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## Implementation and use of patient-reported outcome measures in routine nephrology care

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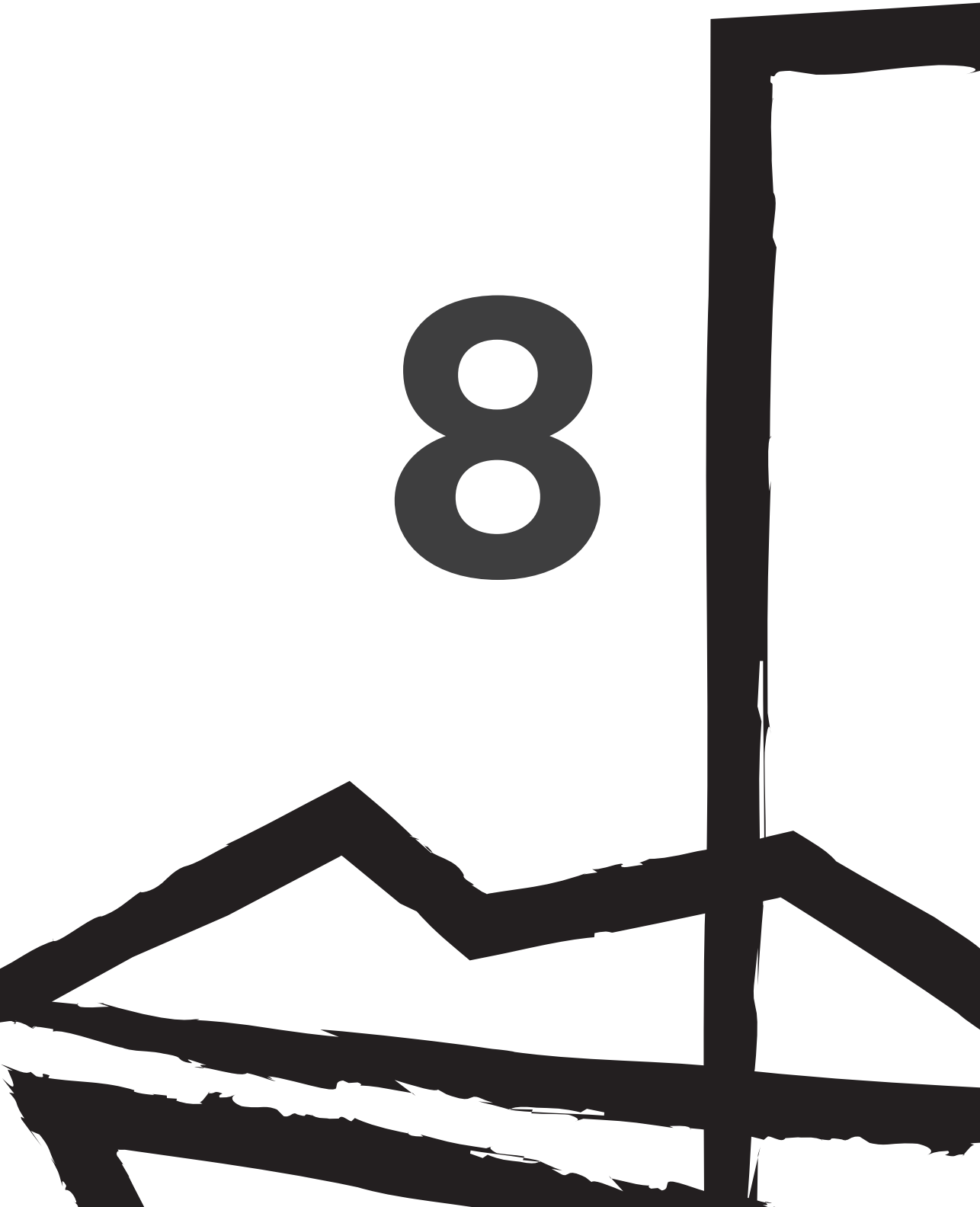
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# **Discussing results of patient-reported outcome measures (PROMs) between patients and healthcare professionals in routine dialysis care: a qualitative study**

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## Abstract

**Objectives:** Patient-reported outcome measures (PROMs) provide insight into patients' experienced health and needs, and can improve patient-professional communication. However, little is known about how to discuss PROM-results. This study aimed to provide in-depth knowledge of patients' and healthcare professionals' experiences with and perspectives on discussing PROM-results as part of routine dialysis care.

**Design:** A qualitative study was performed using an interpretive description approach. Individual semi-structured interviews were conducted with 22 patients and healthcare professionals. Interviews focused on general and specific situations (e.g. addressing sensitive topics or when no medical treatment is available). Interviews were transcribed verbatim and analysed inductively using thematic analysis.

**Setting:** Participants were purposively sampled from 8 dialysis centres across The Netherlands.

**Participants:** Interviews were conducted with 10 patients receiving dialysis treatment and 12 healthcare professionals (nephrologists and nurses).

**Results:** Patients and healthcare professionals provided practical guidance for optimal discussion about PROM-results. First, patients and healthcare professionals emphasized that PROM-results should always be discussed and indicated how to create a suitable setting, adequately prepare, deal with time constraints and use PROMs as a tool for personalised holistic consultations. Second, patients should actively participate and healthcare professionals should take a guiding role. A trusting patient-professional relationship was considered a prerequisite and patient-professional interaction was described as a collaboration in which both contribute their knowledge, experiences and ideas. Third, follow-up after discussing PROM-results was considered important, including evaluations and actions (e.g. symptom management) structurally embedded into the multidisciplinary treatment process. These general themes also applied to the specific situations, for example: results should also be discussed when no medical treatment is available. Though, healthcare professionals were expected to take more initiative and a leading role when discussing sensitive topics.

**Conclusions:** This study provides insight into how to organize and conduct conversations about PROM-results and lays the foundation for training healthcare professionals to optimally discuss PROM-results in routine nephrology care. Further research is needed to provide guidance on follow-up actions in response to specific PROM-results.

## Introduction

People with advanced chronic kidney disease (CKD) experience numerous physical and emotional disease-related symptoms, which have a major impact on their lives and health-related quality of life (HRQOL).<sup>1-3</sup> Although HRQOL and symptom burden have been regarded as highly important by patients and healthcare professionals<sup>4-6</sup>, these outcomes often remain undiscussed and un(der)treated in regular practice.<sup>3, 6, 7</sup> This may in part be explained by the fact that patients do not share everything by themselves, for instance because they do not talk easily about sensitive topics or assume their symptoms are not CKD-related or cannot be treated.<sup>8-10</sup> Additionally, healthcare professionals may consider it challenging to inquire about patients' wide range of symptoms and needs, for example due to time limitations, and remain largely unaware of symptom burden.<sup>7, 11</sup>

Patient-reported outcome measures (PROMs) are questionnaires that assess aspects of patients' perceived health, such as HRQOL and symptom burden, and are reported by the patients themselves.<sup>12</sup> PROMs can play an important role in solving the under-recognition of patient-relevant outcomes by providing insight into and facilitating communication about patients' HRQOL, symptoms and needs.<sup>2, 7, 13-16</sup> Integration of PROMs into routine care has the potential to contribute to a more person-centred approach, incorporating patients' experiences and needs complementary to traditional clinical measures. This provides patients and healthcare professionals with a more complete perspective on how the patient is really doing and could enhance shared decision-making about treatment choices.<sup>2, 13-18</sup> In the Netherlands, PROMs are implemented into routine dialysis care since 2018.<sup>2</sup> Patients are invited 1-2 times a year by their care team to complete PROMs on symptom burden and HRQOL.<sup>2, 19</sup> After completing PROMs, patients and healthcare professionals receive a patient's individual PROM-report and are encouraged to discuss PROM-results during the upcoming consultation.<sup>2</sup> Previous research suggests that using PROMs facilitates patient-professional communication by providing overview and insights, and by prompting discussions about topics that are important to patients.<sup>2, 20</sup> However, it also reveals several challenges in organization and conversations about PROM-results, including: lack of incorporation of PROM-results into electronic health records, limited time during consultations, and lack of knowledge on how to interpret and discuss PROM-results.<sup>21-25</sup> PROMs are relatively new in routine dialysis care, and although research emphasizes the need to discuss PROM-results, little is known about the most optimal way to have this conversation.<sup>2, 14, 26</sup> Therefore, this study aims to provide in-depth knowledge of patients' and healthcare professionals' experiences with and perspectives on discussing PROM-results as part of routine dialysis care.

