



The experiences of community-dwelling individuals with newly diagnosed type-2 diabetes in using patient-reported outcomes in a municipal setting

Eriksen, Jeppe; Bygholm, Ann Kathrin Meilandt; Hudtloff Nielsen, Signe; Bertelsen, Pernille Scholdan

Published in:
Digital Health

DOI (link to publication from Publisher):
[10.1177/20552076221089792](https://doi.org/10.1177/20552076221089792)

Creative Commons License
CC BY-NC 4.0

Publication date:
2022

Document Version
Publisher's PDF, also known as Version of record

[Link to publication from Aalborg University](#)

Citation for published version (APA):

Eriksen, J., Bygholm, A. K. M., Hudtloff Nielsen, S., & Bertelsen, P. S. (2022). The experiences of community-dwelling individuals with newly diagnosed type-2 diabetes in using patient-reported outcomes in a municipal setting. *Digital Health*, 8, 1-23. <https://doi.org/10.1177/20552076221089792>

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal -

Take down policy

If you believe that this document breaches copyright please contact us at vbn@aub.aau.dk providing details, and we will remove access to the work immediately and investigate your claim.

The experiences of community-dwelling individuals with newly diagnosed type-2 diabetes in using patient-reported outcomes in a municipal setting

Digital Health
Volume 8: 1–23
© The Author(s) 2022
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/20552076221089792
journals.sagepub.com/home/dhj
 SAGE

Jeppe Eriksen¹ , Ann Bygholm², Signe Hudtloff Nielsen³
and Pernille Bertelsen¹

Abstract

Objective: The aim of this study was to examine the experiences of citizens with newly diagnosed type-2 diabetes when using a newly developed and implemented patient-reported outcome (PRO) questionnaire as part of clinical practice in a municipal setting. Specifically, the citizens' experiences in completing the PRO questionnaire and using the PRO data in consultations were examined.

Methods: The study was based on participant observations and semi-structured interviews and conducted at the Centre for Diabetes in Copenhagen and online. Participants were recruited deliberately to represent different cases of citizens with type-2 diabetes. Ten citizens were observed during consultation with an healthcare professional (HCP) and subsequently interviewed. The interviews were recorded as audio or video and transcribed verbatim. A thematic analysis was performed on the basis of previously described guidelines.

Results: The PRO instigated reflections and enlightened citizens on disease-specific matters and motivated citizens to engage in self-management activities. During the citizen-HCP consultations, the PRO data prepared the actors before the meeting and enabled structured, effective and relevant conversations. However, the PRO questionnaire lacked response options, triggered citizen concerns about future health conditions and made them unsure if their answers were correct and aware that they lacked disease-specific knowledge. The experiences were linked to the citizens' situation as newly diagnosed with type-2 diabetes.

Conclusion: The informants found the PRO questionnaire and data meaningful and useful. However, adjustments are needed if the PRO instrument is to resemble the disease situation of citizens with newly diagnosed type-2 diabetes.

Keywords

Patient-reported outcome (PRO), patient experience, patient perspective, citizen-HCP consultation, qualitative study, diabetes, municipality

Submission date: 11 October 2021; Acceptance date: 9 March 2022

Introduction

The use of patient-reported outcomes (PROs) has been rapidly spreading across sectors, disciplines and organisations in Denmark.¹ Especially the digitalisation and integration of PROs into clinical practice are noticeable, as they have influenced and broadened the functionality and purpose of PROs.^{2,3} A development that has been instigated by an economic agreement since 2016 between the Danish

¹Techno-anthropology, Department of Planning, Aalborg University (AAU), Aalborg, Denmark

²Health Informatics, Department of Communication and Psychology, Aalborg University (AAU), Aalborg, Denmark

³Centre for Diabetes (CfD), The City of Copenhagen, Copenhagen, Denmark

Corresponding author:

Jeppe Eriksen, Techno-anthropology, Department of Planning, Aalborg University, Rendsburggade 14, Aalborg 9000, Denmark.
Email: je@plan.aau.dk



government and the Danish regions. In this agreement, the parties decided that the development of PRO tools at a national level should be initiated.⁴ In the same period, the report 'Program PRO' was authored by 29 experts in collaboration with TrygFonden and the Knowledge Center for User Involvement (ViBIS). 'Program PRO' describes the quality improvements and practical implications linked to the implementation of PROs in clinical practice. The authors of 'Program PRO' defined PRO as 'data about the patient's health condition such as physical and mental health, symptoms, health-related quality of life and functional ability reported directly by the patient'.⁵ Accordingly, PROs are data that enable healthcare professionals (HCPs) to understand patients' disease situations from their perspective. In 2017, the relevance of PROs in the Danish context was manifested through the PRO secretariat, a subunit under the Danish Health Data Authority that was established to develop and spread PRO tools across sectors. So far, the secretariat has developed questionnaires within the following disease areas, some of which are still in progress:

- Apoplexy
- Cardiac rehabilitation
- Coronavirus disease (COVID-19)
- Diabetes
- Early detection of depression
- Hip and knee arthritis
- Palliative care
- Pneumococcal diseases
- Pregnancy and maternity
- Psoriasis
- Rehabilitation

According to the PRO secretariat, PROs can be used for screening, patient-clinician dialogues, decision making in clinical practice and quality improvements and as a management tool.¹ Especially the digitalisation of PROs has been decisive for the advent of the tools in the Danish context,⁶ as it has allowed the use of PROs as part of an algorithm-based triage system, enabling a more appropriate allocation of resources. This is because the algorithm-based triage system prioritises patients who need these resources the most, whereas patients assessed to have good health statuses are allowed to skip unnecessary consultations.^{7,8} Moreover, the potential of PROs as self-management tools for monitoring disease progression and facilitate treatment adjustment is emphasised in Danish healthcare policies.^{6,9} However, in the present study, we examined patients' experiences in using the nationally developed diabetes questionnaire in which PROs are used as dialogue and decision-making tools within the municipal setting. In this field, patients are the focal subjects, as they are the primary users of the PRO questionnaire. Hence, their

inputs and experiences are focal when the use of PRO instruments in clinical practice is to be optimised.

Other researchers have also examined patients' experiences with and perceptions of PROs in clinical practice. Accordingly, Wu et al.¹⁰ interviewed 42 patients and 12 clinicians. They found that patients value how the PRO system allows them to note issues they want to discuss during patient-clinician consultations. However, the interpretation of PRO scores and the display of PRO data were confusing to the patients, which might be improved with additional and better information. The participants also suggested that the questionnaire should be tailored to the needs of individual patients. Another issue was concerning the value of the PRO solution, which seemed to depend on clinicians' willingness to make use of the PRO data.¹⁰

Liu et al.¹¹ interviewed 51 patients on the barriers and facilitators concerning the use of PROs in the area of hip and knee pains. Their study showed that most patients (34/51) preferred completion of the questionnaire at home and favoured e-mail or text messaging as the delivery method (17/43).¹¹

The third study conducted by Kane et al.¹² examined, via semi-structured interviews, the usefulness of PROs in palliative care. According to the participants, including 18 patients with heart failure and four nurses, PROs elicit unmet needs, promote a shared and more holistic understanding of patients' disease situations and empower patients by enabling them to participate more actively in patient-clinician consultations.¹²

In the Danish context, Mejdahl et al.¹³ investigated patients' perception of PROs in an outpatient setting. On the basis of 12 semi-structured interviews with renal patients and observations of nine patient-clinician consultations, the researchers concluded that PROs might improve patients' understanding of their chronic conditions, enhance patient-clinician communication and increase awareness on psychosocial issues during consultation.¹³ Mejdahl et al.⁷ also scrutinised how 29 patients with epilepsy experienced PROs in three different outpatient clinics. Their results showed that PROs, on the one hand, potentially enhance patients' self-management, health behaviour, feeling of autonomy, communication with HCPs and awareness and understanding of psychosocial issues and other symptoms. On the other hand, the use of PROs might lead patients to feel rejection and disconnection, which occur when feedback on PROs during patient-clinician consultations is insufficient. The purpose of PROs can seem unclear. According to some patients, PRO measures are too standardised, preventing adequate descriptions of their disease situations. Moreover, questions are sometimes too negatively formulated; that is, the wording and content of the questionnaire instigate worries among patients. Lastly, some patients felt unsure of whether they could complete the questionnaire correctly.⁷

The study outlined in this paper concerns a relatively new PRO diabetes questionnaire developed in the Danish

context at a national level. On the basis of the initial pilot tests, the PRO diabetes questionnaire has been evaluated by the developers, which in this case is the PRO secretariat. The overall conclusion is that citizens and HCPs, in general, were satisfied with the questionnaire and that the use of the questionnaire by citizens with type-1 or type-2 diabetes is feasible. The evaluation showed that the PROs prepared citizens before consultation, enabled increased patient participation and ensured a relevant and effective dialogue. Accordingly, the citizens would like to keep using the PRO questionnaire as part of their treatment. Moreover, results from the evaluation indicate that the questionnaire is relevant, comprehensive and meaningful and that the number of questions is fitting. However, according to the participating HCPs, the questionnaire still needs some adjustments to match local needs. Of the citizens, 3–5% believed the questionnaire was difficult to complete and noted that they needed assistance in doing so. On average, the citizens took 16 min to complete the questionnaire.¹⁴ As it is focal that the PRO questionnaire is applicable across sectors and patient cases, scrutinising whether citizens with newly diagnosed type-2 diabetes, who are the main clients in the municipal setting, also found the tool useful is important. The report stated that ‘these citizens did not worry more than others but felt that the PRO questionnaire was less relevant compared to citizens who have had diabetes for more than a year’.¹⁴ This leads to the conclusion that the questionnaire can be used by newly diagnosed citizens with type-2 diabetes.¹⁴ To complement the evaluation by the PRO secretariat, the present study aimed to provide a deeper qualitative understanding of how citizens with newly diagnosed type-2 diabetes perceive the diabetes PRO questionnaire in a municipal health-care setting. Specifically, we examined the experiences of citizens with newly diagnosed type-2 diabetes in (a) the completion of the PRO questionnaire and (b) the use of PRO data during the citizen-HCP consultation. This is a novel study, as it provides relevant knowledge on the use of PROs in a municipal setting from the perspective of citizens with newly diagnosed type-2 diabetes.

Background

The PRO questionnaire

The PRO questionnaire used at the Center for Diabetes (CfD) was developed through eight workshops hosted by the PRO secretariat from June 2018 to December 2018. Four workshops titled, ‘The Clinical Coordination Groups’ (KKG), included various HCPs from different organisational levels, quality improvement workers, representatives from the Danish Diabetes Association (DDA) and Danish Adult Registry (DVDD), one or two patient representatives and a few additional stakeholders. Hence, the first author of the present paper participated in four of

the eight workshops. Besides the KKG workshops, four patient workshops were organised, which consisted of citizens with diabetes. The patient representatives, who shared their disease experiences, were recruited through the DDA. Moreover, they helped identify relevant content to include in the PRO questionnaire, completed and provided feedback on various questionnaires that might constitute the PRO and inputs on the ‘final’ version of the PRO questionnaire. The two types of workshops were conducted chronologically, allowing the decisions and ideas formulated at the KKG workshops to be considered in the patient workshops, where patients’ reactions, inputs and choices were noted and shared at the next KKG workshop through a patient representative.¹⁵ In these workshops and the evaluation reports, the purpose of the PRO questionnaire concerned dialogue, visitation support and treatment supports.^{14,15} Accordingly, PROs are meant to improve patient–clinician consultations by enabling more-effective, structured, relevant, deep, patient-oriented and partner-based conversations. On the basis of the matching expectations and perspectives of patients, the aims of using PROs are to obtain an improved understanding of patients’ disease situations and administer empowering and individualised treatments.¹⁵ In the pilot phase, the questionnaire was tested in four general practitioner (GP) clinics, four municipalities and two hospitals.¹⁴ In this paper, the findings were based on the use of the PRO questionnaire at one of the municipal sites. Finally, the PRO questionnaire consisted of questions from nine different sources, of which the five-item World Health Organization Well-Being Index is probably among the more common ones. A substantial number of questions were integrated from the VBS PRO-DIA project, a regional project on Value-Based Healthcare (VBHC) and diabetes. The project aimed to create PRO tools with the potential to improve decision-making and patient–clinician dialogues in clinical practice and to create measures applicable as part of VBHC delivery. As the VBS PRO-DIA project happened simultaneously with the development and pilot testing of the national PRO diabetes questionnaire, the VBS PRO-DIA group collaborated with the PRO secretariat on the development of a national PRO diabetes questionnaire.^{15,16} In more detail, the questionnaire is divided into 15 different themes/sections.

