Comparing patient and physician preferences for PROM and EQ-5D data visualization: exploring the bigger picture.

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Preface

Before you lies the master thesis "*Comparing patient and physician preferences for PROM and EQ-5D data visualization: exploring the bigger picture.*". It has been written to fulfill the graduation requirements of the Health Sciences program at the University of Twente (UT) in Enschede, The Netherlands. I was engaged in researching and writing this thesis from July 2022 to February 2023.

From completing my bachelor's degree in physical therapy to me writing this preface for my master thesis, my interests in contributing to care that revolves around patients, e.g., patient-centered care, has always been a driving force behind every step in my personal development and career in healthcare. It has also been the reason for choosing this thesis subject. Since delivering healthcare should result in outcomes that matter most to patients and if we, as healthcare professionals, do measure patient reported outcomes, shouldn't patients be included in how we utilize those outcomes? This, to me at least, remains an essential part in delivering patient-centered healthcare.

During this study, I therefore examined what preferences patients and physicians have with regards to what and how outcomes are collected, how these outcomes should be reported back to the patients (if patients even want to do so), and if patients and physicians have differences in how outcomes are collected and utilized? I found that preferences change over time and should be seen as a dynamic process. I gained a better understanding of what matters most to patients and what factors ultimately lead to a better choice regarding medical decisions from both patient and physician perspectives. Furthermore, I learned that struggling and revisiting earlier choices is part of the process. Therefore, this thesis did not only teach me valuable lessons on a professional level but also helped me grow as a person.

I would like to thank my supervisor Dr. Janine van Til for her excellent guidance and support during my thesis. You provided me with challenges and encouraged me to make my own decisions. I can certainly say that I could not have done it without you. I also want to thank Drs. Eline Beens and Dr. Ria Wolkorte for their contributions to the study design and data collection. I would also like to thank the Behavioural, Management and Social Sciences (BMS) lab for providing me with the research software to analyze my data.

Finally, I would like to thank my family and friends for their continuous support. I hope you, my reader, enjoy reading this thesis and would like to thank you for taking the time to do so.

R. D. Vrolijk
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Abstract

Objectives

In the PRODECIDE project, we aim to improve our understanding of how EQ-5D data can be used to support individual patient decisions in the clinical encounter. During this study, a prototype interview guide was developed to gain a better understanding of (1) how EQ-5D data can be used to support individual patient decisions in the clinical encounter, (2) how to visualize EQ-5D data in a way that can be accurately interpreted by patients and physicians, and (3) what factors meet patients' and physicians' preferences in terms of visualization formats?

Methods

An interview guide was developed and refined using the grounded theory method. The interview guide was split into three different parts consisting of questions regarding the usefulness of PROM data in clinical encounters, what EQ-5D data was preferred by the participant and what visualization formats were preferred (which was only included in the patient group). Semi-structured interviews with 10 rheumatoid arthritis patients and 5 physicians were conducted using video calls. Data analysis was completed following open, axial, and selective coding by using qualitative data analysis software (Atlas Ti).

Results

Following data analysis, six distinct themes representing both the patients' and physicians' perspectives were identified. These were: *experiences with PROM use, what to do with PROM outcomes, what information to support PROM outcome display, experiences with EQ-5D use, preferences for EQ-5D system, and factors of influence regarding the level of detail in graphic display*. In general, PROMs were of added value in the clinical encounter because they facilitate self-management and improved patient-clinician communication. For this aim, using the EQ-5D health domains scores was preferred by most participants over a single score representing HRQoL. Adding details that support interpretation such as colour shading, clear axis labels, and descriptive labels were found to be key factors.

Conclusion

This study's findings illuminate that implementing the EQ-5D may contribute to richer consultations in rheumatoid arthritis related care. Dividing HRQoL into multiple domains was preferred over a single score representing all aspects of HRQoL. The addition of clarification options proved to be essential elements in improving score interpretation. The study further demonstrates that preferences regarding visualization of EQ-5D scores can change over time suggesting that EQ-5D data display may require a more dynamic approach.

Introduction

In 2021, the Netherlands had a prevalence of approximately 270.000 people with a rheumatoid arthritis (RA) diagnosis. RA is associated with significant morbidity and mortality which results in substantial healthcare utilization and costs [1]. Due to its chronic and progressive nature, it is especially important to actively monitor patient wellbeing. RA is shown to express major and diverse effects on a patients' health related quality of life (HRQoL) in both physical and mental domains [2]. This is especially important, considering that many patients value HRQoL over disease-related variables such as joint counts and inflammatory biomarkers [3]. Measuring these outcomes can further help patients and physicians in taking well informed medical choices using shared decision-making (SDM).

To help inform patients about potential treatment options, it is important to assess these outcomes from a patient perspective and represent what matters most to patients [4]. These outcomes include a variety of measurements such as complications of treatment, long term consequences and patient reported outcome measures (PROM). PROMs are defined as "any report that comes directly from the patient (i.e., study subject) about the status of a patients' condition without amendment or interpretation of the patients' response by a physician or anyone else" [5]. PROMs aim to identify potential bothersome issues to patients or help set realistic expectations for patients by demonstrating outcomes from patients with similar characteristics. Such outcomes can be measured using various instruments, the most common being the Medical Outcomes Study Short-Form 36 (MOS SF-36), 12 item Short-Form Health Survey (SF-12), the Visual Analogue Scale (EQ-VAS) and the EQ-5D [6, 7, 8]. Several benefits of using PROMs in a clinical setting are improved SDM and patient-physician communication by increasing symptom awareness, prompting patient-physician discussions, and streamlining consultations [7, 9, 10, 11].

The EQ-5D was developed by the EuroQol Group in 1987 as a HRQol measuring instrument. The EQ-5D data is mostly used for assessing healthcare interventions, as indicators in monitoring quality of care, or within the clinical encounter [12]. The EQ-5D comprises three parts: the descriptive system, a visual analogue scale (VAS), and an index value. The descriptive system uses five dimensions; Mobility, Usual Activities, Self-care, Pain & Discomfort and Anxiety & Depression [13]. It can be scored on either a problem level of three or a problem level of five answers possibilities. The EQ VAS is used to capture a respondents' overall assessment of their health by a visual rating scale from 0, representing the worst imaginable health to 100, which represents the best imaginable health [13]. The EQ-5D descriptive system and the EQ VAS are represented in figure 1. The EQ-5D can be complemented by using a weighting system to convert the data following the descriptive system into a single value (i.e. EQ-5D index). The EQ-5D index values are primarily used in economic evaluations and less in individual patient care [12].

Although PROMs can help inform patients in clinical practice, the extent to which these may inform communication or decision making relies, at least partially, on the interpretability of the scores that are generated by the PROM itself. Currently, when PROMs are used in clinical practice to provide feedback to patients and/or physicians, these do not have an established presentation format [14]. Most often, data is presented as raw or summarized data. Bantug et al. therefore performed a systematic review to identify if patients and physicians were able to correctly interpret plain and straightforward graphs representing PROM data [14]. They conclude that for both group-level and individual-level settings, simple representations of PROM data can be correctly interpreted. However, they mention that this is heavily dependent on a variety of factors such as the construction of the visual presentation, graphical literacy of the reader, familiarity with the content,

and the complexity of the underlying construct [14]. They suggest that future research should focus on optimizing strategies regarding graphical visualization of PROMs.

Therefore, more recent studies focussed on various aspects of graphical visualization such as score direction, axis labelling and on score interpretation by patients and physicians [7, 15, 16, 17]. Results indicate that score direction should be labelled and mixed score direction within one figure should be avoided [7, 13]. For conveying score meaning, descriptive labels could be used to assist patient understanding of what the score represents. Examples include extra annotations or colour coding next to the graph which help indicate what a “better” or “worse” score is [7, 17]. Additionally, the inclusion of reference groups or norm population in graphical displays was found to be useful [17, 18].

In 2022, Albers et al. performed a systematic review with the aim to identify patterns in patients’ and physicians' preferences and interpretation accuracy of several visualization formats for PROM data presentation in clinical practice [19]. First, they identified that there is a difference between preferences for outcome visualization and the ability to accurately interpret outcome information between patients and physicians. An example is that for individual-level PROM data, patients and physicians preferred line graphs and bar charts over other visualization formats (heat maps, pie charts, funnel plots, and pictographs). However, patients interpreted bar charts more accurately while physicians had similar interpretation accuracy scores across different visualization formats. Their conclusion was that no graphical visualization format proved to be predominant in terms of preferences and interpretation accuracy for both patients and physicians. To help guide clinical interpretation, mean scores from a norm population, score threshold or patients’ previous scores can be compared. Moreover, the use of colours, threshold lines, or circles to highlight specific scores can help visualize the clinical meaning of PROMs scores that are being compared. Albers et al. describe that a detailed clarification of each graph may be essential to ensure accurate interpretation. Visualization formats should therefore include brief definitions, descriptive labels, descriptions of the PROMs score direction and present a limited number of options within the graph.

