

## Editorial

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# Transparency and standardization in using digital patient reported outcome measures (PROMs)

Laura Beckers

*Department of Rehabilitation Medicine, Care and Public Health Research Institute (CAPHRI), Maastricht University, Maastricht, The Netherlands*  
*E-mail: laura.beckers@maastrichtuniversity.nl*

In rehabilitation medicine, numerous patient reported outcome measures (PROMs) are available to assess biological, psychological, and social factors. These PROMs have a prominent role in clinical care and research. With increasing technological advancements, originally pen-and-paper questionnaires are being digitalized on a large scale. In itself, this is a positive development, given its many benefits. Most importantly, questionnaires are quicker and more convenient for most patients and participants to fill out digitally than on paper. Digital data collection is also generally faster and cheaper for the treatment or research team. Moreover, the adaptability of digital PROMs provides new opportunities. Controlling features can be used, e.g. restrictions on the answers to meet relevant criteria (validation) or questions mandatory to answer to avoid missing values. In addition, questionnaires can be individually tailored through, for instance, skipping questions dependent on the answer to a previous question or computer adaptive testing. This flexibility in assessment comes along with new challenges. These are often overlooked, as well as potential issues with digital PROMs.

Within Centrum Integrale Revalidatie (CIR), a Dutch pain rehabilitation organization with currently six locations, data is collected as part of routine care and used for research purposes as well. The thorough reflection of this organization and our research team during the transition process pointed out many relevant considera-

tions when using digital PROMs. The most important ones I will provide here, followed by a call to action.

In choosing an appropriate data collection system, an apparent condition is that it is in accordance with all general privacy laws and regulations and those specifically applicable to healthcare and scientific research. It may be beneficial to interlink the data collection system with the electronic health record platform. Another aspect is the compatibility of the data collection system with the respondents' device and, if applicable, the web browser. Last, while filling out questionnaires on tablets or smartphones may be preferred by respondents, their small screens are a disadvantage in displaying questions and their answer options.

Regarding the style of digital questionnaires, there are plenty of opportunities, leading to as many decisions to be made, such as follows: will multiple questions be shown simultaneously or will each question be set on a new screen? Are respondents allowed to go back to previous pages of the same or other questionnaires? Is the design of the pen-and-paper questionnaire copied, or is it decided for a consistent layout (e.g. font) for a complete set of questionnaires? Is the presentation of answer options identical to the original questionnaire preferred, or will they be modified to better fit the view on screens (e.g. options shown vertically instead of horizontally)? Often, a trade-off has to be made between comparability with the traditional data collection method and deviations that are expected to increase

usability or data quality. It is also important to realize that features that are aimed to improve quality may have unintended effects. Mandatory questions and their corresponding answer options that are experienced as irrelevant or inappropriate, for example, can lead to invalid answers or respondents terminating filling out the questionnaire. In addition, the user-friendliness may be reduced by design choices, like when a lot of clicking is required to move through the questions or to unfold dropdown lists of answer options.

Digital PROMs also have their limitations, partly depending on the data collection system adopted. While for some the consequences seem relatively small (e.g. no bold fonts available), others are more restrictive. Frequently, issues are associated with the answer options. Some types of answer options (e.g. a numeric rating scale with labels at the ends of the scale) are not compatible with certain data collection systems. The visual analogue scale (VAS) is, in our experience, particularly challenging to use digitally. The length, intended to be 100 mm, generally varies depending on the device as well as the screen settings. Moreover, it is essential but not always the case that the data collection system only registers the VAS score if the respondent moves the cursor. Hence, if a respondent wants to continue to the next page without filling out a VAS score, either a notification should make sure that the question is answered or a missing value should be registered instead of the value that the cursor automatically indicates when the question is displayed. Last, concerns about data security, low digital proficiency among respondents, and technical difficulties can hinder the assessment of digital PROMs.

In my opinion, more awareness is needed for the many methodological choices in the digital assessment of PROMs and how these affect the respondents' outcomes. As a next step, improvements in the rehabilitation field are needed. First, more extensive documentation of the digitalization process is required to increase transparency. In research, this is especially beneficial in studies validating PROMs, as the specific approach may have implications for the generalizability of the results. Scientific reporting guidelines should be extended to fulfil this need. For instance, although the Consolidated Standards of Reporting Trials (CONSORT) statement has an extension on Patient-Reported Outcomes (CONSORT PRO), the assessment information is limited to the data collection method (paper, telephone, electronic, other) [1]. Given the word limits and readability of papers, authors could include the necessary information in a supplemental file. Second, standardization of dig-

ital PROM assessments would aid in comparing and combining outcomes within and between patients and studies. For questionnaires with a manual, it should be updated by including the digital assessment approach. Likewise, core outcome sets as the Dutch Dataset Pain Rehabilitation (DDPR) should provide recommendations for digitalization [2]. Preferably, the procedures and resources for clinical care and research should be adjusted to one another wherever possible. Further work is required to establish the impact of certain decisions or settings. I expect the proposed courses for transparency and standardization to bring digital PROMs to a higher level.

This issue of the *Journal of Back and Musculoskeletal Rehabilitation* includes, among others, research in which PROMs are used as outcome measures as well as an open access paper with clinimetric properties of PROMs as the topic of interest [3]. The latter study investigated whether the Roland Morris Disability Questionnaire and Oswestry Disability Index are interchangeable in patients after lumbar spinal fusion. It is an honour to select one article to be free to read. In this issue, it is a paper authored by Mourits et al. [4]. This cohort study aimed to identify general and military-related prognostic factors to determine the level of recovery in Dutch servicemembers with chronic low back pain who followed a rehabilitation program. All outcome measures and the majority of potential prognostic variables being PROMs is an example of their prominent role in rehabilitation research and, in turn, the importance of optimizing their digital use.

Enjoy this issue. I hope that the contents inspire research on back and musculoskeletal rehabilitation and your day-to-day practice.

## References

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