As Table 1 illustrates, the participating citizens had to answer a variety of questions and 43 questions as a minimum. Further details on the specific content of the PRO questionnaire are accessible in the public reports published by the Danish Health Data Authority.¹⁷

Location of inquiry

Descriptions of the CfD are based on on-site observations, inputs from employees and information from the web page of the CfD. The study was conducted at the CfD, a public rehabilitation centre in the city of Copenhagen. The target

Table 1. Content of the diabetes questionnaire.¹⁷

Themes	Number of questions
Introduction	
1. How are you? (introduction)	0
2. Information about you and your treatment	5
Questions concerning your well-being in general	
3. Health status in general	1
4. Well-being	5 (2) ^a
5. Social support	3
Questions concerning your life with diabetes	
6. Diabetes in your everyday life	3 (3)
7. Diabetes concerns	2
8. Handling of your diabetes	7 (7)
9. Need for support in handling diabetes	2
10. Symptoms	8 (23)
11. Comfort in treatment	1
12. Treatment experience with medicine	(4)
13. Blood sugar regulation	4 (2)
14. Topics for the conversation	2 (2)
15. Thank you for your participation	0

^aConditional questions are included in the brackets.

groups of the CfD are adult citizens with type-2 diabetes and/or heart diseases. The typical user is a newly diagnosed citizen referred to the CfD by a GP or via the hospital. The objective of the CfD is to support and counsel citizens on the management of their diseases by informing and educating them and by holding consultation with them. Therefore, the staff at the CfD are educated nurses, dietitians and physiotherapists with diabetes-specific expertise.¹⁸

Consultations and the use of PROs at the CfD

The CfD offers person-centred rehabilitation programs and courses (e.g. patient education, physical exercises, nutrition

interventions and smoking cessation), tailored to the individual, often in the company of peers, organised either physically or online. The programs are implemented concurrently with regular consultations to continuously assist citizens and follow the progressions of their diseases. The focal aim of the intervention is to elicit and improve self-management behaviour among citizens. In this study, we scrutinised the use of PRO data during the initial ‘clarifying consultation’ (AFK). An AFK lasts around an hour and covers the following:

- (a) Issues and needs important to the citizen
- (b) Citizens’ daily lives and disease management
- (c) Disease-specific information and education
- (d) Enrolment in relevant programs/courses at the CfD
- (e) Disease-related goal setting to improve the citizen’s self-management behaviour.

Before the AFK, the HCP contacts the citizen by phone, and the type of meeting, physical or virtual, and whether the citizen should complete a PRO questionnaire is determined. According to employees at the CfD, citizens are excluded from completing a PRO often because of language barriers, low eHealth literacy, cognitive issues and/or mental conditions. Citizens who agree to complete the questionnaire receive an explanation that the PRO questionnaire concerns their life with diabetes and is used as preparation for the upcoming conversation at the CfD, a procedure underscoring the importance of the citizen’s responses. Citizens are asked to complete a PRO questionnaire before the AFK and at the end of a course/program, allowing the CfD to assess the impact of their interventions by tracking changes in citizens’ PRO scores. When applied during the AFKs, the PROs are used to (a) elicit disease-specific issues relevant to the individual, (b) inform and prepare the participants for the meeting and (c) qualify and improve consultations. After the citizens complete the questionnaire, the PRO scores are interpreted and triaged by algorithms into green, yellow and red categories, indicating citizens’ health statuses in diabetes-relevant areas. In the subsequent consultation, a link between the PRO questionnaire and the PRO data is sought while providing citizens with an explanation that the categorisation of the PRO scores resembles the structure of the questionnaire. Thereafter, the PRO data are scrutinised jointly on a shared screen. At the beginning of the conversation, the topics prioritised by the citizen are taken into consideration to grasp the type of issues that matters the most to the individual. A prioritisation option, complementing the PRO scores, allows citizens to actively rank the importance of conversation topics. During the consultation, the HCP and citizen discuss the PRO scores either by going over them chronologically, focusing on the most alarming issues first, or by diving into the topics highlighted by the citizen. Whichever approach is chosen, the 1-h

conversation should allow the participants to cover all disease-relevant issues.¹⁸

Methods

In general, the reporting of the results in the present study adheres to the checklist: “CONsolidated criteria for REporting Qualitative research” (COREQ).¹⁹ Hence, the COREQ checklist linked to the present study is attached as extra material (see Supplemental Appendix 1).

Source of data

Our data were recorded audio and video of the citizen-HCP consultations. A Dictaphone and the screen capturing tool Free Cam were used for the recordings. All the data were stored exclusively in a secure drive located at Aalborg University. All the participants provided consent by signing a statement-of-consent form.

Informants

The PRO questionnaire is newly developed and only in Danish so far, which means that citizens who could not understand and complete a Danish questionnaire were excluded from the study and accounted for around 40% of the visitors at the CfD. Among the remaining 60% of the participants, participants were handpicked by the HCPs on the basis of their professional judgement. Thus, the HCPs decided who would be offered a PRO questionnaire and participate in the present study. The inclusion process made it reasonable to assume that the participants in this study were among the more resourceful citizens who visited the CfD. The CfD assisted with the recruitment by sorting and contacting individuals deemed eligible by the employees. In this process, the CfD ensured that there was dispersion in sex and age, aligned with the pre-determined inclusion criteria. Hence, on the basis of Bent Flyvbjerg’s (2006) case methodological perspective,²⁰ the selection process was information-oriented; that is, the invited citizens were selected because they were assumed to actively engage in the interviews and help construct relevant intersubjective knowledge. The study is considered a ‘critical case’, which essentially means that the results are expected to be applicable to similar and less critical cases in the area being investigated.²⁰ Thus, we assumed that the potential problems faced by the more resourceful citizens, who participated in the present study, also apply to less resourceful citizens newly diagnosed with type-2 diabetes. Even though problems might vary in character and gravity, the inclusion of informants and character of the study means that the results are relevant in similar settings concerning citizens with newly diagnosed type-2 diabetes. The participants’ characteristics pertaining to age and sex are presented in Table 2.

Table 2. Participants’ characteristics.

	Participants (N= 10)			
	N	%	Mean	SD
Gender				
Male:	6	60		
Female:	4	40		
Age (years)				
30–39:	1	10		
40–49:	3	30	54,4	11,6
50–59:	4	40		
70–79:	2	20		

In addition, the citizens were included in the study because of several commonalities. Thus, the citizens were all newly diagnosed with type-2 diabetes, first-time users of PRO and first-time participants in an AFK at the CfD. Hence, the citizens had no initial impression of PROs or the CfD and lacked diabetes-specific knowledge and experience. “Newly diagnosed” is a vague concept, but in this context, it refers to the fact that all of the participants were diagnosed within the last 2 months before the visit at the CfD and had not formerly received any treatment for diabetes.

After the first ten interviews, the CfD offered to recruit additional citizens to participate in the study, which however was deemed unnecessary as clear patterns in the empirical data indicated that a saturation point was reached.

Interviews and observations

The applied methods were participant observation and semi-structured interviews. The qualitative approach was chosen as the aim of the study was to obtain a deeper understanding of the citizens’ experiences with PRO. Participant observations were used to understand the consultation context and citizens’ backgrounds and disease situations, whereas the interviews were applied to capture the citizens’ subjective experiences and perspectives. Ten consultations were observed followed right after by 10 interviews with the citizens. Two interviews were held physically at the CfD while eight were held virtually, as these consultations took place online. Therefore, an uncomplicated procedure, as the citizen and the researcher just had to stay online after the consultation to continue the talk in the form of a semi-structured interview. The HCPs were only present

during the consultations and not as part of the interviews. All the interviews and observations were conducted by the first author as part of his PhD study on PRO and patient participation. With a background in political and social science and a PhD study rooted in the field of Techno-Anthropology, the first author had experience with the application of qualitative and ethnographic methods prior to the present study. The interviews and observations were conducted in accordance with the guidelines established by Brinkmann and Tanggaard,²¹ Kvale and Brinkmann,²² Malterud²³ and Spradley.²⁴ During the physical observations at the CfD, the researcher positioned himself in a chair in the corner of the meeting room to avoid influencing the consultation as much as possible. At the beginning of the virtual consultations, the researcher turned on the camera to shortly introduce himself and remind the citizen, who also had been informed on the matter during the recruitment process that the researcher would observe the consultation. Afterwards, the researcher turned off his camera and passively listened and observed the conversation. In both scenarios, the researcher would not say anything during the consultation unless addressed by the participants. If that happened, he would respond with short and polite answers. An approach aligned with Spradley's concept of 'passive participation', where observers remain passive and only react in cases where participants approach them directly.²⁴ Field notes were taken during and after the interviews but mainly during the consultations between the HCPs and the citizens. Before the interviews, an interview guide was constructed. The guide was divided into two sections, one focusing on citizens' impression of the use of PRO data during consultation and one capturing citizens' experience of the completion of the PRO questionnaire. As the interviews were conducted directly after the consultation, the first part of the interview initially concerned the use of PRO data during the consultation. Subsequently, the citizens' experiences with the questionnaire were discussed. As the informants were non-experts in the subject, a thorough introduction was provided before each interview to ensure that the informants knew who the interviewer was, understood the purpose of the interview and study, why they were being interviewed and their role in the interview process. The questions comprising the interview guide are listed in Table 3.

Timewise, the interviews lasted 22–33 min. The semi-structured interview design was preferred owing to its flexibility²¹ and because the aim of the study was to capture the patients' perspectives on the PRO. During the interviews, focus on PRO as the primary subject was maintained, which meant that the researcher had to lead the conversations while giving the informants the necessary space to contribute to with individual inputs. A balance had to be maintained, which was another reason for choosing the semi-structured approach. At the beginning of the conversation, most participants acted quite cautiously, probably because of the nature

of the subject. None of them had any prior knowledge of PROs. However, as the citizens understood that the focus was on their subjective perspectives and experiences, they became more confident, relaxed and engaged. Some of the citizens even emphasised how they appreciated being part of the study. Being restricted by regulations to control the spread of COVID-19, this provided them with a chance to talk to different people again and do something different from their trivial everyday life activities, which they appreciated. As Informant G stated while laughing, 'Completing this questionnaire is the funniest thing I have done in the last 14 days'. Typically, the questionnaire was completed 1–2 days before the consultation.