In the PRODECIDE project, we aim to improve our understanding of how EQ-5D data can be used to support individual patient decisions in the clinical encounter. Ernstsson et al. did study how PROM data in Swedish National Quality registries was collected, presented, and used within the healthcare system [12]. They found that 32% of the registries reported individual level EQ-5D data to patients and physicians. However, they do not specify what EQ-5D data (descriptive system, Visual Analogue Scale (VAS), or the index value or EQ-5D values) was presented, or how this data was presented.

As one of the work packages within the PRODECIDE project, we want to explore how to visualize EQ-5D data in a way that can be accurately interpreted by patients and physicians and what meets their preferences in terms of visualization format. During this study, a prototype interview guide was developed to gain a better understanding of (1) how EQ-5D data can be used to support individual patient decisions in the clinical encounter, (2) how to visualize EQ-5D data in a way that can be accurately interpreted by patients and physicians, and (3) what factors meet patients’ and physicians’ preferences in terms of visualization formats to support patients in their decision-making process.

To achieve the aim of the study, the following research questions are formulated:

1. What are patients’ and physicians’ perspectives on the use(fulness) of PROM data in clinical encounters?

2. What are factors that influence patients'- and physicians' preferences with regards to the type of EQ-5D data (descriptive, VAS) used to support patients in their decision-making process in clinical practice?
3. What are factors that influence patients' preferences with regards to the visualization of EQ-5D data in terms of format and level of detail?
4. What are differences between patients' and physicians' preferences with regards to type and visualization of EQ-5D data?

Method

Study overview

For this qualitative study, semi-structured interviews with both rheumatoid arthritis patients and rheumatologists were conducted. A grounded theory method by Corbin and Strauss will be applied during the study [20]. Semi-structured interviews were chosen since these function as a general structure during the interview and can be further complemented by additional follow-up questions that arise during the dialogue between interviewer and participant [21, 22]. During the data analysis, questions in the interview guide can be added, deleted, or further be refined to help develop a theory about the perspectives of patients and physicians regarding EQ-5D data visualizations. Ethical approval for this study has been granted by the ethical review board of BMS at the University of Twente (Req. nr 221116). This report has been written based on the COREQ Checklist [23].

Participants

The participant sampling was completed using a mixture of both convenience and snowball sampling [24]. The participants in the patient group were selected through the TOPFIT citizen lab of the university of Twente (UT). This panel consists of rheumatoid arthritis patients with previous experience in academic research participation. All participants were approached using an e-mail invitation containing a patient information letter and a written informed consent. The second group of participants, i.e., the rheumatologists, were selected using a snowball sampling method. First an invitation containing a summary of the study goals was sent to one potential participant using UT contacts. After receiving this participants' consent, further sampling was done using the participants' work-related network.

The in- and exclusion criteria for the patient group of participants were as follows. Participants had to be at least eighteen years of age to participate and were only eligible if they were diagnosed with rheumatoid arthritis. No further restrictions were imposed on time since diagnosis or severity of the patients' condition. For the second group, all participants had to be attending rheumatologists and work for a Dutch hospital. These hospitals could both be academic or private. No further restrictions were imposed on the physicians' experience.

Data collection

Interviews were conducted between 24 October and 5 December 2022. All participants were interviewed individually using an online meeting Microsoft Teams and on only one occasion a phone call. A total of 15 interviews were performed, 10 of these were in the patient group and 5 in the physicians group. The interviews in the patient group had a duration of 60 minutes. The interviews in the physician group were deliberately shorter (i.e., 30 minutes) since the time that physicians want to allocate to an interview is often limited. In the first four interviews, a second researcher was present to offer support to the main researcher (RV). The remaining interviewers were all conducted by the main researcher.

The interviews were guided by an interview guide consisting of several pre-determined and open-ended questions. The interview guide was developed and discussed with a second researcher prior to the first interview. It was further refined throughout data collection and analyses using memory and quick scan techniques to allow for elaboration of emerging themes. During the interview, the

participants in the patient group were asked to complete the EQ-5D questionnaire. This was done to help familiarize the participants with the questionnaire and thus produce more valid results. Completing the questionnaire was done by screen sharing the EQ-5D, in which the researcher offered additional support by reading the questions to the participant. All questions were completed using Qualtrics on a one-by-one basis. The questions were all based on the EuroQol EQ-5D-5L Qualtrics Self Complete file. Figure 1 and Figure 2 offer an overview of how the EQ-5D was displayed to the participants. All participants were explained that their answers did not have to accurately represent their current health status and that completing the questionnaire was primarily for demonstration purposes. The answers provided by the participants were not collected for further use within this study. The EQ-5D questionnaire was not demonstrated in the physician group due to time constraints.

Figure A

Figure B

Figure C

Figure D

Figure E

Figure 1: The EQ-5D descriptive system following the interview guide

Figure 2: The EQ VAS following the interview guide

The interview guide was developed to (1) elicit the participants experiences and perspective on the collection and use of PROM data in a clinical setting, (2) elicit EQ-5D specific preferences regarding data collection and its use in a clinical setting, and (3) elicit preferences regarding EQ-5D data visualization in terms of format and level of detail. After completing the first round of interviews, the interview guide was further refined and prepared for the second participant group, consisting of physicians. Questions aimed at examining the level of detail in various visualization formats were excluded from the interview guide due to the limited duration of 30 minutes for each interview.

All interviews were recorded using Microsoft Teams video recording. Prior to the interview all participants were asked if they had read the information letter and had any further questions. Following this, the participants were asked on record if they did consent with participation and video recording of the interview. On one occasion it was decided to conduct the interview using a phone call and audio was collected using Apple voice memo software. This was due to some technical problems with Microsoft Teams for the participant. Next, the interview transcripts were downloaded from the Microsoft Teams website and further refined by the main researcher. All transcripts were re-read and edited to ensure no personal information was present. Then all data was made anonymous by adding pseudonyms to the transcripts.

Data analysis

Iteration and emerging design are core elements of qualitative research. First, the collected data was analysed using memory and quick scan techniques solely for the purpose of refining the interview guide for the upcoming interviews. After completing all interviews, the coding strategy provided by Corbin and Strauss was used to analyse the data [21]. This strategy consists of three steps i.e., open coding, axial coding, and selective coding. The open coding process consists of reading the transcripts and dividing the data into discrete parts by labelling all relevant data with codes. The open coding process was revisited multiple times and resulted in a total of 1010 quotations, 151 subcodes, and 27 codes. In axial-coding, all developed codes relating to a particular concept were then grouped into individual themes. These themes represent data with a similar meaning or codes related to another. After axial-coding was completed, 6 distinct themes were identified. These themes are represented in Figure 3. The last step is selective coding. This step connects all categories into one core category. The coding process was completed by the main researcher using qualitative data software Atlas Ti [25].

Results

A total of 15 interviews were conducted. The interviews with the patient group were completed first and had an average duration of 60 minutes. The second round of interviews with the physicians had an average duration of 30 minutes. All identified themes and codes with a complementary definition are displayed in Figure 3.

Themes	**Codes**	**Definition**
Experiences with PROM use		
	Ervaring patienten met invullen PROMs	Hebben patiënten eerdere ervaring met het invullen van PROMs?
	Ervaring reumatologen met afnemen PROMs	Nemen de reumatologen op dit moment PROMs bij patiënten af?
	Perspectief patienten op hoe zij PROMs invullen ervaren	Hoe ervaren patiënen het invullen van PROMs?
	Perspectief Reumatoloog op hoe patiënten PROMs invullen ervaren	Hoe denken de reumatologen dat patiënten het invullen van PROMs ervaren?
	Voordelen van gebruik PROMs	Wat zijn de voordelen van PROMs gebruik voor patiënten en reumatologen?
	Nadelen van gebruik PROMs	Wat zijn de nadelen van PROMs gebruik voor patiënten en reumatologen?
	Toekomst factoren	Wat zijn factoren voor toekomstig PROM gebruik?
What to do with PROM outcomes		
	Proces van PROM gebruik in standaard zorg	Hoe ziet het gebruik van PROMs er volgens reumatologen in een klinische setting uit?
	Krijgt de patiënt PROM uitkomsten zelf te zien?	Krijgt de patiënt PROM uitkomsten zelfstandig terug te zien?
	Uitkomsten terugkoppelen naar patiënten	Worden de PROM uitkomsten door de reumatoloog teruggekoppeld?
	Meerwaarde terugkoppelen uitkomsten	Is er voor patiënten een toegevoegde waarde van PROMs terugkoppelen?
	Uiteindelijke beslissing binnen de zorg	Wat vormt de uiteindelijke beslissing voor de patiënt?
What information to support PROM outcome display		
	Welke aanvullende informatie zou een patiënt willen zien om PROMs te kunnen begrijpen?	Welke informatie zou de patiënt toe willen voegen bij het zien van PROM uitkomsten?
	Welke informatie gebruikt reumatoloog om PROMs te laten zien?	Welke informatie gebruikt de reumatoloog bij het laten zien van PROM uitkomsten?

