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Perspectives of Patients, Nurses, and Nephrologists About Electronic Symptom Monitoring With Feedback in Hemodialysis Care

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Rationale & Objective: Patients receiving hemodialysis experience high symptom burden and low quality of life (QOL). Electronic patient-reported outcome measures (e-PROMs) monitoring with feedback to clinicians may be an acceptable intervention to improve health-related QOL for patients receiving hemodialysis. This study explored patient and clinician perspectives on e-PROMs monitoring with feedback to clinicians.

Study Design: Qualitative study.

Setting & Participants: 41 participants (12 patients, 13 nephrologists, 16 dialysis nurses) who participated in a 6-month feasibility pilot study of adults receiving facility-based hemodialysis across 4 Australian units. The intervention consisted of electronic symptom monitoring with feedback to clinicians, who also received evidence-based symptom management recommendations to improve health-related QOL.

Analytical Approach: Semistructured interviews and focus group discussions explored the feasibility and acceptability of e-PROMs monitoring with feedback to clinicians. We conducted a thematic analysis of transcripts.

Results: We identified 4 themes: enabling efficient, systematic, and multidisciplinary patient-centered care; experiencing limited data and options for symptom management; requiring familiarity with technology and processes; and identifying barriers and competing priorities. While insufficient patient engagement, logistic/technical challenges, and delayed symptom feedback emerged as barriers to implementation, active engagement by nurses in encouraging and supporting patients during survey completion and clinicians' prompt action after symptom feedback were considered to be facilitators to implementation.

Limitations: Limited generalizability due to inclusion of English-speaking participants only.

Conclusions: Patients, nurses, and nephrologists considered e-PROMs monitoring with feedback to clinicians feasible for symptom management in hemodialysis. Clinician engagement, patient support, reliable technology, timely symptom feedback, and interventions to address symptom burden are likely to improve its implementation within research and clinical settings.

Visual Abstract online

Complete author and article information (including a list of the SWIFT Investigators) provided before references.

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Hemodialysis (HD) is associated with poor survival, high symptom burden, and impaired quality of life (QOL).^{1,2} Facility-based HD recipients report health utility of 59% of full health.¹ Patients frequently experience severe symptoms that are underreported and undertreated,^{3,4} including fatigue, pain, nausea, insomnia, anxiety, and depression.^{2,5} Although fatigue, pain, and depression are critically important to patients and health professionals,⁶ only 17% of randomized controlled trials in HD have measured patient-reported outcome measures (PROMs).⁷

Symptom monitoring in patients undergoing chemotherapy improves QOL and survival,^{8,9} but the effectiveness of symptom monitoring in the HD population is uncertain. The Symptom Monitoring With Feedback Trial (SWIFT)¹⁰ is a registry-based, cluster-randomized, controlled trial. The intervention is electronic symptom monitoring every 3 months using the Integrated Palliative Outcome Scale (IPOS-Renal) questionnaire and email-delivered feedback to patients and clinicians of symptom scores with evidence-based symptom management. SWIFT will test whether the

intervention can improve health-related QOL at 12 months in 2,400 adults across 143 Australian HD centers.

As part of the SWIFT pilot study,¹¹ we studied the perspectives and experiences of patient participants, nephrologists, and nurses regarding the acceptability and feasibility of electronic PROMs (e-PROMs) collection with feedback to better inform the use of e-PROMs monitoring in research and clinical settings.^{12,13}

Methods

We followed the published SWIFT protocol¹¹ and Consolidated Criteria for Reporting Qualitative Research.¹⁴ Ethics approval was obtained from the relevant hospital human research ethics committees (HREC/18/CALHN/481; HREC/MML/54599).

Study Design

The SWIFT pilot (ANZCTR Universal Trial Number U1111-1223-8909) was a cluster-randomized controlled

PLAIN-LANGUAGE SUMMARY

Patients who need dialysis can have severe symptoms like anxiety, pain, appetite loss, itching, and disturbed sleep. We are conducting a large clinical trial called SWIFT to learn whether electronic symptom monitoring with feedback to clinicians will reduce patients' symptoms and improve their well-being. We asked patients, doctors, and nurses who participated in the pilot study of SWIFT about their perspectives on collecting information on symptoms to improve the process. Patients and clinicians thought that electronic symptom monitoring with feedback was feasible and suggested strategies to strengthen the SWIFT trial design. These included nurse champions to support patients with survey completion, language options, reliable technology, timely symptom feedback, and effective symptom management.

trial across 4 HD centers in Australia. Between August 6, 2019, and March 20, 2020, adults (≥ 18 years) undergoing maintenance HD were enrolled. Sites were randomized to the intervention arm (symptom monitoring with feedback to clinicians every 3 months) or the nonintervention arm (QOL data collection only). The e-PROMs responses were collected via a tablet at routine HD sessions using quick response (QR) codes unique to each patient. Dialysis nurses were trained to support patients in using the tablet. At all sites, QOL was assessed using the EuroQOL 5 Dimensions, 5 Levels (EQ-5D-5L) instrument¹⁵ at baseline and 6 months. In the intervention arm, symptoms were monitored using the IPOS-Renal¹⁶ survey at baseline and at 3 and 6 months. Opt-out consent was used to minimize selection bias. Individual patients' IPOS-Renal scores were emailed to the dialysis nurse unit managers and the patients' treating nephrologists, with scores of 3 (severe symptoms) or 4 (overwhelming symptoms) highlighted (Item S1). Hyperlinks to evidence-based symptom

management guidelines and resources were provided within the email (Fig 1; Item S2).

After completion of the SWIFT pilot trial, we conducted focus groups and semistructured interviews to elicit the experiences and perspectives of the participating patients, nurses, and nephrologists.

Participants

All participants provided written informed consent before participation. Recruitment for each group ceased at data saturation, when no new themes were identified.

Patient Participants

English-speaking patients aged 18 years or older who completed the IPOS-Renal, EQ-5D-5L, or both at 6 months were eligible to participate. Participants were purposively sampled to capture diverse experiences and perspectives based on demographics (sex, age, ethnicities, and linguistic backgrounds) and time since HD commencement.

Nurses

HD nurses at the participating sites were eligible. We purposively sampled nurses to enable diverse participant ages, roles, and experiences in both trial arms.

Nephrologists

We purposively sampled nephrologists to ensure representative age, sex, experience, practice, and trial intervention experience.

