

The use of outcome data in patient consultations from the healthcare professionals' and patients' perspectives: A mixed methods study

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ARTICLE INFO

Keywords:

Outcome data

Patient participation

Shared decision-making

Patient consultations

ABSTRACT

Objectives: To gain insight into healthcare professionals' (HCPs') perspectives on the use of outcome data in consultations and to understand which aggregated outcomes patients find important.

Methods: This study had a mixed-methods design and consisted of two steps:

1. HCPs (n = 11) were interviewed about the use of outcome data in consultations. Thematic analysis was used for data analysis.
2. Patients with prostate cancer, lung cancer, and inflammatory bowel disease (IBD) completed questionnaires (n = 283) to identify important outcomes. Descriptive statistics were used for data analysis.

Results: HCPs indicated that aggregated outcome data are not routinely used in consultations. They pointed out various barriers to using outcome data, e.g., low response rates of PROMs, and suggested actions to address these barriers, including training of HCPs in outcome data usage. Patients rated the majority of aggregated outcomes as important, although preferences differed between the studied health conditions.

Conclusion: Both HCPs and patients underscored the importance of discussing outcome data in consultations. Nevertheless, HCPs encountered several barriers to using outcome data. Furthermore, patients with different health conditions have somewhat different information needs.

Practice implications: The study identified several actionable steps to enhance the collection and application of outcome data in consultations.

1. Introduction

Value based health care (VBHC) is a healthcare model dedicated to enhancing quality of care, while containing or reducing healthcare costs. In the shift toward a VBHC system, the focus is on maximizing value for patients, where value is defined as outcomes relevant to patients relative to the costs needed to achieve these outcomes [1]. With the introduction of VBHC, outcome data at the level of health conditions have become available [2]. These outcome data encompass clinical outcomes, such as

blood test results, and patient-reported outcomes, such as quality of life [3–5]. Outcome data can be used at the organizational level for quality improvements and to benchmark between healthcare providers [6], or at the individual level to inform the patient, monitor their health status, and support shared decision-making (SDM) in patient consultations [7].

There are two types of outcome data: 1) individual outcome data, i.e., data from one patient, and 2) aggregated outcome data, i.e., data derived from a group of patients. Patient consultations mainly focus on the patient's individual outcome data to track their personal health

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¹ Retired.

<https://doi.org/10.1016/j.pec.2023.108043>

Received 17 March 2023; Received in revised form 23 October 2023; Accepted 28 October 2023

Available online 31 October 2023

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status and quality of life. Meanwhile, aggregated outcome data are mainly used in the context of quality improvement and benchmarking, offering insights into group-level outcomes that can be compared across institutions or over time [8]. However, they can also be used in patient consultations to support SDM, for instance by developing patient-like-me models that predict personalized outcomes based on data from similar patients [9,10].

To effectively use both types of outcome data in patient consultations, two essential factors come into play: active patient participation and training for HCPs. First, active patient participation is needed to select outcomes that are relevant to patients and match their information needs [11]. Current outcome measures are often determined by healthcare professionals (HCPs) without asking patients about their relevance [12]. Moreover, since outcome measures are mostly selected to be used for quality improvement and benchmarking [13–15], these outcomes might not be relevant to discuss in individual patient consultations. Second, training HCPs on how to use outcome data in a meaningful way is a crucial step in the implementation of outcome data in patient consultations [16,17]. Currently, HCPs often lack the necessary knowledge, skills, and sometimes attitudes for using outcome data in consultations [18].

In recent years, several projects have been initiated in the Netherlands to study and improve the use of both individual and aggregated outcome data in patient consultations, such as the SHOUT study, the QLIC-ON study, and the SOURCE study [17,19,20]. However, it remains unclear whether outcome data are used in consultations outside of these projects, and what the perspectives of HCPs and patients are regarding the use of outcome data in patient consultations.

This study aimed to provide a deeper understanding of the use of outcome data in patient consultations in the Netherlands by addressing the following questions: 1) What are HCPs' perspectives on the use of outcome data in consultations?; and 2) Which aggregated outcomes are important to patients and how does that vary across health conditions? The answers to these two questions will provide an integrated view of outcome data usage at the individual patient level and will guide further steps to enhance the use of outcome data in patient consultations.

2. Methods

2.1. Study design

This study employed a mixed-methods design. Using a grounded theory approach, we interviewed HCPs about the use of outcome data in patient consultations. Patients were surveyed to identify which aggregated outcomes they consider important by means of a questionnaire.

2.2. Healthcare professional interviews

The methodology of the qualitative part is described according to the consolidated criteria for reporting qualitative research (COREQ) guidelines [21].

2.2.1. Context

HCPs from the Santeon hospitals were invited for an interview. Santeon is a collaboration of seven non-academic teaching hospitals that collectively strive to improve their care following the principles of VBHC. They are geographically spread throughout the Netherlands, each serving different patient populations. Each hospital has established multidisciplinary Value Improvement (VI) teams for fifteen specific health conditions. The VI teams collect predetermined outcome-, process-, and cost-indicators that are used for benchmarking and improving healthcare quality across all Santeon hospitals [22]. For three health conditions (breast cancer, stroke, and chronic kidney disease) the Santeon hospitals have started a study on the use of outcome data to personalize healthcare (SHOUT-study) [17].

2.2.2. Study sample

We contacted 27 HCPs who had previously participated in a study on patient participation in VBHC via email. The inclusion criterion was: medical specialists and nurses who were part of a VI team and thus had experience with using outcome data for quality improvement and benchmarking. The exclusion criteria were: 1) HCPs from recently started VI teams with limited experience in outcome data collection and 2) HCPs who participated in the SHOUT study [17], as their perspectives might be influenced by their role in the study. Participants were given the choice to conduct the interview face-to-face or via video-conferencing.