	Bijzonderheden vergelijkingsgroep	Bijzonderheden voor het gebruik van vergelijkingsgroepen
Experiences with EQ-5D use		
	Beleving van het invullen van EQ-5D vragenlijst voor patienten	Wat zijn de ervaringen van patiënten bij het invullen van de EQ-5D?
	Ervaring reumatoloog met de EQ-5D	Gebruikt de reumatoloog op dit moment de EQ-5D?
	Welke onderdeel van EQ-5D worden door reumatologen gebruikt?	Welke onderdelen van de EQ-5D worden door de reumatoloog gebruikt?
	Voordeel EQ-5D	Wat zijn de voordelen van de EQ-5D vragenlijst?
	Nadeel EQ-5D	Wat zijn de nadelen van de EQ-5D vragenlijst?
Preferences for EQ-5D system		
	Voorkeur van patiënten voor gebruik systeem	Welke EQ-5D systeem heeft voor patiënten de voorkeur?
	Voorkeur van reumatoloog voor gebruik systeem	Welke EQ-5D systeem heeft voor reumatologen de voorkeur?
Factors of influence regarding the level of detail in graphic display		
	Interpretatie descriptief grafiek	Hoe interpreteren patiënten het descriptieve systeem?
	Interpretatie VAS grafiek	Hoe interpreteren patiënten het VAS systeem?
	Factoren van invloed op het staafdiagram	Welke factoren zijn van belang bij het interpreteren van het staafdiagram?
	Factoren van invloed op het lijndiagram	Welke factoren zijn van belang bij het interpreteren van het lijndiagram?
	Voorkeur staafdiagram vergeleken met lijndiagram	Welke visualisatie methode heeft voor patiënten de voorkeur met betrekking op het laten zien van EQ-5D uitkomsten over tijd?

Figure 3: All categories following coding analysis

Selective coding was completed using the defined categories and resulted in a theory that is discussed in the conclusion section of this study.

Patient group

Patient group characteristics

After the invitation using the UT citizen panel, a total of 26 participants were invited of whom 10 agreed to participate. This was done on a first-come first-served basis. All participants completed the

full duration (i.e., an average of 60 minutes) of the interview. Participants' mean age was 62.2 years (± 8.2). Females (N=9) made up most of this group compared to only one male (N=1). All participants in this group were diagnosed with rheumatoid arthritis with a mean time since diagnosis of 14.1 years (± 6.3). Educational levels varied from high school (N=1), college (N=2), university of applied sciences (N=6) and academic (N=1). A summary of the patient characteristics is represented in Figure 4.

Pseudonym	Gender	Age (years)	Education level	Time since diagnosis (years)	Disease condition
PT1	Female	70	HBO	16	RA
PT2	Female	56	HBO	14	RA
PT3	Male	58	HBO	9	RA
PT4	Female	62	Academic	17	RA
PT5	Female	53	HBO +	9	RA
PT6	Female	56	MBO	22	RA
PT7	Female	64	HBO +	22	RA
PT8	Female	81	HBS	20	RA
PT9	Female	61	HBO +	8	RA
PT10	Female	61	MBO	4	RA
Mean	-	62.2	-	14.1	-
Standard Deviation	-	8.2	-	6.3	-

Figure 4: summary of patient characteristics

Patient perspectives on the usefulness of PROM data in the clinical encounter

How do patients experience PROMs?

All participants report that they had some experience with completing PROM questionnaires. Four out of ten participants complete PROMs on a regular basis with three having to complete a questionnaire prior to their consultation. Six participants had experience with PROM questionnaires but completing PROMs is not incorporated within their RA care pathway.

All participants thought that administering PROM questionnaires in clinical care has positive effects. Several negative effects were also identified and will be discussed shortly. The positive effects mentioned are monitoring disease activity over time if the outcomes were reported back to the participants (PT1 and PT2), increased self-management by feeling more involved in the patients' own care process (PT1, PT4 and PT5), increased awareness (PT1 and PT5), patients feeling better prepared for their consult (PT3, PT6, PT9 and PT10), patients feeling more empowered to express their concerns (PT7), and a better structured and more to-the-point consult (PT8, PT9).

Most participants expected PROMs to be used for either clinical purposes, internal hospital monitoring, or external research focussed on improving care for rheumatoid arthritis patients. Specific examples of how PROMs are thought to improve care are: empower patients to play an active role in medical decisions (PT2, PT3 and PT4), help physicians prepare for their consult with a patient (PT9), allowing physicians to revisit a patients' previous scores and gain an overview over a

longer period (PT9), discussing individual patient scores during a consult (PT2, PT3), monitoring the hospitals performance (PT7), or further development of rheumatoid arthritis related care by research (PT4, PT5 and PT7).

The patients who did complete PROMs prior to their consultation were then asked if PROM outcomes were shared and discussed between patient and physician during their consultation. Some patients report that PROM results were not shared with them (PT2, PT3 and PT6). Not reporting outcomes back to patients was experienced as highly demotivating (PT2 and PT6). PT2 explains that simply mentioning that their outcomes were received and quickly reviewed by the physician would be sufficient. Furthermore, PT2 mentions that she currently does not know why she is asked to complete PROMs and what the aim of conducting PROM questionnaires is. Several patients note that they would like to be able to access their previously completed PROMs outside of the consultation. PT6 explains that if she had access to previous PROM results, this would allow her to compare her current health condition to earlier scores.

Some participants in the patient group mentioned disadvantages of the use of PROMs in clinical practice. Several patients indicate that asking patients to collect PROMs too often could increase burden on patients and result in survey fatigue (PT1, PT7, PT9 and PT10). PT2 further notes that these questionnaires should not be too long since this could also result in survey fatigue. Another disadvantage of using PROMs in clinical practice was found to be that the PROM outcomes can be hard to be confronted with (PT7 and PT9).

In addition to the disadvantages, some patients indicate points of improvement for the use of PROMs. PT2 and PT6 both indicate that prior to the consultation, a reminder to complete the questionnaire would be helpful as patients sometimes overlook PROM questionnaires. A lack of standardisation in score direction across various PROM instruments was also found to be a point of improvement. According to PT1 and PT3, not having a standard score direction can result in confusion for some of the participants (PT1 and PT3). PT1 explains that in some questionnaires a higher score indicates a better health outcome and in other questionnaires a better health outcome is represented by a lower score. PT3 addresses that in some questionnaires the scores range from 0-10 and in others from 0-100. He describes that these varying score ranges do not necessarily impose a problem but explains that it can be difficult to differentiate between what results in a difference between a score of 80 compared to 75. He describes that these varying score ranges do not necessarily impose a problem but explains that it can be difficult to determine what perfect health (i.e., a score of 100) actually represents. He further notes that distinguishing between a score of 75 or 80 can also be difficult. *"De moeilijkheid is om… wat is 100% hè? Wanneer ben je helemaal op je top en wanneer ben je wel slecht? En om dat te gaan vertalen in een percentage? Je ziet dat net ook al met het twijfelen tussen 80 of 75 hè? Want je hebt last van je knie en dus ja. Dat is altijd een beetje moeilijk inschatten, maar ik denk als je het door de regel neemt dan komt dat wel aardig overheen. -PT3"*.

All participants did indicate their preference regarding the frequency in which PROM outcomes should be collected. 4 out of 10 participants preferred collecting PROMs prior to a consultation. 4 participants preferred a frequency of once every three months. One participant stated that collecting PROMs once every six months was sufficient. PT8 did not indicate her preference.

What additional information may support interpretation of PROM scores?

The participants were asked which PROM information would be of interest to them. In the interview guide, three different options were provided as an example 1) the patients' progress or

deterioration over time, 2) the patients' scores compared to those of similar patients, and 3) the patients' score compared to scores of persons without rheumatoid arthritis. Most participants indicated they were most interested in the progression over time. According to participants, comparison over time provides insight into the patients' health condition and allows for further discussion or examination between physician and patient of what could cause increased or decreasing health effects. "*Ja, inderdaad dan die vooruitgang of achteruitgang over tijd. Dat is echt heel belangrijk, want dat is hele goede informatie voor de reumatoloog in verband met het bepalen van medicatie. -PT2"*.