Data Collection

Investigators (E.D. [researcher], P.B. [dialysis nurse, researcher], and K.D. [researcher]) with qualitative research expertise conducted four 90-minute focus groups with either 4 to 5 nurses or patients when COVID-19 restrictions permitted (March–May 2020). We used a private room near the dialysis unit for patients' convenience. Focus group facilitators introduced project aims and used semistructured question guides¹¹ informed by previous research¹⁷ and discussion among the study team. We used a similar

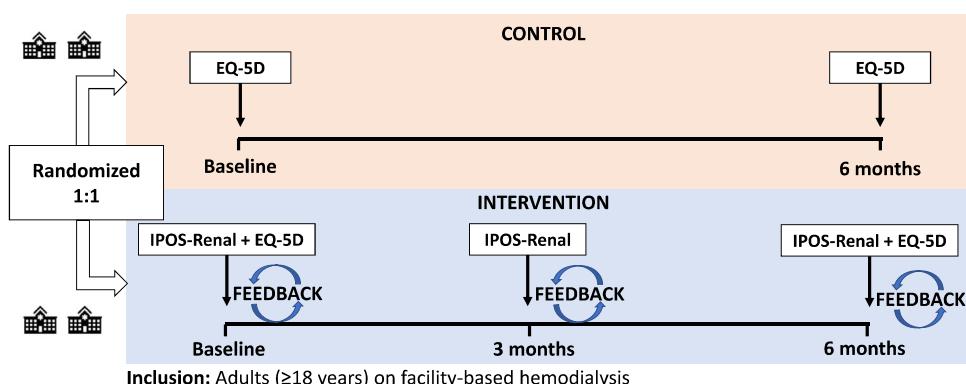


Figure 1. Study schema for the Symptom Monitoring With Feedback Trial (SWIFT). Abbreviations: EQ-5, EuroQOL 5 Dimensions, 5 Levels (EQ-5D-5L) instrument; IPOS-Renal, Integrated Palliative Outcome Scale questionnaire.

question guide for patients and nurses participating in telephone or face-to-face semistructured interviews (April–May 2020). A tablet with the EQ-5D-5L and IPOS-Renal surveys was available during focus groups to aid discussion. A nephrologist and researcher with qualitative research expertise (A.V.) conducted semistructured interviews with nephrologists via videoconference or face-to-face (April–July 2020). All question guides are included in [Item S3](#).

Focus groups and interviews were audio-recorded and transcribed verbatim.

Data Analysis

Two investigators (A.V. and M.D.) read the deidentified transcripts line-by-line to identify and code concepts inductively into themes reflecting stakeholder perspectives on e-PROMs monitoring with feedback in HD using NVivo 12 software (QSR International).¹⁸ Emerging themes were identified within participant groups and subsequently compared between groups. Four authors (R.L.M., E.D., K.D., and P.B.) independently read the transcripts and preliminary themes and discussed feedback with A.V. and M.D. Investigator triangulation ensured that the full range and depth of data were explored.¹⁹ The analytic process was further guided by the normalization process theory,^{20,21} an analytic framework to explain how technology is implemented, embedded, and integrated into health care settings, including perceived benefits and concerns and factors that promote or inhibit “normalization” into practice.

Results

Study Participants

Forty-one participants (13 nephrologists, 16 dialysis nurses, 12 patients receiving HD) were included. The participant characteristics are summarized in [Tables 1](#) and [2](#).

Themes

We identified 4 themes to describe the benefits, concerns, enablers, and barriers of electronic symptom monitoring and symptom management feedback for patients on HD: (1) enabling efficient, systematic, and multidisciplinary patient-centered care; (2) experiencing limited data and options for symptom management; (3) requiring familiarity with technology and processes; and (4) identifying barriers and competing priorities. We describe the themes and subthemes here with illustrative quotations in [Box 1](#) and a thematic schema in [Figure 2](#).

Enabling Efficient, Systematic, and Multidisciplinary Patient-Centered Care

Facilitating Communication and Holistic Care (Clinician and Patient Generated)

Clinicians suggested that systematic PROMs collection with feedback could facilitate communication between themselves and patients and support holistic care. Completing PROMs surveys could help patients share problems not

Table 1. Characteristics of Patient Participants

Variable	Value
SWIFT pilot group allocation	
Intervention	4/12 (33%)
Control	8/12 (67%)
Format	
Interview	7/12 (58%)
Focus group	5/12 (42%)
Female sex	5/12 (42%)
Age, y	69.5 ± 13.41 (39-88)
Ethnicity	
Anglo-Celtic/White/Caucasian	8/12 (67%)
Aboriginal/Torres Strait Islander	2/12 (17%)
Māori/Pacific Islander	1/12 (8%)
Filipino	1/12 (8%)
Country of birth	
Australia	7/12 (58%)
England	3/12 (25%)
Philippines	1/12 (8%)
Tonga	1/12 (8%)
Language spoken at home	
English	9/12 (75%)
Aboriginal or Torres Strait Islander language	1/12 (8%)
Tongan	1/12 (8%)
Spanish	1/12 (8%)
Years on HD	3.2 [2.4-5.0]
Years on kidney replacement therapy	4.5 [2.4-8.6]
Highest level of education completed	
Lower or middle high school	6/12 (50%)
Final year of high school	1/12 (8%)
Vocational training/certificate	2/12 (17%)
University degree	3/12 (25%)
Employment status	
Full time	0/12 (0%)
Part time or casual	0/12 (0%)
Not employed	3/12 (25%)
Studying	1/12 (8%)
Retired	8/12 (67%)

Values are number and percentage, mean ± standard deviation (range), or median [interquartile range]. Abbreviations: HD, hemodialysis; SWIFT, Symptom Monitoring With Feedback Trial.

otherwise disclosed to nurses or nephrologists due to time constraints during a clinic visit, lack of opportunities, fear, embarrassment, or language barriers.

The nephrologists viewed symptom monitoring as an important and timely intervention to focus on quality rather than quantity of life. One said, “We concentrated on numbers for far too long, and we really left the patients out of it.” They stated that PROMs monitoring empowered patients to engage in their HD care actively and achieve personal treatment goals. Some suggested providing patients with opportunities to talk about symptoms might have “therapeutic value,” even if the symptoms could not be substantially improved.

Box 1. Illustrative Quotations from Patients, Nurses, and Nephrologists by Theme and Subtheme**Enabling Efficient, Systematic, and Multidisciplinary Patient-Centered Care****Facilitating communication and holistic care**

"I believe it was quite well done, and it inquired about the right sort of information ... it will be a great help to people in the future." (P2)

"I guess it's another way of getting information from them or allowing them to engage and share information." (Nurse Focus Group 3)

"I think it may facilitate a communication between the physician, the nurse, and the patient. And if it does, that's good." (D1)

"I think it's very valuable also because it's going to increase the engagement of the nursing staff that are caring for the patient with the issues that the patients think are highly relevant." (D4)

"I think it's essential. I think we concentrated on numbers for far too long, and we really left the patients out of it. So my feeling is always that we need to, rather than look at Kt/V, we need to look at the patient and see 'How do you feel? Are you eating well? Are you sleeping well?' as a far more important outcome. And it's more important for the patients. I think the numbers just kept the doctors happy more than anything else. We're scientists, we like numbers, but actually that's not the most important thing for our patients." (D9)

Reliable assessment of change in PROMs

"Say, people on one mode of treatment, like hemodiafiltration, might have better outcomes in pruritus, for example, than people that aren't on ... you could get more research based on that for patient symptom outcomes, not necessarily dialysis outcomes." (N2)

"It will be interesting to see over time just with changing technologies and subtle things we do, whether it is better; and if you're using the same tool, it might be interesting to collect that over time ... Potentially things like the TheraNova membrane [a new dialysis membrane] might have an impact on these important symptoms like fatigue that we become aware of by doing the survey and watching it." (D1)