2.2.3. Data collection

HCPs were interviewed about the use of clinical and patient-reported outcome data, both at the aggregated or individual level, in patient consultations. See Appendix A for the interview guide of these semi-structured interviews. Participants were requested to provide consent to record the interview, and the interviews were transcribed verbatim using transcription software (Amberscript). The first author (HJW) conducted the interviews, made field notes during the interviews, checked the transcriptions, and sent the transcriptions to the participants for a member check. HJW had previous experience with and training in conducting and analyzing interviews. HJW had no prior relationship with the interviewees.

2.2.4. Data analysis

The qualitative data obtained from the interviews were analyzed through thematic analysis. An inductive approach for the coding was used. To ensure the reliability of the analysis, three randomly selected interviews were double-coded by two researchers (HJW and CCB). Any discrepancies were resolved through a consensus meeting after coding these three random interviews. Given the absence of major discrepancies between the two coders, one researcher (HJW) proceeded to code all the interviews, with the second coder (CCB) performing a cross-check. The themes were organized into a schematic overview and discussed with the co-authors. This overview was sent to the interviewees for a member check. Atlas.ti software was used for qualitative data analysis.

2.3. Patient questionnaires

2.3.1. Study sample

Patients with one of the following three health conditions, i.e., prostate cancer, lung cancer, and inflammatory bowel disease (IBD), were recruited via Dutch patient organizations and online forums (Crohn & Colitis NL, kanker.nl, Prostaatkanker Stichting, Longkanker NL, foundation DUOS). The three health conditions were selected based on variations in chronicity and prognosis, with IBD being an incurable chronic disease, prostate cancer being a slow progressive cancer with a high survival rate, and lung cancer being a more progressive cancer with a lower survival rate.

2.3.2. Data collection

Patients were asked to rate the importance of aggregated outcomes on a 5-point Likert-scale. They were also asked whether they preferred merely being informed about the outcome or desired a discussion with their HCP about that outcome. The questionnaires incorporated outcomes that were collected by VI teams for quality improvement of the corresponding health condition. Examples of these outcomes are survival rate, prostate-specific antigen level, malnutrition, patient-reported fatigue, and pain.

The questionnaires were written in Dutch B1 language level (Common European Framework of Reference for Languages) with the assistance of two linguists. An example of a question of the prostate cancer questionnaire is: *'The number of patients that are incontinent after treatment. Do you find this important information?'* Each question on the

importance of an outcome was followed by the question ‘Do you only want to know this information, or do you also want to discuss this information with your healthcare professional?’ The complete questionnaires and response options are available in Appendix B. Each questionnaire ended with an open-ended question, allowing participants to suggest relevant outcome data that had not been covered in previous questions.

To check whether we had reached an inclusive group of patients with regard to health literacy, the three health literacy questions were added to the questionnaire [23].

2.3.3. Data analysis

Outcomes were considered important if patients rated them with a score of four or five (‘important’ or ‘very important’). Analysis was conducted to examine differences between the three health conditions and the type of outcome data (clinical or patient-reported). Descriptive statistical analysis was performed with Excel. Open text data from the questionnaire were categorized by HJW based on similarities between responses from different patients. To enhance reliability and minimize interpretation, HJW discussed the identified categories with several co-authors.

Inadequate health literacy was determined according to established standards in the literature, where an average score of ≤ 2 (on a 5-point Likert-scale) of the three health literacy questions indicates inadequate health literacy [24].

2.4. Patient and public involvement

Two patient advisors were part of the research team and actively participated in research team meetings. Their involvement spanned all aspects of the study, from grant proposal writing and drafting the patient questionnaire to interpreting the results and co-authoring this article.

2.5. Ethical approval

The research protocol for this study was approved by the ‘Santeon Beheercommissie’ (SDB-2022-004). The Medical Ethical Commission-Utrecht declared that no further ethical approval was needed for this study (W22.213). Each participating hospital also obtained approval from their local scientific committee to ensure feasibility. HCPs provided written informed consent to use and store their data for research. Patients were informed about the use of their answers for research and consented to use and store their data for research by completing the questionnaire. No personal identifiers were collected via the questionnaire.

3. Results

3.1. Healthcare professional interviews

Eleven HCPs were interviewed; see Table 1 for interviewee characteristics. The main reason for non-participation of the contacted HCPs was due to time constraints. The interviews had an average duration of 23 (± 6) minutes, excluding the study’s introduction and explanation. Interviews continued until data saturation was reached.

Five distinct themes emerged from the HCP interviews: importance of the use of outcome data, current use of outcome data, barriers to the use of outcome data, proposed actions, and ambitions and future perspectives (see Fig. 1). Illustrative quotes for each theme are presented in Table 2. Overall, HCPs mostly referred to the use of Patient Reported Outcome Measures (PROMs) when discussing outcome data in general.

3.2. Importance of the use of outcome data

The HCPs mentioned several reasons for the importance of using outcome data in patient consultations. First, outcome data aid in treatment decision-making. Second, the use of outcome data empowers

Table 1
Interviewee characteristics.

Characteristics	N (%)
Total	11
Gender	
Male	4 (36%)
Female	7 (64%)
Function	
Medical specialist	6 (55%)
Nurse (practitioner)	4 (36%)
Physician assistant	1 (9%)
Specialism	
Orthopedics	2 (18%)
Inflammatory Bowel Disease	2 (18%)
Lung cancer	1 (9%)
Prostate cancer	3 (27%)
Diabetes	1 (9%)
Birth care	1 (9%)
Coronary artery disease	1 (9%)

patients to actively participate in their care, by allowing them to monitor their own health status and treatment outcomes. Third, HCPs mentioned that collecting outcome data helps to monitor the patients’ health status over time. PROMs were considered particularly valuable for providing accurate insight into a patient’s health status, since patients can complete the questionnaires at home, which gives a more veracious response of the patient. It was also thought that PROMs facilitate discussions about sensitive topics, since patients do not have to bring these up themselves, and the HCP does not need to carefully introduce the topic. In general, nurses tended to place greater emphasis on the positive aspects of PROMs compared to medical specialists.