Analysis

A thematic analysis was performed by the first author and then complemented by interpretations and inputs from the co-authors. Analysis was based on guidelines by Braun and Clarke.²⁵ The analysis consisted of different steps. First, every interview was verbatim transcribed following guidelines by Kvale and Brinkmann²² and Malterud.²³ Interviews were held in Danish and translated into English making it difficult to produce exact verbatim 1:1 versions, however, in the translation process preserving the meaning of the content was prioritised. The transcriptions of the original interviews are full verbatim and can on reasonable request be made accessible. Transcription symbols are added as extra material (see Supplemental Appendix 2). Second, each interview was analysed by sorting the identified themes into different colour categories. The majority of the themes were constructed before the analysis, based on the items in the interview guide, which ensured that topics covering the research questions were addressed during the interviews. According to Braun and Clarke's guidelines, a deductive approach. However, as the interviews were semi-structured new categories emerged as the empirical material was analysed, a process that resembles Braun and Clarke's description of an inductive approach where analytical categories are based on the studies empirical data.²⁵ Therefore, in practice, the analysis was a mix between the deductive and inductive approach. The third step was to assemble thematically related quotes from the various interviews, which resulted in documents focusing on three areas, (a) the citizens' experience with the PRO questionnaire, (b) the citizens' experience with the use of PRO data during consultation and (c) improvements and routine use of the PRO questionnaire and data. Table 4 provides an overview of the themes and subthemes.

Results

In this section, findings based on the interviews with the citizens are unfolded. The section is divided into three areas:

Table 3. The interview guide (translated into English).

<p>General questions</p> <ul style="list-style-type: none"> - Have you been informed about the purpose of the questionnaire? - Have you considered what might be the purpose of applying the questionnaire? - Do you think it might benefit you somehow to complete the questionnaire? - Do you think it might benefit others that you complete the questionnaire? - Did the consultation meet your expectations? How come? <p>The consultation The use of PRO-data:</p> <ul style="list-style-type: none"> - What did you discuss during the consultation? - Were your answers to the questionnaire presented to you during the consultation? How was this done? - Did it affect the conversation with the healthcare professional that your answers from the questionnaire was used? In what way? - Did you discuss any subjects that normally are omitted? Which? - In comparison to former consultations, did the questionnaire make this consultation different somehow? What was different? 		<p>Completion of the questionnaire</p> <ul style="list-style-type: none"> - Was your diabetes situation the same when answering the questionnaire and when participating in the consultation? <p>The citizen's general experience of the questionnaire:</p> <ul style="list-style-type: none"> - Was the questionnaire meaningful to you? Did it make sense to complete such a questionnaire? Did it make sense as you completed the questionnaire? - How did you experience the completion of the questionnaire? Was it burdensome? - How was the length of the questionnaire? - How do you feel about completing similar questionnaires every time you are going to a consultation at the Centre for Diabetes? <p>eHealth literacy/health literacy:</p> <ul style="list-style-type: none"> - Did you feel capable of answering the questions in the questionnaire? How were the language and wording? - Did you understand the questions? Was any of them ambiguous? Can you give an example?
<p>Presentation of the PRO-data:</p> <ul style="list-style-type: none"> - Was the data from the questionnaire shown to you during the conversation? How was this done? Was it comprehensible? - If No: Do you think that data should be presented on the computer and be used during the consultation? - If Yes: What are your thoughts on this, that data is presented on the computer and used during the consultation? Did it affect your conversation? How? Participation in the conversation: <ul style="list-style-type: none"> - Did you feel that the healthcare professional gave you opportunities to participate in the conversation? - Who controlled the conversation? Would you have liked to be more in control or was it appropriate? - Was it a conversation between equal partners or how would you describe your positions during the conversations? - Did the healthcare professional use the data from the questionnaires when making treatment decisions? How exactly? - Did the information from the questionnaire increase your influence when making treatment decisions? 		<p>New knowledge:</p> <ul style="list-style-type: none"> - Did the questionnaire provide an overview of the areas concerning your diabetes that are most important to you? - Did the completion of the questionnaire provide you with any new knowledge or confirmed some of the knowledge you already hold? What type of knowledge? - Were any subjects that you believe are important for others when trying to understand how it is going with your diabetes missing? <p>Are you able to use this knowledge?:</p> <ul style="list-style-type: none"> - Has the questionnaire affected how you manage your diabetes? - Has the questionnaire enhanced your ability to follow healthcare professionals' information and guidelines? - Can you make use of the questionnaire as part of your everyday life? Do you for example feel more capable when handling your diabetes? - What if data was accessible and you were able to follow the progression of your disease, would you make use of that?
<p>Recognition during the consultation:</p> <ul style="list-style-type: none"> - Did you feel heard? Did the healthcare professional listen to you? What gave you this impression? Did the questionnaire have any influence on this? - Did you feel seen? Was the healthcare professional genuinely interested in your situation? How did you sense this? Did the questionnaire have any influence on this? - Were the main subjects in the conversation also those that mattered the most to you or were the subjects decided by the healthcare professional? 		

(continued)

Table 3. Continued.

<p>- Did you have sufficient time to discuss all the issues that the questionnaire highlighted as being important?</p> <p>New knowledge - based on the conversation:</p> <p>- Did the use of the questionnaire during consultation enhance your current knowledge or provide you with new knowledge that might help you handle your diabetes in the future? What type of knowledge?</p> <p>Summative:</p> <p>- Do you think the information from the questionnaire was used appropriately during the onversation or should something be done differently?</p>	<p>Location and mediation:</p> <ul style="list-style-type: none"> - Where did you answer the questionnaire? - If completed at CFD: How was it to complete the questionnaire here at the Centre for Diabetes? - How do you prefer to complete the questionnaire? Do you prefer a certain location? Why is that? - Do you prefer electronic or paper-based questionnaires? Why is that? - Do you have access to the internet and IT equipment? Did it work satisfactorily during the consultation?

Table 4. Overview of the analytical themes.

Themes	Subthemes
Purpose	Informed
	Perception
The consultation	Time
	Decision-making
	Participation
	Control
Data	Use in practice
	Display
	Useful
	Meaningful
The questionnaire	Discrepancies
	Adjustments
	Time of completion
	Location of completion
	Meaningful
	Relevance
	Length
	Comprehensible
Recognition	Heard?
	Seen?
	Partner?
Learning	Empowerment
	Disempowerment
	Information
Self-management	Monitoring
	Progression
	Sundhed.dk
	Incentives

1. Citizens' experience with the PRO questionnaire.
2. Citizens' experience with the use of PRO data during consultation.
3. Improvements and routine use of the PRO questionnaire and data.

Citizens' experience with the PRO questionnaire

Overall, the citizens expressed that the use of the PRO questionnaire was meaningful, relevant and useful; however, some of the content did not resemble their disease situation and adjustments are therefore required if the questionnaire is to match the needs of newly diagnosed citizens with type-2 diabetes.

Meaningfulness. The value of the PRO questionnaire was not always clear to the citizens until after the use of the PRO data during consultation. When asked 'was the completion of the questionnaire meaningful to you?', typical replies were:

'Yes, I actually think so.' (Informant A)

'Yes, it was.' (Informant D)

'Definitely, yes.' (Informant H)

Most of the citizens found the questionnaire meaningful; but some, only to a minor degree as expressed in the following responses:

'Well, I didn't do it for my sake; it was for you guys...that's how I feel when I complete such things.' (Informant B)
 –'Yes, and the things you were asked did that make sense in your situation?' (Researcher) –'Some of them did, others did not.' (Informant B)

'Honestly, no... but here on the other side, I understand its value.' (Informant F) –'Okay, so now it makes more sense after it was used?' (Researcher) –'Yes.' (Informant F)

Purpose. Regarding the purpose of the PRO questionnaire, the participants believed it functioned as a tangible starting point for conversations and an instrument that informed HCPs on citizens' disease situations, ensuring that conversations revolved around issues important to the citizens.

'I will start by asking whether you have been informed on the purpose of the questionnaire?' (Researcher) –'Ehm, yes, I think it was so she was prepared for the conversation we were to have.' (Informant C) –'Okay, so it was for the employee's sake?' (Researcher) –'No, for the sake of the conversation, to locate and talk about the right things.' (Informant C)

'Should I understand it so that you think it is a great tool for you and the employee, that the two of you benefit from it somehow?' (Researcher) –'Yes, and no matter how easy it is to get started with such a thing, having a tangible point of departure is helpful.' (Informant D)

'Have you received any information on the purpose of the questionnaires?' (Researcher) –'Yes... they were to form the basis of the conversation.' (Informant F)

'I reckon that it is something I need to complete because it is a tool that Smith can use, right? That's how I see it... So, of course, you need to complete it, so that the one [the employee] who is sitting with you has a starting point [...]. To me it is logical because otherwise, she wouldn't have any tool. She knows nothing about me other than what she gets from my doctor; to me, it is logical that you have to complete such a thing.' (Informant J)

Relevance. When asked whether the questionnaire mirrored their disease situations and/or expressed a holistic perspective of their conditions, most informants declared that this was the case, as in the following responses:

'Okay, so a proper picture of your disease situation was portrayed, or do you think something was missing if you were to describe your diabetes situation?' (Researcher) –'No, I think, well, no. I think we got all aspects of my disease situation covered.' (Informant I)

'And did it resemble your diabetes situation?' (Researcher) –'Yes, I think so, completely. Yes, it did.' (Informant J)

'It was me [the questionnaire]—I was able to say something. I was able to give my input.' (Informant G)

Hence, the informants believed that there was a link between their respective disease situations and the content of the questionnaire and that their subjective inputs and 'voice' were mediated by the PRO questionnaire.

Length. The informants were also asked about the length of the questionnaire, which produced diverging opinions as follows:

'I just think there were too many questions [...]. Well, now this was important to me because if I receive these types of questionnaires, when I reach page 3, I get bored and put it down. Then, I will not want to answer anymore [questions]. This was to my advantage, so I had to do it.' (Informant C)

'That was no problem.... It was stated that it would take 10 minutes or something like that, and I think it actually took around 10 minutes.' (Informant D)

'It is just too long. There are too many questions to answer.'
(Informant E)

'It was long.... But retrospectively, it probably had the length needed to elucidate all questions concerning diabetes.'
(Informant F)

'I remember that it wasn't long. You didn't sit and [clutching her head].... I don't have time for this... I think it was fine.'
(Informant G)

Hence, some found the length of the questionnaire appropriate, especially when considering the purpose of the questionnaire, whereas others believed it was too long. Moreover, informants I and J explained that the questionnaire continuously gave them a false impression of almost being at the end, but still, they kept getting new questions, which frustrated them. Even though Informant C found the questionnaire too long, he felt obliged to complete it, as it concerned his health. Informant F also found it a bit too long but recognised that it was the length required to generate a comprehensive picture of her diabetes situation. Informant A was at first annoyed of having to complete the questionnaire but was then positively surprised about how easy and fast it was to complete. Informants B, D, G and H believed that the length was fitting, primarily because the questionnaire was concise and easy to answer.

