Patients’ views on routine collection of patient-reported outcomes in rheumatology outpatient care – a multicenter focus group study


1 Danish Hospital for Rheumatic Diseases, Sønderborg, University Hospital of Southern Denmark, Denmark
2 Department of Regional Health Research, University of Southern Denmark, Odense, Denmark
3 The DANBIO Registry and Copenhagen Center for Arthritis Research, Center for Rheumatology and Spine Diseases, Centre for Head and Orthopaedics, Rigshospitalet, Glostrup, Denmark
4 Patient research partner, Denmark
5 The Danish Rheumatism Association, Denmark
6 Department of Rheumatology, Odense University Hospital, Odense, Denmark
7 Department of Clinical Medicine, Faculty of Health and Medical Sciences, University of Copenhagen, Copenhagen, Denmark

Jette Primdahl, RN, MPH, PhD, Professor
Dorte V. Jensen, MD, Head of Secretariat
Rikke H. Meincke, MPH, PhD
Kim V. Jensen, patient research partner
Connie Ziegler, patient research partner
Stig W. Nielsen, patient research partner
Lillian Dalsgaard, patient research partner
Malene Kildemand, RN, MSciH
* Merete L. Hetland, MD, PhD, DMSc, Professor
* Bente A. Esbensen, RN, MSciN, PhD, Associate Professor

* These authors contributed equally to the project.

This article has been accepted for publication and undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record. Please cite this article as doi: 10.1002/acr.24019

This article is protected by copyright. All rights reserved.
Corresponding author

Bente Appel Esbensen, Copenhagen Center for Arthritis Research (COPECARE), Rigshospitalet, Valdemar Hansens Vej 17, Entrance 5, 2600 Glostrup, Denmark
Email: bente.appel.esbensen@regionh.dk

Abstract

Objective To explore the patients’ views of the collection and use of patient-reported outcomes (PROs) as part of routine care in patients with Inflammatory arthritis (IA).

Methods We conducted a qualitative focus group study based on interviews in each of the five geographical regions of Denmark. The analysis was based on content analysis. Four patient research partners were involved in the study.

Results In total, 32 adult patients (21 female) with rheumatoid arthritis (n=21), psoriatic arthritis (n=6) and axial spondyloarthritis (n=5) participated. Mean age 60 (range 32-80).

Five themes were derived from the analysis: Need for information about why the data are collected, reflecting patients’ uncertainty as to whether the collection of PROs primarily served to monitor their own disease, to save money or to gather data for research purposes; Inclusion of PROs in the consultation, encompassing patients’ expectations of active use of the PRO data during talks with rheumatologists or nurses; Reflections on how to respond the PROMs to obtain high quality data, referring to patients’ concerns about how to respond “correctly” and issues that could affect their responses; PROs should address the individual’s challenges, reflecting the need for a more individualized approach; and Possibilities for improvement in the use of PROs, referring to patients’ ideas for the future use of PROs.
Conclusion Information and dialogue regarding the purpose of PRO collection, how to respond to PROMs correctly and inclusion of the PRO data in the consultation are of importance to patients with IA who routinely complete PROs.

Significance and Innovations

- Patients willingly respond to PROMs as part of routine care, and they expect their answers to be actively included in the dialogue with clinicians during consultations.
- It is important to inform patients about the purpose and use of the PRO data, and health professionals should repeat this information at regular intervals.
- There is some uncertainty among patients as to how to respond to some PROMs correctly.
- Not all issues of importance for the patients are covered by PROs. Dialogue with the patient is important to complement the PRO data in routine care.