3.3. Current use of outcome data

There are variances in the current use of outcome data among HCPs. Aggregated outcome data were predominantly used for quality improvement rather than in patient consultations. The use of individual clinical outcome data, such as monitoring blood values, was seen as common clinical practice, whereas the use of PROMs would require a new way of working according to HCPs. Some HCPs acknowledged that even though PROMs had been implemented for their health condition, they or their colleagues do not consistently discuss them with their patients. HCPs reported the use or development of various tools, such as decision aids or dashboards, to visually present outcome data and to support treatment decision-making based on these data.

3.4. Barriers to the use of outcome data

HCPs encountered several barriers to the use of outcome data. First, they noted a lack of practical support, including IT assistance or dedicated staff responsible for PROMs implementation. Second, HCPs pointed out that the quality of aggregated outcome data is often insufficient to use it in clinical practice, as it frequently originates from a small and non-representative sample of patients. Third, several HCPs believed or experienced that the discussion of PROM data is burdensome, as it can consume additional time, while others believed it might save time. A few HCPs considered PROM outcomes as ‘too soft’ and outside the scope of their responsibilities. Fourth, HCPs mentioned that they prefer traditional conversations with their patient over using tools such as decision aids. Fifth, HCPs indicated that they find it challenging to translate outcome data into treatment decisions. Last, the low response rate of PROMs was cited as a barrier. HCPs identified four possible reasons for the low response rate of PROMs: (1) patients do not see the point of completing PROMs, (2) patients simply forget to complete PROMs, (3) patients lack an incentive to complete PROMs when the HCP fails to discuss them during their consultation, and (4) patients are already burdened with numerous questionnaires.

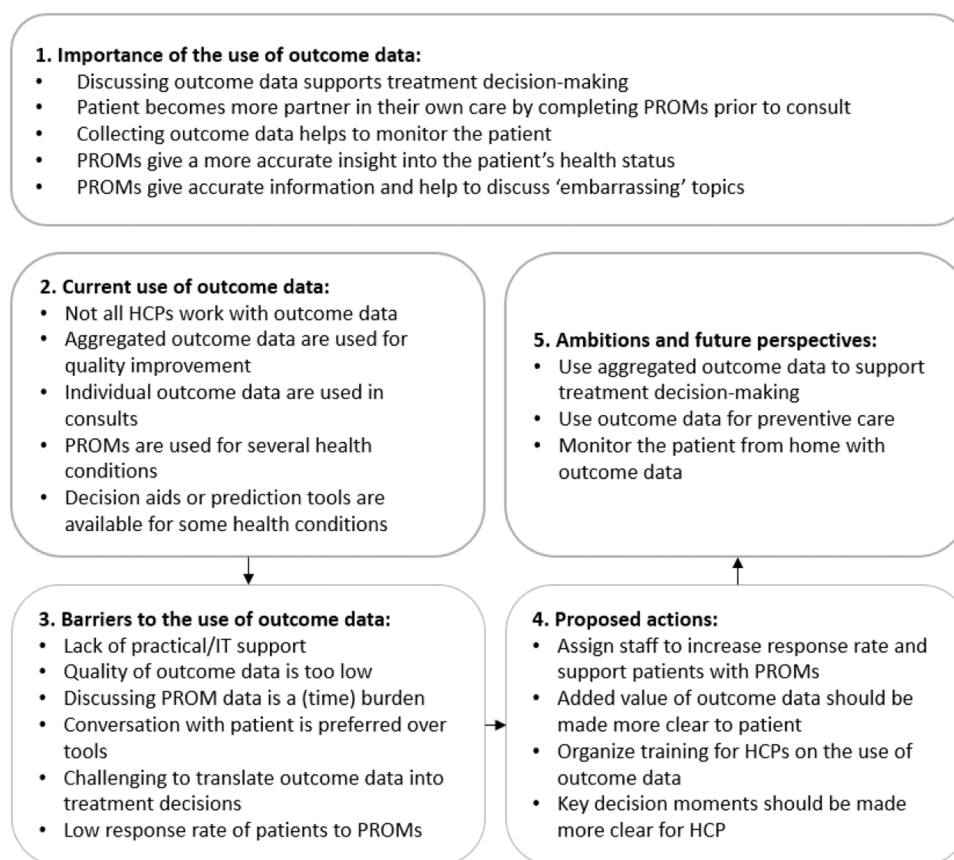


Fig. 1. Themes identified from interviews with healthcare professionals (n = 11). HCP = healthcare professional, PROM = patient reported outcome measure.

3.5. Proposed actions

To solve the abovementioned barriers, HCPs reported the need for support staff to coordinate PROMs, as well as to inform and assist patients with PROM completion. In particular, patients unable to complete PROMs themselves should be offered support, possibly by having someone (e.g., a nurse) present in the waiting room with a tablet to aid patients in completing the questions. Furthermore, HCPs recommended educating patients about the advantages of discussing outcome data in clinical practice to enhance their motivation for completing PROMs. Additionally, HCPs reported a need to be trained on how to effectively use outcome data in consultations (e.g., by having insight into key decision moments).

3.6. Ambitions and future perspectives

All HCPs believed that outcome data will assume a more prominent role in healthcare in the future. They expressed a desire to incorporate aggregated outcome data in patient consultations to support treatment decision-making. They also aspired to use outcome data for preventive care, since it can help them to detect symptoms earlier. HCPs envisioned a future where patients receive more care from home, as outcome data enable the HCP to remotely monitor their patients.