6 out of 10 participants addressed that comparing their individual scores to scores of similar patients did not interest them. *"Dat heeft in mijn ogen geen zin van wat hun wel of niet meer kunnen. En ook niet zonder reuma, want hier heb je mee te dealen. -PT3"*. Most mention that rheumatoid arthritis results in significant different health outcomes for each individual patient which makes comparing patients unfeasible. "*Wij zeggen ook letterlijk in onze lessen, geen twee patiënten hetzelfde en geen ziekteverloop hetzelfde. En zelfs al heb je hetzelfde ziekteverloop, het feit alleen al dat misschien de ene moeder is met kinderen en ik (ik heb geen kinderen) maar wel een baan. Dat kan al een wereld van verschil in beleving geven. -PT5"*. Some patients further report that they do not wish to compare themselves to others since it does not affect their own outcomes or how they experience their condition (PT3 and PT7). However, several patients state that would have been interested in comparing individual scores to those of similar patients early in their disease course. Some participants indicate that in early disease stages a comparison could be useful in setting expectations and reducing disease related concerns. PT1 and PT3 explain that the urge to compare scores with those of similar patients does decrease over time due to increased knowledge and experience on how rheumatoid arthritis affected their own life. "*He, nu weet ik dat als ik een aanval krijg, ja dat duurt hopelijk misschien twee dagen of misschien een week en daarna gaat het wel weer goed. Dan kun je weer dingen oppakken, ja en dat zijn ervaringen. Die moet je eerst ondergaan voordat je dat echt ja... zeg maar kan accepteren. -PT3"*.

If individual PROM scores would be presented to those of similar patients, the participants found the comparison group had to be specifically defined around their own patient characteristics. A few examples of characteristics include gender, age, time since diagnosis and the presence or absence of comorbidities.

How are PROMs used in clinical decision-making?

The patients explain that discussing PROM outcomes could influence their medical decision making by providing a wider view on what patients themselves can change in their daily functioning. However, most patients further describe that the predominant factor in eventually making a health-related decision would still primarily be based on the personal experience of the physician. PT6 explains she trusts the physician in making a decision that fits her needs. She expresses concerns about patients making decisions concerning matters they do not fully understand and mentions that these decisions cannot be made due to highly varying patient preferences and circumstances. *"Want je ziet hè dat op Facebook ook mensen… ja zeggen, ik moet met dit beginnen of met dat beginnen, wat zouden jullie doen? Kijk ja. Ja, dan krijg je daar 84 opmerkingen over. En denk ik, wat moet je daarmee? Er zijn altijd mensen die het beter weten dan de arts en dan denk ik of brand je daar nou niet de vingers aan. -PT6"*. Nonetheless, several patients mention that the extent to which a decision is based on the opinion and experience of their physician heavily depends on their relationship with the physician, with the duration of the relationship being a key factor of influence (PT7).

Patient preferences with regards to the type of EQ-5D data used to support decision-making

None of the participants had any prior experience with completing the EQ-5D questionnaire although most participants were familiar with the domain scoring system and the VAS system themselves. Many participants found the EQ-5D questionnaire easy to comprehend and that completing the EQ-5D did not require a lot of time. No participants experienced any major difficulties while completing the EQ-5D questionnaire.

Nine out of ten participants preferred filling in the descriptive system of the EQ-5D over the VAS score. The two most common reasons for this preference were 1) the ability to simply select from predetermined answer categories that correspond best to the patients' current situation. The descriptive system provided patients with clear examples of health scenarios and was found to be better comprehensible. *"Nou omdat daar natuurlijk al antwoorden staan die van toepassing kunnen zijn. Dat is dan alleen maar even een vinkje zetten en klaar. -PT10"*. The second reason for preferring the descriptive system over the VAS system was 2) that dividing a more general term such as 'your health today' into smaller subcategories (i.e., Mobility, Self-care, Usual activities, Pain/Discomfort, and Anxiety/Depression) grants patients the ability to specify in what health domain they experience problems (PT3 and PT7). *"Ja, ik denk toch wel indelen. Dat je dan toch wel meer kan specificeren. -PT3"*.

The VAS system was preferred by PT6 who indicated that this allowed for more precision. Terms such as 'slight' or 'moderate' in the descriptive system were difficult to comprehend and depend on the perception of each individual person according to PT6. *"Als je die andere vragen hebt, wat is er matig? Matige pijn... dat is voor jou anders dan voor mij. -PT6"*. Other participants experienced several difficulties with the VAS system. Although assigning a score itself was perceived as a simple task, some had troubles when assigning a VAS score. They indicate that it is quite difficult and might be too complex to reliably score their health and distinguish what results in a score of 75 or 80 (PT2, PT3, PT5 and PT9). The definition of health in general was found to be too broad resulting in difficulties when comparing individual scores (PT2 and PT5). Moreover, according to PT5, an additional comment field to further explain the rationale for assigning a specific score would be necessary.

Most patients preferred to discuss the EQ-5D outcomes with their physician after they completed the EQ-5D questionnaire. Even though the outcomes produced by the questionnaire were found to be non-specific by the patients, most report that they would like to use the EQ-5D results in their care pathway. Several experienced benefits of using the EQ-5D include patients feeling more prepared prior to their consult (PT5), a more structured dialogue between the physician and patient (PT9), and increased awareness of the patients' current health condition (PT6).

Patient preferences with regards to visualization of EQ-5D data in terms of format and level of detail

Overview of the EQ-5D visualization and patient interpretation

In general, all patients preferred that their PROM outcomes were reported back to them. Bar charts were used to visualise outcomes and all bar charts are displayed in figure 5. Figure 5A was used as a starting point in which patients were asked to explain what outcomes were presented to them. Following this question, further visualization options were evaluated which are also displayed in

Figure 5. The included bar charts in this figure only represent the EQ-5D descriptive system since most participants preferred the descriptive system over the EQ-5D VAS. 7 out of 10 participants were able to correctly interpret the bar chart. PT6 and PT8 both thought that the chart also represented averages. Furthermore, PT8 and PT10 misinterpreted the score direction of the chart as they experienced a lower score to represent a better EQ-5D descriptive outcome.

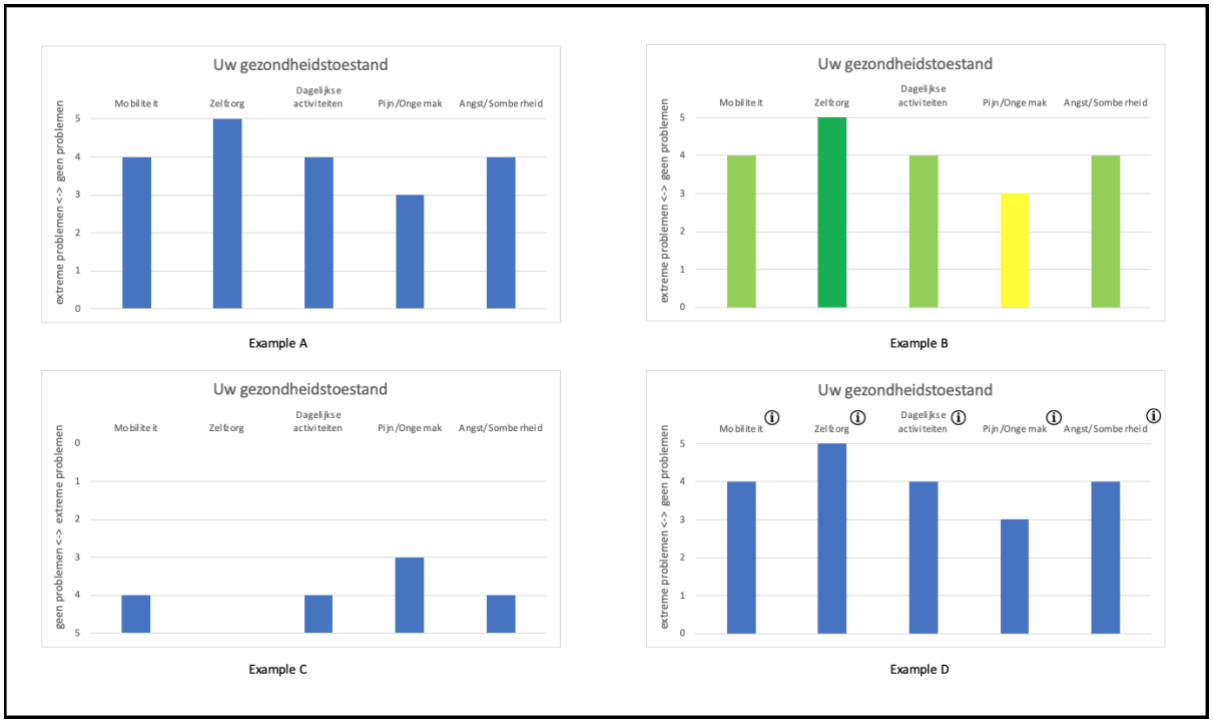

Figure 5: different visualization formats

Patient preferences for the visualizations' level of detail

Preferences for scoring range and score direction differed with 6 versus 4 participants preferring a higher score to represent better health outcomes (Figure 5A). Moreover, these 6 participants all indicated that better health outcomes should be displayed by higher bars within the chart. 4 out of 10 participants stated that a lower score should indicate better health outcomes. In addition to a lower score indicating a better health outcome, PT2, PT3 and PT4 mention that a perfect EQ-5D outcome should be represented by a completely empty graph and only if score deviations did arise that the bars should be displayed (Figure 5C). However, PT7 also favoured a reversed score direction but did prefer higher bars in the bar charts indicating a better health outcome and only wanted to reverse the scoring range (e.g., 0 indicating better health outcomes and 5 indicating worse health outcomes).