## Methods

### Design and participants

A qualitative study was performed using an interpretive description approach. An interpretive description methodology captures the experiences and perspectives from practice, and intends to gain a deep understanding of the topic at hand and to generate knowledge that can enhance clinical practice.<sup>27-29</sup> Individual semi-structured interviews were conducted between April and September 2021, with patients receiving dialysis treatment and healthcare professionals involved in dialysis care – all experienced with completing and discussing PROM-results. Purposive sampling was applied to capture perspectives from a heterogeneous patient-sample based on age, gender and dialysis modality (haemodialysis [HD] or peritoneal dialysis [PD]) and healthcare professional-sample based on age, gender and occupation (nephrologists and nurses). Participants were recruited from 8 dialysis centres across The Netherlands (Provinces Gelderland, Noord Brabant, Noord Holland, Overijssel, Zuid Holland, Utrecht) participating in the Dutch PROMs-registry. Healthcare professionals were recruited through the researcher (EvdW) and patients through their care team, until data saturation was reached (i.e. when little or no new concepts arose from subsequent interviews).<sup>30</sup> All participants received written study-information and provided written informed consent. The study was approved by the Medical Research Ethics Committee (METC-LDD, N20.097). Recommended guidelines and checklists (e.g. the COnsolidated criteria for REporting Qualitative research [COREQ]) were used to conduct and report this study.<sup>31,32</sup>

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### Interview and data collection

An interview guide (Supplementary Table S1) was developed based on previous research<sup>2, 6, 14, 23, 26</sup>, discussion among the research team, and in collaboration with four patients from regional and national kidney patients associations (Diavaria and NVN). Individual interviews were performed through videocalls (Zoom)<sup>33</sup> or by telephone for patients without access or skills to use electronic devices. Interviews were carried out by two female researchers: EvdW (health scientist, PhD-candidate) and JM (medical scientist, PhD-candidate), who were trained by an experienced qualitative researcher, YM (medical psychologist, PhD). No relationship existed between participants and interviewers. Interviews were digitally recorded and field notes on non-verbal communication were made.

Prior to interviews, participants completed a brief questionnaire to collect socio-demographic information. Additionally, patients completed the PROMs used in Dutch dialysis care<sup>2</sup>: 12-item Short Form Health Survey (SF-12)<sup>34</sup> to assess generic

HRQOL and Dialysis Symptom Index (DSI)<sup>19, 35</sup> to assess CKD-specific symptom burden. Patients received their personal PROM-report and healthcare professionals received a mock PROM-report.

During interviews, participants were asked about: experiences with and perspectives on optimal ways to discuss PROM-results (part A), and perspectives on dealing with specific situations that might complicate discussions about PROM-results (part B). All questions were open-ended and responses were further explored using additional questions and probes. Participants received a summary of the main findings at the end of the study.

## Analysis

Interviews were transcribed verbatim. Transcripts were analysed inductively using thematic analysis.<sup>36, 37</sup> Open line-by-line coding of transcripts was done by two researchers (EvdW, JM). Coding strategies and interpretations were discussed with a third researcher (YM) to ensure consistency. Subsequent analyses were performed in two parts. Part A: experiences and perspectives on optimal ways to discuss PROM-results were analysed. Axial coding was applied by constant comparison, grouping similar concepts into themes and organizing them hierarchically. Preliminary themes were discussed within the multidisciplinary research team to ensure triangulation. Part B: data about specific situations were compared with identified themes from part A; in other words, did the same or different themes apply to these specific situations? Analyses were performed using Atlas.ti (GmbH, Berlin, version 9). Finally, illustrative quotes were selected and translated from Dutch to English by one researcher (JM) and translated back (i.e. from English to Dutch) by a second researcher (EvdW) to ensure accuracy.

## Patient and public involvement

Four patients from regional and national kidney patients associations (Diavaria and NVN) were involved in the development of the interview guide. One patient representative (HB) is part of the research team and was involved in designing the study, interpreting the results and revising the manuscript.

**Table 1. Participant<sup>a</sup> and interview characteristics**

	Patients (n=10)	Healthcare professionals (n=12)
<b>Gender, male</b>	5 (50.0)	4 (33.3)
<b>Age, years</b>	62.1 ± 14.5	52.0 ± 7.0
<b>Marital status</b>		
Married/partnered	7 (70.0)	10 (83.3)
Widowed/single	3 (30.0)	2 (16.7)
<b>Ethno-cultural group<sup>b</sup>, Dutch</b>	10 (100.0)	12 (100.0)
<b>Educational level<sup>c</sup></b>		
Low	2 (20.0)	
Middle	5 (50.0)	
High	3 (30.0)	12 (100.0)
<b>Employment</b>		
Full-time	1 (10.0)	8 (66.7)
Part-time	1 (10.0)	4 (33.3)
No, retired	5 (50.0)	
No, disabled due to health	3 (30.0)	
<b>Years since diagnosis</b>	17.5 (10.8-24.8)	
<b>Years since dialysis initiation</b>	4.5 (2.9-16.5)	
<b>Dialysis modality</b>		
HD, centre	6 (60.0)	
HD, home	1 (10.0)	
PD	3 (30.0)	
<b>Dialysis sessions per week</b>		
2 sessions (HD)	1 (10.0)	
3 sessions (HD)	4 (40.0)	
4 sessions (HD)	2 (20.0)	
7 sessions (PD)	3 (30.0)	
<b>PROM scores</b>		
Physical HRQOL (0-100)	37.6 ± 9.0	
Mental HRQOL (0-100)	51.3 ± 10.3	
Number of symptoms (0-30)	8.7 ± 4.1	
Symptom burden score (0-150)	22.0 (15.8-27.3)	



<b>Healthcare profession</b>		
Nephrologist		8 (66.7)
Nurse practitioner		2 (16.7)
Nurse		2 (16.7)
<b>Years involved in dialysis care</b>		20.2 ± 7.7
<b>Experience with PROMs-results, times discussed<sup>d</sup></b>	2.0 (1.0-3.0)	20.0 (12.0-35.0)
<b>Interview duration, minutes</b>	63.2 ± 16.5	58.4 ± 13.5
<b>Interview setting</b>		
Face-to-face (videocall)	6 (60.0)	12 (100.0)
Telephone	4 (40.0)	

*Descriptive statistics were conducted using SPSS (IBM, Armonk, NY, USA, version 25.0): participant characteristics were presented as number (proportion), mean ± standard deviation or median (interquartile range) where appropriate.*

<sup>a</sup> *Additional information regarding non-participation: two more female nurses provided informed consent, but cancelled the interview and withdrawn from the study due to too busy schedules (data not shown).*

<sup>b</sup> *Self-reported ethno-cultural group: "What ethnic group do you consider yourself belonging to?"*

<sup>c</sup> *Educational level according to International Standard Classification of Education (ISCED) levels 2011, classified as low: primary, lower secondary or lower vocational education; middle: upper secondary or upper vocational education; high: tertiary education (college/university).*

<sup>d</sup> *During the interview, participants were asked to estimate the number of times they had discussed PROM-results as part of routine dialysis care.*

*Abbreviations: HD, haemodialysis; PD, peritoneal dialysis; PROM, patient-reported outcome measure; HRQOL, health-related quality of life.*

## Results

### Participant and interview characteristics

All characteristics are shown in Table 1. In total, 22 interviews were conducted with 10 patients and 12 healthcare professionals. Interviews lasted on average 61±15 minutes. Patients' mean age was 62±15 years, half of them was male, seven patients received HD and three PD. Eight nephrologists and four nurses participated, with a mean age of 52±7 years and four of them were male.

## Part A: Experiences and perspectives on optimal ways to discuss PROM-results

Three overarching themes were identified and will be discussed below, with corresponding subthemes and illustrative quotations. Additional quotations are provided in Table 2.

**Table 2. Illustrative quotations of patients and healthcare professionals for identified themes and subthemes (part A)**

### 1. Organization and basic principles of discussing PROM-results

#### 1.1 Suitable setting for discussing PROM-results

That she says “well, we will plan a consultation and we will actually discuss those subjects”. That makes that you come to the consultation with a different attitude. (*Patient, age: 70-80y*)

Maybe it should be told more clearly in advance that the PROMs will be discussed during the annual consultations, and that the PROMs determine what will be discussed during the consultations. (*Nephrologist, age: 50-60y*)

What I find difficult with PROMs is that patients also participate in research and already get so much questionnaires. [...] And because they get the same questions from different angles, they get the idea that nothing is happening with it. (*Nurse, age: 50-60y*)

I think the annual consultation is actually ideal, because then you are alone with the patient instead of in the shared dialysis room. It is easier then to discuss such sensitive topics. (*Nephrologist, age: 50-60y*)

Yes, I believe that the nephrologist is the right person. Why? Because they know the person. And two, they know the numbers of the patient. The lab values, because they have them, so they can give their medical opinion on it. (*Patient, age: 40-50y*)

A dialysis patient is never actually sick by themselves, their surrounding suffer from it too. And this is also an opening to talk about that. (*Nephrologist, age: 40-50y*)

Well once a year, I think, is more than enough. Unless someone indeed has a lot of issues, maybe then it is interesting to do it more often. (*Patient, age: 40-50y*)

#### 1.2 Preparations by patients and healthcare professionals

I prepare myself for this consultation, but I also expect that from you [the healthcare professional]. (*Patient, age: 70-80y*)

Well, maybe, they [patients] underestimate their input, also in the preparation. [...] So, like “this may help you to prepare for the conversation and it would be useful if you select the point of attention that you would like to discuss, that you find important”. Then you put the balance and interests a bit towards the patient. But my experience is that my patients don’t come into the consultation room that way... (*Nephrologist, age: 40-50y*)

For people who may find it difficult or not dare to say it at the moment: write it down beforehand. Write down what bothers you and what you want to talk about. (*Nephrologist, age: 40-50y*)

Leading up to the conversation I have a piece of paper at hand and write down all the questions that come to my mind. She [nephrologist] laughs when I take out the piece of paper and says "let's go". (*Patient, age: 70-80y*)