3.7. Patient questionnaires

A total of 283 patients completed the questionnaire. This included 72 patients with lung cancer, 104 patients with prostate cancer, and 107 patients with IBD. Seven of the respondents had low health literacy.

Generally, patients considered the majority (77%) of the aggregated outcome data (encompassing both clinical and patient-reported data) as crucial to support treatment decision-making. When evaluating

individual outcomes, it was evident that lung and prostate cancer patients rated the majority of outcomes, either clinical or patient-reported, as important, while IBD patients tended to prioritize patient-reported outcomes, such as fatigue and pain, over clinical outcomes (see Fig. 2).

Prostate and lung cancer patients expressed the need to discuss most of the patient-reported and clinical aggregated outcomes with their HCP (69% and 76% respectively) instead of solely receiving information about it. In contrast, IBD patients indicated that they wanted to discuss only 42% of all patient-reported and clinical outcomes with their HCPs, and for 40% of all outcomes they were content with merely being informed about them. The majority of outcomes that IBD patients wanted to discuss with their HCP were patient-reported (see Fig. 3).

In the open text fields, patients expressed the desire for more insight into alternative treatment options, future perspectives, the treatment process, personalized treatment outcome expectations, outcomes from different hospitals, and relevant research and trials. Lastly, patients wished to discuss the impact of their disease or treatment on their daily lives, including the impact on relationships and work.

An integrated overview of both the qualitative and quantitative results can be found in Appendix C.

4. Discussion and conclusion

4.1. Discussion

This study underscores the importance of using outcome data in patient consultations from both the HCPs' and patients' perspectives. HCPs emphasized that aggregated outcome data are preliminarily used for quality improvement. Furthermore, since HCPs are used to discussing individual clinical outcomes with their patients, they mainly talked about patient-reported outcome data during the interviews. Patients rated the majority of aggregated outcomes, both patient-reported and

Table 2
Identified themes with quotes from the healthcare professionals interviews (n = 11).

Theme	Quote
Importance of the use of outcome data	<i>"So you can say [to the patient]: 'choose the treatment that you prefer, because now you know what to expect' [based on outcome data]" – Medical specialist 1</i> <i>"The use of a questionnaire that the patient has to complete from home makes it easier [for the patient] to write it [embarrassing symptoms] down, so that I already know this and can bring it up during a consultation instead of the patient [having to bring it up]" – Nurse 1</i> <i>"It [outcome data] is very valuable, because you can give the patient insight in the changes over time" – Medical specialist 2</i>
Current use of outcome data	<i>"I think it [using PROMs] is challenging, because it requires a new way of working. But if you want what is best for the patient, I would recommend using PROMs" – Physician assistant 1</i>
Barriers to the use of outcome data	<i>"Currently we are waiting [with sending out PROMs], because the IT doesn't have staff to support us" – Medical specialist 3</i> <i>"Often I do not have PROMs data available (...) People are not very motivated to complete the questionnaire." – Medical specialist 4</i> <i>"And it is a little time-consuming to prepare and discuss it [PROMs]" – Nurse 2</i> <i>"I do not use it [decision aid] anymore, because the tool was more steering than the conversation with the patient. That did not work for me, to look at the screen with a patient to see what he has answered. I prefer the conversation over the system." – Nurse 2</i>
Proposed actions	<i>"It will only work if you have a nurse that is responsible for the PROMs, but then the money is often lacking" – Medical specialist 5</i>
Ambitions and future perspectives	<i>"When patients can measure their blood sugar from home and send it to us, and they feel fine, that will be advantageous for us, and for the patient too, since they don't have to come to the hospital every time" – Nurse 1</i>

clinical, as important. Nevertheless, the information needs regarding these aggregated outcomes varied among the three patient groups. Meanwhile, the HCPs experienced several barriers to using outcome data in patient consultations, such as low response rates of PROMs. They proposed actions to address these barriers, e.g., assigning staff to assist patients in completing PROMs. Last, both HCPs and patients expressed several ambitions and desires to increase the use of outcome data in consultations in the future.

According to HCPs, several barriers limit the use of outcome data in patient consultations. First, discussing outcome data is believed to be time-consuming, which can be linked to the often mentioned barrier in the literature that SDM is time-consuming [25–27]. However, some HCPs in this study believed that discussing outcome data might actually save time in patient consultations, as it ensures that patients are better prepared for their consultation and that HCPs are more up-to-date on the patient's health status. A recent systematic literature review concluded that SDM, in general, does not necessarily prolong consultations, supporting our finding [28]. Moreover, some HCPs highlighted the challenge of translating outcome data into treatment decisions, indicating a potential misinterpretation of HCPs regarding the use of outcome data, since outcome data cannot be directly translated into treatment decisions, but can be used to support conversations hereon [17]. Last, several HCPs expressed a preference for traditional conversations with their patients over using decision aids. This barrier might show another possible misinterpretation among HCPs, as decision aids are not developed to replace the traditional conversation with the patient, but rather to facilitate more structured and coherent consultations. This allows HCPs to engage in more essential conversations with their patients [29].

According to the HCPs, several actions could be undertaken to enhance the use of outcome data in patient consultations and to address the aforementioned barriers. First, the HCPs suggested that staff is

needed to increase PROM response rates. However, we believe the issue lies not in staff shortages but in the improper integration of PROMs into the workflow. This leads to HCPs forgetting to discuss PROMs, which in turn leads to patients lacking an incentive to complete them. A systematic review already pointed out that this 'design-phase' of PROMs is often overlooked [30]. Furthermore, HCPs stressed the importance of training them on the use of outcome data in clinical practice, which is a recurring recommendation [31–33]. Therefore, widespread training of HCPs in the use of outcome data in patient consultations is imperative. Last, HCPs pointed out the need to have more insight into key decision moments (i.e., important decisions in the patient pathway, such as choosing between surgery or conservative treatment [34]) to recognize when to use outcome data in their consultations. Developing care pathways can aid in identifying these key decision moments [35]. Several of these actions are already undertaken in pending initiatives such as the SHOUT-study [17], indicating that these actions should shift from the research setting to implementation in daily practice. Altogether, these practical suggestions could contribute to improved quality and use of outcome data. Moreover, raising awareness among both patients and HCPs about the importance of using outcome data in patient consultations is essential.