"It may help them to see—should they be changing something, or are they becoming more frail and should they actually think about advanced care planning." (D13)

Increased flexibility and ease of electronic data capture

"The electronic ones [surveys] are a lot better. Paper is no good because I've got to press hard on it, you see, and it just folds downwards." (P5)

"One of the beauties of using technology like this is you can easily translate the question easier than trying to conduct interviews or something like that when you need in-person translators." (D13)

"I thought an app which is accessible by an iPad might be better for the outpatients with impaired eyesight. You can blow it up as big as you can so they can read it." (D1)

"Some of them, I'd leave it [the tablet] with them, and then I'd turn around and they'd be done ... like the younger ones or the ones that were fairly tech savvy, they'd be done in a heartbeat." (Nurse Focus Group 3)

"I guess some of our younger patients—and in time as computer literacy seeps into the elderly—it may be easy to do it on their computer at home and collected, and even look at what variation depending on whether they're on dialysis or not ... In terms of making things efficient, I think just doing it on a device when they're on dialysis is the right time." (D1)

Experiencing Limited Data and Options for Symptom Management**Depersonalization of care**

"I don't think a questionnaire is any good. It's got to be from the person who's putting you on the dialysis machine". (P1)

"My personal preference to ask patients about their symptoms is a much more open-ended qualitative approach of asking patients about them and explore if they want to talk about them." (D12)

"If it's being done as part of clinical care, I don't find it very caring." (D12)

Perceived inability to intervene

"I think they try to manage them the best they can, but I don't think they can do much about itching, can they?" (P5)

"The longer they're on dialysis, I think the more pronounced those problems become, and I don't think there is going to be an easy fix to alleviate those problems." (Nurse Focus Group 1)

"If the same symptoms keep coming back and no one can fix them, then it may lead to frustration on everyone's part." (D1)

Time lag for feedback

"A lot of people are doing surveys, you don't get the results; if you give them a problem, you don't hear back from them, and we go onto the next survey and we go nowhere." (P1)

"They've either had it dealt with by the time the email came to us, or it was no longer a problem, or they had other problems that were more pressing instead." (Nurse Focus Group 2)

"The biggest thing's to try to link the feedback to the clinic appointment. I think if you just send out the email and the patient does not come for another 6 weeks, you are not going to get any traction." (D5)

Uncertain validity and reliability of survey data

"I don't tell them because they don't understand; they're not interested." (P5)

"They may not get the gist of the question that you're trying to ask them, and they're pushing these buttons thinking, 'Oh well, just push that button, that one looks okay, that one's okay.' You know, they're not thinking about it." (P5)

(Continued)

Box 1 (Cont'd). Illustrative Quotations from Patients, Nurses, and Nephrologists by Theme and Subtheme

"What bothers me is not necessarily what bothers them. I think if you've got a nurse's bias in there, it can change your results quite a lot." (N3)

"Getting uptake across every patient is going to be really difficult to do, and often the ones that would refuse to do it are probably the ones who are going to benefit most from the information being gathered." (Nurse Focus Group 2)

"I'm always concerned if somebody is assisting too much that it can alter the answers that are being given." (D9)

"I think also patients are often really concerned because they're in a dependent relationship with the doctors as well as with the nursing staff. But particularly with the nursing staff, they're quite reluctant to complain." (D4)

Requiring Familiarity With Technology and Processes***Embedding e-PROMs collection into routine care***

"I don't mind doing it; it doesn't bother me. You're just sitting there doing nothing anyway, so sometimes it's nice to use your brain." (P7)

"I know when they're here you've got a captive audience, and that sort of helps." (Nurse Focus Group 2)

"The more you do it, the more routine people will think it is, and they'll just keep doing it." (D4)

"I look forward to the IPOS-Renal data from SWIFT being presented within my unit in some of our monthly KPI and audit meetings ... because that will put symptom burden on the radar and probably slowly change the clinical focus that way." (D7)

Assistance to enhance uptake

"Well, for older people like myself that are not particularly familiar with technology, get one of the staff to help you do it, so it's simple." (P2)

"The staff didn't have any problem with loading it and working it. They very quickly understood the scanning system; and talking the patients through the basic techniques of using it, that wasn't a problem." (N1)

"I think there would have been far less uptake of people completing the survey if the nurses weren't assisting the patients to do it." (Nurse Focus Group 2)

"If I give people information and if we give them an opportunity to experience it in a positive, safe environment, would that improve the uptake? Well, it did, going from—I think it was 38% up to 76% or something." (N2)

Clarity about e-PROMs purpose and use

"The nurse brought it to me, she explained what it is, and she said what the idea was all about." (P1)

"I think most staff would be happy once they had a bit more education to use it." (N3)

"People will want to do it if they see some relevance, or they won't." (D5)

Comfort and willingness to use technology

"I found it pretty easy, but then again I'm—I hang around with my iPad and my computer as well at home, so it didn't faze me. If people don't know how to use an iPad they might have a bit of difficulty, but I had no problem." (P4)

"If it was in a simple format, I'd use that, but if it's too complicated, I'd go back to the pen and paper." (Patient Focus Group)

"I think a lot of the elderly, like elderly Italians, are used to FaceTiming their kids and things, so they're actually getting the idea a lot more about how to use these things." (D9)

Individualizing data collection

"I think if they have the ability to do it from their own piece of equipment in their own time, it might be more beneficial." (Nurse Focus Group 2)

"In terms of frequency of PROMs data collection, I think that really should be determined based on individual patients ... It might be that there are problems that happen on other days where that instrument or tool or measure would have been useful, but it doesn't get applied. So flexibility is important as well." (D7)

"I think that it has to be tailored to the individuals ... Whether it's on an iPad or a tablet or a mobile phone, I don't really have a strong feeling one way or the other." (D6)

Identifying Barriers and Competing Priorities***Physical limitations encumbering survey completion***

"Yeah, it would have been pretty clumsy trying to balance it [tablet computer] on my knees and scroll through answering questions." (P2)

"Usually, they were visually impaired or wore glasses and the writing on the iPad was too small." (N1)

"There were a couple of the elderly patients that really struggled with the dexterity to actually press the correct spot that they wanted." (N3)

"If they have a fistula, they can't move it. They don't want to move that arm because they're scared, and they're quite dominant in that hand for doing things." (Nurse Focus Group 3)

Low educational attainment and language limitations

"Some of the other patients who haven't got a good command of English may not understand the questions." (P5)

"That question about 'Do you feel at peace over the last week'—well, what does that mean? People hear that, and they go, 'What, was I dead?' because that's what they associated peace with. So it's trying to explain that sentence in a different context. So I used the word, 'Did you feel contented over the last week?'" (Nurse Focus Group 1)

"I think language barriers was one of our biggest issues within our patients ... There's quite some different nationalities in there, and they struggle to read English, so that was very difficult; they opted out of the program for that reason." (N3)

(Continued)

Box 1 (Cont'd). Illustrative Quotations from Patients, Nurses, and Nephrologists by Theme and Subtheme

"I think there's pretty good evidence that Aboriginal and Torres Strait Islander patients respond better to visual representations." (D13)