Patient-reported outcome measures (PROMs) for the collection of patient-reported outcomes (PROs) are increasingly recognized as important prerequisites for shared decision making and quality improvement and, since the 1980s, they have gradually become part of standard practice in rheumatology (1-3). The specific PROMs can be used to collect data, monitor progress, facilitate the identification of challenges and aid the clinical management of individual patients (1, 4). PROs can encompass issues such as the patient’s health status, symptoms, quality of life, mental status or functional status (1, 4, 5). Inflammatory arthritis (IA) (e.g. rheumatoid arthritis (RA), psoriatic arthritis (PsA) and axial spondyloarthritis (axSpA)) are characterized by joint swelling, pain, stiffness, fatigue, reduced functional ability and psychological and social challenges (6-8). To assess treatment effect and fluctuations in disease activity, symptoms, functional ability and the impact of the disease are monitored (9-11). For this purpose, PROMs have been developed and validated. To our knowledge, in rheumatologic care, patients’ experiences of the routine collection of PROs, and how PRO data are used during consultations have not yet been explored. DANBIO is a Danish, national clinical quality registry in which PROs from patients with IA have been...
collected for more than 15 years as part of routine care (12, 13), using touch screens in the waiting area before outpatient consultations (14). Examples of PROs in DANBIO are functional status, pain, fatigue, quality of life, and symptom state. In 2017, ≈46,000 unique patients with IA reported PROs in DANBIO at a total of ≈80,000 visits, which makes DANBIO a suitable source for studying patients’ views on the collection of PROs. Thus, the aim of this study was to explore patients’ views of the collection and use of PROs as part of routine care in patients with IA.

Patients and methods

Design
This was a qualitative exploratory study based on focus group interviews (15). We conducted one focus group interview in each of the five geographical regions of Denmark. Four patients with IA (KVJ, CZ, SWN, and LD) participated as patient research partners during all phases of the project, except during the interviews (16, 17).

Collection of PRO data in DANBIO
Data are collected in DANBIO as part of routine care to obtain information about patients’ disease course, monitor treatment, improve quality of treatment and for research purposes. Joint counts, treatment, laboratory results, physician’s/nurse’s global score, etc. are collected by the physician or the nurse (13, 18, 19). The PROMs collected in DANBIO encompass: the Health Assessment Questionnaire (HAQ) (20), which measures functional status, together with three additional questions from the multi-dimensional MD-HAQ (about leisure time activities, sleep and anxiety), visual analogue scales (VAS) for pain, fatigue and patient global scores, patient acceptable symptom state “Think about all the ways in which your arthritis has affected you in the last 48 hours. If, in the coming months, it continued to affect you in the way it has during the last 48 hours, would that be acceptable to you?”, and an anchoring question “Since your last visit has your arthritis become (mark only one) …” with seven possible answers on a Likert scale, ranging from “much worse” to “improved a lot”. For patients with PsA and axSpA, the Bath Ankylosing Spondylitis Disease Activity Index (BASDAI) (21, 22) and Functional Index (BASFI) (22, 23) are also collected.
Participants
Patients with IA were eligible to participate in the focus groups if they had been diagnosed at least one year prior to the interview and had experience of entering PRO data into DANBIO. To recruit patients, a brief invitation to participate in a focus group interview was shown on the touch screen after eligible patients had finished answering PROMs. Patients who accepted the invitation received written information and a consent form from the DANBIO administration followed by oral information. Using a purposive criterion-based sampling strategy (24) that aimed for maximum variation in gender, age, diagnoses, and disease duration, 10-12 patients were recruited for each of the five focus group interviews. All participants were offered reimbursement of transport expenses but were not offered any other compensation.

Procedure
An interview guide was developed, covering five broad research topics (Table 1). Two study group members (BAE and JP) shared the task of moderating the interviews, starting with an open-ended question, i.e. “What do you think of, if I mention the touch screen in the waiting room?” Probes like “Please give an example” or “Please describe in more detail” were used to broaden the group discussions. The co-moderator assisted in recording the interviews, observed group interactions, took notes and contributed with clarifying questions. Each focus group interview was planned to last 1-1½ hours and took place in meeting rooms at the hospitals. During the interviews, coffee, tea and cake were available.

Analysis
After each interview, the moderator and co-moderator shared their initial impressions. The interviews were transcribed verbatim and transcripts were reviewed by the moderators. All transcripts were uploaded to NVivo (version 11, QSR International) for analysis, which was based on qualitative content analysis (25). Initially, all meaning units were coded based on the five topics in the interview guide (deductive analysis) (Table 1). The subsequent inductive analysis focused on the manifest content, followed by a focus on the latent content across all interviews. The analyses and subsequent sorting of all codes into potential categories were performed by each of the two moderators independently. Then, they met
Gradually, a condensation of categories into more overarching themes was achieved.