Last, differences in information needs were observed among patients with different health conditions. IBD patients tended to assign lower overall importance to aggregated outcomes compared to lung and prostate cancer patients, possibly because IBD patients often receive personalized treatment [36], rendering aggregated outcome data less informative for them. These patients might benefit from patient-like-me models, where they can gain insight into expected treatment outcomes based on data from patients with similar characteristics and treatments [37,38]. Moreover, prostate and lung cancer patients wanted to discuss the majority of the outcomes with their HCP, while IBD patients indicated that being informed on the outcome data is sufficient. These differences might be explained by the fact that patients with chronic health conditions, such as IBD, are more familiar with self-management than cancer patients [39], and are therefore more used to interpreting and applying information independently. All in all, the different information needs among patients suggest that patients may benefit the most from tailored and personalized outcome information.

There are a few important limitations of this study that deserve consideration. First, our aim was to interview both HCPs and patients, but HCPs were hesitant to recruit patients for the interviews due to their own lack of familiarity with the use of outcome data in consultations. Consequently, our results provide insight into which outcomes are important to patients, but not into how to use and when to discuss them in clinical practice from the patient's perspective. Research has shown that the method of communicating outcome information significantly influences how patients perceive it [40,41]. Second, we aimed to include an inclusive sample of patients, including patients with low health literacy, by simplifying questionnaire language and distributing the questionnaire via different forums and platforms, but only seven patients with low health literacy responded to our questionnaire. However, we believe that having low health literacy does not affect the type of outcomes that is important to these patients, but rather influences the method of how these outcomes should be used, discussed, or provided to them. Future studies should therefore include a larger number of patients with low health literacy potentially by employing more inclusive research methods, such as graphical presentations instead of text-based questionnaires. Third, our study exclusively focused on the use of outcome data in Dutch hospitals. While our findings offer important insights, we recognize that the current state of outcome data collection and usage varies greatly between countries. For instance, a review on the implementation of PROMs in Western countries revealed a significant concentration of relevant articles from the Netherlands, suggesting that the Netherlands might be ahead in the collection of PROM data compared to other countries [42]. Last, we found some differences in perspectives among different types of HCPs, including specializations