Fitting in with existing routines

"Well, it's all right for me because I'm usually awake and alert, either listening to the radio, reading the paper, or watching TV. But a lot of them, as soon as they get there, they go to sleep." (P3)

"It seemed you didn't really get enough time to think, because don't forget the nurse that brings that iPad to you has got other things on her mind at the moment because she's looking after, in our case, another 8 patients." (P1)

"Sometimes all they want to do is go to sleep when they get here or get into the TV." (Nurse Focus Group 2)

"Some of them may already have a routine, and it would seem like we're encroaching on that routine, whereas others would be more than happy to take that on board, so that may be a barrier depending on the patient." (D8)

Survey fatigue

"There were patients who were more than happy to do it the first time but didn't want to do it subsequent times, and there were some who it was, 'I'll do whatever you want,' and some who just said they weren't going to do it." (Nurse Focus Group 2)

"If you ask people too frequently, there will be a saturation point where people either are frustrated with the process of completing it or sick of being asked the same questions." (D13)

Abbreviations: D, doctor; (e-)PROMs, (electronic) patient-reported outcome measures; KPI, key performance indicator; N, nurse; P, patient.

Reliable Assessment of Change in PROMs**(Clinician Generated)**

Although clinicians often explored symptoms during consultations, they highlighted several benefits of standardized PROMs capture. Monitoring symptoms over time enabled clinicians to assess temporal trends and changes in response to specific interventions and life events. Clinicians felt e-PROMs collection enabled patients to track symptoms and possibly compare experiences with their peers. PROMs collection facilitated comparisons of symptom burden within and across kidney services, enabling assessment of effects of unit-level policy and treatment changes on patient outcomes.

Increased Flexibility and Convenience of Electronic Data Capture (Clinician and Patient Generated)

Patients and clinicians considered electronic surveys to be easier to complete and more efficient than paper surveys. Clinicians noted the benefits of an electronic survey interface for PROMs collection, including ease of access to different language options, larger font, visual prompts, and audiovisual assistance. Patients viewed e-PROMs collection as more environmentally friendly than paper surveys and found it easier to use a touch screen rather than pen and paper. Automated reminders could ensure timely survey completion. Graphical representation of symptom burden or QOL trends over time and comparisons were mentioned as additional possibilities. Although patients shared a device within the dialysis unit for this study, they also felt it would be feasible to use their own devices.

Experiencing Limited Data and Symptom Management Options**Depersonalization of Care (Clinician and Patient Generated)**

Some patients and clinicians raised concerns about the impersonal nature of surveys, which could deter patients

from completing them because of an inability to clarify and explore responses. They believed that the survey might be a substitute for a clinical conversation rather than a conversation starter. Patients felt a survey could and should not replace therapeutic interactions with nurses. "Adding in the personal touch" of a dialysis or supportive care nurse going through the survey was one way in which nurses could mitigate the perceived impersonal nature of e-PROMs data collection.

Perceived Inability to Intervene (Clinician and Patient Generated)

Concerns about the limited ability to improve symptoms was shared by all groups. Some clinicians worried that repeatedly asking patients to report symptoms without an ability to improve them could be confronting, discouraging, and frustrating for patients and their treating team. Clinicians and patients questioned the usefulness of collecting symptoms if they were not to be managed promptly, and they advocated for better systems to address symptom burden in a timely and effective way. However, both nephrologists and nurses found that the links to evidence-based symptom management were useful. One patient stated, "We can do this [complete surveys] until we're blue in the face, but unless something is actually being actioned upon, then there's no point." Participants were skeptical as to whether the intervention would be useful without knowing whether there is an added benefit to repeated e-PROMs collections.

Time Lag for Feedback (Clinician and Patient Generated)

Clinicians worried that delays in feedback would render patients' symptoms irrelevant by the time they could address them: "How relevant can the information be if it's from a survey 3 months' ago?" said one nurse. The nephrologists preferred to receive feedback immediately before their patients' clinic appointments, and the nurses

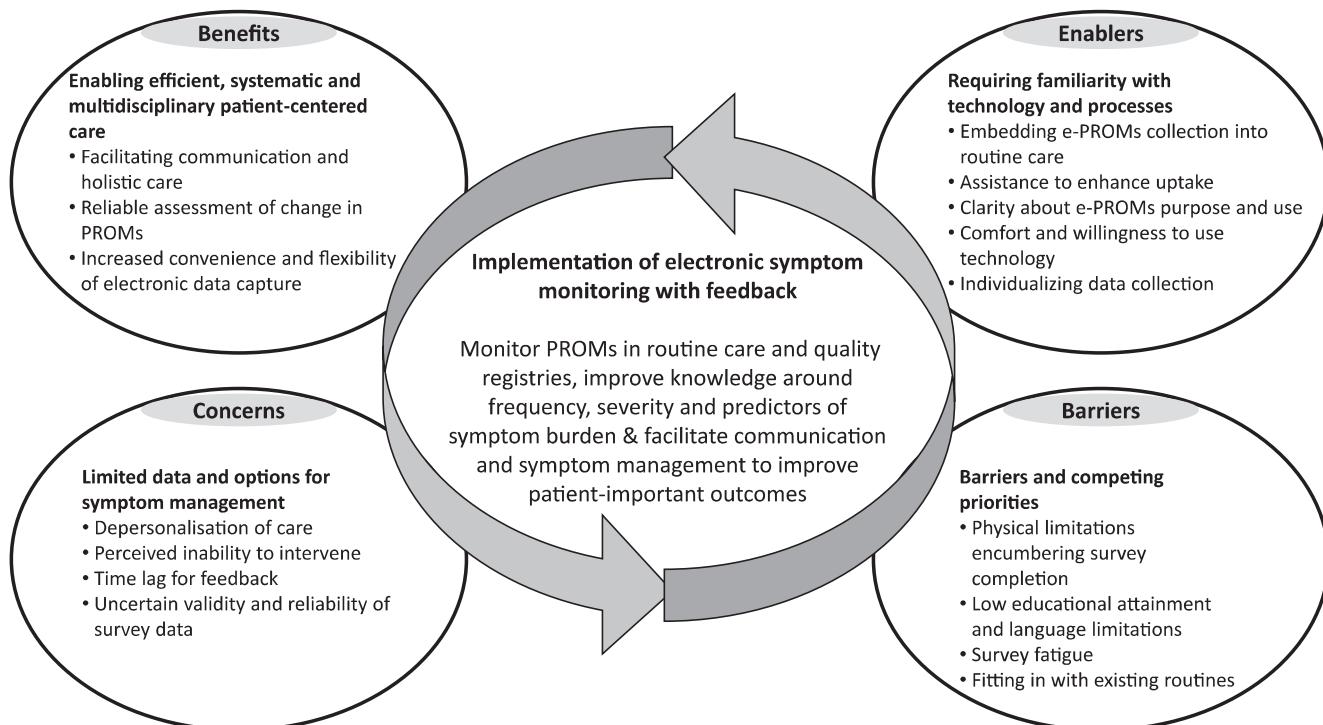


Figure 2. Relationship between themes. Abbreviation: (e-)PROMs, (electronic) patient-reported outcome measures.

advocated for real-time feedback to facilitate immediate action. The patients were particularly concerned about whether their symptoms would be addressed promptly.

