P8: That question, I think is, the last question [Q7] there is, if you are satisfied with life in general? I think that is a hard question to answer. You have to say it within the confines of being on dialysis. You know, my life would be completely different if I didn't have to come here three times a week.*

Similar notions were expressed by other patients when discussing how their vascular access impacted aspects of life, such as relationships (Q6), hobbies, social activities, or things they enjoy (Q5, Q9) or work and study (Q10). Patients felt they did not see their vascular access as an interference to these aspects of

life as they had already accepted prioritizing their health over such things, often noting the alternative was simply death.

*P16: It is awful at having a fistula but I don't know how else you would say it "interfered", because if it was going to interfere with your hobbies, if your hobby was weight lifting, do you know what I mean? It is definitely interfering with it but it is not. You would weight it up, wear a fistula or die.*

*P21: The thing is, the alternative to getting this is death so how can I be unhappy about it really.*

### Layout and Interface of Questionnaires

When asked about their preferences in using a digital tablet or paper-based form, most replied that they preferred using the tablet, citing the ease of use of completing the questionnaires on a tablet during dialysis, during which their dominant hand may be used for vascular access and hence, writing would be difficult. This feedback was given with the hindsight that not everyone is confident in using computers and therefore alternatives should also be offered.

*P8: And for people who, if you are going to do the questionnaire for people who are on dialysis it is actually quite hard to write. Some people have their fistula in their dominant hand, I don't fortunately, but even just writing can be awkward but some people are a bit funny about computers. So I don't know, you maybe have to do a bit of both.*

Another justification for paper over digital included the ability to review all questions and answers on a single page, which the patient recognized is possible on a screen but can be challenging.

A common theme amongst patients was the desire to provide open responses rather than selecting from a numerical range on a Likert scale, noting that they would be able to provide different answers to questions or add information to justify responses. One patient agreed with the clinician that analyzing open responses were more comfortable but could be more difficult to analyze, noting the opposite was true for the Likert scale responses. This discussion highlights the need to consider the balance between what is easier for the user to answer and what is easier for the researcher to analyze.

*C1: So, for an obvious evaluation it is easier just to have a range, of course, but I totally understand that it is more comfortable to give free answers.*

*P16: Yes, I mean, I get that it is easier to calculate but it is harder to answer sometimes. See, I don't think you are always going to get a more accurate, in that sense, because people are just going to go, I suppose, do you know what I mean...*

### Clinician Interviews

The 2 clinical researchers who administered the questionnaires were also interviewed to gain an understanding of their observations of patients' interactions with each QoL questionnaire on the digital tablet during treatment. Thematic analysis of interviews with the two clinical researchers (C1, C2) identified the following themes.

### Layout and User Interface

The delivery of the QoL measures through the App [11] on a tablet device resulted in some issues to the layout of questions onscreen. For example, the SF36 was described as challenging, due to the length and interface of the questionnaire.

To maintain the validity of the QoL measures, they were implemented into the tablet without modification to their original

presentation as possible. In the case of the SF36, this meant all 36 questions were presented on a single screen. Compared to the other measures, this made it difficult for patients to focus on individual questions (C1 described scrolling the screen for the patient so the current question was positioned at the top of the screen). The limitations of the one-page questionnaire also caused issues where scrolling caused text to go offscreen, notably where the question was part of a group under the one domain or heading.

*C1: It's not question by question, confusing to focus on one question, the way its presented is very difficult.*

In contrast the EQ5D5L and VASQoL were preferred for their question-per-page layout and shorter length. The EQ5D5L was praised for implementing large buttons onscreen for displaying 5 responses (Q1-5), which visually changed color when selected, rather than simplistic radio buttons.

*C2: They liked the big boxes. They liked when they hit it, it changed color and they knew it had been recorded. It was big visual feedback.*

### Question Relevance to Patient and Difficulty

Patients found some questions in the SF36 less relevant, in contrast to the EQ5D5L and VASQoL, which were described as "relevant, practical simple questions". This was attributed to patients understanding the question in context to their situation i.e., a patient living with a chronic condition and high treatment burden. C2 noted a "ceiling effect" in responses reflected this fact as well. Both discussed how some questions naturally required more time for reflection. For example, patients often paused on the VASQoL Q8 (which questions the patient on if they feel involved in their care) to verify their input with the researcher. Patients' situations also appeared to determine their response time to the final two questions of the VASQoL, focusing on interference with work/study and hobbies and interests. This indicates the nature of the questions may require additional time, for both reflection and verifying responses in respect to the individual's circumstances.