Ethics
All participants gave written consent to participate after receiving oral and written information. Permission was obtained from the Danish Data Protection Agency (j.no.2012-58-0004). No formal permission from the Research Ethics Committee was needed, in accordance with Danish law (j.no. 17021849). The study complies with the ethical principles of the Declaration of Helsinki. All participants committed themselves to treating the interviews confidentially.

Results
In total, 585 patients received the invitation; of these, 201 (34.4%) indicated an interest in participating. We managed to get in touch with 131 of these, of whom 52 agreed to participate. A total of 32 showed up for interview. Twenty-one (66%) were female, mean age 60 (range 32-80) (Table 2). The five focus group interviews were conducted during September 2017 and lasted 74-82 minutes.

The structured analysis resulted in five themes (A-E), which are listed in Table 3 together with numbered quotes that support the findings. Each number refer to a specific patient.

A: Need for information about why the data are collected
In general, the participants were positive regarding answering PROs before the consultations, but they felt uncertain about their purpose. They had received too little information about the use of the data. Also, the information was provided only on one occasion, which for some had been many years previously, so they did not recall the information. (Quote # P11) Participants had various suggestions as to what the purpose of PRO collection could be: To gain experience of the effects and side effects of the medicine, to work towards individualized treatment and to obtain information on the effects and side
effects of the new biological preparations (biosimilars) compared to the original products. Some were uncertain as to who would get access to the data and whether data were saved. In general, however, there was an expectation that the data were used for statistical purposes and research. Some believed that the collection of PRO data in DANBIO was primarily time-saving for the physician and nurse, and some thought it would result in a reduction of costs for the department. Two feared that the answers could have consequences for their medical treatment and, in the worst case, result in the withdrawal of effective medication. (Quotes # P4, P13, and P20) Some had been told by the rheumatologist that their subjective perception was very important, which left the participants with a positive feeling.

B: Inclusion of the PROs in the consultation

The participants expressed a wish to include the PRO data in the consultation to qualify the dialogue. Several participants had learned that their responses had been used in assessing the disease activity, the response to medical treatment and to monitor change of treatment. (Quote # P15) Others had not discussed their answers with the rheumatologist/nurse and they did not always discuss the topics that currently were of importance to them. Few had experienced being shown the screen with the data, and none knew about the opportunity to view data over time with disease activity level in colors. (Quotes # P11, P28 and P32) Some felt uncomfortable at the thought that it might be a waste of time to answer the same questions again and again. If the rheumatologist commented on the responses, it was taken as a sign that the rheumatologist used the data, but often such a dialogue was lacking. (Quote # P22) Answering PRO questions prior to the consultation stimulated the patients to prepare for the consultation and reflect over their illness and restrictions in daily life, and whether this had changed since the last consultation. Some thought that PROs took away time from the consultation because the rheumatologist/nurse looked through the answers while the participants were in the consultation. Several mentioned that the rheumatologist/nurse could prepare for the consultations and use the participants’ responses as a tool for guidance and decision making, which could help inform and enrich the dialogue. Participants liked to talk with the professionals about their current situation, how they were doing, how they lived with arthritis and how they could get specific help to cope with their disease. (Quote # P32)
C: Reflections on how to respond to PROMs to obtain high quality data

Most participants found that some of the questions on the screen (e.g., pain and fatigue) were easy to understand but could be difficult to answer. They expressed uncertainty about whether they should compare to their habitual level of, e.g., pain and fatigue or to a day without arthritis, i.e. without pain or fatigue. Several mentioned that they probably would have responded differently to, e.g., pain questions if they had early RA, compared to having established RA. The weather, the way their day shaped up, how long they had had arthritis, whether they answered the questions without privacy, and time since last medication were mentioned as factors which could influence their responses. (Quotes # P14 and P11) Others sometimes found it difficult to think, e.g., half a year back to recapture how they were doing at the last consultation. (Quote # P4) Some dressed up the answers a bit or made themselves seem a little worse than they were. This could be because they entered the data in a public space, because they were afraid that there would be nothing to talk to the physician about or because they thought it could have consequences for their medical treatment. (Quotes # P22, P13 and P21) Answering PROs tended to become routine, because participants had answered the same questions many times before. (Quote # P20)