The original bars in the bar chart displaying EQ-5D data were presented in a blue colour. This was found to be calming and easy to understand by most participants. *"Ik vind zo de kleur blauw, dat vind ik wel prettig. Het is rustig en duidelijk. -PT2".* Nine participants were asked if they valued having multiple colours (e.g., green, yellow, orange, and red) or shades highlighting better or worse PROM outcomes (Figure 5B). Four participants found that colour highlights provided an easy overview of important scores and allowed for a simpler interpretation. An additional four participants did not experience benefits of colour highlights but indicate that it might be helpful for

other patients. They all mention that colour highlights would not hinder them in interpreting their own PROM outcomes. However, PT7 and PT8 both mention that additional colours could further complicate their ability to correctly interpret the bar chart. PT6, PT8 and PT9 explain that by providing detailed information, for instance by using a legend, confusion regarding the interpretation of the bar chart could be reduced. PT1 describes that adding alarming colours such as red and orange, might startle her at first. An alternative highlighting option, i.e., cross or dot hatching was brought up by PT5 since this could help colour blind patients with chart interpretation but was found to hinder other participants (PT6, PT7, PT8 and PT9).

Axis labelling in the EQ-5D descriptive system was found to be useful by all participants. The displayed labels “geen problemen <--> extreme problemen’ and “Uw gezondheidstoestand” for axis labelling in the EQ-5D descriptive system were found to be easy to understand by all participants and did not result in further comments. In the EQ-5D VAS, PT6 reports that she would prefer “slecht naar goed” instead of perfect health as she feels that perfect health cannot be achieved. Several participants further indicate that the specific date on which they completed the PROM questionnaire should be displayed.

The domains within the descriptive system were all named according to the EQ-5D questionnaire. This resulted in the following labels: mobiliteit, zelfzorg, dagelijkse activiteiten, pijn/ongemak, en angst/somberheid. These labels were generally interpreted correctly, however some participants indicate that it would be helpful if an information button or an additional legend containing a small explanation of what the EQ-5D domain represents was added (Figure 5D). PT8 describes that this might be beneficial since patients often forget what the domain represents.

Patient preferences for the visualizations’ level of detail over time or in comparison to peer groups

In terms of visualising the EQ-5D outcomes over time and as a comparison between the patient and peer groups consisting of similar patients, 9 out of 10 preferred the EQ-5D descriptive system over the EQ-5D VAS in clinical care. 8 out of 9 participants stated that they favoured bar charts of line graphs (Figure 6A). One participant favoured the line graphs over the bar chart (Figure 6B). For the EQ-5D VAS a bar chart was also preferred over a line graph.

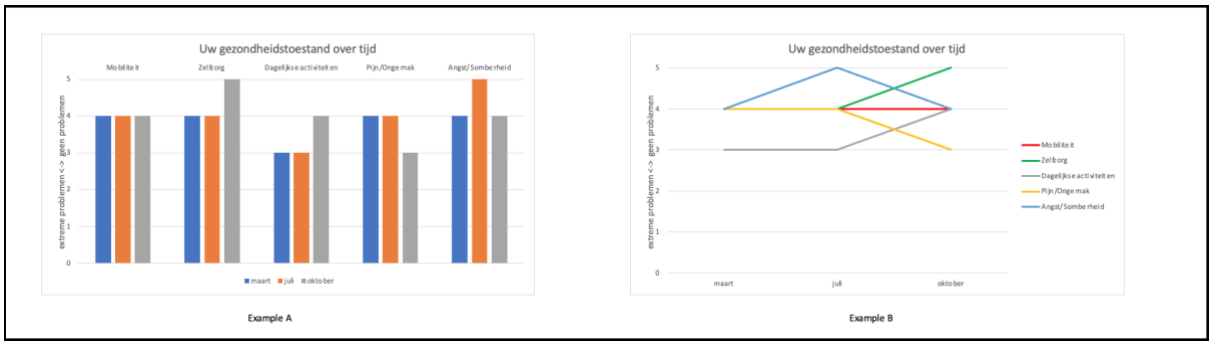

Figure 6: different visualization formats for score comparison over time

Most participants report that line graphs containing multiple EQ-5D domains were too complicated. This was due to overlapping lines resulting in a cluttered image. However, this changes if longer time periods were compared (i.e., multiple years) in which some participants did prefer line graphs over

bar charts since some report that at this point outcomes represented by bar charts would become difficult to distinguish (PT2, PT3 and PT5). PT2 mentioned that this option would become useful if data over at least 1,5 years were to be compared. Separated line graphs were demonstrated as an alternative option but were not preferred by the participants. Most indicate that all domain scores should at least be represented in one graph. PT4 explains that this could be solved by using a dynamic selection system in which she can manually filter the different EQ-5D domains that are most relevant to her. *"Ja, dus misschien de opties die voor mij niet van toepassing zijn, bijvoorbeeld voor mij vandaag angst en somberheid, die heb ik nooit. Dan kan ik dat even uitzetten. -PT4"*. Despite her solution, she still prefers displaying the EQ-5D data in a bar chart.

Physician group

Physician group characteristics

Participants in the physician group were approached using a snowball sampling method. A total of 8 physicians were invited of whom 5 agreed to participate. All participants completed the full duration of the interview on a first-come, first-served basis. This group consisted of mostly males (N=4) compared to one female (N=1). Mean experience in the current role was 10,6 years (± 4,5). Furthermore, all were attending rheumatologists, and some had additional functions (e.g., providing education to students and chief technical operations). 4 out of 5 participants (N=4) were primarily practising in regional medical centres and one in an academic centre. A summary of the patient characteristics is displayed in Figure 7.

Pseudonym	Gender	Type of institution	Clinical role	Type of work	Experience in current role (years)
RA1	Male	Academic	Attending clinician	Inpatient rheumatologist	5
RA2	Male	Regional	Attending clinician	Inpatient rheumatologist	12
RA3	Male	Regional	Attending clinician	Inpatient rheumatologist	17
RA4	Male	Regional	Attending clinician	Inpatient rheumatologist	8
RA5	Female	Regional	Attending clinician	Inpatient rheumatologist	11
Mean	-	-	-	-	10,6
Standard Deviation	-	-	-	-	4,5

Figure 7: summary of physician characteristics

Physician perspectives on the usefulness of PROM data in the clinical encounter

What PROMs are used?

All physicians report that they currently use PROMs. The main uses for PROMs by physicians were in a clinical setting, for benchmarking, and research purposes. RA1, RA2 and RA5 report that the administered PROM questionnaires mainly cover the International Consortium for Health Outcomes

Measurement (ICHOM) domains for inflammatory arthritis. The most common PROM questionnaires were the Health Assessment Questionnaire (HAQ) (N=4) and the VAS for pain (N=3). Furthermore, RA1 and RA3 both report that the VAS for fatigue is currently being used in patient care. RA1 mentions the use of the EQ-5D index value. RA2 further reports that the disease activity score (DAS) is used and RA3 uses the 36-item Short Form Health Survey (SF-36). Moreover, the EQ-5D descriptive system is being used by RA5.

How do physicians experience PROMs?