*C2: Whenever they think about things, they think about context in terms of their situation.*

### Question Design

With the three QoL measures differing in length and question design, there was discussion about how this influenced patient response times. Again, the SF36 was problematic, with question format changing often i.e., 3-point Likert to 5-point Likert scales, creating a "unstructured" questionnaire (C2).

The EQ5D5L had a similar issue where the final question (Q6) shifted from choice of 5 responses to simple statement to an analogue scale, with sudden changes in layout and the addition of instructions on how to respond to the scale contributing to additional time spent on the question. The numerical nature of the scale was also discussed, as C1 observed patients found identifying with a number more difficult, with similar observations made during the VASQoL and the 10-point Likert scale. C2 supported this when noting patient feedback on the use of statement to anchor responses in the EQ5D5L (Q1-5). Both were aware patients had shown a preference for open-ended responses but noted that open-ended responses are harder to analyze.

*C2: Statement anchoring – patients fed back they found that easier to complete. They could identify which statement they could apply to them.*

C1: It's so much easier to give open answers and give everything that's on your mind. It's harder to link to a number. It'd be harder to analyze open answers.

**Interruptions and Motivation**

A key factor in those that took widely differing time to complete the questions (outliers) was interruptions from medical interventions, dialysis machines or nurses and distractions such as snacks and tea trolleys, televisions or phone calls. This was also related to their motivation to complete the questionnaires, as C1 noted most patients were keen to take part at Week 1 but this enthusiasm decreased as the study continued until completion at Week 6. While this is discouraging, it demonstrates dialysis patients are willing to try and engage with something new if it distracts them from their lengthy sessions, as long as it does not add to their exiting burden.

C1: There are lots of reason for distraction. Every distraction is welcome. They would just put the tablet away and do something different.

**QoL Measure and Completion Time**

To determine if there was evidence of a learning curve or boredom, the total time to complete each questionnaire was compared between Weeks 1 and 6. There were no trends in relation to response times either overall, or by patient characteristics including age (under 65, 65 and over) or deprivation category (Scottish Index of Multiple Deprivation [13], most deprived vs least deprived).

**Time for Questionnaire Completion**

The time taken to complete the questionnaires varied widely (the median time for SF36, EQ5D5L and VASQoL was 392, 91 and 149 seconds, respectively). The longest time recorded was almost half an hour (1794 seconds or 29.9 minutes) by a patient completing the SF36, whereas the shortest time recorded was 17 seconds for completing the EQ5D5L (see Table 2).

**Time Spent on Individual Questions**

As well as overall completion time, we were interested in the time spent to complete individual questions of each questionnaire. Given the widely differing number of questions, the percent of the total completion time each question took was calculated and thus allows for comparison across all three questionnaires (Figures 1, 2 and 3). It had been postulated that for all three questionnaires, the first question would require more time than most other for familiarization with the presentation of the question and the response choices. However each questionnaire differed widely in the times taken to complete each question.

The response time for the VASQoL questions were all similar, except for Q8, which had higher response times, after Q1. The VASQoL does not have a change in response range or layout as the other two measures do. Q1 asks patients to select a response to the statement: "In the last week I feel I have been included in decisions about the care of my line / fistula / graft", focusing on the patients' perception of their care and relationship with healthcare providers. The greater response time implies greater engagement and consideration for the response.

The SF36 question response time were longer for Q3, Q13, Q17, Q20, Q23, Q32 and Q33. These questions characterized by differing response ranges and layout (e.g., Q2 is presented as one singular question using a 5-point Likert scale whereas Q3 is the start of a grid of ten questions using a 3-point Likert scale under one shared question or domain).

Table 2 – Time for Questionnaire Completion

	Time for completion (seconds)			
	Median	IQR	Min	Max
SF36	392	282 – 540	85	1794
EQ5D5L	91	68 – 117	17	1118
VASQoL	149	110 – 226	35	888