Comprehensible. On the question, 'Were you able to understand and answer the questionnaire?' the citizens replied as follows:

'Yes... this thing was very easy, you were [at the website] and then you answered.'
(Informant A)

'You faced some questions that made you think, 'What should I answer here?' which put you in a situation where you think, 'Am I providing the correct answers?'
(Informant E)

'Yes, well, I had no problems. I didn't have any trouble with that.'
(Informant F)

'Yes, I think so.... There was just a few where I was insecure.'
(Informant I)

'But I think the questionnaire was easy to complete. I had no issues with that at all. It was easily understandable, and I had no problems completing it.'
(Informant J)

On the one hand, the citizens were able to understand the questions and complete the questionnaire. On the other hand, they experienced lacking sufficient knowledge to answer the questions appropriately. Essentially, the citizens understood the wording of the questions, but the questions

generated insecurities by confronting the citizens with issues that they, as newly diagnosed with type-2 diabetes, were unable to properly respond to. Informants A and E believed that they had answered wrongly on some of the questions owing to uncertainties, which bothered Informant E, as he feared that the 'wrong answers' might have led him down the wrong path in the questionnaire. As a result, he had to answer irrelevant questions.

Learning, empowerment and disempowerment. The questionnaire's educational potential was also examined by asking the citizens whether the questionnaire provided them with any new knowledge. When asked directly, most informants indicated that the questionnaire provided them with no new knowledge, as expressed in the following:

'Nah, I don't really think so.'
(Informant B)

'It didn't make me think—it didn't.'
(Informant F)

'No, I don't think so.'
(Informant I)

However, during other parts of the conversation, the participants explained how the questionnaire on specific issues actually did enlighten them. Hence, even though they, to some degree, were unconscious about the effects of the questionnaires, it seemed to have an educative and/or empowering impact on several of the informants, as described in the following:

'Did you have intercourse or something?' 'God, does diabetes also give you trouble with that?'
(Informant A)

'There was one question where I answered, 'Damn, I didn't know that.... There was an item where I thought, 'Oh well, at least that made me a bit smarter [...]. I didn't know that thing with the feet and eyes either, which my doctor explained to me, but I didn't know that before either [...]. I think it was regarding heart symptoms....'
(Informant C)

'The questionnaire didn't provide me with any knowledge. However, it enabled me to conclude that there are things I do not know that I ought to know.... But the questionnaire didn't provide me with any new knowledge. As I completed it, it provided me with no new knowledge. It just showed me that with those questions, then I must assume that I am expected to be able to answer the questions, and I just need say, "Well, I am not able to do that with the knowledge I currently have."' (Informant D)

'But it might be because I didn't know that several of the questions had anything to do with diabetes. I learned, that your sleep and other things are linked to diabetes. I did not know that.'
(Informant F)

‘This questionnaire helps me reflect upon myself and my life. Well, not all of it, but on what I need, the type of support I need and the help and assistance I need....’ (Informant G)

‘That must be about sexuality. I hadn’t considered that, as I was a bit “Aha”-like because I didn’t know that it might affect it because I definitely have a desire for sex with my husband, but for many reasons, I have been under mental pressure, and I have been really mad at him, so I never linked the two in my mind.’ (Informant H)

Hence, the informants emphasised that the questionnaire increased their awareness of issues on, for example, intercourse, sexuality, feet/podiatry, eyes, heart symptoms and sleeping. Moreover, Informant G reported that the questionnaire provided her with a broader perspective on diabetes, as she no longer perceived diabetes as simply a physical condition but as something that affects several aspects of a person’s life. Hence, the questionnaire provided the informants with a broader perspective on diabetes and initiated reflections on their disease situations and needs. By contrast, Informant D described how the questionnaires affected him by exposing his lack of knowledge. He explained that he did not have the required knowledge to appropriately answer the questionnaire, which frustrated him because he assumed that a questionnaire on his personal health situation would be relevant to him. Hence, he concluded with a sense of guilt that he lacked the needed knowledge to complete the questionnaire correctly. Therefore, Informant D is an exemplary case of how discrepancies between an individual’s disease situation and the content of the questionnaire potentially have a disempowering effect. This is because the questionnaire makes citizens aware of their lack of knowledge and inferior ability to manage their health.

Similarly, the completion of the questionnaire had a dual effect on the participants, which might be referred to as the ‘concern/motivation’ dilemma, as demonstrated in the following:

‘I felt a bit more concerned after I had [completed the questionnaire] because there was a question on how I inject myself [...] I was like, “Bloody hell,” but at the same time I was thinking, “At least I am not that sick.”’ (Informant B)

‘Yes, I wrote that it seemed concerning, right, because “Are you able to control your blood sugar?” If you don’t know how to control your blood sugar, right, and you are asked whether you are able [to control your blood sugar], then you might sit and think, “Yes, maybe I ought to know that, but how do I do that? What equipment do I need?”’ (Informant D)

‘It didn’t give me any learnings. It gave me concerns because the risk of blood clot made me worry.... One of them [the questions] was on heart rhythm or heart pains or breathlessness—that was one of the questions. The other thing was where you had the opportunity to mark the topics you would like to discuss [during consultation]. Blood stuck was an option, which is a disease you obviously do not want, which is why they made me think [the questions] [...], well it makes me think that, “Okay, now I really need to pull myself together”, and then acquaint myself with this [diabetes] and then do something about it.’ (Informant H)

‘There was one about blood sugar, and as Smith said, “Don’t worry,” but I think when you get those numbers, I need to measure my blood pressure for 3 months. Then, I’m completely, “God, it is 160 something. Now I get nervous.” Why don’t the stupid pills work? All of a sudden, you see things differently.... It is when you complete the questionnaire, and then you think, “God, I am worried”, because my blood pressure has been too high for the last 8 days, when I have measured it, you know what I mean?’ (Informant J)

Informant B started worrying after having answered the questions on insulin injections, whereas the questions on blood clots, heart issues and breathlessness had a similar effect on Informant H. Informant J explained that her blood pressure had been too high for some time, which is one thing. The problem was that the questionnaire disclosed the potential consequences of too high blood pressure over a period, which made her anxious. Even though the questionnaire made informants B, D and H worry, the content of the questionnaire also made them realise that other cases are worse. Consequently, the prospect of such future disease scenarios motivated them to engage more actively in the management of their diabetes.

Location and mediation. Another topic is concerning the location of completion and mediation of the questionnaire. None of the citizens had any sort of technical problems during completion. Nine completed the digital PRO questionnaire on a device at home, while one of the citizens completed it at work. When asked about the location of completion and mediation of the questionnaire, the informants responded as follows:

‘You preferred at home, you know why that is?’ (Researcher) – ‘With my cup of coffee you know, I can fart whenever I like, right? I can be myself’ (Informant A) – ‘So the setting is a bit more relaxing, you can sit and reflect on....’ (Researcher) – ‘Yes, it is much greater. I mean, what if someone passes by and notices what I am writing. Yeah, I don’t want that [...], and then you save

time. There is also the bus back and forth and the time spent on the bus.’ (Informant A)

‘What if you had an option to complete it at the CfD, what would you prefer, that they had a tablet or you had to answer from home?’ (Researcher) –‘Yeah, then I would rather answer at home in advance....’ (Informant D) –‘Okay, is there a reason for that?’ (Researcher) –‘Well, then, it is done with, right, and I can do it whenever I like. If I have to show up somewhere half an hour before the meeting to answer a questionnaire, well, then it is half an hour of my workday that I lose.’ (Informant D)

‘Was it fine to complete at home? How would you feel about completing it at the centre instead, or would you prefer the current solution, how is that?’ (Researcher) –‘Preferably at home, or I think it might not matter. I think you give different answers in the company of others, and then you are honest in a different way, or if there are some questions you do not understand, then there might be someone you can ask [at the site], right? But at home, you only need to be honest towards yourself, but you might risk that you are completing it while you are roasting a beef, right? Then you just click rapidly [to get it over with].’ (Informant G)

‘What if you were able to complete it at the centre instead, what do you think about that in comparison to completing it at home? Do you have a preference?’ (Researcher) –‘I really liked the way it was done that I was able to complete it from home. I liked it that way because you sat on your own and were allowed and had the time to do it. At home, you have the time needed. If I had to go to the centre, then I would constantly think, “Oh, I need to hurry,” so I wouldn’t be relaxed....’ (Informant H)

The current distribution of the questionnaire entailing completion from home was preferred by all; however, some were willing to answer at the site if required, whereas others considered that to be an annoyance. The advantage of completing the questionnaire at home was according to the citizens’ the privacy, the flexibility in when to complete the questionnaire, the wider time frame for completing it, the comfort that home settings offer and the fact that one does not need to spend too many working hours on the matter and can skip the tour back and forth to the CfD. Especially the privacy that this delivery method offered was valued by the citizens. Informant G believed that completion at the site also would have its advantages, as it might improve honesty and allow for professional assistance. Regarding the mediation of the questionnaire, all the citizens appreciated and preferred the current digital mediation. A few would be willing to complete a paper-based version as well because they fancied activities involving paper or

owing to the assumption that the simplicity of completing a paper version was similar to completing a digital one. Others had a strong preference for digital solutions for ergonomic reasons in the case of Informant A, as he experienced less pain in his hands when completing digital questionnaires, and in the case of Informant C, he acknowledged that the paper-based questionnaire he received typically ended up in the bin.

Citizens’ experience with the use of PRO data during consultation

The participants were also interviewed on their experiences with the use of PRO data during the consultation.

Time. When asked whether the time was enough to discuss important matters during the consultation, the citizens’ common replies were as follows:

‘Lots of time, as we haven’t had anything but time.... Yeah, there was plenty of time, and I had plenty of time to formulate and explain myself....’ (Informant A)

‘Yes, I think so, yeah. I actually think so. I think it was perfect.’ (Informant E)

None of the citizens felt that time was an issue because a 1-h-long AFK conversation allowed discussions of all the subject matters elicited by the PRO questionnaire.

Decision-making, participation and control. Informants were also asked who they thought controlled the conversations, whether they were involved in the decision-making process and if the degree of involvement matched their preferred degree of involvement. On the aspect of decision making, the informants believed that they were involved and embraced the parts of the information that were useful in their respective disease situations:

‘Well, I would like to lower my blood sugar and get rid of my medicines, if possible. That’s what I want, so I know I need support and assistance of some sort. So in these types of situations, I think, “Okay, I might be able to use that, and that is not usable at all”, and then make my own way cause it needs to fit into my life....’ (Informant B)

‘Yes, we talked about [diabetes-related issues] all the time. She allowed me the opportunity to say yes or no....’ (Informant C)

‘Yes, I felt I made the decisions....’ (Informant G)

‘I think so [...]. It was not like he pressured me, that I needed to start on that and that and so on. I was free to choose, to take it nice and easy, to choose for myself.’ (Informant H)

‘Concerning the decisions that were made about your future course, did you have any influence on those?’ (Researcher) – ‘Yes, I was asked about all the things, if I wanted to participate, so yes, I think so.’ (Informant I)

The citizens felt no pressure when choosing courses and programs to join or when considering choices concerning lifestyle changes. Thus, they felt that they were allowed to balance potential lifestyle changes with individual circumstances. This also meant that they had the opportunity to accept or decline initiatives, inputs and referrals offered by the HCPs. This is exemplified by Informant B’s comment that he considered the options offered but only adhered to those that matched his lifestyle. Informants C and G felt they were the ones making the decisions, but all the participants’ degree of involvement matched their individual preferences. Consequently, the citizens had varying perceptions of who controlled the conversation as indicated in the following responses:

‘That was me.’ (Informant A) – ‘And that was actually also the way you wanted it to be, is that correctly understood?’ (Researcher) – ‘Yes, to unload all the stuff....’ (Informant A) – ‘Yes, okay, so you were allowed to have the type of conversation that you wanted, is that correctly understood?’ (Researcher) – ‘Yes, I was, yes.’ (Informant A)