The physicians mostly report positive effects of administering PROM questionnaires. Most physicians explain that the consultations are more to-the-point and cover a wider range of topics (RA1, RA2, RA3 and RA4). RA4 reports that he feels better prepared prior to the consultation. *"Als je het eenmaal doorhebt en je bekijkt dat even voordat je de patiënt naar binnen roept, ja dan heb je al globaal wel een indruk over hoe de vork in de steel zit. -RA4"*. Interestingly, RA4 addresses that once a physician is used to incorporating PROMs, this could further reduce the time required for the consultation. Furthermore, by simply addressing standard topics as described by a protocol or only viewing patient problems using a medical perspective, RA1 and RA2 feel like that would sell patients short. RA3 and RA5 further illustrates that although using pure medical perspectives such as the erythrocyte sedimentation rate might be clinically relevant, they do not directly correspond to how a patient experiences their disease activity in terms of pain, stiffness, or dependency on others (i.e., HRQoL). They further explain that PROMs must be collected in order to evaluate if a treatment contributes to improved HRQoL for the patient. When asked about how RA1 and RA2 thought that patients would experience completing PROMs, both describe that patients face mixed feelings about PROMs since they feel that PROMs can result in additional burden on the patient. However, RA2 also mentions that patients are able to significantly broaden their view on how they perceive health. He explains that patients can usually focus too much on one specific health domain and thus create mismatches between what a physician establishes and what the patient actually experiences. By administering PROMs, patients are less likely to primarily focus on one health aspect and remain open minded in expressing their concerns during the consultation. A similar experience was shared by RA1. Additional benefits of collecting PROMs were identified as useful for research purposes and the ability to benchmark PROM outcomes across internal departments or external healthcare organisations. However, this proved to be quite controversial due to differences in case-mix and is currently outside of the scope of this study.

Several disadvantages of collecting PROMs were identified. The first being that the frequency in which PROMs are collected along with the length of the questionnaires themselves can be a substantial burden on patients. This was reported by all interviewed physicians, who indicate that collecting PROMs prior to a consultation would yield in sufficient information and do not require PROMs to be collected more frequently. RA3 mentions that ideally all PROM results can be shared across different hospital departments. He feels that this could reduce the amount of administered PROM questionnaires and thus the burden on patients, as most HRQoL questionnaires cover the same health domains anyway and HRQoL does not change over a small period of time. A secondary pitfall of PROMs is that the surveys are not very responsive (RA3 and RA5). Most PROM surveys have a long history since their introduction. With the rapid changes in patient populations and treatment efficacies over the past few decades, a lot of surveys do end up with ceiling or floor effects. *"De meeste instrumenten die zijn weinig responsief he, dat zijn vaak instrumenten die 20 jaar geleden ontwikkeld zijn met de populaties van 20 jaar geleden. Dus het functioneringsniveau van onze patiënten is nu gigantisch veel hoger dan het functioneringsniveau van mensen 20 jaar geleden omdat we gewoon veel betere behandelingen hebben gekregen. Dat betekent dat je in de instrumenten die we nu gebruiken heel veel bodem en plafond effecten ziet. -RA3"*. Furthermore, RA3

explains that several of the currently used PROM questionnaires do not correlate with the required or expected functionalities in our contemporary society. *"Dus de HAQ-vraag bijvoorbeeld: kan je in en uit bad komen? Ja, niemand heeft een bad. Iedereen gaat dus gewoon onder de douche he. Of kun je een pond suiker op een plank leggen? Ja, dat is natuurlijk heel abstract terwijl je eigenlijk zou moeten vragen: kun je je smartphone bedienen? Dat is natuurlijk veel meer een relevant construct voor fysiek functioneren voor patiënten nu. -RA3".*

A third drawback in collecting PROM data was reported by RA3 and RA4. They mention that most PROM surveys have a static nature. Patients are frequently asked to complete the same surveys, containing the same questions as previously completed surveys for consultations in the past. RA4 explains that this process can result in survey fatigue and thus may compromise a patients' answers. By providing more dynamic questionnaires such as computer adaptive testing (CAT questionnaires), patients are being challenged and might be better motivated (RA3, RA4). RA1 further reports that the various treatment options often do not yield in one single best solution, and the best treatment for a patient is not always the one that results in the best PROM outcomes. He provides an example: *"Iemand die graag reist die zal je minder snel een prik geven bijvoorbeeld en dan hebben die PROMs daar helemaal geen... die zijn daarop niet van toedoen. -RA1"*. Additionally, RA5 illustrates that conducting PROMs offer patients a chance to express their feelings and health problems without directly having to open themselves towards a physician. She explains that while conducting PROMs may help some patients in feeling more comfortable to express feelings or concerns, one of the pitfalls might be that patients lean towards providing socially desirable answers. This can result in the physician underestimating a patients' health status.

How are PROMs used in clinical decision making?

The physicians included in this study all used PROMs in their clinical consultations. 4 out of 5 physicians report that their patients were asked to complete the PROMs prior to their consultation. RA5 currently does not use PROMs but she explains that this was due to technical changes within the care pathway. She expects that completing PROMs prior to a consultation would be added in the near future. The PROM outcomes were mostly collected in a patient dashboard. All physicians describe that they quickly evaluate the patient dashboard and scan the collected PROM outcomes for deviations or abnormalities. The deviations were then discussed during consultation with the patient. Furthermore, all physicians mention that the PROM outcomes should be shared with patients. Even if the physician thought that there were no problems that required immediate attention, RA4 explains that he always thanks the patients for completing the PROM questionnaire. He emphasizes that this might help in keeping patients motivated to complete the PROM surveys. When asked if the dashboard was always available to the patient, most report that this was not the case. RA1 and RA2 both explain that patients should get their outcomes reported back to them, but express concerns about patients that use their previous scores as benchmarks for how they are currently experiencing their health, which might not accurately reflect a patients' health condition.

All physicians did discuss the PROM outcomes with their patient, this was done by comparing an individual score to the patients' previous score. RA2, RA3 and RA4 indicate that they might see some use for comparing their patients' individual scores to those of similar patients as it could help form patient profiles. These profiles can then be used as references for possible expected treatment outcomes. However, a problem that was mentioned by RA3 is that for this comparison to work, the peer group would have to be comparable to the individual patients' characteristics, i.e., an adequate case-mix must be present. RA3 and RA4 immediately conclude that this is currently not possible due to the enormous amounts of data that would be required. RA2 further explains that they conducted similar studies among their own patient population to understand if this would be helpful for their

patients. He mentions that their patient panel did not experience any added value in comparing themselves with similar peer groups. RA2 clarified that in their study, individual patients only wanted to benchmark their own previous scores.

Experiences with regards to the type of EQ-5D data used to support clinical decision-making

Most physicians (N=4) did currently use some part of the EQ-5D questionnaire in their clinical care. RA3 and RA5 both reported the use of the EQ-5D descriptive system although for RA3 this was not standard protocol. RA1 confirmed he used the EQ-5D index value and RA2 was not able to recall which specific subparts of the EQ-5D were used in their clinical care. RA4 addresses that the EQ-5D was not incorporated in his clinical care since other questionnaires were preferred due to management related decisions made in the past.

All physicians report that PROM questionnaires should at least cover multiple health domains. This is also applicable to the EQ-5D in which all physicians prefer the EQ-5D constructs of the descriptive system over a VAS score representing health in general. The EQ-5D was found to be nonspecific and did not result in detailed outcomes concerning rheumatoid arthritis (RA1, RA2, RA3 and RA4). However, several physicians explain that this could also be experienced as a valuable aspect. For instance, RA1 clarifies that he had an encounter with a patient who was presented with a very low EQ-5D index value but did not report to experience any RA related health problems. When the EQ-5D was discussed with the patient, she explained that she dealt with multiple issues within her social circle. RA1 further explains that the EQ-5D provides physicians with a tool to take a broader approach which sometimes can elaborate on what a patient is experiencing. A similar experience was shared by RA5, who indicated that the EQ-5D descriptive system helped her envision how her patients experience daily functioning instead of only focussing on physical functioning. Moreover, she values the anxiety and depression constructs in the EQ-5D descriptive system since these constructs can be difficult to address during the consultation. Having a completed EQ-5D descriptive system, and mainly the anxiety and depression constructs, provides her with the opportunity to discuss anxiety or depression more easily.

Future trends for PROM use

Furthermore, RA3 feels like future trends in collecting PROMs tend to focus on standardising PROMs across health domains using a more generic approach. This way PROMs can be used across different clinical departments instead of only focussing on condition specific PROM questionnaires. He feels that this might reduce burden on patients and result in a more pleasant experience for patients. He further explains that patient specific problems regarding disease activity would be discussed during consultation regardless of whether the corresponding PROMs were collected. RA3, RA4 and RA5 experience that generic PROM measurements such as the EQ-5D provide sufficient information for an effective consult. “Ik denk dat het gewoon een mooi begin van het gesprek met de patiënt ook weer is. Dus dat zou ik niet helemaal nog verder uitzoeken dan, dat zou ik eerder in het gesprek doen eerlijk gezegd. -RA5”. Moreover, RA1 finds that the EQ-5D should be complemented with additional PROMs that contain more condition specific constructs but did emphasise that the EQ-5D offers valuable information within clinical care. RA2 did not experience the EQ-5D to offer any additional value.