The conversations are better, because you already know the patient's experience. You are prepared, you can better come to a solution and the patient feels better heard. (*Nephrologist, age: 30-40y*)

### 1.3 Dealing with time constraints

We are always puzzling with our time, so we have to prioritize. (*Nurse, age: 50-60y*)

The advantage is immediately also a disadvantage, because you now get a complete picture, but then you have to make a selection again of the things we can do something about and what we are going to work on. (*Nephrologist, age: 50-60y*)

Look, now it is also a time issue, a certain time has been set aside for it and then you cannot go through the entire questionnaire in detail. (*Patient, age: 70-80y*)

It is also much more efficient for me as a doctor. [...] For patients that did not complete the PROMs, I do not ask 30 questions about symptoms, there is no time for that. (*Nephrologist, age: 30-40y*)

### 1.4 PROMs as tool for personalised holistic consultations

Well, I find it extremely insightful and useful. New things come up, even when you see someone weekly and ask them how they are doing. If you look at the Dialysis Symptom Index especially, sometimes complaints and things come up that bother people a lot, and which they otherwise would have never told about, and which I apparently have not asked them about specifically before. I think that is very valuable. (*Nephrologist, age: 50-60y*)

Well, it makes you think about your own situation. That is the positive thing of it. (*Patient, age: 70-80y*)

These [PROMs] also highlight questions that you, and maybe even a doctor, would not normally ask. (*Patient, age: 40-50y*)

I think it is a great addition to the conversation, because you now hear directly from the patient what he/she experiences. So it gives you the opportunity to primarily focus on what the patient reports as most burdensome. (*Nephrologist, age: 50-60y*)

Well, to me it is very important that it comes from the patient. Do not necessarily only look at the numbers. The colours can help you to identify where the biggest problems occur, but you should try to ask the patient what he thought of filling it in and what he thinks are the most important outcomes. (*Nurse, age: 50-60y*)

I use it as a topic of conversation, and do not show 'you score very low on this'. It feels different then, as if they get some sort of grade, like 'you did a bad job'. (*Nephrologist, age: 50-60y*)

I am not here for the kidney. I am here for the patient. (*Nephrologist, age: 30-40y*)

That you want to see the progression of PROMs over time. So those PROMs should be in the electronic health record, in a kind of dashboard, so that you can quickly see what is going on. *(Nephrologist, age: 50-60y)*

### 1.5 Always discuss PROM-results

You should not have them fill in the questionnaires and leave it at that. If that happens the questionnaires may not be filled in year after year. If you have been mentioning something for years and nothing is being done with it... Yes... *(Nurse, age: 50-60y)*

My role is to make clear everything can be discussed, that the patient feels invited to share complaints, that I am open to talking about that too. [...] And then the patient decides how long and how extensively we talk about it. *(Nephrologist, age: 40-50y)*

There is nothing as annoying as coming in with questions and still leaving with questions. *(Patient, age: 60-70y)*

Maybe sometimes as a doctor you get that feeling of "there is nothing I can do about it, why would I discuss it then?", but for a patient it can be enough to know that they are not the only one, that it is part of the disease, or that it is because of their diabetes and vascular disease and dialysis. The doctor cannot do anything about it, but at least I understand why. *(Nephrologist, age: 40-50y)*

When it is continuously being made discussable it diminishes the burden I think. [...] They can explain what is happening, why something is not possible and why something is not necessary, and what may be the consequences. Well, that can be very reassuring for the patient, I think. *(Patient, age: 70-80y)*

The nurse can often reassure you, or well, to the extent that the subject remains discussable. I think having a listening ear is just important. *(Patient, age: 60-70y)*

## 2. Roles of and interaction between patients and healthcare professionals

### 2.1 Patient's role: active participant

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You want the patient to take a more directive stance, but we are not there yet. That will gradually become the case. I mean, the moment that they are more familiar with it and can compare with previous times, then I think it will go the way you want it to. *(Nephrologist, age: 60-70y)*

Well I think the nephrologist should [take the initiative]. I am the one who has ticked the boxes, but that is to indicate how I am doing. I do not see that I should then take the lead in the conversation and say "let's talk about the PROMs" or "I have filled this in for this and this reason". *(Patient, age: 70-80y)*

That he/she [the patient] initiates what to discuss, and also thought about ideas... on how problems can be solved, or what is supportive. Together, together searching for the best solution. That is, I think, also with compliance, when the patient feels he is cooperating and that you decided together how to continue, that it works better. *(Nurse, age: 50-60y)*

Well, things about dialysis and kidneys; she [healthcare professional] knows more about that. But everything beyond that, the complaints I have, then it often comes more from my side than before. *(Patient, age: 30-40y)*

But I was always the one that had the last word and I enjoy that because I am the boss of my own body and not the doctor, just to be clear. *(Patient, age: 40-50y)*

## 2.2 Healthcare professional's role: guide

Uhm yes, I think that as a healthcare professional I am in the lead, because the patient comes into the conversation with an open mind and does not feel a clear purpose in that conversation. So I think it is quite an open approach, in which I am more in the lead than the patient is. It is not that I am not open to the patient being more in control, but yeah, they do not see the purpose of it in advance. *(Nephrologist, age: 40-50y)*

And I notice that it is quite difficult to assign that role to the patients, because before you know it, if the patient does not pick it up, you are back in your old role. *(Nephrologist, age: 60-70y)*

The opening is then with the nephrologist, who says "I see that you have filled this in". That is how I would do it. Asking "How did you get that answer?", "What is on your mind" and "What is going on?". *(Patient, age: 70-80y)*

Because nowadays the doctor more often has an advisory role, instead of a decisive role. And yes... It has actually always been that way. We have always thought that they know much better, so we will just do what they say. But in the meantime people are becoming more stubborn and it might also be useful to improve communication in that regard. *(Patient, age: 30-40y)*

I think it is good to articulate that you see what is happening, because you cannot decide for someone if they do not want to talk about it or if they just find it hard to talk about it. *(Nephrologist, age: 40-50y)*

I think sometimes we talk too much, but that above all we should also listen very carefully. We should also listen to non-verbal signals and uhm, really connect, try to feel, to understand what that patient wants from you. *(Nephrologist, age: 40-50y)*

## 2.3 Trusting patient-professional relationship

I think in that sense we do have a trusting relationship with the patient, where they have to feel the freedom to discuss everything. *(Nephrologist, age: 40-50y)*

How the doctor and patient interact with each other. I know nephrologists in the hospital and I even know what they have for dinner so to speak. That is how the communication is. But for the patient that is of course simply amazing. Because if something is up, you can bring it up much more easily. I think that that works much better for the patient, also in the treatment plan. *(Patient, age: 60-70y)*

Firstly, there must already be a trusting relationship between the healthcare professional and the patient. That is extremely important. I always think about how I would experience something. And if the doctor was a complete stranger to me, I would also think "well, never mind.". So I think trust is extremely important. *(Nurse, age: 50-60y)*

And I also expect that from the nephrologist, when you know each other already for 10-12 years. This guiding through the trajectory... until, yeah, when you don't need to go to the hospital anymore... *(Patient, age: 70-80y)*

There needs to be a relationship over a longer period, otherwise you cannot discuss these topics. [...] Because she [nephrologist] can tell me 'you can always talk with social work', but then I feel like 'ok, but I have not known them for 10 years'. Of course, it could be [helpful]... but, the doctor knows me and my situation. *(Patient, age: 70-80y)*

Something was bothering me once, and immediately there was a social worker right in front me. I really do not want all that. *(Patient, age: 60-70y)*

This is much more human. How do you experience this, what does it mean for you and your environment? [...] So now when a PD nurse calls me by my name, I notice that. I like that. But I remain the patient and she remains the healthcare professional. The roles do not change, but the relationship becomes a bit more human. I experience that to be very pleasant. *(Patient, age: 70-80y)*

## 2.4 Patient-professional collaboration

It is actually always a two-way. Like, I myself or the doctor of course asks a question, and search for a solution... The doctor gives options and then I respond what I think is best, what fits me best, because I am still the boss of my own body and my lifestyle. *(Patient, age: 40-50y)*

Well I think just 50/50... Sometimes I have something to add and sometimes she has something to add. And yes, just have a conversation from person to person. *(Patient, age: 50-60y)*

Well, I think it is important that as a patient you do not put yourself in the underdog position. I think it is best if you feel a little bit equal to each other. In that manner you might actually remove some barriers for the patient. *(Patient, age: 60-70y)*

A new integration into your consultations, you have to find a mode in that. *(Nurse, age: 50-60y)*

I think the biggest barrier is that there are... yeah, I call them 'old-fashioned-doctors' or 'my-will-is-law-doctors'... That's were the biggest hurdle is, I think. *(Patient, age: 30-40y)*

Not everyone takes the floor. That also has to do with generations. Young people will do that, that is no problem. But older people, yeah, they find it difficult. *(Nephrologist, age: 60-70y)*

Sometimes there are cultural differences. Something that we may consider normal to talk about, can be something you do not talk about for them. I think that at some point there has to be respect for that too. *(Nurse, age: 50-60y)*