Fig. 1 – VASQoL Question Completion Time

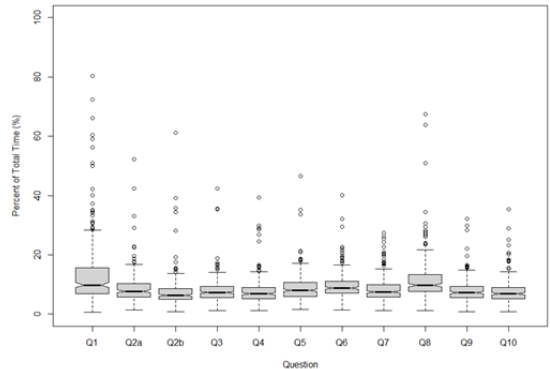


Fig. 2 – SF36 Question Completion Time

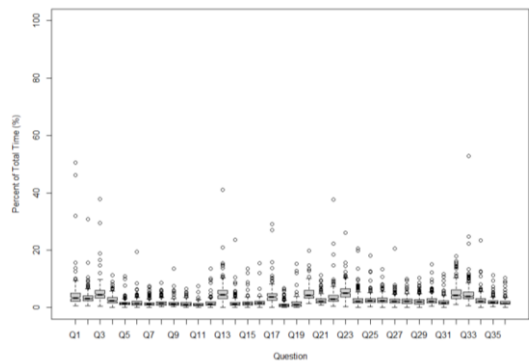
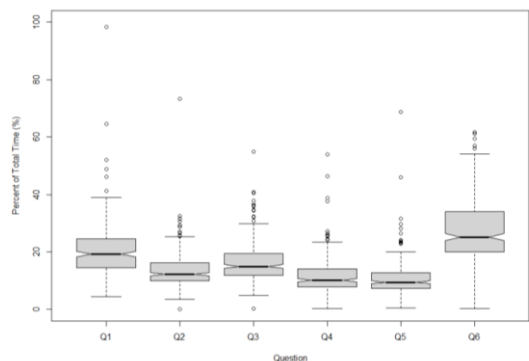


Fig. 3 – EQ5D5L Question Completion Time



Interestingly there is a consistent reduction in response times for the EQ5D5L as the patient completes the questions, except for Q3 and Q6 (the visual analogue scale). Notably, Q6 is the only question from the three measures where the median is

greater than 20% of total time taken. Q6 does include a change in layout and question format (shifting from 5-point Likert to an analogue scale of 0 to 100). Q3 is longer in length than the other five text-based questions and asks patients to select a response regarding the problems about carrying out usual activities which is broader than the other questions covering several "activities" which may be important individually (e.g., family and work may be impacted very differently).

Considering the additional response times Q3 of the EQ5D5L and Q8 of the VASQoL, the context of these questions may be considered "emotionally loaded". For example, the VASQoL (Q8) requires the patient to consider their engagement in their care and the relationship with their healthcare providers, while the EQ5D5L (Q3) asks about several aspects of the patient's life in a single question.

## Discussion

The layout and delivery of QoL measures via a mobile App [11] presented unique challenges where patients were unable to view the entire questionnaire onscreen but was acceptable where questions were presented one-by-one. The presentation and format of questions was a common theme discussed by patients and researchers, cited for delays in completion time. Additional time was required to familiarize with the new format (this can be seen in Figure 2 where the median time increases where questions change format often). These findings support the principle that single-question formats should be used over matrix-question formats [14] (such as the SF36 utilizes) and suggest more consideration is required when converting QoL measures from traditional paper-and-pen to digital formats, to both preserve the validity of the measure while ensuring it is also accessible and designed to make the task of reading questions, following instructions, and recording answers as easy as possible [15].

The content of the questions asked by the QoL measures varied in relevance and significance to patients based on their situation, as individuals living with a chronic health condition and high treatment burden. This often resulted in a binary approach to responses, with some showing they did not feel their treatment interfered with their life as long as it was prolonging it and failing to see relevance in the question. Other questions however required additional time for reflection upon important or sensitive aspects of the patients' lives e.g., relationship with healthcare providers or family and friends. This suggests careful consideration is required when applying QoL measures with chronic disease patients, as they may have different priorities and understandings of QoL than other patient populations. Patients also suggested open-responses as opposed to relating to a numerical value from a Likert scale, but these add additional complexity to analysis [14]. Statement anchors such as those the EQ5D5L uses however were more easily identified with and could be a suitable compromise to this issue.

Finally, while interruptions were an issue this paper does raise the possibility of using timing information to highlight questions that a clinician may wish to discuss further. We will investigate this possibility in future studies.

## Conclusions

This mixed-methods work has combined quantitative and qualitative data collection and analysis from CKD patients and two researchers to identify design considerations for digital QoL

measures and their acceptability with this population. Considerations include consistency in question format and layout and considering the relevance of QoL-related topics in regards to patients living with a chronic disease and high treatment burden.

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