Discussion

In this exploratory study, we aimed to improve our understanding of how EQ-5D data can be used to support individual patient decisions in the clinical encounter. We found that all participants in both the patient and physician group experienced positive effects of collecting and using PROM data in the clinical encounter. Our findings are in line with those of Yang et al. who performed a systematic review which aimed to provide a better understanding of the impact of PROM use on patient-clinician communication in oncology [10]. The five main effects, namely 1) feeling more prepared prior to the consultation [26, 27], 2) better structured and more to-the-point consults [28, 29], 3) consultations cover a wider array of health topics [27, 30], 4) increased self-management by feeling more involved in the patients' own care process [31], and 5) patients feeling more empowered to express concerns regarding their condition [27, 32, 33], found in our study were also observed in the included studies reviewed by Yang et al. Another study further reports that discussing patient outcomes between the patient and physicians leads to increased perception of PROM benefits [34].

Several patients in our study describe that they prefer to always have access to their PROM outcomes. Some explained that they wanted to use completed outcomes from the past as reference to how they were currently experiencing their health. This differed from statements made by most of the physicians who explain that patients having access to their PROMs could result in distorted outcomes. To the best of our ability, no studies were found that confirmed nor contradicted these findings. Future research may focus on examining if access to previous completed PROMs does affect how patients report current health outcomes.

Collecting PROMs did also result in some negative effects such as increased burden on the patient due to the frequency of collecting and the number of PROMS that are being collected. The systematic review by Nguyen et al. found that the most frequent patient-level barrier reported in the literature was the time for patients to complete PROMs [35]. This study was performed in a routine oncology setting and the authors describe that due to the nature of oncologic conditions, patients often undergo multiple time-consuming appointments, procedures, and tests. The time required to complete PROMs may be perceived differently in oncologic conditions compared to RA. Our study also found that if PROMs are collected but not discussed during consultation, this results in less motivated patients to respond to PROMs. This was also reported by Carfora et al. who showed that PROMs were used inconsistently during consultations and found similar results in their systematic review [36]. Moreover, Talib et al. explain that participants in their study doubted whether providers even reviewed their PROM data which results in patients that are less motivated to respond to PROMs. They conclude that although PROMs may have multiple benefits, if providers do not value and use patient-reported data, the benefits may not be fully realized [37].

The EQ-5D was found to be easy to complete by all patients. Some patients indicate that the questionnaire did not allow them to address RA specific problems. These patients explain that although the EQ-5D may be a valuable tool to describe their current HRQoL, they still prefer to address RA specific problems during consultation. This leads them to question the additional benefits that the EQ-5D may offer. Studies by Aiyegbusi et al. and Philpot et al. both found that patients preferred condition specific PROMs over generic PROMs [38, 39]. Aiyegbusi et al. describe that responding to the construct *'anxiety and depression'* in the descriptive system of the EQ-5D would be challenging as these are very different concepts. However, for future use of PROMs, most physicians in our study indicate that they expect a shift towards measuring generic instead of condition specific PROMs. They explain that this reduces the burden of collecting PROMs on patients since generic PROMs can be used across multiple different clinical departments and HRQoL outcomes often do not rapidly change over time [40, 41]. Several physicians further indicate that the

EQ-5D would yield sufficient information prior to the consultation since condition related concerns are discussed with the patient regardless of whether PROMs are complete. This may allow patients to further elaborate on their concerns during consultation and thus still captures the complete scope of the patients HRQoL. This trend is also seen in other approaches for using PROMs in the clinical encounter such as the patient-reported outcome measurement information system (PROMIS). The PROMIS uses more generic items banks to measure symptoms and quality of life indicators applicable to a range of chronic conditions [42, 43, 44]. It shows promising results in terms of measurement precision and reducing burden on patients in self-reported function in RA patients [45]. However, the PROMIS does comprise a significantly larger array of items compared to the EQ-5D. Therefore, further research is required to evaluate what items in generic PROM instruments result in sufficient information for physicians prior to consultation.

As described previously, the EQ-5D was found to be easy to complete by all patients. All, except one participant preferred the descriptive system over the VAS score, as health is subject to various factors and thus can be demanding to describe in a single entity. Both the patient and physician groups explain that they preferred to divide health into multiple domains as it would allow them to elaborate on why a certain score was assigned. This concept is also described by Boateng et al., who indicate that the use of multiple items to measure an underlying construct can lead to more accurate findings [46]. Several participants further experienced difficulties in completing the VAS scale since it was hard to reliably distinguish between a score of 75 or a score of 80. Janssen et al. found similar outcomes and described that this might be due to the respondents mentally dividing the VAS continuum into a smaller number of segments, a concept first described by Preston & Colman [47, 48].

For comparing patients' EQ-5D outcomes, most patients preferred to benchmark their scores to their own previous scores over time. Several patients describe that comparison of individual scores to those of peer or reference groups could be useful in early stages which is consistent with findings by other studies [17, 18]. However, many patients explain that this preference changes over time as most currently do not experience this comparison to be of additional value. Although, allowing patients to specify the peer group in terms of gender, age, time since diagnosis, and co-morbidities did improve the relevance of having access to peer groups. Most patients indicate that 1) they feel that it is too difficult, if not impossible, to compare one patient with another since every patient experiences their condition in a different way. 2) Having knowledge about the scores of others does not affect personal outcomes or experiences. Therefore, this study demonstrates that patient preferences regarding PROM display do change over time and should thus be seen as a dynamic process. It further supports the suggestion made by Albers et al. that developing a dynamic dashboard for PROM feedback, patients and clinicians can change between different graphical visualization formats depending on individual patient preferences may help improve interpretation of PROMs scores [19].

The level of detail for the EQ-5D visualizations were only discussed with patients. Bar charts were considered as easy to understand and most patients were able to correctly interpret the visualization. Scoring range and direction remained inconclusive with several patients preferring a higher score to indicate better health outcomes while other patients preferred lower scores to indicate better health outcomes. In contrast, other studies found more consistent results and observed that higher scores to indicate better health outcomes were more accurately interpreted and more likely to be clear to patients. Albers et al. further suggest that by improving directional consistency and the use of clear label ratings (i.e., consistent scales), PROMs can be presented more accurately which may lead to increased interpretation accuracy by patient and clinicians. Adding clarification options such as colour shading, descriptive labels, clear axis labelling, and brief

definitions of what the PROMs represent were found to be useful by several patients and is in line with findings of others [18, 19, 49, 50]. Some patients in this study did not find these options useful but mention that the options would not hinder their interpretation of the PROM visualization.

This study demonstrates that individual patient preferences for presenting data varies significantly from the type of data that is displayed (i.e., comparison to peer groups or not) to the type of visualization that is used (i.e., using bar charts versus line graphs) and even the level of detail that is proved to support the patients' interpretation. A possible explanation for the inconsistency within our results may be the relatively small sample size. Further research containing larger sample sizes are required to reliably conclude patient preferences for presenting PROM data.

The results of this study should be interpreted with caution due to the use of a relatively small sample size. As a result of time constraints (i.e., several months) only 10 patients and 5 physicians were included in the study. Reliable assessment towards the preferences of clarification options that support patients in interpreting graphical displays could be not achieved. An explanation would be that the explorative nature of the study in which the interview guide was edited and refined based on concepts from previous interviews led to a wider scope and thus did not result in data saturation. To achieve data saturation and conceptualize a theory that is embedded within the collected data, additional interviews will be required to explore additional concepts [20, 24]. However, the study did successfully identify several factors that influence patient preferences with regards to the visualization of EQ-5D data in terms of format and level of detail. Future studies should focus on the impact that these factors have on patient interpretation accuracy of the EQ-5D.

Our study did not include patients with limited health literacy which may limit this study's results. All patients had prior experience in completing PROMs and most patients had a higher level of education compared to the Dutch mean population [51]. Differences in health literacy levels can result in different preferences in HRQoL visualizations [52]. Some patients with limited levels of health literacy may not understand the connections between different graphical elements nor the longitudinal nature of data presented from left to right [53]. Therefore, health literacy should be included as a factor in studies dealing with data interpretation and can be measured using the validated Health Literacy Questionnaire (HLQ) [19, 54].

Conclusion

PROMs provide valuable information to both patients and physicians. This study's findings illuminate that implementing the EQ-5D may contribute to richer consultations in rheumatoid arthritis related care. To improve the usefulness of discussing the EQ-5D outcomes, dividing HRQoL into multiple domains was preferred over a single score representing all aspects of HRQoL. Adding individual comparison over time or comparison to peer groups may support interpretation by patients. Clear axis labelling, adding colour shading and standardizing scoring range and directional proved to be essential elements in improving interpretation of scores during clinical encounters. The study further demonstrates that preferences regarding visualization of EQ-5D scores can change over time. Therefore, the solution in optimally presenting EQ-5D outcomes to patients and physicians may lie in dynamic visualization formats.