‘If I ask you, “Who controlled the conversation?” what would you reply then?’ (Researcher) – ‘Well, Smith did.’ (Informant C) – ‘Yes, and was that fine by you that it was like that?’ (Researcher) – ‘Yes, preferably, it was very fine. I know nothing about diabetes, so I think it was very good that she controlled the conversation.’ (Informant C)

‘I almost think we both did. Well, there was not. I said what I had to say, and I believe she said what she had to say, so I did not feel like one of us was in control, no, nope....’ (Informant E)

‘Well, since Smith has the professional knowledge, then, of course, it is her [who is leading the conversation], but I did not feel like I was restrained. I felt like I was just as much part of the conversation, but of course, she is the one managing the topics....’ (Informant F)

‘Smith did, I think he did really well. I sometimes babble on and on, where he kind of stuck to the topic, right?’ (Informant H) – ‘Okay, and was that in accordance with your preference and was that also how you preferred the conversation, or would you have liked to be more in charge?’ (Researcher) – ‘No, no, no, what he did was correct because there needs to be a sort of system in it [the conversation]. We had a deadline also....’ (Informant H)

‘Well, I would say Smith, and I also think that was the purpose’ (Informant J) – ‘And was that also how you wanted it to be?’ (Researcher) – ‘Yes, fine, it was great [...]. I don’t think she was too controlling at all. It was a really comfortable conversation....’ (Informant J)

Informant A believed he controlled the conversation and was able to elaborate on all the issues important to him. Informants C, F, H, I and J perceived the HCP to be in control of the conversation, which suited them best, as HCPs are professionals and experts and therefore ought to lead the conversation. According to the citizens, the advantage of the expert-led conversations was the structure they provided, ensuring discussions of all relevant topics while being comfortable and aligned with individual preferences. Informants D and E experienced the conversation as a balanced affair, with talks going back and forth, where both the citizen and the HCP expressed what they had in mind.

Recognition. When asked whether they felt heard and seen during the consultation, the citizens’ reactions were as follows:

‘Yes [...], well, our talk was based on my answers. I think that shone through.’ (Informant B)

‘Yes, I think so. Yes, yes, I think so. It was about me; it was not about, well... it was not about Smith.’ (Informant D)

‘Yes, indeed I was, absolutely. I certainly felt that she saw me, yes.’ (Informant E)

‘Yes, very much so.’ (Informant F)

‘Definitely, yes, definitely....’ (Informant H)

‘Yes, definitely, I did.’ (Informant J)

Use and display of data. The interviews also concerned the citizens’ perceptions of the use and presentation of PRO data during consultation. Informants A and B, who participated in physical consultations, and informants H and I, who participated in the digital meetings, found the use of PRO data confusing. Informants A and B, who attended a physical consultation, had difficulties following what was going on during the consultation. Informant A found the positioning of the TV screen displaying the PRO data problematic because it was placed at the side next to him and the HCP. This confused him, as he had to constantly change focus between the screen and the HCP. Considering the importance of the subject matter, he would have preferred a more intimate face-to-face conversation. Informant B believed that HCPs should get to know the citizen a bit before elaborating on the PRO data and that better guidance

of citizens might be achieved through smarter use of the mouse cursor. Informants A and H noticed that the display of data during the consultation was different and less simple than the setup in the questionnaire. Therefore, they suggested, as in the following responses, that instead of showing all categories concurrently, PRO data related to specific questions should be displayed one at a time:

‘Regarding the data shown on the screen while you were talking, did you look over here [pointing to the screen]?’ (Researcher) – ‘Not that much.... No, because she mentioned something, and then we sat like this again, right? [Referring to the face-to-face position]’ (Informant A) – ‘Yeah, okay... You were more like this with her [gesticulating the face-to-face position] and not that occupied with the screen?’ (Researcher) – ‘No, I was not, no [...]. It also looked completely different on the screen compared with on the computer when I sat at home [...]. I thought, “What is that over there?” [...] There was all sort of things. Everything was on the screen [...]. There was only one thing at a time on the screen at home, right?’ (Informant A)

‘When the display on the screen was divided into green and red and yellow categories, then....’ (Researcher) – ‘That seemed a bit confusing’ (Informant A) – ‘It was a bit confusing, or?’ (Researcher) – ‘Yes, I think so because it didn’t look the same as on the screen [referring to the display of the questionnaire during completion] [...]. I would like to have one thing at a time, one box at a time—“Bing!”—to fill the entire screen. I couldn’t help glancing at all the other [answers].’ (Informant A)

‘Was it possible to follow [the PRO data displayed on the computer screen]? I noticed that you looked a bit [making a funny face], as if it were a bit confusing to you or something.’ (Researcher) – ‘Yeaahhh, it was not that clear, I guess [...]. She could have had something like a mouse or something else maybe to point with....’ (Informant B) – ‘Yes, to clarify what she was talking about?’ (Researcher) – ‘Yes, to make it clear what things she was talking about.’ (Informant B)

‘How do you feel about the way your answers were presented to you?’ (Researcher) – ‘Yeah, well, maybe it went a bit too fast. They came right away as she put up that screen.... I would have liked to get to know her a bit first—to talk a bit before I had to make up my mind about all this [referring to PRO data].’ (Informant B)

‘I saw the connection, but I think I liked it better as it were when I sat with it on my own. It was clearer when Smith sat with it, and I got a glimpse at it. When all the topics stand next to one another and down, I become a bit more

distracted, so one question at a time would have been better and ensured a better focus for sure....’ (Informant H)

‘And the way data that were used during the conversation with Smith, did that make sense?’ (Researcher) – ‘Well, it was not that easy to follow, yeah, I don’t know. Maybe it was a bit confusing how she went ahead.’ (Informant I)

Most citizens who participated in the digital meeting appreciated the green, yellow and red categorisation, as it was intuitive and easy to comprehend:

‘It seemed like Smith picked the yellow and red ones. Do you think there should have been more focus on the green ones to point out that you are doing quite well or you think it’s fine?’ (Researcher) – ‘No, well, if I had been very depressed or down or something, then it would probably have been good that she was able to highlight some of the good things that might be useful psychologically. I think it was fine, you know. Let’s talk about the things that matter, and all the other stuff is not important.’ (Informant C)

‘The way data were presented here while you were talking, was that meaningful?’ (Researcher) – ‘Yes, I actually think it was.... Yes, I think it was quite smart actually, that you... Now, I haven’t tried Teams that much yet, but that you are able to share the screen, so it is not just her sitting there telling and reading, but you actually are able to visually follow. That actually seems like a really, really, good idea—that you see the scores, that you score points, the yellow and green. If there is something, then you can, “Oh, ups.” Here, there is something I need to be aware of.’ (Informant E)

‘How about the way it was presented [PRO data] [...], was it confusing or did it work well?’ (Researcher) – ‘I think it functioned really well. It wasn’t confusing, and it was great that it was divided into colours so you knew what mattered. That also made it easier for Smith to talk with me and for me to understand what is important.’ (Informant F)

‘So one might say that it actually helped you during the conversation?’ (Researcher) – ‘Yes, certainly, and it was great that she shared the screen, so I could also see it [the PRO data], right? I think that was really good, and then I really like that it is coloured, that it was green and yellow and grey or whatever colour it was, right? So it provided a super easy overview [...]. I think it was really good. I think it was nice to go over the main points and not to dive deeply into each of them, as several of mine were green, and I had a specific aim with the conversation today....’ (Informant G)

‘The way Smith used it [PRO data] during the conversation—that the categories were shown on the screen—did that make sense to you?’ (Researcher) –‘That was really nice, really nice, especially with the red, yellow and green. That is something everyone understands.... Well, I think it was very good [...]. I remembered my answers; I was actually able to remember the red, yellow and green as they were shown, and I was very happy about the green ones.’ (Informant J)

The shared screen option was emphasised as a valuable feature, as it allowed the citizens to watch their PRO scores and follow issues elaborated upon by the HCPs. As a result, the citizens acquired an improved understanding of the severity of specific disease issues and identified areas that needed attention in the future. Hence, the informants acknowledged that the red and yellow categories made them aware of alarming issues, whereas the green answers might have had a positive effect, as exemplified by Informant J’s response.

The influence of data. Another topic was concerning how the application of PRO data affected the citizen-HCP consultation. Several of the citizens explained that it had no effect and that the use of PRO data was redundant, as the citizens would have brought up the issues no matter what, as expressed in the following responses:

‘How would you describe the role of the questionnaire?’ (Researcher) –‘Ehm, I don’t really know. Normally, I don’t give a damn about such things [...]. Yeah, it didn’t do that much [...]. Nope, I don’t think so.’ (Informant A)

‘When your answers were displayed today, were there moments during the conversation where you thought, “Oh, that is interesting,” or something like that, or don’t you think it provided you with any sort of new knowledge?’ (JE) –‘No, I actually don’t think it did....’ (Informant B)

‘But I think that our agreements on the decision, treatment and program that we agreed that I should participate in would have been reached even without the questionnaire....’ (Informant F)

‘Okay, and if I ask whether the data did something in this context....’ (Researcher) –‘Ehm, I’m not sure how that would be the case [...]. Yes, I know what you mean, yes, but I have to say, I don’t think the data had much of an impact. That is my impression....’ (Informant I)

However, other parts of the interviews revealed that the PRO data affected the consultation to some extent and in different ways (e.g. by eliciting issues relevant to the informants), as demonstrated in the following:

‘Yeah, there was the one with intercourse.... Now I got this one with me at home [information folder on sexual dysfunctionality]. It was actually really good [...]. Yes, and about mental issues, I was able to tell here—that I haven’t been well mentally....’ (Informant A)

‘Then there is a question concerning knowledge. In the conversation with Smith, did you at any point acquire new knowledge in connection to your diabetes?’ (Researcher) –‘Yes [...], that I am able to get subsidies and that I should find another podiatrist, one who is able to treat the wounds I have on my ankles [...]. Yes, and an eye doctor. There were several things I did not know.’ (Informant I)

‘I didn’t have many expectations. The only expectation I had was to make a goal and plan. That’s why I feel relieved now, ‘cause I’m not alone in this.... In that way, I think he did really well to inform me, “You know what this is?” “No, I don’t.” “Fine, then I can tell you so and so and if you would like to know more here is a link.”’ (Informant H)

The PRO data facilitated the disclosure of issues of mental and sexual characteristics in Informant A’s case. Informant H no longer felt alone in the management of her disease, primarily crediting the employee, facilitated by the information offered by the PRO data. On the contrary, Informant I gained knowledge on how to take care of physical issues related to his feet and eyes. How PRO data structured and made the conversation more effective and relevant was the feature most frequently highlighted by the citizens:

‘What do you think the data did? (Researcher) –‘Well, the data I answered with? Well, they provided us with a starting point, right? You can see that you have answered this, so Smith didn’t have to say, “I think you feel like this,” and then I had to reply, “No, I do not feel like that.” Now, we factually were able to look back—“What did you answer?”—and then I could comment on them, “Well, the reason I have answered this is due to lack of knowledge [...].” It provided us with common knowledge of why I had answered as I did, and I was made aware of what was actually asked in cases of insecurity.’ (Informant D)

‘I think it provided us with a framework, a point of departure. Smith might say, “You are right that your mental health is 80 out of 100,” right? And then I might reply, “Yes, but I also feel really well at the moment,” and I think he was able to hear that, and then we do not need to discuss that further, and there were other things that were more hidden.’ (Informant D)