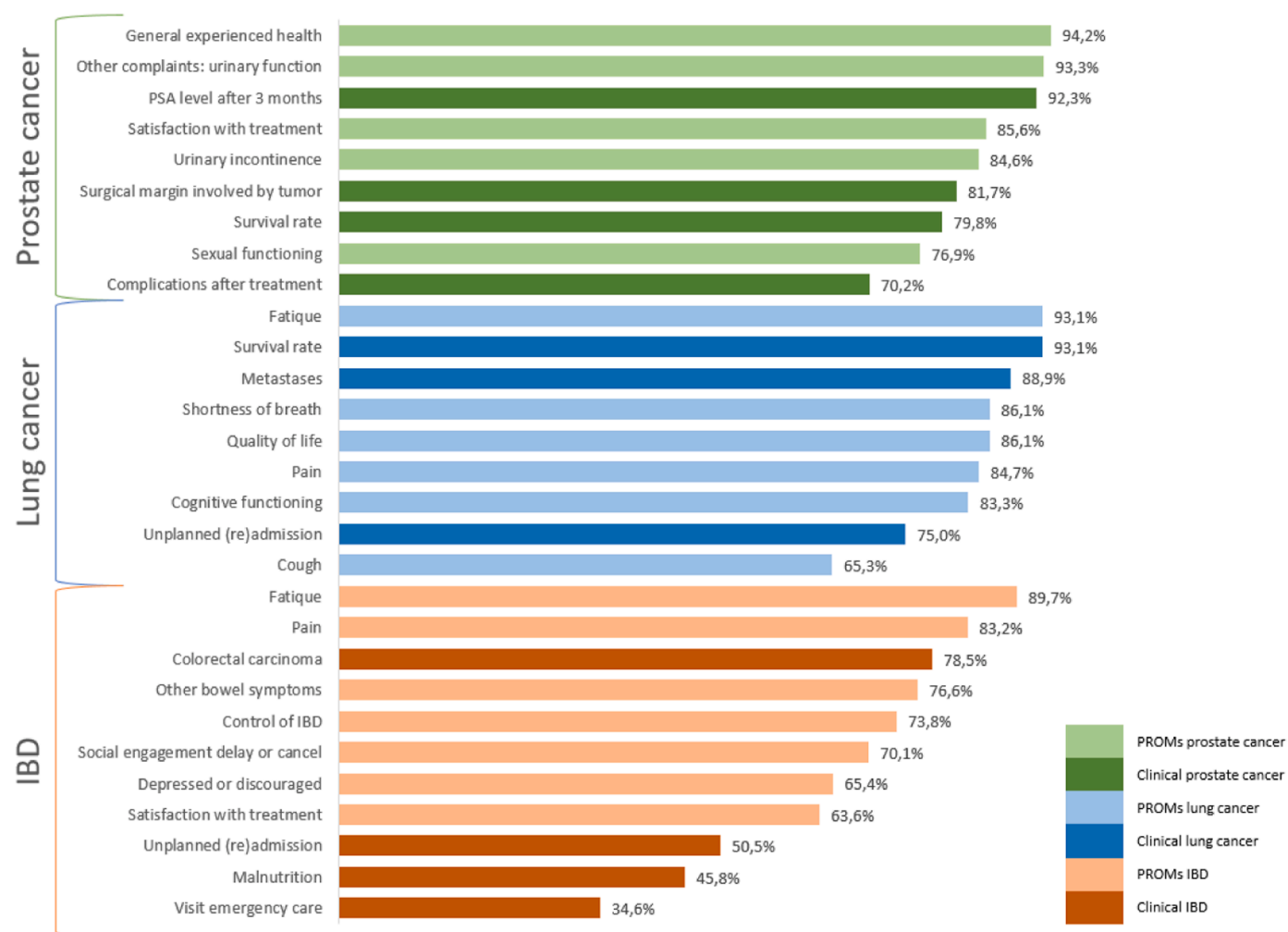


Fig. 2. Percentage of patients who rated outcome as important or very important for three health conditions. PROMs= patient reported outcome measure. IBD= inflammatory bowel disease.

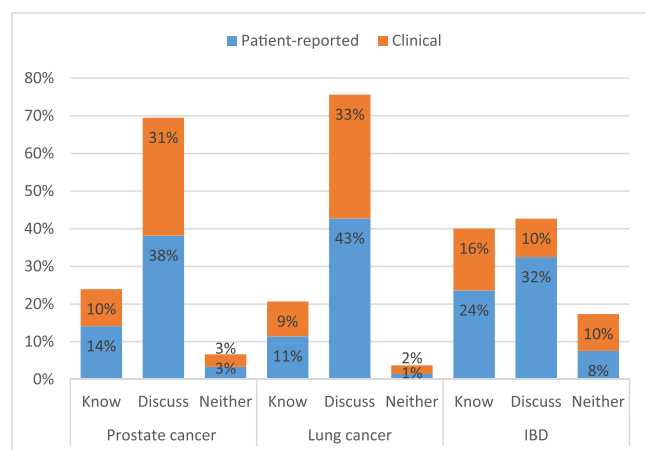


Fig. 3. Percentages of total of outcomes that patients want to know or also discuss with their healthcare professional for three health conditions. IBD= inflammatory bowel disease.

and roles. We believe that it is a significant topic that warrants further in-depth investigation in future studies.

5. Conclusion

This study shows that aggregated outcome data are often not used in patient consultations, despite the importance patients and HCPs attach to having insight into this type of data during consultations. Furthermore, the information needs of patients concerning outcome data differs between different health conditions. Currently, HCPs encounter several barriers to using outcome data in patient consultations and propose multiple actions to address these barriers.

5.1. Practice implications

Practical steps to enhance the use of outcome data in consultations include training of HCPs on the use of outcome data, and the integration of PROMs into the workflow to ensure that HCPs consistently discuss them, which in turn would result in an incentive for patients to complete them. Moreover, HCPs should receive better guidance on how to use outcome data in patient consultations, as several misconceptions about their usage were identified. Overall, the results of this study can be used to improve the use of the different types of outcome data in patient consultations. Future studies should focus on patients' perspectives regarding outcome data selection, collection, presentation, and usage in consultations.

Funding

This work was funded by the Netherlands Organization for Health Research and Development, ZonMw [05160472110004], and contributed to the national program for value-based healthcare of the Dutch Ministry of Health, Welfare, and Sport. ZonMw was not involved in the collection, analysis and interpretation of the data, writing of the report, or decision to submit the article for publication.

CRediT authorship contribution statement

Henrike J. Westerink: Visualization, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization, Writing - original draft, Writing - review & editing. **Cato C. Bresser:** Formal analysis, Writing - review & editing. **Mirjam M. Garvelink:** Supervision, Methodology, Funding acquisition, Formal analysis, Conceptualization, Writing - review & editing. **Cornelia F. van Uden-Kraan:** Supervision, Methodology, Funding acquisition, Formal analysis, Conceptualization, Writing - review & editing. **Ouisam Zouitni:** Methodology, Formal analysis, Writing - review & editing. **Hans A.J. Bart:** Methodology, Funding acquisition, Formal analysis, Conceptualization, Writing - review & editing. **Philip J. van der Wees:** Supervision, Methodology, Funding acquisition, Formal analysis, Conceptualization, Writing - review & editing. **Paul B. van der Nat:** Supervision, Methodology, Funding acquisition, Formal analysis, Conceptualization, Writing - review & editing. **Santeon Patient Participation Study group:** writing – review & editing.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

We extend our gratitude to all the patients and healthcare professionals who contributed to this study. Furthermore, we want to thank the participating patient organizations and fora (Crohn & Colitis NL, kanker.nl, Prostaatkanker Stichting, Longkanker NL, foundation DUOS) for distributing the questionnaire. Lastly, we would like to thank the members of the Santeon Patient Participation Study Group for their contributions to this study.

Privacy statement

I confirm all patient/personal identifiers have been removed or disguised so the patient/HCPs described are not identifiable and cannot be identified through the details of the story.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.pec.2023.108043](https://doi.org/10.1016/j.pec.2023.108043).