Uncertain Validity and Reliability of Survey Data (Clinician and Patient Generated)

Clinicians and patients highlighted several issues around e-PROMs collection that could limit their validity, reliability, and usefulness. Participants raised concerns about the limited information captured from surveys containing predominantly “closed” responses. Some patients felt they could not sufficiently describe their symptoms and experience in an online survey. The nephrologists described the survey responses as relatively “crude measurements” of symptom burden requiring further exploration with patients. Some nephrologists worried that survey responses may tempt clinicians to treat symptoms without investigating and establishing the etiology first.

Some clinicians were concerned about potential proxy bias introduced by nurses or caregivers assisting with survey completion. This could also result in under-reporting of symptoms due to patients’ concerns that responses could impact negatively on their relationship with the treating team: “Patients are quite reluctant to complain because they’re in a dependent relationship with the doctors as well as with the nursing staff” (nephrologist). Patients questioned the usefulness of survey data in cases of half-hearted patient engagement and nondisclosure of problems due to assumptions that clinicians “don’t

understand” or are “not interested.” Some patients questioned the generalizability of survey data if clinicians “can pick and choose who [in their dialysis unit] does the survey.”

Table 2. Characteristics of Clinician Participants

Variable	Nurses	Nephrologists
SWIFT pilot group allocation		
Intervention	9/16 (56%)	7/13 (54%)
Control	7/16 (44%)	6/13 (46%)
Format		
Interview	3/16 (19%)	13/13 (100%)
Focus group	13/16 (81%)	
Female sex	11/16 (69%)	6/13 (46%)
Position		
Consultant nephrologist	NA	13/13 (100%)
Nurse unit manager	3/16 (19%)	NA
Registered/enrolled nurse	13/16 (81%)	NA
Years of HD experience, y	8.8 [3.5-10.0] ^a	20 [14-25]
In-center HD patients per nephrologist	NA	55 [30-65]
Patients’ HD clinic frequency, mo	NA	2.42 ± 0.45 (2-3)

Values are number and percentage, mean ± standard deviation (range), or median [interquartile range]. Abbreviations: HD, hemodialysis; NA, not applicable; SWIFT, Symptom Monitoring With Feedback Trial.

^aMissing data for n = 9 nurses.

Requiring Familiarity With Technology and Processes

Embedding e-PROMs Collection Into Routine Care (Clinician and Patient Generated)

Clinicians and patients identified several facilitators to embed e-PROMs collection into routine HD care. Patients receiving HD were considered a captive audience. Patients found it easy and convenient to complete e-PROMS during dialysis “when you’re just sitting there doing nothing anyway” and when nurses were available for assistance. Clinicians suggested that integrating regular e-PROMs collection into routine dialysis care would make the process easier and more efficient over time. The focus of dialysis management could be shifted away from biomarker surrogates toward more patient-centered outcomes: “It will put symptom burden on the radar and probably slowly change the clinical focus that way.” Some clinicians proposed symptom monitoring should be “ingrained in practice” and become a key performance indicator.

Assistance to Enhance Uptake (Clinician and Patient Generated)

All groups considered nursing support to be central to successful e-PROMs collection. Nurses could explain the purpose and value of e-PROMs data collection, help patients navigate the survey, overcome technological issues by setting up the electronic device, assist patients with impaired vision or dexterity, and arrange for additional support via an Aboriginal Liaison Officer or interpreter to assist in e-PROMs completion. The staff noted survey participation rates were higher when dedicated nursing staff took ownership of survey completion and helped patients as needed.

Good Communication About e-PROMs Purpose and Use (Clinician and Patient Generated)

Clinicians emphasized that clear communication to all staff in the unit of the purpose, process, and value of symptom monitoring was critically important for successful implementation of e-PROMs collection: one nephrologist noted, “buy-in and engagement of nursing staff is absolutely critical.” Active implementation would help nurses engage and assist with data collection, motivate patients to share their outcomes to facilitate communication with their nephrologists, and foster awareness in the treating team to focus on and manage patients’ symptom burdens. Nurses valued an initial introduction to how to use the tablet, scan the patients’ QR code, and navigate the surveys. A nephrologist stated, “you have to have everyone on the same page understanding what the tool is, what it’s really meaning, and how you’re going to implement the pathway.” Successful implementation of symptom monitoring with feedback was considered to require a whole-of-team approach from junior members to clinical

leaders, nursing and allied health staff, and the patient and their family or caregiver.

Comfort and Willingness to Use Technology (Clinician and Patient Generated)

Familiarity with technology was an important enabler to e-PROMs data collection. Patients accustomed to electronic devices perceived completion as simple and straightforward. Older patients who were less familiar with technology became capable after initial assistance from staff.

Individualizing Data Collection (Clinician Generated)

Electronic data collection was preferred because it offered more flexibility in displaying the survey (larger font size, audio versions, and different languages), and facilitated storage, processing, visualization, and distribution of survey data. The optimal survey frequency proposed by clinicians was every 2 to 3 months to strike a balance between risking survey fatigue and gaining meaningful and longitudinal information. The frequency should be individualized with more frequent monitoring when symptom burden was expected to change—for example, after HD initiation or an acute illness or life event. Nephrologists favored receiving the feedback via email, preferentially including a summary of all their patients’ scores and trends over time.

Identifying Barriers and Competing Priorities

Physical Limitations Encumbering Survey Completion (Clinician and Patient Generated)

Visual Impairment: Nephrologists, nurses, and patients discussed difficulties reading the survey due to poor eyesight and/or inappropriate font size. One nurse described showing patients the “zoom in” function on the tablet to enable them to complete the survey independently.

Dexterity: Patients and nurses discussed how some patients dialyzing via an arteriovenous access feared moving their arm and did not wish to complete the survey while on the machine.

Low Educational Attainment and Language Limitations (Clinician and Patient Generated)

All groups considered low literacy a barrier to survey completion. Patients unable to read would require additional assistance from nursing staff. Nurses and patients reported difficulties in understanding some survey questions and requiring nurses to clarify their meaning.

Clinicians and patients highlighted language as another important barrier to broad implementation of e-PROMs, with language options required for non-English-speaking patients for whom symptom burden was often not adequately communicated and addressed.

Fitting in With Existing Routines (Clinician and Patient Generated)

Clinicians and patients discussed how some patients may be uninterested due to lack of motivation, tiredness, or competing routines during their dialysis (eg, television, reading, or sleeping). Some nurses found assisting patients to complete e-PROMs was challenging due to clinical duties. Some patients felt the nurses' clinical duties and limited time added to their time pressures to complete surveys; one said, "It seemed you didn't really get enough time to think, because don't forget the nurse that brings that iPad to you has got other things on her mind."

Survey Fatigue (Clinician Generated)

Clinicians, but not patients, identified survey fatigue as a barrier, stating that some patients may have become less motivated or engaged to complete the survey if asked the same questions too frequently, particularly if their symptoms had not changed. One nurse described how some patients were happy to complete the survey the first time but not subsequent times.