‘What do you think about these data, did they do anything?’ (Researcher) –‘Yes, I think so, ‘cause it kind of equipped

her, right? We didn't sit at an empty table and didn't need to reinvent the wheel, nope. I actually think, of course, that after some fine-tuning, it will be a great tool.' (Informant E)

'Well, I just think it was great that I could prepare and help and prepare whoever I was going to have a meeting with as well, so we didn't have to show up completely blank and be like, "Hi, who are you? Tell me about yourself" [...] It is nice to have something tangible that I have answered already and considered what I would like to talk about or how I believe I need support, so I think it is really, really nice, the display [of PRO data] functions as a memo to remind me what I answered....' (Informant G)

'The way it [PRO data] was used during the consultation, did that make sense to you?' (JE) –'Yes, definitely, it made sense because it is all connected, and it is not like you as a private person have the required knowledge, so even though you know that things are interdependent, you cannot connect the dots. That is what Smith does—he connects the dots in a way that is most appropriate for me personally [...]. The questionnaire is personalising it [the conversation], so it is not a generalisation. It is not everyone with diabetes at a time, but it is actually my everyday life, my problems, my disabilities, my weight, and so on....' (Informant H)

'How about these data, what do you think? Did the data do anything for the conversation?' (Researcher) –'Yes, I think it was fine to have something concrete to relate to and go over based on my answers. I think that was great; it also helped me a bit, it enabled me to follow [the conversation]. She didn't just ask all sorts of questions that I had no idea where they came from.' (Informant I)

Hence, the PRO data allowed citizens to identify and disclose problematic issues; provided the conversation with a constructive and tangible starting point based on shared knowledge on the citizen's disease situation; ensured a more effective consultation, as the HCPs and the citizens were prepared; as a memo throughout the conversation, assisted the HCPs and the citizens; and enabled a personalised and relevant conversation on alarming issues and those most important to the citizen.

Improvements and routine use of the PRO questionnaire and data

Discrepancies. When the citizens were asked if anything was missing in the questionnaire, the consensus was that the questionnaire was a valuable tool in the AFK conversation. However, at the same time, the citizens got the impression that the questionnaire was not adjusted to the needs of

citizens with newly diagnosed type-2 diabetes, as reported in the following:

'Well, there was something. Where I wrote or clicked 'not relevant'... that concerned measuring my blood sugar every day, and that's not for me—that's not relevant for me.... That's why I am thinking that if it [the questionnaire] was divided maybe into three categories, there is no reason for me to get a question regarding my blood sugar, right? [...] Some need to inject themselves, right? And need to monitor their blood sugar constantly. They are pretty sick, and I am not there yet [at that stage].' (Informant B)

'Yes, I clicked 'no' at the beginning—that I didn't, that it was type 2 diabetes, that it had nothing to do with insulin, and yet I got a question on that, which annoyed me a bit.' (Informant C)

'Again, when I am being asked, "How did it go last time you were at the podiatrist?" well, 'I can't tell you because I haven't been there... but I can see that I was supposed to.' (Informant D)

'It's very long, and of course, some of the things you were asking are relevant, but there are also other things if you sent it to a newly diagnosed, one might sit and think, "Hmm, what does this mean?" when you have spoken really only with your doctor about it [...]. Principally, there ought to be two questionnaires, one for newly diagnosed citizens and one for someone who had it [diabetes] for a long time because if we... There were lots of questions that I had no idea what they meant [...]. It will be a fine tool for the users; it just needs to be fine-tuned.' (Informant E)

'Yes, I think it was fine. I just thought that some of the things were irrelevant in my situation, but then you just provide a short answer and move on.' 'What was it that didn't fit with your situation?' (Researcher) –'Well, I don't use insulin... I just take a tablet. There were some detailed questions [on insulin], those I just moved over fast and provided short answers.' (Informant I)

'I noticed that you spoke with Smith about a treatment because you were uncertain what was meant....' (Researcher) –'Yes, yes, I can't remember the formulation. At that point, I was a bit insecure of what was meant [...]. I was not sure whether treatment referred to everything and whether it also concerned how I eat and my physical activity and all those things 'cause one might say that is also part of the treatment or if treatment just referred to medication.' (Informant J)

These mismatches between the informants' disease situations and the content of the questionnaire also meant that

some of them demanded broader response categories and the option to add information on other aspects linked to their diabetes situation. The citizens believed that especially additional information on other chronic conditions that bothered them was something relevant to pass on to the HCPs, as indicated in the following responses:

‘Was there anything else that should have been part of the questionnaire...?’ (Researcher) – ‘Yes, my disabilities.’ (Informant A) – ‘But your disabilities, were they not part of the questionnaire?’ (Researcher) – ‘No, it didn’t say anything about my osteoarthritis, for example, “Do you have any pain in...?”’ (Informant A)

‘Yes, it struck me that they are not asking more about or that they do not consider whether you have a job. How do you combine the condition with being part of the labour market? It seems like they think that citizens with diabetes are not doing anything during daytime [referring to having a job] [...]. If you are sick, then you can’t work. That’s the impression I get.’ (Informant B)

‘I missed an option allowing me to answer, “I have no idea,” right? Like that [question], “Are you able to control your blood sugar?” there it would have been nice to be able to answer, “I have no idea that I should be able to do that” (Informant D) – ‘So it’s not relevant, is that correctly understood?’ (Researcher) – ‘Yes, but that is wrong... it is not “not relevant”. It is very relevant, but I am not able to answer the question.... So that option allowing me to reply, “You know what, I have no idea. You might as well have asked me about a location on the dark side of the moon.”’ (Informant D)

‘To understand you correctly, were you uncertain whether you were able to answer the questions properly?’ (JE) – ‘Yes, where you actually wanted to answer “not relevant”, but it....’ (E) – ‘It was an option?’ (JE) – ‘Nope, it was not, no [...]. I think you should have been able to say, “That is not relevant to me right now,” and tick a box with that option.’ (Informant E)

‘Well, as I said to Smith, whether it is because I am newly diagnosed, I don’t know, but in many of those items on symptoms, where you describe how you are, there was no option allowing you to write, “Well, those I’ve had for the last 20 years.” I mean, you might have disabilities that not are related to diabetes at all... but there was no option to write about those... and then there was a question on sexuality. It was not possible to answer, “not relevant”, so I had to answer “no”, but I mean [finds question inappropriate due to age] [...]. There were several things, I believe so, that may be considered disadvantages of the questionnaire. I got annoyed of those who made the questionnaire

because they should be able to think beyond themselves, as not all of us are [sexually active].’ (Informant F)

‘Well, to come up with an example, I ticked the box indicating that I am sleeping poorly. Then, there should have been an additional box that says, “Did you also sleep poorly before you had diabetes?” “Yes I did.”’ (Informant F)

‘There were some questions I wasn’t able to answer, as I needed a “not relevant” or “I can’t answer that” option.’ (Informant G) – ‘Do you remember the questions it concerned?’ (Researcher) – ‘One of them was the one with medicine, I believe, and blood sugar [...]. Maybe there was something with prehistory ‘cause I don’t really have any history since I just received the message from my GP like a month ago or something. Right, so I don’t really have a history [with diabetes], and I would like to indicate that to provide a different type of answer, so when numbers are presented statistically, then people can see that the response was “not relevant” or “not yet”, something like that’ (Informant G)

‘There was among other things, “Do you wake up too early in the morning?” Then I thought, too early in the morning, what is that? I mean, I am retired. I have nothing I need to get up to. As I told Smith, I am awake 1.5–2 hours every night all year round. That option was not included. There were many others, but personally, I missed that one.’ (Informant J)

Adjustments. Consequently, several of the informants came up with suggestions on how to potentially alter or change the questionnaire to better fit their needs as follows:

‘But that is why I am thinking that maybe, there should be [a system], for example, “Okay, this guy he is here. He should answer question A. This guy, he is there. He should answer question B. This question, this guy, he is there. He should answer question C,” right? So maybe there should have been three categories instead.’ (Informant B) – ‘Yes, so it should be adjusted to the situation of the individual?’ (Researcher) – ‘And be more targeted, for example, “Where are you [disease situation]?” “What type of diabetes do you have?”’ (Informant B)

‘Well, when you make these [PRO questionnaires], then you might add something like, “Would you like to clarify your answers?” Then there is a quick version, where you run over things, and a version if you find it really joyful... “Do you wish to clarify your answers?” or something. Then one might say “yes”, and the person will receive five additional questions—that would be smart.’ (Informant C)

‘Well, there was just one thing... Maybe you should receive a first [version] questionnaire the first time and then next time, a more comprehensive questionnaire because then you might be able to answer questions like, “Is your podiatrist satisfied with your feet?”’ (Informant D) – ‘So the first time should be a bit different compared to the next one?’ (Researcher) – ‘Yes, right, like an entry level, where you might say, “Well, I have lots of problems with my feet or my eyes are jumping around in my head.”’ (Informant D)

As the quotes reveal, informants A and F were concerned of the lack of historical information and narrow scope of the PRO questionnaire. The response options in the questionnaire referred to a narrow and recent period, and answers were automatically linked to the patient’s diabetes. According to the informants, these limitations provided the HCPs with a false understanding of their disease situations because some of these disabilities had been an issue for a longer time, independent of their current diabetes situation. Hence, Informant A requested a free text option that would allow him to provide information on other disabilities, and Informant F would like a ‘click’ option to indicate whether her disabilities were an issue prior to her diabetes diagnosis. Informant B thought that a more tailored questionnaire would be beneficial, a solution resembling the computer adaptive testing approach. Thus, he believes that informants should receive questions based on their individual disease situations instead of a ‘one size fits all’ solution. Informant C preferred a short-form questionnaire. If respondents wished to provide more detailed answers, they should have an option to complete additional questions. An approach is needed that might ensure that both those, like himself, who want to get it over and done with and those who prefer to explain things in more detail are taken into consideration. Informants D and E believed that the first questionnaire, given to those newly diagnosed with diabetes, and the subsequent ones should be different. The point being that citizens’ disease situation changes over time, which means that the type of questions they can answer differ. Hence, newly diagnosed citizens with type-2 diabetes should receive the simplest version of the questionnaire. Informants B, C, D, E, F and G were concerned about having to answer questions not currently relevant to their diabetes situations. If the citizens have to answer such questions, an option to click ‘not relevant’ or ‘not currently relevant’ would be useful. For informants B, D and G, the irrelevant questions concerned the management of their blood sugar. Informants C, I and J answered unnecessary questions on insulin and insulin pumps, which annoyed Informant C, as he had noted that those types of questions were irrelevant to him. Informant D had a different approach to the problem, as he had to assume that the included questions were relevant to him, why else would he receive such questions? Nonetheless, he was not able to answer all the questions appropriately

and therefore wished he had the answer option, ‘I have no idea.’ Similarly, Informant G would welcome answer options such as ‘I can’t answer that’ or ‘not yet’. An important issue according to Informant G is that the data she passed on should be valid by representing her current disease situation correctly. Informant F would have liked a ‘not relevant’ option on the questions concerning her sexuality, which she implied was necessary because of her age. The citizens also suggested additional content to the questionnaire. Informant B found it peculiar that no questions concerning citizens’ current employment situation were included, as he found the link between citizens’ well-being and employment status to be focal. The exclusion of employment status in the questionnaire gave Informant B the impression that the developers perceived citizens with diabetes as unemployed people. Informant J was not sure what was meant by the term ‘treatment’, whether it narrowly referred to medicine or if it included everything that had to be performed to manage her diabetes.