Disclaimer

The interviewer did not have any personal relations to the participants included in this study. All participants were informed about the researchers and the study's aims and goals in a patient information letter.

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Conflict of interest

The authors declare that there are no financial or other conflicts of interest.

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Appendix A

Patient information folder

Proefpersoneninformatie voor deelname aan onderzoek

Hoe moet informatie over verwachte uitkomsten van een behandeling voor patiënten er uit zien?

Officiële titel: Preferences and needs for presenting PROM data to inform patients about expected health outcomes in order to support Shared Decision-Making in clinical practice

Inleiding

Beste meneer/mevrouw,

Met deze informatiebrief willen we u vragen of u wilt meedoen aan ons onderzoek. Meedoen is vrijwillig.

In deze brief worden drie dingen uitgelegd.

1. Waar gaat het onderzoek over?
2. Wat betekent het om mee te doen?
3. Wat zijn de voordelen en nadelen

Het is veel informatie. Dus neem rustig de tijd om de informatie door te lezen. Daarna mag u kiezen of u mee wilt doen. Als u wilt meedoen, kunt u het formulier doornemen dat u vindt in bijlage B. Dit wordt tijdens het interview met u besproken.

Stel uw vragen

U mag mij altijd mailen of bellen als u vragen heeft. Het zou ook goed zijn als u de volgende dingen doet:

- Praat met uw partner, familie of vrienden over dit onderzoek
- U kunt vragen stellen aan een onderzoeker die niet betrokken is bij dit onderzoek. De contactinformatie staat bij onafhankelijke deskundige weergegeven.
- Informatie lezen op www.rijksoverheid.nl/mensenonderzoek.

1. Algemene informatie
Dit onderzoek wordt uitgevoerd door een Master student Gezondheidswetenschappen aan de Universiteit Twente in samenwerking met een onderzoeker van de Universiteit van Twente. Het onderzoek wordt betaald door de EuroQol Research Foundation.

Voor dit onderzoek vragen we patiënten en zorgverleners om mee te doen.

2. Onderwerp en doel van het interview
Als iemand ziek is, wordt er vaak gekeken naar welke behandeling het beste zou zijn. De patiënt en arts kiezen dan samen welke behandeling uiteindelijk wordt gegeven. Om hier een goede keuze in te maken is het belangrijk dat de patiënt weet wat de verwachte uitkomsten van de behandeling voor hem/haar persoonlijk zijn. We weten nu nog niet hoe deze informatie eruit moet zien zodat patiënten en artsen het gemakkelijk kunnen gebruiken bij het maken van een goede keuze. In dit onderzoek gaan we daarom kijken naar het geven van informatie aan patiënten over uitkomsten van een behandeling. We willen graag weten hoe deze informatie er volgens u uit moet zien. Als we dit weten kunnen we namelijk een hulpmiddel maken die deze informatie op een goede manier aan artsen en patiënten laat zien. We hopen dat dit patiënten helpt om samen met hun arts een keuze te maken welke behandeling het beste voor ze is.

3. Vertrouwelijkheid en anonimiteit
Uw gegevens worden geanonimiseerd uw privacy te beschermen. Dit betekent dat uw persoonlijke gegevens niet worden gekoppeld aan de gegevens die wij in het onderzoek verzamelen. Daarnaast kan niemand in rapporten of publicaties terughalen dat het over u ging.

Alleen de onderzoeker heeft toegang tot uw naam en contactgegevens. Deze worden na uw deelname aan het onderzoek verwijdert, tenzij u aangeeft ook aan andere onderzoeken deel te willen nemen.

4. Resultaten van de interviews
Uw antwoorden op de vragen uit dit interview worden verzameld, gebruikt en tot slot bewaard om de vragen van dit onderzoek te kunnen beantwoorden en de resultaten te kunnen publiceren. Uw antwoorden zullen middels video-opnames worden verzameld.

De resultaten en uw gegevens zullen voor een periode van 10 jaar worden bewaard op een beveiligde locatie aan de universiteit van Twente. Deze termijn is wettelijk vastgelegd voor wetenschappelijk onderzoek.

5. Randvoorwaarden
Deelname aan het onderzoek is geheel vrijwillig. U mag op elk moment gedurende het onderzoek stoppen. U ontvangt geen financiële vergoeding voor uw deelname aan dit onderzoek.

U heeft zelf geen voordeel van meedoen aan dit onderzoek. Als u wel meedoet aan het onderzoek, helpt u ons als onderzoekers. Door de informatie die u ons geeft, kunnen patiënten en artsen samen beter keuzes maken voor de behandeling van de patiënt.

Het nadeel dat u kan ervaren als u meedoet aan het onderzoek, is de tijd die het u kost om met de onderzoeker te praten.

6. Duur van het interview
Het interview zal online worden afgenomen en zal in totaal ongeveer één uur of 60 minuten duren. Na een half uur of 30 minuten zal een korte pauze plaatsvinden waarbij u zult worden gevraagd naar of u nog voldoende energie heeft om door te gaan.

7. Vragen

Vragen over het onderzoek kunt u stellen aan de onderzoeker. Heeft u een klacht? Bespreek dit dan met de onderzoeker. Wilt u dit liever niet? Ga dan naar de klachtenfunctionaris van Universiteit Twente. Zijn contactgegevens vindt u in bijlage A.

Heeft u voor aanvang van het interview nog vragen of opmerking die u aan de onderzoeker zou willen bespreken?

8. Hoe geeft u toestemming voor het onderzoek?
Nadat u de informatiebrief heeft doorgelezen kunt u eerst rustig nadenken over dit onderzoek. Voor dat het interview begint zal de onderzoeker de informatiebrief nog kort met u doornemen.
Daarna vertelt u de onderzoeker of u de informatie begrijpt en of u wel of niet wilt meedoen. Als u mee wilt doen, dan wordt het interview en de video-opname gestart. Hierna wordt u nogmaals gevraagd of u akkoord bent met deelname aan het onderzoek.

Dank voor uw tijd.

Hartelijke groet,

Eline Beens, onderzoeker aan de Universiteit Twente
Rik Vrolijk, master-student aan de Universiteit Twente

9. Bijlagen bij deze informatie

A. Contactgegevens
B. Toestemmingsformulier

Bijlage A: contactgegevens

Hoofdonderzoeker:	Name: Confidential
	E-mail: Confidential
	Tel: Confidential
Coördinerend onderzoeker:	Name: Confidential
	E-mail: Confidential
	Tel: Confidential
Master student:	Rik Vrolijk
	E-mail: Confidential
	Tel: Confidential
Onafhankelijke deskundige:	Name: Confidential
	E-mail: Confidential
	Tel: Confidential
Klachten:	Name: Confidential
	E-mail: Confidential
	Tel: Confidential
Functionaris voor de Gegevensbescherming:	Name: Confidential
	E-mail: Confidential

Voor meer informatie over uw rechten kunt u contact opnemen met de hoofdonderzoeker.

Bijlage B: toestemmingsformulier proefpersoon

Behorende bij het onderzoek: *Hoe moet informatie over verwachte uitkomsten van een behandeling voor patiënten er uit zien?*

- Ik heb de informatiebrief gelezen. Ook kon ik vragen stellen. Mijn vragen zijn goed genoeg beantwoord. Ik had genoeg tijd om te beslissen of ik meedoe.
- Ik weet dat meedoen vrijwillig is. Ook weet ik dat ik op ieder moment kan beslissen om toch niet mee te doen met het onderzoek. Of om ermee te stoppen. Ik hoef dan niet te zeggen waarom ik wil stoppen.
- Ik geef de onderzoekers toestemming om mijn gegevens te verzamelen en gebruiken. De onderzoekers doen dit alleen om de onderzoeksvraag van dit onderzoek te beantwoorden.

Wilt u in de tabel hieronder ja of nee aankruisen?

Ik wil meedoen aan dit onderzoek	Ja ☐	Nee☐
Ik geef toestemming om mijn gegevens te bewaren om dit te gebruiken voor ander onderzoek, zoals in de informatiebrief staat.	Ja ☐	Nee☐

Mijn naam is (proefpersoon): .....

Handtekening: ..... Datum : __ / __ / __

Ik verklaar dat ik deze proefpersoon volledig heb geïnformeerd over het genoemde onderzoek.

Wordt er tijdens het onderzoek informatie bekend die die de toestemming van de proefpersoon kan beïnvloeden? Dan laat ik dit op tijd weten aan deze proefpersoon.

Naam onderzoeker (of diens vertegenwoordiger):.....

Handtekening:..... Datum: __ / __ / __

Aanvullende informatie is gegeven door:
Naam:.....
Functie:.....

Handtekening:..... Datum: __ / __ / __

De proefpersoon krijgt een volledige informatiebrief mee.