D: PROs should address the individual’s challenges

There was a desire for greater variation in possible answers, to reflect their current state more accurately. Participants also suggested having the opportunity to answer the questions, e.g., monthly from home, because that would better reflect the fluctuating condition of their arthritis. (Quotes # P11, P15 and P25) In all the interviews, participants mentioned that they considered some of the questions in the HAQ-questionnaire were superfluous and irrelevant; e.g., questions about getting in or out of a bathtub, getting in and out of a car or whether one can walk 3 km. (Quote # P20) The participants called for more interactive questions and answers, e.g., being able to indicate painful areas on a mannequin or to include images illustrating the kind of water faucet in question. (Quote # P17) Participants wanted to be able to skip irrelevant questions. They missed questions about the use of painkillers, side effects of treatment, challenges with work, questions about feet, sexuality and lifestyle to reflect the problems they experienced. The participants considered it a limitation if the rheumatologists based their assessments solely on the
participants’ answers in situations where the questions did not reflect the challenges they were experiencing. (Quotes # P14 and P7) The participants also suggested questions about whether they were considering longer treatment intervals, had explanations for disease flare-ups, and whether there were topics they wanted to discuss with the rheumatologist. (Quotes # P12 and P1)

E: Possibilities for improvement in the use of PROs

Some found the lack of privacy when entering data (on the touch screens in the waiting room) to be a problem and suggested that the screens be shielded from the waiting area. They liked the proximity to the secretaries, who could help when needed. The option to answer the questions from home via the Internet, on a computer, tablet or smartphone was discussed. This would allow better documentation of variations in symptoms over time. While many supported this option, some individuals would lack the necessary equipment, have difficulty managing it or might not want to use this option. (Quote # P11) In several interviews, there was an interest in being able to see one’s previous answers at home over a longer period of time. However, it was also mentioned that if one knew the previous answers, this could influence the current response.

Discussion

To the best of our knowledge, this is the first qualitative study to report patients’ views on the collection and use of PROs as part of routine rheumatology care. The participants of the five focus groups, who all suffered from IA, were positive towards answering PROs in connection with the consultation. Most of them knew that the data was used for statistics and research, but overall they would like the individual PRO data to be included more actively in the consultations to improve the dialogue with rheumatologists and nurses. This is in accordance with the present global focus on user involvement and shared decision making (26, 27). Lack of knowledge about the purpose of the collection of PROs had an impact on motivation to answer the PROs. Most of the participants did not recall having received any introduction to DANBIO and the PRO data. Thus, providing systematic and repeated information to patients about the purpose and use of the collection of PRO data seems to be important, to ensure sustained motivation to respond. Some uncertainty was
expressed regarding the interpretation of questions, e.g., a clearer definition of the reference point (with or without arthritis), the time frame in question and how to handle the registration of fluctuations in disease activity. Ong et al. (28) also found that people’s answers may depend on the reference point, which may change over time and respondents may provide a wider time frame than requested (28). Our findings indicate that patients need additional information to harmonize the way they answer the PROs, and we identified several factors that could influence the participants’ responses. This is of particular importance when PRO data are used for research purposes and for national and international benchmarking.

Answering PROs often initiated reflections on patients’ actual situations as a preparation for the subsequent consultation. Some participants were worried that the use of PROs could take time from the dialogue with the physician or nurse during the consultation and suggested that the clinicians look at the responses before rather than during the consultation. Some also wondered whether the clinicians might interpret their answers as the “truth” about how they felt, without asking them for validation. A recent guide on how to implement PROs in clinical practice describes the importance of introducing the patients to how to respond to PROs, and that clinicians should pose additional questions during consultations, to ensure they understand the patient’s challenges (29). The PROMs did not always reflect the challenges the participants experienced. Discordance between patients’ and clinicians’ assessments of disease activity and disease impact is well known (27, 30, 31), and thus the clinician and patient should review the responses together (27) and include the patient’s perspectives by asking further about recent flare-ups and disease impact.