Recommendations for e-PROMs Collection and Feedback

The insight provided by patients and clinicians has resulted in 7 major changes to the design and conduct of the SWIFT summarized in Box 2. Recommendations to facilitate e-PROM collection and implementation in research are provided in Box 3.

Discussion

Patients receiving HD, nephrologists, and nurses participating in the SWIFT pilot considered the use of tablet-based e-PROMs data collection with feedback to clinicians to be a feasible and acceptable intervention. Participants viewed regular electronic data collection during HD as the most efficient, convenient, and flexible way to capture and summarize patients' symptoms. Addressing concerns of insufficient patient engagement, logistic/technical challenges, and delayed symptom feedback would likely ensure successful implementation of this intervention in clinical research. The nurses' active engagement in encouraging and supporting patients during survey completion and clinicians' prompt action following symptom feedback were thought to improve the uptake and acceptability of symptom monitoring and management.

Routine monitoring of PROMs is increasingly considered an integral component of value-based, patient-centered health care.^{22,23} Consistent with previous studies,²⁴⁻²⁷ patients and clinicians in this analysis supported regular e-PROMs collection with feedback to manage patients' symptom burden and improve their general well-being. However, clinicians and patients were skeptical that routine PROMs collection would be effective in the absence of high-quality evidence showing clinical

Box 2. Summary of Changes Made to the SWIFT Process

- 1. Nurse champion:** Dedicated nurse champion(s) to explain trial purpose to patients and HD staff, encourage survey completion, and assist with data entry for patients with visual impairment, poor literacy, or dexterity issues.
- 2. Internet access:** To reduce survey interruptions due to poor connectivity, use of device memory cards rather than online upload to capture data.
- 3. Consent process:** A video added to explain SWIFT embedded in the e-consent process on the tablet before completing the baseline survey.
- 4. Multiple language:** options Patient information sheets and survey made available in 7 different language options (Arabic, Greek, Italian, Korean, Simplified Chinese, Traditional Chinese, and Vietnamese).
- 5. Staff education regarding assistance:** Written and verbal instructions provided on acceptable (eg, reading survey questions/responses, typing answers as instructed by patients, holding tablet, changing survey language) and not acceptable (eg, making decisions for patients) actions when assisting patients with survey completion to mitigate bias.
- 6. Feedback process:** Patients allowed to choose to receive their symptom scores via email or printout.
- 7. Evidence-based symptom management recommendations:** Emerging evidence on symptom management monitored by trial investigators and links to symptom management recommendation guidelines updated as new evidence arose.

Abbreviations: HD, hemodialysis; SWIFT, Symptom Monitoring With Feedback Trial.

benefits in the kidney disease population. Studies in people with cancer receiving chemotherapy have shown that PROMs collection improved health-related QOL and communication between patients and clinicians and reduced hospitalization and death.^{8,9} Similar evidence is lacking for kidney disease management and transferability of evidence from oncology is problematic due to differences between the 2 populations. Patients receiving chemotherapy for cancers often experience symptoms related to their treatment and have targeted treatment options available (eg, for nausea). Symptom management in patients receiving HD can be more challenging because symptoms are often multifactorial and underlying mechanisms may be inadequately understood.

Implementing routine e-PROMs collection to inform clinical care requires infrastructure to support efficient data collection with feedback and a structured approach to analyzing and responding to PROMs information. Information technology will facilitate integration of e-PROM data into research and clinical practice. The technology acceptance model is a widely applied model to describe consumers' acceptance and behaviors in the context of health-related information technology and is an appropriate theoretical framework to evaluate acceptance and promote implementation.²⁸ Electronic medical records with integrated alert systems could ensure rapid access to PROMs data alongside other clinical patient information to facilitate timely feedback and action by the treating team.²⁹

Box 3. Recommendations for e-PROMs Collection and Feedback in Research

Facilitation of e-PROMs Data Collection

- Delivered electronically via preferred device (eg, via app/email link; tablet, phone, or computer)
- Dedicated nursing time to assist with survey data collection (eg, HD nurse, supportive care nurse)
- Clear explanation of purpose, process, and value of e-PROMs collection
- Multiple language options
- Engaging interface (eg, large font, introduction video, audio option)
- Memory card to avoid reliance on Wi-Fi and internet access disruptions
- Data collection during dialysis session preferred
- Survey frequency every 2 to 3 months with flexibility according to individualized circumstances
- Timing of survey close to clinic appointment

e-PROMs Survey Feedback

- Delivered via email or electronic medical record report as part of a clinical decision support system
- Provided to treating team (eg, treating nephrologist, nurse unit manager) and patient
- Lag time minimized between survey and feedback
- Accompanying guidelines to facilitate symptom management
- Alert system for severe or overwhelming symptoms to prompt action
- Display of individual temporal trends of symptom scores and summative data at unit level

e-PROMs Implementation Strategies

- Symptom review as part of regular dialysis reviews (eg, blood results, clinical parameters)
- Clear instructions on how to operationalize the outcome measure in clinical practice
- Patient and clinician involvement
- Comparative data at unit level and temporal trends
- Dissemination of incentives associated with e-PROMs collection (eg, reimbursements)

Abbreviations: e-PROMs, electronic patient-reported outcome measures; HD, hemodialysis.

For broader implementation of long-term monitoring of standardized PROMs across kidney service providers and patient groups, national kidney registries could provide a more suitable infrastructure for research and clinical care.¹² About 25% of kidney registries in middle- to high-income countries and 50% in low-income countries collect PROMs.³⁰ Several studies have successfully piloted registry-based PROMs collection in patients with advanced kidney disease. The response rates in these trials were less than 40% of eligible participants with large intercenter variability (2%-98%).^{25,26} Motivation and engagement of clinicians and patients in the process of PROMs collection have been identified as crucial determinants of successful uptake of this intervention.¹³

Despite broad consensus that PROMs are integral to providing patient-centered care, high-quality evidence is required to confirm the clinical benefits of routine PROMs

collection and management in patients with kidney disease.²⁹ Several trials are currently evaluating PROMs monitoring and management in advanced kidney disease³¹⁻³³ and will inform whether PROMs collection improves patient outcomes, the optimal mode of PROMs collection, efficient and effective strategies for data analysis and feedback, and the best management of complex symptoms in patients with kidney failure. SWIFT is currently ongoing and will demonstrate how kidney registries might provide the infrastructure required for large-scale, pragmatic, cluster-randomized, controlled trials to evaluate the clinical benefit and cost-effectiveness of PROMs-based interventions.

In response to this study, SWIFT has undergone revision to enhance trial success. (1) Dedicated nurse champions have been trained to engage patients in the study and assist with survey completion without influencing patients' responses. (2) Data capture using the device's memory card instead of online upload has been used to reduce survey interruptions due to connectivity problems. (3) An introduction video explaining the study has been embedded in the e-consent process. (4) Multiple survey language options have been provided. (5) Staff have been educated regarding patient assistance. (6) Patients can now choose to receive their own symptom scores via email or printout. (7) Symptom management recommendations have been updated regularly as new trial evidence emerged.