We have a multicultural group of patients. So there is a language barrier and yeah, then discussing something like sexuality with an interpreter in the middle... So certain topics may remain underrecognized, just because of the circumstances. *(Nurse, age: 50-60y)*

## 3. Follow-up on PROM-results discussions

### 3.1 Follow-up actions and evaluations embedded into treatment process

I think that action points should be formulated, so that is what I do. There should also be some sort of feedback towards the patient, so I write that down as well and I often bring that up during the dialysis visits. So I build in these kinds of moments of evaluation. *(Nephrologist, age: 30-40y)*

Uhm yes, those are often more supportive types of treatment. I believe that it is not about the major decisions surrounding dialysis and transplantation, but more focused on things like do we have to lower the phosphate levels, is the patient anaemic, should we do something about the fluid retention because the patient experiences shortness of breath? So it is more about the finetuning than the bigger picture. *(Nephrologist, age: 50-60y)*

My doctor often looks at what is important and what to discuss. And where... for them it is more like where the most benefit can be gained. *(Patient, age: 30-40y)*

Yeah, quality of life, I find more difficult to act upon. I actually look into what is the problem and is this something we can solve. [...] And that has to do, I think, with that we as doctors like to do something. *(Nephrologist, age: 50-60y)*

And it doesn't have to be an answer that solves all my issues. That is not what I mean. More like, is there an answer? *(Patient, age: 40-50y)*

Ideally you would have a treatment or guideline available for every complaint, so you can treat the patient and evaluate whether the symptoms are decreasing. *(Nephrologist, age: 40-50y)*

### 3.2 Multidisciplinary process

Kidney patients often have a multitude of problems. I think that for a doctor, or for a nephrologist in this case, it is very important to acknowledge that there are other problems and to refer the patient if necessary. *(Patient, age: 60-70y)*

I am now kind of the playmaker that says "this should go there, and that should go there". *(Nephrologist, age: 50-60y)*

Look, when you are on dialysis the nephrologist is your central doctor. So he/she is the starting point from which you can go in different directions. *(Patient, age: 30-40y)*

I talk with colleagues, I email other healthcare professionals: can you answer this, is it ok if I do this or give that, so I ask for help. Discuss. *(Nurse, age: 50-60y)*

We have of course multidisciplinary consultations, with social work, dieticians, and sometimes we invite spiritual caretakers or a psychologist, or we invite the general practitioner to join online. And of course with the nurses and other colleagues, and then with that group we look into what we can improve and where we can adapt the treatment plan. *(Nephrologist, age: 50-60y)*

## THEME 1: ORGANIZATION AND BASIC PRINCIPLES OF DISCUSSING PROM-RESULTS

Patients and healthcare professionals described experiences and advised on how to organize conversations about PROM-results, such as organizing a suitable setting, adequate preparation and dealing with time constraints. Additionally, they described that PROMs should be considered a tool for personalised holistic consultations and PROM-results should always be discussed.

### 1.1. Suitable setting for discussing PROM-results

Patients and healthcare professionals gave a univocal description of how conversations about PROM-results should be organized. First, PROM-results should be available on time: they recommended to invite patients to complete PROMs 2-6 weeks in advance and announce that PROM-results will be discussed, in what way and for what purpose, to ensure patients do not think “nothing is being done with it”. Second, patients and healthcare professionals stated that PROM-results should be discussed face-to-face in a consultation room that ensures a safe and private setting. PROM-results were mostly discussed during annual consultations, which was considered very suitable. They advised that patients discuss PROM-results with the nephrologist or nurse who knows the patient best. Many recommended to invite the patient’s partner or a close relative, as this may provide valuable insights for all attendees. Third, all patients and healthcare professionals considered a conversation about PROM-results once per year sufficient. Some patients and healthcare professionals suggested to schedule additional conversations when many symptoms or important changes in treatment or health occur.

### 1.2. Preparations by patients and healthcare professionals

All patients and healthcare professionals advised that both prepare for conversations about PROM-results. They suggested that patients think beforehand about their own results, whether they have questions, and what they would like to discuss and receive support on. They advised healthcare professionals to examine which topics emerge from the PROM-results and which treatment-options are available; this helps to inform patients and quickly get to what is important to them:

*“You should not open the list when you are already there with your patient. Take some time to prepare it, to discuss it, and then it really is an addition to the annual consultation.” (Nurse/50-60y)*

Additionally, healthcare professionals indicated that they always prepared discussions on PROM-results. Patients and healthcare professionals indicated that in practice patients often did not prepare, for example because it was not clear to patients that, when and how PROM-results would be discussed.

### 1.3. Dealing with time constraints

Most healthcare professionals and some patients experienced time constraints. Often, more topics emerged from PROMs than can be discussed during one consultation. Healthcare professionals indicated that they solve this by prioritizing and



focusing on the most important 3-4 topics, identified by patients or themselves. Some healthcare professionals indicated that PROMs also save time, because you get to the point more quickly: more information is gained, but with PROMs there is no need to spend time asking questions about symptoms that patients do not have:

*“People who use PROMs are especially happy that they can work in a more focused way and that they do not lose time.” (Nephrologist/50-60y)*

#### **1.4. PROMs as tool for personalised holistic consultations**

Many healthcare professionals and some patients argued that PROMs are a tool to improve communication during consultations:

*“Discussing PROM-results is not an aim in itself, it is a tool to conduct the conversation well and to do justice to what is important to the patient.” (Nephrologist/40-50y)*

Many patients and healthcare professionals stated that using PROMs during consultations helped to focus on what is important to patients. They shared that PROM-results can serve as a ‘conversation-starter’ to discuss topics that were otherwise not brought up - PROM-topics but also overarching topics such as treatment continuation or death. Additionally, some patients and healthcare professionals described that PROM-results can stimulate self-reflection and awareness in patients, which may result in better understanding and confirmation of their experienced health, although it can also be confronting:

*“At times I find it difficult to hear that my condition is less good than that of a seventy-eighty year old. On the other hand, it is also something that I clearly run into: it really bothers me more than others, so it also validates that I didn't just make it up.” (Patient/30-40y)*

Furthermore, many healthcare professionals and some patients indicated that the overview of PROM-results and comparison of scores with other dialysis patients, provides a sense of ‘how someone is doing’ and insight into ‘what is normal’. Some of them emphasized that this comparison should only be used as a tool to better understand PROM-results, and not as a grade or treatment-target. Although most patients and healthcare professionals indicated that using PROMs provided a more complete picture, many healthcare professionals also mentioned technical

barriers: PROM-results are not yet integrated into electronic health records, which makes it more challenging to get a complete overview in combination with biomedical results and to evaluate changes over time. Implementation into electronic health records was considered an important next step to support personalised holistic consultations.

### 1.5. Always discuss PROM-results

Almost all patients and healthcare professionals indicated that discussing PROM-results is essential, and some even argued that PROMs should only be collected on condition that results are discussed:

*“If you have indicated that you experience certain problems, then it must be discussed, otherwise such a questionnaire is useless.” (Patient/60-70y)*

Many patients and healthcare professionals indicated that discussing PROM-results is important “to make clear that everything can be discussed, now or at any given moment”, and that there is an opportunity to start a conversation about it. Furthermore, patients and healthcare professionals indicated that discussing PROM-results in itself, can already help: patients do not always expect or want something to be done about symptoms, but they do sometimes want to talk about it with their healthcare professional – to inform them or to feel seen, heard and understood by them:

*“A listening ear from the doctor is most important. Whatever complaint you have, it can be small for the doctor, but big for you. That you are taken seriously.” (Patient/60-70y)*

Additionally, patients and healthcare professionals indicated that explanation and clarity (e.g. about causes, prognosis and treatment-options for symptoms) is important for patients, because better understanding can help to accept and cope with the disease.

## THEME 2: ROLES OF AND INTERACTION BETWEEN PATIENTS AND HEALTHCARE PROFESSIONALS

Patients and healthcare professionals described the patient’s role as active participant and the healthcare professional’s role as guide. They indicated that a trusting patient-professional relationship is a requirement and affects what conversations about PROM-results yields. They described the interaction as a collaboration and considered this the optimal approach.

### 2.1. Patient's role: active participant

Patients and healthcare professionals described the patient's role as active participant in the discussion. Healthcare professionals would like patients to take more control when it comes to PROM-results, but acknowledged that this is not easy for all patients. Contrary, most patients indicated that they usually wait for the healthcare professionals' initiative: even when they feel empowered enough to articulate their experiences and needs, they believe it is not their role to bring up PROM-results or to structure conversations:

*"During a consultation, I think I will feel empowered enough to take the initiative. But still, the doctor needs to give you enough space to do something with it." (Patient/60-70y)*

Both patients and healthcare professionals indicated that, ultimately, patients decide whether or not something is discussed and follow-up actions are taken.

### 2.2. Healthcare professional's role: guide

Patients and healthcare professionals described a guiding role for healthcare professionals in taking initiative and providing structure in PROM-results conversations. Healthcare professionals are expected to ask patients to expand on their experiences and needs to gain a deeper understanding, and to facilitate prioritizing outcomes and actions. Some healthcare professionals indicated that they would prefer to be less steering in conversations and find it challenging to facilitate rather than direct conversations, especially when patients have a 'wait-and-see' attitude. Patients indicated they are used to the healthcare professionals' leading role and this also worked well in discussing PROM-results:

*"The healthcare professional should facilitate and guide the conversation. So take someone by the hand and ask questions." (Patient/40-50y)*

Many patients and healthcare professionals considered a personal approach as essential, for example: healthcare professionals should verify whether they have drawn correct conclusions from PROM-results and patients' explanations, and whether they understand patients' needs.