The European League Against Rheumatism (EULAR) developed recommendations for a core data set to support observational research and clinical care in RA (32), which provides a good basis for future collection of observational data in clinical registers such as DANBIO. Our study shows that it is highly relevant to involve patient representatives in the selection of PRO questions to be used in clinical practice. However, it is also important to discuss what can be reflected by PROs and which issues need to be discussed directly with the patient.
There was a high level of interest among participants for an option to view their answers over time, and additional topics, such as work and foot problems and being able to raise issues they wanted to discuss with the clinician, were suggested. This is in accordance with findings from Philpot et al.’s qualitative study on patients’ views on barriers and benefits related to the use of PROMs in clinical practice (33). The DANBIO database provides an opportunity to show the development of disease activity in color codes and PRO data over time on the computer screen. The participants could not recall that they had been shown this feature, but this probably is not the case in all settings where DANBIO is used and may also reflect recall bias.

In accordance with Philpot et al.’s findings (33), the participants suggested omitting redundant questions and adding, e.g., photos of the water faucet in question to help their understanding. Examples of questions that did not make sense for the participants in the assessment of functional status (HAQ, MD-HAQ), the repetitive character of response options and the need for questions that have relevance for the patients, are in accordance with Ebbevi et al.’s qualitative interview study (34) about how people with RA experience the use of HAQ in routine care. The identified need to be able to skip irrelevant items is in line with the findings from Ong et al. (28). Here, individual patients judge the relevance of the specific items and may skip the ones they do not think apply to them. The patients may not recognize that it is important to answer all questions to obtain complete data for research. This should be part of the introduction to the patients about DANBIO.

Some participants asked for an opportunity to answer the PROs on their own electronic device. This would help ensure privacy and provide an opportunity to complete PROs in-between planned consultations and thus meet the participants’ need to report fluctuations in their disease. The patients emphasized that it should be optional. The DANBIO database is currently testing at-home solutions (35).

The findings indicate that it is not only the patients who need information about the use of PRO data in DANBIO. The clinicians also need to align how they inform the patients about the purpose of the collection of PRO data, what they are used for and which reference the patients are expected to use when they are asked about their level of, e.g., pain and fatigue.

This article is protected by copyright. All rights reserved.
The clinicians may need training to gain confidence making use of PRO data together with the patient during consultations and to provide them with information of relevance.

**Limitations and strengths of the study**
The exploratory approach, employing qualitative focus group interviews, was useful, as little was known about the topic (15). The group interactions during the interviews assisted the participants in exploring their own points of view and encouraged a range of responses that provided valuable insights into their perspectives. The results have high degree of external validity, since the interviews included patients with RA, PsA and axSpA and variations in gender, age, disease duration as well as five different geographical regions that covered both university and local hospitals. Although we used a purposive criterion-based sampling strategy, age and diagnoses were not evenly spread across the interviews. Of the 585 patients who were invited to respond to the invitation question, the majority (n=384) were not interested or were not able to participate in a focus group interview. Other patients and patients from other hospitals may have different experiences. Furthermore, clinicians may have used the PRO data, but without explicating this in the dialogue with the patient.

Triangulation within the research team, including patient research partners, rheumatologists, and rheumatology nurses, enhanced the trustworthiness of the study. DANBIO continuously aims to improve patients’ contribution to consultations. Inclusion of patient representatives in the steering committee and the involvement of patient research partners in this study reflect this ongoing process.

In summary, patients are willing to answer PROs as part of standard clinical practice, and they want to know what the data are used for and how to answer the questions correctly. The involvement of patients in the selection of PROMs is relevant. The patients want their responses to be used actively in the consultations with rheumatologists and rheumatology nurses. During the consultations, the clinicians should discuss the PRO data with the patients and ask whether the patients experience other challenges. Both patients and clinicians can use the PROs to prepare for the subsequent consultation and improve the dialogue.
Acknowledgments

The authors thank the participants for generously sharing their experiences with PROs in rheumatology care. Thanks to the participating Danish departments of rheumatology and to ZiteLab for helping with IT (recruitments of participants). Thanks to Lorna Campbell for help with language edition.

Conflicts of interest and funding

The authors declare that they have no competing interests.

References


This article is protected by copyright. All rights reserved.


28. Ong BN, Hooper H, Jinks C, Dunn K, Croft P. ’I suppose that depends on how I was feeling at the time’: perspectives on questionnaires measuring quality of life and musculoskeletal pain. Journal of health services research & policy. 2006;11(2):81-8.

Table 1. Interview guide

1: Knowledge about DANBIO
How were you introduced to data entry into DANBIO? What do you think the data are used for?