References

- Porter ME. What is value in healthcare. *N Engl J Med* 2010;23:2477–81. <https://doi.org/10.1056/NEJMp1011024>.
- Vijverberg JRG, Daniels K, Steinmann G, Garvelink MM, Rouppe van der Voort MBV, Biesma D, et al. Mapping the extent, range and nature of research activity on value-based healthcare in the 15 years following its introduction (2006–2021): a scoping review. *BMJ Open* 2022;12:e064983. <https://doi.org/10.1136/bmjopen-2022-064983>.
- Wu AW, Snyder C, Clancy CM, Steinwachs DM. Adding the patient perspective to comparative effectiveness research. *Health Aff (Millwood)* 2010;29:1863–71. <https://doi.org/10.1377/hlthaff.2010.0660>.
- Anker SD, Agewall S, Borggrefe M, Calvert M, Jaime Caro J, Cowie MR, et al. The importance of patient-reported outcomes: a call for their comprehensive integration in cardiovascular clinical trials. *Eur Heart J* 2014;35:2001–9. <https://doi.org/10.1093/eurheartj/ehu205>.
- FDA, Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labeling Claims, (2006).
- Steinmann G, Delnoij D, van de Bovenkamp H, Groote R, Ahaas K. Expert consensus on moving towards a value-based healthcare system in the Netherlands: a Delphi study. *BMJ Open* 2021;11:e043367. <https://doi.org/10.1136/bmjopen-2020-043367>.
- van der Nat PB. The new strategic agenda for value transformation. *Heal Serv Manag Res* 2022;35:189–93. <https://doi.org/10.1177/09514848211011739>.
- Dorr MC, van Hof KS, Jelsma JGM, Dronkers EAC, de Jong RJB, Offerman MPJ, et al. Quality improvements of healthcare trajectories by learning from aggregated patient-reported outcomes: a mixed-methods systematic literature review. *Heal Res Policy Syst* 2022;20(1):13. <https://doi.org/10.1186/s12961-022-00893-4>.
- Witteveen A, Vliegen IMH, Sonke GS, Klaase JM, Ljzerman MJ, Siesling S. Personalisation of breast cancer follow-up: a time-dependent prognostic nomogram for the estimation of annual risk of locoregional recurrence in early breast cancer patients. *Breast Cancer Res Treat* 2015;152:627–36. <https://doi.org/10.1007/s10549-015-3490-4>.
- Damman OC, Jani A, de Jong BA, Becker A, Metz MJ, de Bruijne MC, et al. The use of PROMs and shared decision-making in medical encounters with patients: An opportunity to deliver value-based health care to patients. *J Eval Clin Pract* 2020;26:524–40. <https://doi.org/10.1111/jep.13321>.
- Beyer K, MacLennan SJ, Moris L, Lardas M, Mastris K, Hooker G, et al. The key role of patient involvement in the development of core outcome sets in prostate cancer. *Eur Urol Focus* 2021;7:943–6. <https://doi.org/10.1016/j.euf.2021.09.008>.
- Kersting C, Kneer M, Barzel A. Patient-relevant outcomes: what are we talking about? A scoping review to improve conceptual clarity. *BMC Health Serv Res* 2020;20(1):16. <https://doi.org/10.1186/s12913-020-05442-9>.
- Kim AH, Roberts C, Feagan BG, Banerjee R, Bemelman W, Bodger K, et al. Developing a standard set of patient-centred outcomes for inflammatory bowel disease-an international, cross-disciplinary consensus. *J Crohn's Colitis* 2018;12:408–18. <https://doi.org/10.1093/ecco-jcc/jjx161>.
- Seligman WH, Das-Gupta Z, Jobi-Odeneye AO, Arbelo E, Banerjee A, Bollmann A, et al. Development of an international standard set of outcome measures for patients with atrial fibrillation: a report of the International Consortium for Health Outcomes Measurement (ICHOM) atrial fibrillation working group. *Eur Heart J* 2020;41:1132–40. <https://doi.org/10.1093/eurheartj/ehz871>.
- Alguiré B, Ramirez JP, Salt M, Sillett N, Myers SN, Alvarez-Cote A, et al. Development of an international standard set of patient-centred outcome measures for overall paediatric health: A consensus process. *Arch Dis Child* 2021;106:868–76. <https://doi.org/10.1136/archdischild-2020-320345>.
- Santana MJ, Haverman L, Absolom K, Takeuchi E, Feeny D, Grootenhuys M, et al. Training clinicians in how to use patient-reported outcome measures in routine clinical practice. *Qual Life Res* 2015;24:1707–18. <https://doi.org/10.1007/s11136-014-0903-5>.
- Hackert MQN, Ankersmid JW, Engels N, Prick JCM, Teerenstra S, Siesling S, et al. Effectiveness and implementation of SHARED decision-making supported by OUTcome information among patients with breast cancer, stroke and advanced kidney disease: SHOUT study protocol of multiple interrupted time series. *BMJ Open* 2022;12:e055324. <https://doi.org/10.1136/bmjopen-2021-055324>.
- Nic Giolla Easpaig B, Tran Y, Bierbaum M, Arnolda G, Delaney GP, Liaw W, et al. What are the attitudes of health professionals regarding patient reported outcome measures (PROMs) in oncology practice? A mixed-method synthesis of the qualitative evidence. *BMC Health Serv Res* 2020;20. <https://doi.org/10.1186/s12913-020-4939-7>.
- H.W.M. van Laarhoven, Evidence Based Information Provision to Improve Decision Making After Oesophagogastric Cancer Diagnosis (SOURCE), ClinicalTrials.Gov. (2020). <https://clinicaltrials.gov/ct2/show/NCT04232735?term=NCT04232735&draw=2&rank=1>.
- Engelen V, Haverman L, Koopman H, Schouten-van Meeteren N, Meijer-van den Bergh E, Vrijmoet-Wiersma J, et al. Development and implementation of a patient reported outcome intervention (QLIC-ON PROfile) in clinical paediatric oncology practice. *Patient Educ Couns* 2010;81:235–44. <https://doi.org/10.1016/j.pec.2010.02.003>.
- Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Heal Care* 2007;19:349–57. <https://doi.org/10.1093/intqhc/mzm042>.
- Daniels K, Rouppe van der Voort MBV, Biesma DH, van der Nat PB. Five years' experience with value-based quality improvement teams: the key factors to a successful implementation in hospital care. *BMC Health Serv Res* 2022;22:1271. <https://doi.org/10.1186/s12913-022-08563-5>.
- Chew LD, Griffin JM, Partin MR, Noorbaloochi S, Grill JP, Snyder A, et al. Validation of screening questions for limited health literacy in a large VA outpatient population. *J Gen Intern Med* 2008;23:561–6. <https://doi.org/10.1007/s11606-008-0520-5>.
- Fransen MP, Van Schaik TM, Twickler TB, Essink-Bot ML. Applicability of internationally available health literacy measures in the Netherlands. *J Health Commun* 2011;16(Suppl 3):134–49. <https://doi.org/10.1080/10810730.2011.604383>.
- Légaré F, Stacey D, Turcotte S, Cossi MJ, Kryworuchko J, Graham ID, et al. Interventions for improving the adoption of shared decision making by healthcare professionals. *Cochrane Database Syst Rev* 2014. <https://doi.org/10.1002/14651858.CD006732.pub3>.