### 2.3. Trusting patient-professional relationship

Patients and healthcare professionals described that the regular contact in dialysis care is a strong facilitator to feel connected and build a trusting relationship, which

was considered a prerequisite to conduct adequate PROM-result conversations:

*“Depending on trust, you tell someone more or less.” (Patient/70-80y)*

Some patients mentioned that the close relationship can also give rise to expectations regarding healthcare professionals’ engagement, which goes beyond nephrology care. Some patients and healthcare professionals mentioned that feeling connected can be a reason why patients sometimes prefer to talk about PROM-results with their nephrologist or nurse rather than other healthcare professionals (e.g. social worker or psychologist), while also acknowledging differences in expertise.

#### **2.4. Patient-professional collaboration**

Patients and healthcare professionals indicated that discussing PROM-results provides most benefits when approached as a collaboration, in which patients and healthcare professionals contribute their own knowledge, experiences and ideas, and together consider what suits the patient best:

*“We have an agreement that I will already think about the solution myself. Then I come to her and explain: ‘This is the complaint and I think this is the solution for this reason’. Then she says what she thinks the solution is. Then we discuss it and ultimately arrive at the best solution together.” (Patient/30-40y)*

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Many patients and healthcare professionals believed that this person-centred collaboration is now more adopted compared to the past. Some healthcare professionals explained that discussing PROM-results takes some practice to become familiar with and integrate into consultations:

*“In the beginning, it was a bit uncomfortable, because you get a lot of information and you don’t know how to process and discuss it with the patient.” (Nephrologist/30-40y)*

Patients and healthcare professionals indicated that clear, open and honest communication from both sides is very important, and considered it important to acknowledge and verify non-verbal communication. Many healthcare professionals and some patients mentioned that interpersonal differences, for example in cultural or religious beliefs, can make discussing PROM-results more challenging. It

then takes more effort to understand each other and to articulate needs and suggestions:

*“When the patient’s view is very different and it goes against my gut feeling. That are the most difficult conversations.” (Nephrologist/40-50y)*

Some patients and healthcare professionals shared that consequently, certain topics may remain undiscussed, for example sexual dysfunction in the presence of a family member.

### **THEME 3: FOLLOW-UP ON PROM-RESULTS DISCUSSIONS**

Patients and healthcare professionals stated that discussing PROM-results, including follow-up actions and evaluation, should be part of routine care and integrated into the multidisciplinary treatment process.

#### **3.1. Follow-up actions and evaluations embedded into treatment process**

Patients and healthcare professionals indicated that it does not stop after discussing PROM-results: follow-up actions and continuous evaluation over time are part of this process:

*“That she [nephrologist] asks at the next consultation ‘Has it improved sir?’... So that you do not get a feeling like ‘the conversation is done, the results end up in a drawer and the person [patient’s perspective] does not matter’.” (Patient/70-80y)*

Several healthcare professionals stated there is a need for guidance on how to act on PROM-results: they now tend to focus on symptoms for which they know treatment exist and less on medically ‘non-treatable’ symptoms or HRQOL, because they like to have “something to offer”. Many patients indicated that they desire explanations and clarity about symptoms and their treatments, even when there are only few or no treatments available. Most patients and healthcare professionals described the influence of PROMs as ‘fine-tuning’ of treatment, since information and conversation about PROM-results help to personalise treatment:

*“With PROMs, you can support patients where they experience problems. We used to look at laboratory values and blood pressure, but sometimes patients do not benefit from that. But if we work on the limited energy, we also build on a better quality of life.” (Nurse/50-60y)*

### 3.2. Multidisciplinary process

Patients and healthcare professionals described follow-up actions on PROM-results as a multidisciplinary process, guided by patients' attending nephrologist and/or nurse practitioner - also called "the playmaker" in this context. This healthcare professional consults with colleagues within (e.g. during multidisciplinary meetings) and outside the care team, and refers patients for appropriate care:

*"There may be things that require other healthcare professionals and then you refer [...] to the general practitioner, other medical specialists and paramedics." (Nephrologist/50-60y)*

Patients and healthcare professionals considered referral an appropriate response to certain PROM-results: patients should be able to discuss all topics with their attending nephrologist or nurse practitioner, but this healthcare professional is not expected to act upon all PROM-results.

### Part B: Specific situations

Patients' and healthcare professionals' perspectives on specific situations are described below, while highlighting themes (by means of the letter 'T') from part A that were most strongly reflected (see Table 3 for illustrative quotations). For all situations, similar themes emerged as in part A. However, for sensitive topics, the roles of and interaction between patients and healthcare professionals slightly differed: compared to other topics, healthcare professionals were expected and advised to take more initiative and a leading role in conversations.

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#### SITUATION 1: NO CHANGES OR NEW TOPICS

Patients and healthcare professionals emphasized that when PROM-results have not changed or revealed new topics, it should still be discussed (T1.5), to verify interpretation of PROM-results (e.g. because the patient's situation or opinion may have changed [T1.4]) and whether the patient wants to further discuss it (T2). Many mentioned that, due to the frequent contact between patients and healthcare professionals (T2.3), topics may have been discussed already. They stated that, in most cases, it is then sufficient to only briefly discuss PROM-results, simply to confirm the situation is stable, that the healthcare professional is aware of the PROM-results and that everything can be discussed (T1.5, T2).

#### SITUATION 2: SENSITIVE TOPICS

Patients and healthcare professionals indicated that PROMs can serve as a tool,

'a conversation starter', to discuss sensitive topics such as sexual problems, depression and death, that probably remained undiscussed otherwise (T1.4-1.5). In contrast to less sensitive topics (compared to general topics from part A), both patients and healthcare professionals experienced and advised healthcare professionals to up the leading role and take the initiative (T2.2) to talk about sensitive topics, "because patients have already taken the first step by reporting their complaints". Many stated that the conversation should be initiated by healthcare professionals as if it is any other topic, suggesting that "it is normal to talk about these topics" (T1.5), but with additional care, for example: use open questions, so that patients can decide what and how much they want to share (T2.1). Healthcare professionals should acknowledge and verify non-verbal communication, and ask whether patients want to talk about it at all (T2), at that moment or later (to ensure a safe environment [T1.1] and feeling prepared [T1.2]), with this or another healthcare professional (feeling connected and trust are highly important [T2.3]), and with or without others present (e.g. partner or interpreter) (T1.1, T2.4). Furthermore, all patients and healthcare professionals indicated that topics such as sexual problems, depression and death can be difficult to discuss for the patient. Although all patients recognized that such topics can be challenging for healthcare professionals as well, only few healthcare professionals confirmed this - most indicated that "no topic should be difficult for them".

### **SITUATION 3: NO MEDICAL TREATMENT**

Patients and healthcare professionals indicated that also outcomes for which there is no medical treatment available should be discussed, since patients experienced and reported these complaints. They described that healthcare professionals can also support patients on these topics by listening to them (T1.5) and referring them to other healthcare professionals for non-medical support (e.g. regarding coping or lifestyle). Yet many healthcare professionals also described their discomfort when discussing symptoms for which they feel there is no solution. Most patients, however, indicated that they do not expect a solution for all symptoms, but do want explanation and clarity on potential causes, prognoses and options that may provide relief (e.g. things they can do themselves and/or with support from other healthcare professionals [medical or paramedical]) (T3).

### **SITUATION 4: FACTORS NOT RELATED TO KIDNEY DISEASE OR DIALYSIS TREATMENT**

All patients and healthcare professionals emphasized that everything can be discussed, whether or not it is directly related to CKD or dialysis treatment (e.g. co-

morbidities or life events) (T1.5). The nephrologist or nurse is considered the initial person to discuss PROM-results, as they are the patient's first point of contact, who have a complete overview and understanding of the patient's situation, and can refer to the proper healthcare professionals for additional support (T1.4, T2-3). Although most healthcare professionals acknowledge that everything can be discussed with them (T1.5), they also strongly felt the need to define their responsibilities and manage patients' expectations towards them (T2-3). Many patients and healthcare professionals described that identifying potential causes and responsible (para)medical fields also helps patients to understand the symptoms and treatment options (T3).