2: Physical surroundings
What is your experience with the use of the touch screen? E.g., its physical location and positioning for data entry

3: Views on the PRO questions
Do you understand the questions? Are there any questions you feel uncertain about? Are there any questions you would suggest leaving out? Are there questions you think are missing?

4: Use of the data in the outpatient consultations
Please share your experiences regarding the use of data in the consultations. If used, how does this impact the quality and dialogue? How can the data be used to improve the dialogue with the rheumatologist or the nurse?

5: Suggestions for further development in the use of DANBIO
Do you have any suggestions for further development? What kind of information do you need regarding the use of data in DANBIO? What could motivate you to continue entering data?
Table 2. Recruitment and characteristics of the participants in the five focus groups

<table>
<thead>
<tr>
<th>Total</th>
<th>FG1</th>
<th>FG2</th>
<th>FG3</th>
<th>FG4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Invited (n)</td>
<td>585</td>
<td>122</td>
<td>104</td>
<td>137</td>
</tr>
<tr>
<td>Interested (n)</td>
<td>201</td>
<td>50</td>
<td>40</td>
<td>45</td>
</tr>
<tr>
<td>Agreed to participate (n)</td>
<td>52</td>
<td>10</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Participants (n)</td>
<td>32</td>
<td>6</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td>Diagnosis (n)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>RA</td>
<td>21</td>
<td>3</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>PsA</td>
<td>6</td>
<td>3</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>axSpA</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Female (n)</td>
<td>21</td>
<td>4</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Age (years)*</td>
<td>57</td>
<td>52</td>
<td>61</td>
<td>54</td>
</tr>
<tr>
<td>(Age range, years)</td>
<td>(32-80)</td>
<td>(37-80)</td>
<td>(48-72)</td>
<td>(45-61)</td>
</tr>
<tr>
<td>Years since diagnosis*</td>
<td>10 (2-29)</td>
<td>14 (4-29)</td>
<td>11 (5-15)</td>
<td>9 (5-14)</td>
</tr>
</tbody>
</table>

* mean (range); FG=Focus group, n=number, RA=Rheumatoid arthritis; PsA=Psoriatic arthritis; axSpA=Axial Spondyloarthritis


Table 3. The five themes (A-E) with numbered quotes to illustrate each theme. The numbers P1, P2, etc. refer to the participant number

<table>
<thead>
<tr>
<th>A. Need for information about why the data are collected</th>
</tr>
</thead>
<tbody>
<tr>
<td>A1: But I’m only told to go over there and sit down and fill this out, and I’ve never been given any real explanation (P11)</td>
</tr>
<tr>
<td>A2: Will they take statistics from the data we give? Like statistical extracts? I mean, one could imagine that, when you now have, we now have those who have started biological treatment, they can go in and check how they are doing (P4)</td>
</tr>
<tr>
<td>A3: I was told that it wasn’t for my benefit. It would be for the benefit of future patients, by me answering the questionnaire. And I’d do that with pleasure, in the hope that someone would have it easier than I did (P13)</td>
</tr>
<tr>
<td>A4: Yes, I do also think that it could be that there are also statistics. But I think, as well, there are some savings in it. Because then the rheumatologist does not have to spend time asking ... but then I think, what if they take this medicine from me (P20)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>B. Inclusion of PROs in the consultation</th>
</tr>
</thead>
<tbody>
<tr>
<td>B1: But, in my experience, they have used them in a situation where I had been taken out of biological treatment for three years, and I was going back on it. ... I sat with the rheumatologist, who went back and looked at the figures, both from before I started the biological treatment the first time and the period during biological treatment and then in that period I’ve had, where I haven’t been having biological treatment. So there I felt that they used it (P15)</td>
</tr>
<tr>
<td>B2: I have never been shown the result, that much I can say (P11)</td>
</tr>
<tr>
<td>B3: Actually, I’ve always believed that it was something that was saved in some big database or other somewhere and that there were researchers who sat and looked at it. I had actually never understood completely that it was something that one could use in the consultation (P28)</td>
</tr>
<tr>
<td>B4: There is no dialogue with the rheumatologists when you come in. It’s not so much about whether I can open and close a jar. That’s not one of the things that I find challenging. But the fatigue and whether I have pain or don’t have pain, that’s NEVER ever discussed when you go in there (P32)</td>
</tr>
<tr>
<td>B5: And then, the last time I was at the physician’s, I asked him, because I didn’t think it gave a true picture of how I was doing. I found out from him that he used it somehow to see how I was. But what I was missing was access to knowledge based on the questions (P22)</td>
</tr>
<tr>
<td>B6: I think that, instead of standing and filling out a questionnaire where I can easily say “yes” to all the questions because it’s not that, that I find challenging. I would much rather talk to the rheumatologist about how I actually am, and what my challenges are, and if she has any tips about that (P32)</td>
</tr>
</tbody>
</table>
C. Reflections on how to respond to the PROMs to obtain high quality data