The limitations of our study should be noted. Due to unforeseen COVID-19 restrictions enacted during the pilot study period, some of the intended focus groups with patients and nurses were converted to semistructured interviews. Study participants who agreed to and completed the study were likely to include early adopters and supporters of e-PROMs, and our findings may not have been transferable to all HD units (eg, private dialysis facilities) and patients (eg, those who declined participation). The intervention-group patient numbers were small, potentially limiting the depth of experience of completing the IPOS-Renal questionnaire. Tablet-based sample versions of the IPOS-Renal survey were provided to all patients in focus group discussions to maximize feedback. The study was conducted in English, thereby limiting transferability of findings to patients from culturally and linguistically diverse backgrounds.

This study shows that clinicians and patients consider e-PROMs data collection with feedback in HD using the infrastructure of a national kidney registry to be feasible and acceptable. Clinician engagement and patient support from nursing staff, reliability of technology, timely symptom feedback, and availability of interventions to treat symptoms are likely to improve acceptance and impact of symptom monitoring in clinical research.

Supplementary Material

Supplementary File (PDF)

Item S1: Example of feedback emails.

Item S2: Links to evidence-based symptom management recommendations.

Item S3: Question guides for hemodialysis patients, nurses, and nephrologists.

Article Information

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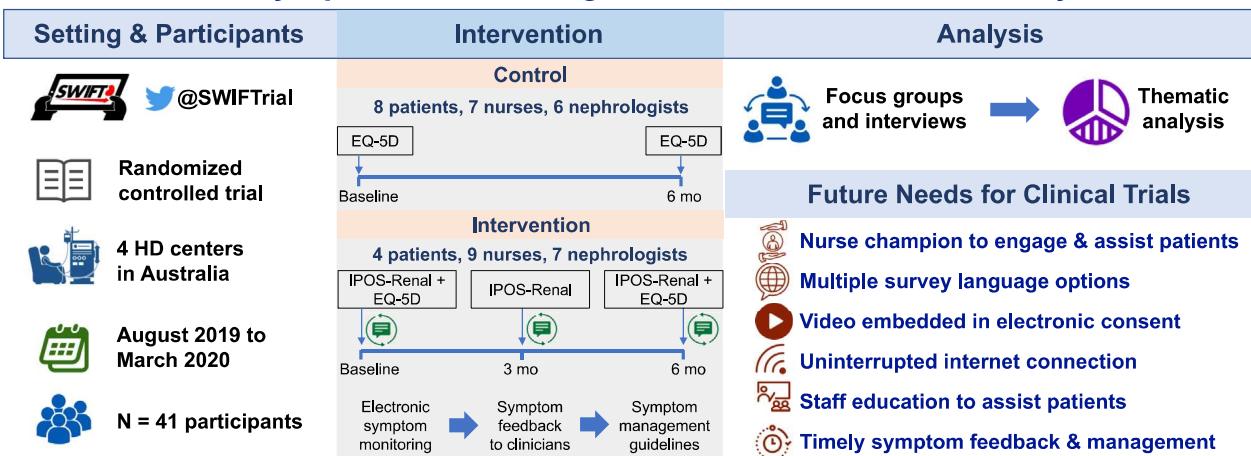
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Perspectives of Patients, Nurses, and Nephrologists About Electronic Symptom Monitoring With Feedback in Hemodialysis Care



CONCLUSION: Electronic symptom monitoring in HD with feedback is feasible and uptake is enhanced by nurse-led patient assistance, engaging & reliable technology, and timely symptom feedback & management.

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Item S1. Example of feedback emails

Dear Renal team,

There have been no IPOS-Renal Symptom scores of 3 or 4 indicating severe or overwhelming symptoms identified for your patients in this haemodialysis unit.

The Excel file attached contains symptom scores for all patients in the haemodialysis unit.

If you have any questions please email: kathryn@anzdata.org.au

Kind Regards,

Symptom monitoring WIth Feedback Trial (SWIFT) Team

If concerning symptoms identified

Dear Renal team,

IPOS-Renal Symptom scores of 3 or 4 indicate severe or overwhelming symptoms that have been recently identified for the following patients:

First name	Last name	Symptom	Score
Pepe	Romano	Pain	3*
		Nausea	4*
Patricia	Boswell	Itching	4*
John	Ling	Sore or Dry mouth	3*
		Shortness of Breath	3*

Link to evidence-based guidelines for management of these symptoms:

INSERT LINK/S BELOW

The pdf attached contains symptom scores for all your patients in this haemodialysis unit. All symptoms scoring 3 or 4 from this list have been identified above.

We encourage you to discuss these symptoms with your patient at their next visit; and encourage you to refer them to relevant existing services as necessary, e.g. Renal Supportive Care, Palliative Care, Pain Clinic.

If you have any questions please email: kathryn@anzdata.org.au

Kind Regards,

Symptom monitoring WIth Feedback Trial (SWIFT) Team

Item S2. Links to evidence-based symptom management recommendations



Symptom monitoring WIth Feedback trial (SWIFT)

Below are a list of available publications/guidelines published recently for management of individual symptoms assessed by the IPOS-Renal

Pain management:

- [Supportive Care: Integration of Patient-Centered Kidney Care to Manage Symptoms and Geriatric Syndromes \(See Table 2, pg 1887, Pain sub-heading\)](#)
- [Clinical Pharmacology Considerations in Pain Management in Patients with Advanced Kidney Failure \(See Figure 3, pg 926\)](#)

Nausea:

- [Supportive Care: Integration of Patient-Centered Kidney Care to Manage Symptoms and Geriatric Syndromes \(See Table 2, pg 1886, Nausea and vomiting sub-heading\)](#)

Vomiting:

- [Supportive Care: Integration of Patient-Centered Kidney Care to Manage Symptoms and Geriatric Syndromes \(See Table 2, pg 1886, Nausea and vomiting sub-heading\)](#)

Poor appetite:

- [Clinical Practice Guideline Undernutrition in Chronic Kidney Disease \(See Undernutrition guidelines 3.1-3.4, pg 22\)](#)
- [Cochrane Database of Systematic Reviews: Megestrol acetate for treatment of anorexia-cachexia syndrome \(Use of megestrol acetate for anorexia, Not specific to dialysis populations\)](#)

Constipation:

- [Management of Constipation in Patients with Chronic Kidney Disease](#)

Itching:

- [Supportive Care: Integration of Patient-Centered Kidney Care to Manage Symptoms and Geriatric Syndromes \(See Table 2, pg 1886, Pruritis sub-heading\)](#)
- [Treatment of Uremic Pruritus: A Systematic Review](#)

- [New guidelines on managing generalised pruritus](#)

Difficulty Sleeping:

- [Supportive Care: Integration of Patient-Centered Kidney Care to Manage Symptoms and Geriatric Syndromes \(See Table 2, pg 1886, Subheading Sleep disorders\)](#)
- [Cochrane Database of Systematic Reviews. Interventions for improving sleep quality in people with chronic kidney disease](#)

Restless legs:

- [Supportive Care: Integration of Patient-Centered Kidney Care to Manage Symptoms and Geriatric Syndromes \(See Table 2, pg 1886, RLS sub-heading\)](#)

Depression:

- [Supportive Care: Integration of Patient-Centered Kidney Care to Manage Symptoms and Geriatric Syndromes \(See Table 2, pg 1886, Depressive symptoms sub-heading\)](#)

Item S3. Question guides for hemodialysis patients, nurses and nephrologists

1. Interview and focus group question guide for hemodialysis patients

General experiences completing e-PROMs

- Tell me about your experiences of completing the surveys on the tablet computers at your HD unit?
 - When/at what time point did you complete them?
 - Where?
 - What did you like and dislike about it?
 - Opinions of electronic/tablet surveys versus pen and paper surveys?
- Tell me about any difficulties you had completing the survey
- Did you need help completing the questionnaires? (e.g. from a nurse), If so:
 - What exactly did you need help with?
 - Who helped you? Were staff readily available to assist you?
 - Did this solve the issue/problem?