Routine use of PRO questionnaires. Lastly, the routine use of the PRO questionnaire in clinical practice and the citizens’ digital access to their PRO data were discussed. When asked about their opinion on the routine use of PRO, which means that they would have to complete questionnaires continuously, the informants replied as follows:

‘I think that would be a good thing, then they would know something about you beforehand.’ (Informant A)

‘I think that is okay as long as it is being used for something, then I don’t mind contributing.’ (Informant B)

“No problem. It might even make sense, right? [...] Especially if you have an option to compare your results with former results, where you have the historical progression to see in what direction it’s going.” (D)

‘I think that would be too much... or I don’t know. That would, in principle, be possible. Now I am sitting here thinking, “That would actually be possible,” because there are things that might change before the next consultation [...]. Yes, of course, if it is there to offer her [the HCP] an updated journal showing progression, then it might actually.... Yes, then I think it would make sense.’ (E)

‘No, I don’t think it would, no, but it also depends on how you... I mean, when I was at the GP for the first conversation, I made a long list with a lot of questions, and I would do the same to a meeting here [at the CfD], which I haven’t done for today because of the questionnaire.’ (Informant F) – ‘Yes, okay, you think it would have been easier if you had just made the list, is that correctly understood?’ (Researcher) – ‘Henceforth, then I would answer yes... but as I also said, in retrospect, I do see the purpose of

the questionnaire at least for first-time consultations.’ (Informant F)

‘Fine, well, if it was the same questionnaire all the time, then I would probably think it was a waste of time. Now Smith and I are meeting again in a few weeks. If I had to complete the same questionnaire before then, that would be okay, but if I then had to meet with her again and it was the same [questionnaire] once again, then I think it would be a waste of time... but if I had to go somewhere else and receive such a questionnaire, then I think it would be fine.’ (Informant G)

‘That is a good question. I actually don’t know. I think now that I have done it this one time, you know. It has a purpose because now I can get started with things, but if I had to do it every time... but I do realise that there are changes every fourth week. Now a new month is coming, which changes my life, right? And another new month is coming, which leads to changes because I start changing my habits, so it is a sort of diary but having to answer all the questions [is burdensome].’ (Informant H)

When asked, ‘Would you use the PRO data if accessible?’ the citizens provided the following answers:

‘I don’t think so, no. I normally don’t care about such things.... You know, I can feel it myself. Well, do I feel better? Yes, I feel better.’ (Informant A)

‘Yeah, I don’t know. I honestly don’t believe I would do it for anything. I don’t know. What would change? Won’t I just answer the same questions every time?’ (Informant B)

‘Well, that is like weight loss and exercise and things like that. If you can follow something over a period, then I would definitely do it... and to see if there is something health-related, with values or something making you think about how much you exercise, eat and other things, then I would definitely find it interesting [...]. I am always up for gadgets where you can measure things—that is fun....’ (Informant C)

‘Well, I think I would accept it and use it, but, yes, I would probably do that because you need to accept the offers you are given to improve your everyday life and make it easier to go through life, so I would see if it was something for me, and if not, I could just stop using it.’ (Informant F)

‘I wouldn’t use it because I am feeling good, but if I don’t feel well, then I would because it is great that you can follow your development... But my questionnaire is mostly green, and I expect it to stay that way. Now I start

working on it [her health] to get better so it won’t be less green.’ (Informant G)

‘Well, I wouldn’t want to do it, but if I was asked to do it, then I would do it, also because I see that it is relevant because it enables you to follow your progression and relapses....’ (Informant H)

The informants found the use of PROs as part of their routine care and digital access to their PRO data relevant. However, their willingness to continuously complete the questionnaires and make use of the PRO data varied. Informants A, B, G and H were not interested in making use of digitally accessible PRO data. Informant A was not interested because he was uninterested in digital solutions and did not need digital data because he believed that his body signals how he is doing. Informant B does not see how the PRO data might assist him, and Informant G did not need digital PRO data because she felt well, which she expects to continue. However, implicitly, she indicated that if she started feeling worse, the PRO data would be useful to her. Even though Informant H understands how the digital solution might provide her with an overview of her disease progression, she would not be interested in following her PRO data unless it is mandatory. Informant C often used digital solutions and would therefore be very interested and make use of the PRO data if they were digitally accessible. Informant F would try using the PRO data if these were accessible to explore whether it might benefit her somehow. Informant A believed that the routine use of PRO questionnaires would be beneficial, as it ensures that HCPs know how the citizen is doing before the consultation. Informant B thought that the routine use of PRO data would be fine as long as it is being used and have value in clinical practice. Informant D would not mind completing questionnaires every time before consultations, especially if the data are usable comparatively to show disease progression. Informant E reckoned that it would be burdensome, but he also recognised that it might be relevant to complete PRO questionnaires continuously, as his health probably changes over time; hence, he believed that the generated data would be helpful for HCPs. Informant F would prefer to manually make a list with relevant topics; however, she acknowledges that the questionnaire has some value in the initial meeting, as participants do not know one another. Informant G would agree to complete the same questionnaire at one site a few times and when moving back and forth between healthcare providers but finds it a waste of time if she often needs to complete PRO questionnaires at one site. Informant H recognises the value of continuous PRO completion, as the questionnaire captures changes over a period and, therefore, might function as a digital diary. However, at the same time, she

believes it is burdensome; hence, her stand on the matter is ambiguous.

Discussion

The citizens' experiences indicate that in general, they found that not only was the questionnaire relevant, meaningful and useful but also that it warrants adjustments to match the needs of patients as newly diagnosed with type-2 diabetes.

Some of the results in the present study are consistent with the findings of other studies on patient experiences with PROs. For example, Liu et al.¹¹ found that citizens prefer to complete questionnaires at home and to have them delivered digitally.¹¹ In the present study, the digital solution was preferred owing to ergonomic reasons; negative attitudes towards paper-based questionnaires; the simplicity of this solution, as all participants had access to the Internet and the opportunity to skip a tour back and forth to the CfD. Hence, all of the informants preferred the digital delivery method. However, the participants had only tried the digital home solution, which might have made them more inclined to prefer this specific solution. Liu et al.¹¹ found that home settings are preferred for completion because it means that less time needs to be allocated for a consultation visit. They allow patients to decide when to answer the questionnaire and how much time they want to spend on it, reducing time pressure. Patients preferring completion at one site emphasises the advantage of getting the health task done all at once.¹¹ Similarly, the citizens in the present study appreciated the flexibility in time when completing the questionnaire, the effective use of time in general and the comfortability of the home interior. The most decisive factor when explaining why completion at home was preferred was the privacy it ensured, which Zimlichmann et al. also found to be a relevant factor.²⁶ As one of the citizens in this study argued that completion at a site might also have a certain advantage, as it provides access to professional assistance, a feature that has particular relevance to patients with low health literacy.²⁷

The purpose of the PRO questionnaire seemed clear to the citizens, as they agreed that it was meant to improve the citizen-HCP consultation. Hence, the citizens seemed well informed on the purpose of PROs at the CfD. However, their narrow perception of the purpose of PROs indicates that a simple and concise introduction to the purpose of PROs was given; even though, the purposes and functionalities of PROs are multifaceted.^{2,3} A simple and contextual explanation are justifiable considering that patients should only receive relevant information for the purpose of PROs. However, if citizens only perceive the questionnaire as an HCP-oriented tool applied during the consultation, then it might be difficult to instigate patient participation and self-management via PRO data. Thus, in

the future, information also verbalising PROs as a self-management tool seems advisable.

Too lengthy questionnaires require attention in PRO development workshops and a theme in scientific studies on PROs as well.²⁸ In the present study, most citizens found the length of the questionnaire fitting, whereas some emphasised that it was a bit too long. Health literacy is another relevant topic when discussing the quality of PRO questionnaires. Hence, studies have shown that the required reading levels of PRO questionnaires are often too high.^{29,30} Even though health literacy was not examined explicitly, on the basis of the fact that all participants were able to read and understand the questions, this might not be an issue with the present PRO questionnaire. However, as noted in the Methods section, the citizens who participated in this study were probably not among the least resourceful patients, which means that further studies in this area are advisable. What was shown to be a problem though was the content of the questionnaire, considering that the target group, in this case, were citizens with newly diagnosed type-2 diabetes. Hence, their lack of knowledge became clear when they completed the questionnaire, which caused insecurities and a feeling of answering incorrectly. Accordingly, it is reasonable to assert that the questionnaire might also have a disempowering effect on some of the newly diagnosed citizens with type-2 diabetes. In other words, the citizens were asked questions that did not match their current disease situations. Mejdahl et al.⁷ also found that the use of PROs might lead to feelings of rejection and disconnection due to a lack of feedback on PRO scores during the consultation. The patients explained that the PRO measures were too standardised, not allowing them to sufficiently describe their disease situation, and negatively formulated. As a result, the wording and content of the questionnaire made the patients worry about their disease situations and unsure of whether they completed the questionnaire correctly.⁷ Our findings indicate that the 'concern/motivation' dilemma and similar patient experiences disclosed in the present study were not unique. Issues have been raised that emphasise the importance of modifying the PRO questionnaire according to the needs of citizens with newly diagnosed type-2 diabetes. A point aligned to the findings in the study of Wu et al. is that the participants underscored that the questionnaire had to be tailored to the needs of the patients.¹⁰ In spite of the need for corrections, the completion of the PRO questionnaire also had positive outcomes, as it enlightened, empowered and motivated the citizens. Thus, the questionnaire improved the citizens' knowledge of physical, mental and other issues; granted them a feeling of not being alone in the management of their diseases and motivated them to improve their self-management of their diseases.

Findings on the use of the PRO questionnaire and data during consultations in the present study link to the study

by Kane et al., who demonstrated that PROs elicit unmet needs, provide a holistic understanding of the patient's disease situation, empower patients and promote patient participation.¹² In the same vein, Mejdahl et al. concluded that PROs provide patients with an improved understanding of their disease, enhanced communication during the patient–clinician consultation and accentuated psychosocial issues during these consultations.¹³ In 2018, Mejdahl et al. confirmed that patient–clinician communication and awareness and comprehension of psychosocial issues were improved but also showed that PROs might have positive effects on patients' self-management, health behaviour and feelings of autonomy.⁷ In the present study, the PRO data applied during consultation had an educative effect, as it improved citizens' understanding of their disease situations; revealed empowering potential; disclosed physical and mental symptoms; prepared participants before the consultation and assisted them during the consultation; and functioned as a conversation starter and enabled structured, relevant, effective and holistic conversations. Moreover, some of the citizens believed in the routine use of PROs and were keen to actively use PRO data as some sort of self-management tool, whereas others found the PRO data less relevant and the continuous completion of the questionnaire too burdensome.

In a hospital setting, studies have indicated that time is an issue if PROs are to provide a detailed and holistic understanding of patients' disease situations.^{31,32} However, in this study, time was sufficient according to the citizens. There might be various reasons for this. First, PROs were applied during an AFK, which is an hour-long introductory talk. Second, the conversation occurred in a municipal setting, where workflows and consultations probably are different from those in outpatient clinics. Another topic was concerning the citizens' involvement in the decision making and their perceived control during the consultation. Thus, citizens felt recognised and involved to a degree matching their individual preferences and believed that the decisions made were consistent with their needs and wishes. Hence, it is interesting that Wu et al. found that a PRO system, which enabled patients to mark the issues they wanted to discuss during the patient–clinician consultation, was acceptable to patients. In the same study, the interpretations of PRO scores were problematised, as the display of PRO data was a confusing experience to the patients. Therefore, additional and improved information on PRO scores were suggested as a possible solution.¹⁰ In the present study, the citizens approved the analytical colour division (green, yellow and red), as it was intuitive and easy to interpret. However, aligned with patient experiences from former studies,^{33–35} some of the citizens demanded improved explanations of the results, simpler displays and better guidance in the interpretation of PRO scores. In the physical consultations, the findings indicated that HCPs must consider how they position the

screen that displays the PRO data and constantly ensure that citizens are aware of the subject being discussed. The citizens underscored that attention should be primarily on red and yellow scores, confirming that the current approach enacted by the HCPs aligned with the citizens' preferences. However, the visualisation of the green categories was clearly useful, as it enabled the citizens to show and tell HCPs how well they were doing, assuring the HCPs and themselves that they took their new situation with diabetes seriously.