C1: I had to define what a good day is for me now, in relation to before I became ill. These days a good day is something entirely different from when I was well, you know? (...) So I find myself thinking if I’m completing them correctly (P14)

C2: You can have a day where you feel really well. So I am in great doubt about what I should write. Because I can have a day where I can’t reach the upper shelf, but on the day I’m sitting there [and answering the questions], I can. So I write, you know, at the top end, and in that way I think, maybe, that it’s a little bit untrustworthy (P11)

C3: They just say it to me: “I can see that you responded that you are better than before, because I can see what you responded on the screen earlier”. Yes, well, it’s actually true that I am better than before. But it is also my challenge, that I can’t always remember what I answered the last time (P4)

C4: I make it look a bit too rosy because it is a public space, as opposed to when I sit and talk to the physician (P22)

C5: ... it is difficult to answer it absolutely 100% properly, because I also think that I would never get any medicine if I wrote that I’m really well (P13)

C6: About that exact point, about answering a bit more positively than one is. That thought has gone through my mind sometimes. If I was to complete it on a day where I thought, “what an off-day I’m having today”. Two days later, it might not be. And if the [response] is used to describe my general picture, then I think that, maybe, it’s a bit uncomfortable. So, in that case, I might also dress it up a bit, and say “no, actually, it’s going really well, even though it’s not going so well today. And I don’t know either if it will go well tomorrow” (P21)

C7: ... sometimes you run through it a bit lightly, you know? I mean, it has to be completed a bit quickly. But if you knew the purpose, or if it was to be used by someone researching (...) one would take it a bit more seriously (P20)

D. PROs should address the individual’s challenges

D1: One could say, if it was once a month or certainly during the first while after one has started, one would get a more detailed picture of how people actually are, and how it works and with the medicine and so on (P11)

D2: ... we miss that bit, where one can respond about having a bad patch during the 8-week period that has just gone (P15)

D3: ... it’s exactly what’s missing in many places – that one has the chance to specify something. Either, as you say, with a line or that there are some choices. I can walk 0-1000 meters or 1000-3000 meters or 5000+, or this or that (P25)

D4: So, some of them are silly, aren’t they? I mean, that one about whether you can walk 3-4-5 km? Yes, but in what length of time ...? Yes, she certainly can if she has all day to do it. I’m sure we all can if we spend the day doing it, and some days we could also do it in a short time, right? (P20)

D5: ... It might be an idea to have a picture of the faucet underneath because there is a big difference between living in a building from 1960 or a modern building (P17)

D6: So, it’s a bit strange, I think, that there’s only one question about work. So, that one about whether you can work 7.5 hours a day or 7.4 hours a day. That’s all there is about work (P14)
<table>
<thead>
<tr>
<th>D7: ... because sometimes I wonder why they come in and say: “Yes, well, it looks as if you are doing really well.” I certainly haven’t written anything about that (P7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>D8: ... if you have completed the questionnaire, and you are feeling really bad, then there could well be a question “Why do you think that is?” I mean, what has happened, pneumonia or something (P12)</td>
</tr>
<tr>
<td>D9: ... if there was something that one was in doubt about, then you could tick a box and say: “That’s actually something that I would like to talk to the rheumatologist about. Oh! There were actually two things here, that we need to talk about” (P1)</td>
</tr>
<tr>
<td>E. Possibilities for improvement in the use of PROs</td>
</tr>
<tr>
<td>E1: That you go to a website, or maybe make an app, where you can sit at home (...) It’s actually quite pleasant that you could take your iPad or your phone or something in the morning with your morning coffee and then do it at the pace you want (P17)</td>
</tr>
</tbody>
</table>