Specifics of e-PROMs

- How did you find completing the quality of life survey (show example of questions) on the tablet?
 - Type of questions – being asked about symptoms & quality of life issues
 - How did you find the layout of the questions on the screen?
 - How did you find using the touch screen function?
 - Can you describe how it was to complete whilst in the dialysis chair receiving therapy? (prompts: blood lines, dominant vs. non-dominant hand, fistula, physical symptoms)
 - The case/stand (and use of dominant or non-dominant hand)
 - When and where do you think would be the best to ask patients to complete these surveys when they're at a dialysis appointment?

Impacts of feedback of results to clinicians

- Did your doctor or nurse discuss your symptoms with you at any time in the last 6 months? Did you mention any symptoms to your doctor or nurse?
 - If so, what can you recall from that discussion? What was helpful/unhelpful?
 - What happened after that discussion? Did this lead to a change in your care/management (e.g. referred to another doctor)?
- How would you like to receive feedback/follow-up of this sort of information if the hospital collects it from you?

Concluding questions

- If a researcher was to get patients to complete these questions on a tablet differently, what would you suggest?
- What advice would you give to another patient who has not completed this survey before?
- Do you have any other thoughts or opinions you'd like to share about 1) how we can collect symptom burden and quality of life information from dialysis patients? 2) how we can use tablets in dialysis units to do this?

2. Interview guide for nephrologists

General questions about PROMs collection

- Tell me about your views of PROMs collection in routine care of dialysis patients?
- What are the facilitators to collecting PROMs in routine care?
- What are the main barriers to collecting PROMs in routine care?
- Previous use or planned future use of PROMs
 - Clinicians title/role within their unit or service
 - Has this changed your conversations with patients, nursing, allied health or other medical staff? In what ways?
 - Prior experience with 1) collecting/reviewing PROMs data 2) addressing symptoms of concern for patients and making referrals/changes in management

Specific questions

- Who should ePROMs data be fed back to and actioned by? Why?
- When do you think would be the optimal timing to collect PROMs?
- What do you think would be the best mode of collecting PROMs data from patients (tablets in HD sessions, mobile app, at which appointments, with which member of their care team?)
- How did you find the e-mail feedback system of IPOS-Renal Symptom scores?
 - What did you like about it? What would you change?
 - Timing of e-mails in relation to next clinical encounter with patients?
 - Was there information not included that you would have liked to receive?
 - Was unnecessary information included?
 - Presentation of and access to symptom management guidelines?
- Tell me about the discussions you had with your patients about their 'troubling' symptoms after you had received the results
- What was your perception of how patients found discussing these issues with you? (e.g. fatigue, pain)
- Did receiving the ePROMs data result in changes to your management or care of patients?

- How? What did you do?
- Referrals? To whom?
- Response to management of particular symptoms

Concluding questions

- If you were to design and implement a system for PROMs collection – what would be the key features you suggest?
- Do you have any other ideas for how PROMs data may be collected and fed back and displayed to treating clinicians?
- Is there anything else you'd like to provide feedback on?

3. Interview and focus group guide for nurse unit managers & nursing staff

Introduction and general questions about PROMs collection

- Nursing staff's role(s) in the unit
- How would you describe the familiarity or competency of you/your unit with technology and electronic tablets?
- Can you tell me about the role you played in your unit in participating in this trial?
 - How did you find the mechanisms for identifying patients (QR scanning)?
 - Entering patient identifier information into tablet?
 - Administering the questionnaires to patients?
 - Using the instruction manuals/guides for administering and collecting the data?
- Can you tell me about any technical issues you experienced administering the tablets?
- Training/support for nursing staff to deliver ePROMs to patients?
 - Who is the best person/people to do this?
 - What are the frequent problems requiring assistance?
 - How prepared did you feel in terms of delivering the ePROMs and assisting patients if required?
- Can you tell me about any time when a patient required assistance to complete the questionnaires?
 - Who did they ask for?
 - What were the issues that frequently came up?
 - Were these easily resolved? How long did they take? What is nursing staff's opinion of this? (Burdensome or not an issue)
- What issues, if any, did you observe patients have with the tablets?
- What have been your past experiences collecting PROMs
 - How? Paper or electronic?

- Who collects? How often?
- Who are results fed back to? How well are these results followed-up/actioned?
- How did you find the administrative actions on the tablets? (e.g. prompts, reminders, auto-filled patient details, search function)
- When would you say is the *optimal timing* of administering the ePROMs measures? (Before, during or after the dialysis session)
- Where would you say is the *optimal setting* to collect PROMs? In waiting room, in clinics, at home?
- What would you say is the optimal frequency of collecting PROMs? Every 3 months, every 6 months or yearly?

Feedback

- Did receiving the feedback of patient's results lead to any changes in your management/care of them? Follow-up with patient or treating nephrologist?
- Who would you suggest this information/data be fed back to, and why?
- What would be the optimal way of presenting the information? What did you like or dislike about the e-mail?

General questions about implementation of ePROMs data capture and feedback

- What do you think are the main barriers to PROMs collection in dialysis units?
- What do you think would enable ease of PROMs collection in routine care – beyond the trial?
- If you were to provide feedback on how this trial could be run differently, what would you suggest?
- What would you say were the main enablers and barriers to ePROMs uptake and implementation?
- Is there anything you wish you knew/had been explained to you at the beginning of study?
- Is there anything else you would like to add/provide feedback on?

Reference:

Duncanson E, Bennett PN, Viecelli A, Dansie K, Handke W, Tong A, Palmer S, Jesudason S, McDonald SP, Morton RL; Symptom monitoring With Feedback Trial (SWIFT) Investigators. Feasibility and acceptability of e-PROMs data capture and feedback among patients receiving haemodialysis in the Symptom monitoring WIth Feedback Trial (SWIFT) pilot: protocol for a qualitative study in Australia. BMJ Open. 2020 Nov 6;10(11):e039014. doi: 10.1136/bmjopen-2020-039014. © Author(s) (or their employer(s)) 2020. Reproduced with permission of the copyright holder. Original content published by BMJ with a CC BY-NC license; commercial reuse prohibited.