Lastly, the findings from the present study are considered in comparison with the results from the national evaluation report, where the conclusion was that 'these citizens did not worry more than others but felt that the PRO questionnaire was less relevant compared to citizens who have had diabetes for more than a year'.¹⁴ An interesting quote is that the findings in this evaluation report implicitly support the focal finding in this study that the questionnaire is not adequately tailored to citizens with newly diagnosed type-2 diabetes. The report also explains that the questionnaire might make citizens worry about their disease situations. On the basis of these results, we do not know whether citizens with newly diagnosed worry more than others but find it striking that all the citizens who participated in the present study indicate, in one way or the other, that some of the questions asked were irrelevant and that some of the questions instigated worries. Hence, it makes sense that some of the HCPs who participated in the pilot tests of the questionnaire noted that it still needs some adjustments. The positive effect on the conversation emphasised in the national evaluation, the fitting length of the questionnaire and the relative ease in completing the questionnaire for most citizens, to a large extent, align with the findings from this study. In other words, the findings from this study do not, on a general level, diverge from those in the national report; however, on the basis of these findings, the conclusion is not that all is fine but that fine-tuning of the questionnaire is recommended. Thus, the specific and deeper focus in a municipal context has enabled an improved understanding of the experience of newly diagnosed citizens with type-2 diabetes and the adjustments required to match their needs.

The limitations of this study concern the limited number of participants; hence, the inclusion of more citizens would, to some degree, have nuanced the findings further. However, the inclusion of more citizens was an option, but because consistency and commonalities were observed in several of the patient experiences, this was not deemed necessary. The interviews with the citizens were conducted right after the consultation, which means that the citizens' experiences with the questionnaire were a few days old. Hence, think-aloud tests to further scrutinise the findings of the present study by examining the citizens' reactions towards the questionnaire in real-time are encouraged.

Conclusion

In general, the newly diagnosed citizens with type-2 diabetes found the use of the PRO questionnaire and data valuable, relevant, meaningful and helpful. However, it was also clear to them that the questionnaire did not resemble their respective disease situations adequately, as reflected in their suggestions concerning future revisions of the questionnaire and how alternative approaches might be better for newly diagnosed citizens with type-2 diabetes. On the one hand, the questionnaire has the potential to enlighten, motivate and empower citizens; disclose different types of symptoms and issues; integrate patients' perspectives and make the citizen-HCP conversation structured, relevant and effective. On the other hand, the diabetes PRO questionnaire frustrated the citizens and made them worry. In short, the questionnaire is an advantageous instrument in municipal healthcare practice but requires adjustments to match the needs of citizens with newly diagnosed type-2 diabetes. The citizens would accept the routine completion of the PRO questionnaire, and some found the use of PRO data as a self-management tool relevant. Most important was that the completion and the use of PRO data were relevant and meaningful in accordance with their disease situation.

Acknowledgements: We thank the CfD for giving us access to conduct the study, the employees for their participation and the citizens for their engagement and great contributions.

Conflict of interest: All authors declare that they have no financial or non-financial interests that may be relevant to the submitted work. SHN is an employee at the CfD but utterly assisted by providing background knowledge and recruiting participants.

Contributorship: JE conducted the study and analysed the data. PB and AB supervised and contributed to the interpretation of the results. SHN functioned as gatekeeper who recruited the participants and contributed to the sections on CfD and their use of PROs. All authors have read and approved the final version of the manuscript.

Ethical approval: Not applicable.

Funding: The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the Danish Center for Health Informatics, The Department of Planning, Aalborg University, The Danish Health Data Authority.

Guarantor: JE.

ORCID iD: Jeppe Eriksen  <https://orcid.org/0000-0003-0751-4437>

Supplemental material: Supplemental material for this article is available online.

References

1. PRO Secretariat. PRO-området, <https://pro-danmark.dk/da/omraader> (2021, accessed 11 October 2021).
2. Eriksen J, Bertelsen P, Bygholm A, et al. The digital transformation of patient-reported outcomes' (PROs) functionality within healthcare. In: Pape-Haugaard LB, Lovis C and Cort Madsen I (eds) *Digital personalized health and medicine—proceedings of MIE 2020*. Amsterdam: IOS Press, 2020, pp.1051–1055.
3. Eriksen J, Bygholm A and Bertelsen P. The purpose of patient-reported outcome (PRO) post its digitalization and integration into clinical practice: a redefinition resembling PROs theoretical and practical evolvement. *Appl Sci* 2020; 10: 1–16.
4. Ministry of Finance. *Aftaler om den kommunale og regionale økonomi for 2016*. <https://fm.dk/udgivelser/2015/oktober/aftaler-om-den-kommunale-og-regionale-oekonomi-for-2016/> (2015, accessed 11 October 2021).
5. ViBIS. *Program PRO*. Kbh.: ViBIS, <https://danskepatienter.dk/om-danske-patienter/publikationer/anvendelse-af-pro-data-i-kvalitetsudviklingen> (2016, accessed 11 October 2021).
6. Ministry of Health, Ministry of Finance, Danish Regions, et al. *A coherent and trustworthy health network for all—digital health strategy 2018–2022*. <https://sundhedsdatastyrelsen.dk/da/diverse/download> (2018, accessed 11 October 2021).
7. Mejdahl CT, Schougaard LMV, Hjollund NH, et al. PRO-based follow-up as a means of self-management support—an interpretive description of the patient perspective. *J Patient Rep Outcomes* 2018; 2: 38.
8. Schougaard LMV, Larsen LP, Jessen A, et al. Ambuflex: tele-patient-reported outcomes (telePRO) as the basis for follow-up in chronic and malignant diseases. *Qual Life Res* 2016; 25: 525–534.
9. Danish Regions. *Handleplan for Bedre Brug Af Sundhedsdata I Regionerne*. <https://www.regioner.dk/media/3120/brug-af-sundhedsdata-handleplan-for-bedre-brug-af-sundhedsdata.pdf> (2015, accessed 11 October 2021).
10. Wu AW, White SM, Blackford AL, et al. Improving an electronic system for measuring PROs in routine oncology practice. *J Cancer Surviv* 2016; 10: 573–582.
11. Liu TC, Ohueri CW, Schryver EM, et al. Patient-identified barriers and facilitators to pre-visit patient-reported outcomes measures completion in patients with hip and knee pain. *J Arthroplasty* 2018; 33: 643–649.e1.
12. Kane PM, Ellis-Smith CI, Daveson BA, et al. Understanding how a palliative-specific patient-reported outcome intervention works to facilitate patient-centred care in advanced heart failure: a qualitative study. *Palliat Med* 2018; 32: 143–155.
13. Mejdahl TC, Nielsen BK, Hjollund NH, et al. Use of patient-reported outcomes in outpatient settings as a means of patient involvement and self-management support—a qualitative study of the patient perspective. *Eur J Pers Centered Healthc* 2016; 4: 359.

14. PRO Sekretariat. *Pilotafprøvningsevalueringsrapport vedr PRO-diabetes*, <https://pro-danmark.dk/da/omraader/diabetes> (2021, accessed 11 October 2021).
15. PRO Sekretariat. *Opsamlingsrapport fra workshopforløb for udvikling af PRO-værktøj indenfor Diabetes*, <https://pro-danmark.dk/da/omraader/diabetes> (2019, accessed 11 October 2021).
16. McKinsey & Company. *Det tværregionale projekt om værdibaseret - Bilag C*, <https://www.regioner.dk/media/11349/bilag-c-oversigt-over-hvert-delprojekt.pdf> (2019, accessed 11 October 2021).
17. PRO Sekretariat. <https://skema.pro-danmark.dk/> (2021, accessed 11 October 2021).
18. Center for Diabetes – Kbh. Center for Diabetes, <https://diabetes.kk.dk/> (2021, accessed 11 October 2021).
19. Tong A, Sainsbury P and Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Heal Care* 2007; 19: 349–357.
20. Flyvbjerg B. Aalborg Universitet five misunderstandings about case-study research Flyvbjerg, Bent. *Qual Inq* 2006; 12: 28.
21. Karpatschof B. Den kvalitative undersøgelsesforms særlige kvaliteter. In: Brinkmann S and Tanggaard L (eds) *Kvalitative metoder: en grundbog*. Copenhagen: Hans Reitzel, 2015, pp.443–462.
22. Kvale S and Brinkmann S. *Interview: det kvalitative forskningsinterview som håndværk*. 3rd ed. Copenhagen: Hans Reitzel, 2015.
23. Malterud K. *Kvalitative metoder for medicin og helsefag*. 4th ed. Oslo: Universitetsforlaget, 2017.
24. Spradley JP. *Participant observation*. New York: Wadsworth Thomson Learning, 1980.
25. Braun V and Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; 3: 77–101.
26. Zimlichman E. Using patient-reported outcomes to drive patientcentered care. In: Grando M, Rozenblum R and Bates D (eds) *Information technology for patient empowerment in healthcare*. Berlin: De Gruyter, 2015, pp.241–256.
27. Jahagirdar D, Kroll T, Ritchie K, et al. Using patient reported outcome measures in health services: a qualitative study on including people with low literacy skills and learning disabilities. *BMC Health Serv Res* 2012; 12: 31.
28. Gensheimer SG, Wu AW and Snyder CF. Oh, the places we'll go: patient-reported outcomes and electronic health records. *Patient* 2018; 11: 591–598.
29. Adams J, Chapman J, Bradley S, et al. Literacy levels required to complete routinely used patient-reported outcome measures in rheumatology. *Rheumatol (United Kingdom)* 2013; 52: 460–464.
30. Atcherson SR, Zraick RI and Brasseur RE. Readability of patient-reported outcome questionnaires for use with persons with tinnitus. *Ear Hear* 2011; 32: 671–673.
31. Basch E, Iasonos A, Barz A, et al. Long-term toxicity monitoring via electronic patient-reported outcomes in patients receiving chemotherapy. *J Clin Oncol* 2007; 25: 5374–5380.
32. Mejdahl CT, Schougaard LMV, Hjollund NH, et al. Exploring organisational mechanisms in PRO-based follow-up in routine outpatient care—an interpretive description of the clinician perspective. *BMC Health Serv Res* 2018; 18: 1–13.
33. Brundage MD, Smith KC, Little EA, et al. Communicating patient-reported outcome scores using graphic formats: results from a mixed-methods evaluation. *Qual Life Res* 2015; 24: 2457–2472.
34. Smith KCKC, Brundage MDMD, Tolbert E, et al. Engaging stakeholders to improve presentation of patient-reported outcomes data in clinical practice. *Support Care Cancer* 2016; 24: 4149–4157.
35. Hildon Z, Allwood D and Black N. Making data more meaningful: patients' views of the format and content of quality indicators comparing health care providers. *Patient Educ Couns* 2012; 88: 298–304.