**Table 3. Illustrative quotations of patients and healthcare professionals for specific situations in discussing PROM-results (part B)**

### 1. No changes or new topics

I actually have few or no complaints, so yes, then I think that it does not need to be discussed. Well, it can always be mentioned that "I have looked at it and I see that you have no complaints or that you are doing fine with that." (*Patient, age: 60-70y*)

Not much I think. If you have already discussed it extensively and nothing changes and the needs of the patient have not changed either.. Yes, then I take it for notice. (*Nephrologist, age: 50-60y*)

And you can of course, certainly for quality of life, raise the topic in general; what keeps the patient busy. And sometimes it happens that you notice something and think hey, we should talk about that a bit further. (*Nurse, age: 50-60y*)

So then I would suggest that the doctor decides together with the patient, do you feel the need or do we skip it this time? (*Patient, age: 40-50y*)

The answers may be the same, but the circumstances can vary. Yes, then you will have to have the same conversation, and maybe it does not take as long. Yes, that is basically what happens medically as well. (*Patient, age: 70-80y*)

### 2. Sensitive topics

I do think that these are things that you should always discuss, yes. Because the more we discuss these kinds of things, the more the taboo disappears, the easier it becomes to discuss these kinds of things. (*Patient, age: 30-40y*)

Yes, and maybe also to indicate that it's OK to talk about this. That you indicate as a healthcare professional that you find it normal and that more people have problems with this. So that it also feels safe to talk about this. [...] Because yes, if it bothers them, it should be possible to discuss it. (*Nurse, age: 50-60y*)

Yes, you know, [sexual dysfunction] it's at the top of the list as the most distressing symptom in male dialysis patients, yes... I mean, the idea of that PROM is that you get insight into what bothers patients. Yeah, if this comes up then I think you can't ignore that. No matter how uncomfortable the subject may be for many. (*Nephrologist, age: 40-50y*)



There are quite a few points that you say well, that is a bit more sensitive, perhaps also to the nephrologist. But I do think you should be able to discuss that. [...] The patient experiences that and brings it up. So he [healthcare professional] has to meet him and indicate "I would rather have that you discuss this with a colleague... I'm having some trouble with it." So... Well, I'd only respect that. *(Patient, age: 70-80y)*

Well, discreetly. The patient must of course feel safe, there must already be a trusting relationship, that is extremely important. I always think for myself, how would I experience that? If the doctor were a complete stranger, I would also think well never mind. And also mention that it may be a difficult topic, but that you will figure it out together. And the healthcare professional may also sometimes say that he finds it difficult, and show a certain vulnerability. That can of course also comfort the patient. *(Nurse, age: 50-60y)*

It was about death, and a social worker was with me and stammered and I said hey, I don't know what you want to say, but just tell me... Then you notice that not everyone is used to discussing certain topics. *(Patient, age: 40-50y)*

Well I think that the healthcare professional should first determine whether it is important to discuss; Do you think it is important to talk about it? Do you want to talk about it? And what do you want to say about it? *(Patient, age: 70-80y)*

I just openly ask if they want to discuss it and if they say no I respect that. So there is also a kind of shared decision-making in which topics you want to discuss together or not. We also discuss the possibility of discussing it with someone else and then it is up to the patient... a patient also has the right not to discuss things with me. *(Nephrologist, age: 50-60y)*

Discuss, discuss. Don't make your taboo the patient's taboo. You know, taboos arise when you make a fuss about it. So, just be open, honest... and also clearly give space. And there is no need to talk about it, that is not an end in itself. The PROMs aren't there because you need to talk about everything, but you do need to see if the patient wants to talk about it, and if he doesn't, then don't force it. Because you are there for the patient, and the patient is not there for you. *(Nephrologist, age: 40-50y)*

### 3. No medical treatment

Yes, listening, I think.. to the inconvenience. And more... more often ask how these things are going. Because I think talking about it will help that patient. *(Patient, age: 70-80y)*

Sexuality is also a topic that we doctors usually do not bring up. [...] The problem is that I can't do much either. I can of course refer... if they wish. [...] The point is, I can bring up a topic, but then I cannot offer a solution. Yes, I find that difficult. *(Nephrologist, age: 60-70y)*

I think you just have to be honest with this; at the moment we don't have a medical solution for you, but we might be able to look into things beyond that. Perhaps there are things that you can solve with fitness or food, for example. *(Patient, age: 30-40y)*

But in any case discuss why nothing could be done about it. I mean, are there no pills, is there no ointment or is there any other way, things like that. That it is explained why nothing can be done about it. I would consider that very important. *(Patient, age: 70-80y)*

If the patient indicates that they are bothered by this, then they should be able to discuss it. That can also be a relief, that people are listening. I think it should be discussed and then you can also confirm, even if we can't do anything with it. I think that also does something for the patient. *(Nurse, age: 50-60y)*

And, what I also mention is that we cannot change some complaints in that it is present, but we can change the way you look at it and how it hinders you in your daily life. Together we can look at how we can best approach this. And sometimes social work can provide support, or medical psychology, or dietetics. So I try to help them in that way. *(Nephrologist, age: 40-50y)*

The patient often does not expect me to solve the problem. That is also the reason why he often does not discuss it at all, because he really feels that I am not going to change that. But, often just that short explanation that you explain I have seen that you suffer from it, that may be difficult for you, and this is the reason why it occurs. That often is enough. *(Nephrologist, age: 40-50y)*

You can't be good at everything. No... I mean, it's nice if there's a solution, but I can imagine that she can't solve everything. *(Patient, age: 60-70y)*

#### 4. Factors not related to kidney disease or dialysis treatment.

But certainly if it is in that area, that they are struggling, are sad, worrying, yes then I realize... I'm still the nephrologist, so it's important that I let them know that I've heard it and that I'm taking it seriously and want to do something about it, but I'm not going to solve it. So yes, I will talk to the patient; do you want to do something with this, and what do you want me to do with it? And that could indeed be a social worker, general practitioner or... someone in the family you talk to. *(Nephrologist, age: 40-50y)*

Yes say a good talk with the nephrologist about the social aspects, yes... But she might say yes, but that's not my area of expertise... [...] And there can of course be things of which she says I know too little about this, I would..., that is what I mean by guidance, here I would say well, you could contact the social worker. *(Patient, age: 70-80y)*

And, that would of course be very short-sighted if I were to say I have my own subject and I stick to that. I can't imagine a nephrologist looking at his profession that way. *(Nephrologist, age: 50-60y)*

It is of course influenced by many more things than just your illness... the environment also determines how you feel, how you react to other people and how people react to you. So your environment also matters. *(Patient, age: 70-80y)*

And it is also important that the doctor finds out whether there may be other causes for the complaints, in addition to kidney disease in this case. And then look again where the appropriate support can be found for those complaints. *(Patient, age: 60-70y)*

Often you cannot make that distinction. I mean, many complaints are multifactorial, and by mentioning that, they also understand that some things won't go away completely. *(Nephrologist, age: 40-50y)*

Look, sometimes you don't know why you feel something... Is it because of the cancer that I feel insecure, or is it because of my kidneys? I do not always know that. And I would also not know where to go with these questions. *(Patient, age: 70-80y)*

## Discussion

This qualitative study investigated patients' and healthcare professionals' experiences with and perspectives on optimal ways to discuss PROM-results in routine dialysis care. Three overarching themes were identified describing the organization and basic principles of discussing PROM-results, the roles of and interaction between patients and healthcare professionals, and follow-up after PROM-results discussions.

The majority of existing literature is theoretical and focuses on potential benefits and mechanisms explaining *why* PROMs contribute to patient-professional communication.<sup>14, 16</sup> Our study adds to this literature by providing in-depth knowledge on *how* to discuss PROM-results based on experiences and insights from routine nephrology care, resulting in practical guidance that is directly applicable to real-world practice. Our results showed similarities to the findings in the literature reviews of Greenhalgh et al. and Schick-Makaroff et al., for example: PROMs help to start conversations through patients' self-reflection, the confirmation that everything can be discussed or "permission to raise issues", by providing a tool for discussion and articulation of experiences (e.g. sensitive topics such as sexual problems and depressive symptoms) and needs, and by increasing healthcare professionals' insight into and awareness of patient-relevant outcomes.<sup>14, 16</sup> Moreover, in line with and building on their findings<sup>14, 16</sup>, we found that a good patient-professional relationship is crucial for discussing personal concerns, needs and PROM-results, and that the frequent contact in dialysis care was considered a strong facilitator in building this trusting relationship. In The Netherlands, it is common practice that patients have one primarily responsible nephrologist and nurse, and therefore most patients already have established patient-professional relationships when discussing their PROM-results. Our results suggest that this is a good foundation for getting the most out of discussing PROM-results in routine dialysis care and potentially also in other chronic care settings.

Notable in our research is the difference between what is pursued and experienced, when it comes to patient-professional interaction. Healthcare professionals in particular expressed they would like patients to have more control, while at the same time acknowledging they struggle with not being too dominant and directing in conversations. Although healthcare professionals expressed preference for a guiding role, no suggestions were made on what or how they could change their own approach in practice. The preferred patient-professional interaction aligns with the deliberative model as described by Emanuel & Emanuel (1992).<sup>38</sup> Although our findings and literature suggest that patients' autonomy and values are increasingly given place in practice, further guidance may be needed to create a partnership as in the deliberative model.<sup>39</sup> Currently, healthcare professionals may not be aware of or actively choose a communication style, and literature also shows that it may be challenging for health-

care professionals to change their usual approach despite new insights and awareness.<sup>14</sup> We believe that recognition is the first step and change may require further guidance, training and practice.<sup>40</sup> Though, our research already provides some suggestions to enhance patients' initiative, for example: healthcare professionals could inform patients beforehand about the aim and relevance of PROMs, and about when and how they can share their experiences, concerns and questions about PROM-results; this may encourage patients' preparation, awareness that everything can be discussed and empower them to raise topics during consultations.