- [26] Holmes-Rovner M, Valade D, Orlowski C, Draus C, Nabozny-Valerio B, Keiser S. Implementing shared decision-making in routine practice: Barriers and opportunities. *Heal Expect* 2000;3:182–91. <https://doi.org/10.1046/j.1369-6513.2000.00093.x>.
- [27] L  gar   F, Ratt   S, Gravel K, Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: Update of a systematic review of health professionals' perceptions. *Patient Educ Couns* 2008;73:526–35. <https://doi.org/10.1016/j.pec.2008.07.018>.
- [28] Veenendaal H van, Chernova G, Bouman CM, Etten-Jamaludin FS van, Dieren S van, Ubbink DT. Shared decision-making and the duration of medical consultations: A systematic review and meta-analysis. *Patient Educ Couns* 2023; 107:107561. <https://doi.org/10.1016/j.pec.2022.11.003>.
- [29] Dobler CC, Sanchez M, Gionfriddo MR, Alvarez-Villalobos NA, Singh Ospina N, Spencer-Bonilla G, et al. Impact of decision aids used during clinical encounters on clinician outcomes and consultation length: a systematic review. *BMJ Qual Saf* 2019;28:499–510. <https://doi.org/10.1136/bmjqs-2018-008022>.
- [30] Foster A, Croot L, Brazier J, Harris J, O'cathain A. The facilitators and barriers to implementing patient reported outcome measures in organisations delivering health related services: A systematic review of reviews. *J Patient-Rep Outcomes* 2018;2:1–16. <https://doi.org/10.1186/s41687-018-0072-3>.
- [31] Porter I, Gon  alves-Bradley D, Ricci-Cabello I, Gibbons C, Gangannagaripalli J, Fitzpatrick R, et al. Framework and guidance for implementing patient-reported outcomes in clinical practice: evidence, challenges and opportunities. *J Comp Eff Res* 2016;5:507–19. <https://doi.org/10.2217/ce-2015-0014>.
- [32] Brunelli C, Zito E, Alfieri S, Borreani C, Roli A, Caraceni A, et al. Knowledge, use and attitudes of healthcare professionals towards patient-reported outcome measures (PROMs) at a comprehensive cancer center. *BMC Cancer* 2022;22:161. <https://doi.org/10.1186/s12885-022-09269-x>.
- [33] van der Willik EM, Milders J, Bart JAJ, Bos WJW, van Ittersum FJ, Ten Dam MAGJ, et al. Discussing results of patient-reported outcome measures (PROMs) between patients and healthcare professionals in routine dialysis care: a qualitative study. *BMJ Open* 2022;12:e067044. <https://doi.org/10.1136/bmjopen-2022-067044>.
- [34] NHS, Shared Decision Making Programme Decision point maps, n.d.
- [35] A. Coulter, A. Collins, Making shared decision-making a reality, London King's Fund. (2011).
- [36] Kingsley MJ, Abreu MT, Personalized A. Approach to managing inflammatory bowel disease. *Gastroenterol Hepatol (N Y)* 2016;12:308–15.
- [37] Engels N, van der Nat PB, Ankersmid JW, Prick JCM, Parent E, The R, et al. Development of an online patient decision aid for kidney failure treatment modality decisions. *BMC Nephrol* 2022;23:236. <https://doi.org/10.1186/s12882-022-02853-0>.
- [38] Cramer-van der Welle CM, Kastelij   EA, Plouvier BC, van Uden-Kraan CF, Schramel FMNH, Groen HJM, et al. Development and Evaluation of a Real-World Outcomes-Based Tool to Support Informed Clinical Decision Making in the Palliative Treatment of Patients With Metastatic NSCLC. *JCO Clin Cancer Inform* 2021;5:570–8. <https://doi.org/10.1200/CCL.20.00160>.
- [39] Miller WR, Lasiter S, Bartlett Ellis R, Buelow JM. Chronic disease self-management: a hybrid concept analysis. *Nurs Outlook* 2015;63:154–61. <https://doi.org/10.1016/j.outlook.2014.07.005>.
- [40] Vromans RD, Pauws SC, Bol N, van de Poll-Franse LV, Krahmer EJ. Communicating tailored risk information of cancer treatment side effects: Only words or also numbers? *BMC Med Inform Decis Mak* 2020;20. <https://doi.org/10.1186/S12911-020-01296-7>.
- [41] Vromans RD, Van Eenbergen MC, Geleijnse G, Pauws S, Van De Poll-Franse LV, Krahmer EJ. Exploring cancer survivor needs and preferences for communicating personalized cancer statistics from registry data: qualitative multimethod study. *JMIR Cancer* 2021;7. <https://doi.org/10.2196/25659>.
- [42] Eijssink JFH, Fabian AM, Vervoort JPM, Al Khayat MNMT, Boersma C, Postma MJ. Value-based health care in Western countries: a scoping review on the implementation of patient-reported-outcomes sets for hospital-based interventions. *Expert Rev Pharm Outcomes Res* 2023;23:1–13. <https://doi.org/10.1080/14737167.2023.2136168>.