Another remarkable finding is that healthcare professionals tend to prioritize topics for PROM-discussions based on perceived 'treatability of symptoms', while at the same time emphasizing that PROM-results and *all* topics should always be discussed, irrespective of the situation (e.g. whether or not there is a medical treatment available or it is CKD-related), and that discussing PROM-results in itself can already help. This underlines the importance of asking, articulating and verifying what is important to patients and what their needs are, and the central role (i.e. the "playmaker" role) assigned to the attending nephrologists and/or nurses in dialysis care (i.e. discussing all topics and, if needed, referring to other [para]medical healthcare professionals when necessary); this role in nephrology may be broader than in other medical fields, for example: a study in oncological care found that discussions and further exploration based on PROM-results were limited to cancer-related issues.<sup>41</sup>

Most of the barriers identified in this study are in line with and add to literature on PROM-implementation into routine care.<sup>21-25</sup> However, our study shows a different nuance regarding time constraints, namely: using PROMs itself is not time consuming (some stated that it even saves time), but the fact that it reveals new topics that would otherwise remain unnoticed and undiscussed. This nuance does not discard that time management can be challenging, but it primarily confirms a major advantage of using and discussing PROMs namely that we gain a more complete, person-centred overview of how patients are really doing. Moreover, we expect time challenges to diminish over time: it will most likely take less time once patients and healthcare professionals have become familiar with discussing PROM-results<sup>12</sup>, and topics will be discussed gradually over the CKD-trajectory, resulting in less topics to discuss compared to the first PROM-discussion.<sup>42</sup>

Our findings confirm that using PROMs can facilitate person-centred care<sup>14-17, 43</sup>, and form the foundation for training healthcare professionals in discussing PROM-results. See also Box 1 for a brief overview of the practical guidelines and considerations. These practical guidelines can be used to develop novel or adapt existing training-tools (e.g. the PROMunication tool developed in cancer care by Skovlund et al.<sup>15</sup>) for the nephrology care setting. Training healthcare professionals in how to use and

discuss PROM-results can improve shared decision-making, since both the information obtained with PROMs and a good patient-professional communication, enhance this process.<sup>44</sup>

Further research is needed to investigate whether and how discussing PROM-results can improve actual patients' outcomes (e.g. HRQOL).<sup>45</sup> Moreover, healthcare professionals expressed the desire for guidance on actions that can be taken in response to PROM-results. Literature also suggests that healthcare professionals are not always aware of all available treatment-options to improve symptom burden<sup>11,24</sup>, hereby underlining the need for further research on and development of a guide to improve symptom-management and HRQOL.<sup>46</sup>

Our study elucidates in-depth knowledge of patients' and healthcare professionals' experiences with and perspectives on optimal ways to discuss PROM-results in routine dialysis care. Participants had experience with completing and discussing PROM-results, resulting in knowledge that is directly applicable to real-world practice. We achieved saturation and demonstrated robustness of our results by exploring specific situations in addition to the general dialysis context. Limitations include that, despite efforts to achieve heterogeneous samples, our results are shaped by people who are willing to participate in interviews, which may limit the transferability of the findings to the total population. For example: participants may have a more positive attitude towards research, healthcare and PROMs. Patients and healthcare professionals who are struggling with or who experienced little benefit from using PROMs, may not have felt addressed, motivated or comfortable enough to participate in the interviews. Though, our participants also shared critical notes, explained that discussing PROM-results took practice, and provided examples of patients and healthcare professionals who believe or behave otherwise. Moreover, all participants were Dutch and hence, topics such as cultural differences and language barriers were primarily uncovered via second-hand information (e.g. healthcare professionals' perspectives). Finally, we should be aware that our own experiences and preconceptions may have coloured our results (i.e. research reflexivity)<sup>32</sup>, even though multiple researchers with different backgrounds have performed interviews and interpreted data.

In conclusion, this study provides in-depth knowledge into patients' and healthcare professionals' experiences with and perspectives on the organization of, the roles of and interactions between patients and healthcare professionals in, and follow-up on PROM-results discussions. Our findings form the foundation for training of healthcare professionals regarding optimal ways to discuss PROM-results in routine dialysis care. Further research is needed to provide guidance on follow-up actions in response to PROM-results to ultimately improve patients' outcomes.

**Box 1. Brief overview of practical guidelines and considerations for optimal discussion about PROM-results between patients and healthcare professionals.**

## **1. Organization and basic principles of discussing PROM-results**

### **1.1 Suitable setting for discussing PROM-results**

- Invite patients to complete PROMs 2-6 weeks in advance.
- Inform patients that, how and why the PROM-results will be discussed.
- Discuss PROM-results face-to-face, in a safe and private setting, e.g. during annual consultations (once per year is sufficient).

### **1.2 Preparations by patients and healthcare professionals**

- Both prepare the discussion about PROM-results: think beforehand about what to discuss, if and what support is needed, and which options exist.

### **1.3 Dealing with time constraints**

- PROMs provide additional information on how the patient is really doing. As a patient and healthcare professional: together prioritize and discuss the 3-4 most important topics.

### **1.4 PROMs as tool for personalised holistic consultations**

- Use PROMs as a tool that provides guidance on what is important to the patient.
- Use PROM-results as a 'conversation-starter' to discuss topics that otherwise remain undiscussed (e.g. sensitive topics such as sexuality).
- Use PROMs to gain insight and overview through patients' self-reflection, comparative information and a more complete picture.

### **1.5 Always discuss PROM-results**

- Discussing PROM-results is an essential part of using PROMs in routine care.
- Discuss PROM-results to make clear that any topic can be discussed and to create an opportunity to start a conversation about these topics.
- Discuss PROM-results as discussing itself also helps patients to inform or to feel seen, heard and understood by their healthcare professional.

## **2. Roles of and interaction between patients and healthcare professionals**

### **2.1 Patient's role: active participant**

- As a patient: take the initiative and articulate your experiences and needs.
- As a healthcare professional: realize that patients often wait for their

healthcare professional's initiative and, if so, explicitly provide them the space to share experiences and needs.

## 2.2 Healthcare professional's role: guide

- As a healthcare professional: take up a guiding role and provide structure in the conversation; ask patients to expand on their experiences and needs, help to prioritize topics and actions, and verify your interpretation and conclusions.

## 2.3 Trusting patient-professional relationship

- The nephrologist and/or nurse who knows the patient well should conduct the conversation; feeling connected and a trusting relationship is a prerequisite to discuss PROM-results and to share personal concerns, experiences and needs.

## 2.4 Patient-professional collaboration

- Both contribute your own knowledge, experiences and ideas, and together consider what suits the patient best.
- Interpersonal differences can be a barrier; take the time and effort to understand each other and articulate needs and suggestions.

## 3. **Follow-up on PROM-results discussions**

### 3.1 Follow-up actions and evaluations embedded into treatment process

- Follow-up actions and evaluations are part of the process of discussing PROM-results.
- As a healthcare professional: provide patients with explanation and clarity about their symptoms and treatment options; patients do not expect a solution for all symptoms.
- Take PROM follow-up actions for fine-tuning of treatment; information and conversation about PROM-results help to personalise treatment.

### 3.2 Multidisciplinary process

- Incorporate PROM follow-up actions into the multidisciplinary process, guided by the nephrologist or nurse practitioner.
- Discuss all topics, regardless of the situation (e.g. when no medical treatment is available or experiences are not directly related to CKD) and refer to other (para-)medical healthcare professionals when needed and desired by patients; referral is an appropriate response to PROM-results.

## References

1. Almutary H, Bonner A, Douglas C. Symptom burden in chronic kidney disease: a review of recent literature. *J Ren Care* 2013;39(3):140-50
2. van der Willik EM, Hemmelder MH, Bart HAJ, et al. Routinely measuring symptom burden and health-related quality of life in dialysis patients: first results from the Dutch registry of patient-reported outcome measures. *Clin Kidney J* 2021;14(6):1535-44
3. Raj R, Ahuja KD, Frandsen M, Jose M. Symptoms and their recognition in adult haemodialysis patients: Interactions with quality of life. *Nephrology (Carlton)* 2017;22(3):228-33
4. Manns B, Hemmelgarn B, Lillie E, et al. Setting research priorities for patients on or nearing dialysis. *Clin J Am Soc Nephrol* 2014;9(10):1813-21
5. Urquhart-Secord R, Craig JC, Hemmelgarn B, et al. Patient and Caregiver Priorities for Outcomes in Hemodialysis: An International Nominal Group Technique Study. *Am J Kidney Dis* 2016;68(3):444-54
6. de Jong Y, van der Willik EM, Milders J, et al. Person centred care provision and care planning in chronic kidney disease: which outcomes matter? A systematic review and thematic synthesis of qualitative studies : Care planning in CKD: which outcomes matter? *BMC Nephrol* 2021;22(1):309
7. Weisbord SD, Fried LF, Mor MK, et al. Renal provider recognition of symptoms in patients on maintenance hemodialysis. *Clin J Am Soc Nephrol* 2007;2(5):960-7
8. Pugh-Clarke K, Read SC, Sim J. Symptom experience in non-dialysis-dependent chronic kidney disease: A qualitative descriptive study. *J Ren Care* 2017;43(4):197-208
9. Aresi G, Rayner HC, Hassan L, et al. Reasons for Underreporting of Uremic Pruritus in People With Chronic Kidney Disease: A Qualitative Study. *J Pain Symptom Manage* 2019;58(4):578-86.e2
10. Flythe JE, Dorough A, Narendra JH, Forfang D, Hartwell L, Abdel-Rahman E. Perspectives on symptom experiences and symptom reporting among individuals on hemodialysis. *Nephrology Dialysis Transplantation* 2018;33(10):1842-52
11. Feldman R, Berman N, Reid MC, et al. Improving symptom management in hemodialysis patients: identifying barriers and future directions. *J Palliat Med* 2013;16(12):1528-33
12. van der Willik EM, Terwee CB, Bos WJW, et al. Patient-reported outcome measures (PROMs): making sense of individual PROM scores and changes in PROM scores over time. *Nephrology (Carlton)* 2021;26(5):391-9
13. Etkind SN, Daveson BA, Kwok W, et al. Capture, transfer, and feedback of patient-centered outcomes data in palliative care populations: does it make a difference? A systematic review. *J Pain Symptom Manage* 2015;49(3):611-24
14. Greenhalgh J, Gooding K, Gibbons E, et al. How do patient reported outcome measures (PROMs) support clinician-patient communication and patient care? A realist synthesis. *J Patient Rep Outcomes* 2018;2:42
15. Skovlund PC, Ravn S, Seibaek L, Thaysen HV, Lomborg K, Nielsen BK. The development of PROMunication: a training-tool for clinicians using patient-reported outcomes to promote patient-centred communication in clinical cancer settings. *J Patient Rep Outcomes* 2020;4(1):10



16. Schick-Makaroff K, Levay A, Thompson S, et al. An Evidence-Based Theory About PRO Use in Kidney Care: A Realist Synthesis. *Patient* 2022;15(1):21-38
17. Noonan VK, Lyddiatt A, Ware P, et al. Montreal Accord on Patient-Reported Outcomes (PROs) use series - Paper 3: patient-reported outcomes can facilitate shared decision-making and guide self-management. *J Clin Epidemiol* 2017;89:125-35
18. Carfora L, Foley CM, Hagi-Diakou P, et al. Patients' experiences and perspectives of patient-reported outcome measures in clinical care: A systematic review and qualitative meta-synthesis. *PLoS One* 2022;17(4):e0267030
19. van der Willik EM, Meuleman Y, Prantl K, et al. Patient-reported outcome measures: selection of a valid questionnaire for routine symptom assessment in patients with advanced chronic kidney disease - a four-phase mixed methods study. *BMC Nephrol* 2019;20(1):344
20. Greenhalgh J, Dalkin S, Gooding K, et al. Functionality and feedback: a realist synthesis of the collation, interpretation and utilisation of patient-reported outcome measures data to improve patient care. Health Services and Delivery Research. NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK., Southampton (UK): 2017.
21. Foster A, Croot L, Brazier J, Harris J, O'Cathain A. The facilitators and barriers to implementing patient reported outcome measures in organisations delivering health related services: a systematic review of reviews. *J Patient Rep Outcomes* 2018;2:46
22. Nelson EC, Eftimovska E, Lind C, Hager A, Wasson JH, Lindblad S. Patient reported outcome measures in practice. *Bmj* 2015;350:g7818
23. Boyce MB, Browne JP, Greenhalgh J. The experiences of professionals with using information from patient-reported outcome measures to improve the quality of health-care: a systematic review of qualitative research. *BMJ Qual Saf* 2014;23(6):508-18
24. Evans JM, Glazer A, Lum R, et al. Implementing a Patient-Reported Outcome Measure for Hemodialysis Patients in Routine Clinical Care: Perspectives of Patients and Providers on ESAS-r:Renal. *Clin J Am Soc Nephrol* 2020;15(9):1299-309
25. Anderson NE, McMullan C, Calvert M, et al. Using patient-reported outcome measures during the management of patients with end-stage kidney disease requiring treatment with haemodialysis (PROM-HD): a qualitative study. *BMJ Open* 2021;11(8):e052629
26. Greenhalgh J, Long AF, Flynn R. The use of patient reported outcome measures in routine clinical practice: lack of impact or lack of theory? *Soc Sci Med* 2005;60(4):833-43
27. Thorne S, Kirkham SR, MacDonald-Emes J. Interpretive description: a non-categorical qualitative alternative for developing nursing knowledge. *Res Nurs Health* 1997;20(2):169-77
28. Thompson Burdine J, Thorne S, Sandhu G. Interpretive description: A flexible qualitative methodology for medical education research. *Med Educ* 2021;55(3):336-43
29. Thompson S, Schick-Makaroff K. Qualitative Research in Clinical Epidemiology. In: Parfrey PS, Barrett BJ, editors. *Clinical Epidemiology: Practice and Methods*. Springer US, New York, NY: 2021; 369-88.

30. Morse JM. The significance of saturation. *Qual Health Res* 1995;5(2):147-9
31. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care* 2007;19(6):349-57
32. Amir N, McCarthy HJ, Tong A. Qualitative Research in Nephrology: An Introduction to Methods and Critical Appraisal. *Kidney360* 2021;2(4):737-41
33. Archibald MM, Ambagtsheer RC, Casey MG, Lawless M. Using Zoom Videoconferencing for Qualitative Data Collection: Perceptions and Experiences of Researchers and Participants. *International Journal of Qualitative Methods* 2019;18:1609406919874596
34. Ware J, Jr., Kosinski M, Keller SD. A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity. *Med Care* 1996;34(3):220-33
35. Weisbord SD, Fried LF, Arnold RM, et al. Development of a symptom assessment instrument for chronic hemodialysis patients: the Dialysis Symptom Index. *J Pain Symptom Manage* 2004;27(3):226-40
36. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology* 2006;3(2):77-101
37. Green J, Thorogood N. Thematic content analysis. *Qualitative methods for health research*. 4th ed. SAGE: 2018; 258-68.
38. Emanuel EJ, Emanuel LL. 4 Models of the physician-patient relationship. *Jama-Journal of the American Medical Association* 1992;267(16):2221-6
39. Borza LR, Gavrilovici C, Stockman R. Ethical models of physician - patient relationship revisited with regard to patient autonomy, values and patient education. *Medical-Surgical Journal-Revista Medico-Chirurgicala* 2015;119(2):496-501
40. Damman OC, Verbiest MEA, Vonk SI, et al. Using PROMs during routine medical consultations: The perspectives of people with Parkinson's disease and their health professionals. *Health Expect* 2019;22(5):939-51
41. Greenhalgh J, Abhyankar P, McCluskey S, Takeuchi E, Velikova G. How do doctors refer to patient-reported outcome measures (PROMS) in oncology consultations? *Qual Life Res* 2013;22(5):939-50
42. Takeuchi EE, Keding A, Awad N, et al. Impact of patient-reported outcomes in oncology: a longitudinal analysis of patient-physician communication. *J Clin Oncol* 2011;29(21):2910-7
43. Feldthusen C, Forsgren E, Wallström S, et al. Centredness in health care: A systematic overview of reviews. *Health Expectations* 2022;25(3):885-901
44. Elwyn G, Frosch D, Thomson R, et al. Shared decision making: a model for clinical practice. *J Gen Intern Med* 2012;27(10):1361-7
45. Johnson JA, Al Sayah F, Buzinski R, et al. A cluster randomized controlled trial for the Evaluation of routinely Measured PATient reported outcomes in Hemodialysis care (EMPATHY): a study protocol. *BMC Health Serv Res* 2020;20(1):731
46. Meuleman Y. Integrating Patient-Reported Outcome (PRO) measures into Dutch dialysis care: Toward a PRO Treatment Guide to achieve optimal multidisciplinary and personalized dialysis (Dutch Kidney Foundation projectcode: 21OM+002). 2022.

## Supplemental Material for Chapter 8

**Table S1. Main topics with example questions\* for individual semi-structured interviews with patients and healthcare professionals**

### **Part A**

#### **Experiences with discussing PROM-results**

- *How often have you discussed the PROM-results, and in what setting?*
- *How did you experience the discussion about the PROM-results?*
- *What went well when discussing the PROM-results, and what could be improved?*
- *What was the role of the healthcare professional/patient, and of yourself, during the conversation?*
- *What were your expectations for discussing the PROM-results, and what did it bring you?*

#### **Perspectives on optimal ways to discuss PROM-results**

- *What should be the purpose of discussing the PROM-results?*
- *How can it be ensured that what is important to the patient emerges during the conversation?*
- *How would you describe the ideal conversation about the PROM-results?*
- *What are barriers for having this ideal conversation, and what could be done to overcome these barriers?*
- *How can a conversation about PROM-results contribute to the treatment or wellbeing of the patient?*
- *What should be done after discussing the PROM-results?*

### **Part B**

#### **Perspectives on dealing with specific situations in discussing PROM-results**

- *How should the PROM-results be discussed if:*
  - *no changes or new topics emerge?*
  - *it is about a sensitive topic that someone doesn't talk about easily?*
  - *there is no medical treatment for the symptoms that emerge?*
  - *factors not related to kidney disease or dialysis treatment (e.g. comorbidities or life events) may have caused the decreased quality of life or symptoms that emerge?*

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\* Example interview questions are shown. During the interviews responses were further explored using additional questions and probes.