



Aalborg Universitet

AALBORG UNIVERSITY
DENMARK

The Digital Transformation of Patient-Reported Outcomes' (PROs) Functionality within Healthcare

Eriksen, Jeppe; Bertelsen, Pernille Scholdan; Bygholm, Ann Kathrin Meilandt

Published in:
Digital Personalized Health and Medicine

DOI (link to publication from Publisher):
[10.3233/SHTI200322](https://doi.org/10.3233/SHTI200322)

Creative Commons License
CC BY-NC 4.0

Publication date:
2020

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

[Link to publication from Aalborg University](#)

Citation for published version (APA):
Eriksen, J., Bertelsen, P. S., & Bygholm, A. K. M. (2020). The Digital Transformation of Patient-Reported Outcomes' (PROs) Functionality within Healthcare. In L. B. Pape-Haugaard, C. Lovis, I. C. Madsen, P. Weber, P. H. Nielsen, & P. Scott (Eds.), *Digital Personalized Health and Medicine: Proceedings of MIE 2020* (pp. 1051-1055). IOS Press. Studies in Health Technology and Informatics Vol. 270 <https://doi.org/10.3233/SHTI200322>

General rights

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

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

Take down policy

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

The Digital Transformation of Patient-Reported Outcomes' (PROs) Functionality Within Healthcare

Jeppe ERIKSEN^{a,1}, Pernille BERTELSEN^b, Ann BYGHOLM^c

^{a,b}Department of Development and Planning, Aalborg University

^cDepartment of Communication and Psychology, Aalborg University

Abstract. This paper elucidates how the functionality of Patient-Reported Outcome (PRO) has evolved due to its digital transformation. Hence, PROs traditional use within healthcare is described and compared to the application of electronic PROs (ePROs); leading to a discussion regarding PROs functionality. The literature included in this paper stems from a systematic scoping review. The digitalization supplements former functionalities of PRO by enabling timely, accessible, systematic and progression oriented data; however, further improvements are necessary to enhance PROs application in current healthcare.

Keywords. Patient-reported outcome, PRO, digital mediation, ePRO and PROs functionality

1. Introduction

Patient-reported outcomes (PROs) are increasingly used in current healthcare due to their multidimensional functionality, among other things, made possible by the digitalization of PRO. An alteration in the use and mediation of PROs, which have shown to be feasible [2], also as part of clinical practice [1].

A commonly used definition of PRO was coined by the American Food and Drug Administration (FDA) in 2009, stating that PRO is: “Any report of the status of patient’s health condition that comes directly from the patient, without interpretation of the patient’s response by a clinician or anyone else” [3].

Traditionally, PRO-questionnaires was used to test the effect of new drugs on patients, and as aggregated data targeted research purposes [5]. However, more extensive use of PRO in clinical practice is currently gaining ground within healthcare. Thus, data is no longer preserved clinicians and scientist, since PRO-data now is expected to inform, include and actively engage patients in managing their own disease [6]. Therefore, PROs integration into clinical practice has altered its current purpose and functionality [7].

Hence, this paper provides an overview of PROs functionality pre and post its digitalization and discuss ongoing challenges.

2. Method

The literature included in this article stems from a systematic scoping review regarding the link between PRO and patient participation. A comprehensive review,

¹ Corresponding Author: je@plan.aau.dk.

which therefore also provides an overview of PROs functionalities and digital transformation. Hence, the articles in this paper are a selective extraction, included if they pertain to PROs functionality pre or post its digital mediation.

The publications were identified using the following databases: PubMed, Embase, CINAHL and Scopus. The objective was to identify associations between patient participation and PRO. When conducting the search, the word ‘patient-reported outcome’ was included every time, and then combined with search words covering either: ‘patient recognition’, ‘patient participation’ or ‘patient empowerment’. Exclusion criteria pertained to studies regarding primary care, traditional research studies where PRO was used as a secondary endpoint and studies where children were the subject field. Inclusion criteria consisted of articles covering, e.g. PROs used at hospitals or outpatient clinics, articles examining PROs effects, directly as well as indirectly. This strategy resulted in 6.895 articles; decreasing to 4.343 after duplicates had been removed. After reading and sorting the abstracts 256 articles were fully read and assessed for eligibility [8]; hereof, 27 articles are included in this article.

3. Applications of PRO

3.1. PROs functionality

Originally, PRO was used for group-level research and medical research, as supplement data/secondary outcome measures in clinical trials, e.g. in randomized controlled trials (RCT) studies, testing new drugs and evaluating the comparative effectiveness of healthcare interventions. Thus, the collection of PRO-data established a systematic approach when eliciting patients perspective on what mattered to them regarding their health status, their experiences pertaining to adverse effects, side-effects, comorbidity, and the burden of illness or treatment [5][9].

Therefore, the integration of PRO means that the evaluation of treatment no longer merely is based on objective criteria and physicians assessments, but on patients’ perceptions and experiences as well [4]. A shift of focus in healthcare interventions, emphasizing the importance of patients health-related quality of life (HRQoL) to complement more traditional survival measures [10].

3.2. ePROs functionality

Furthermore, the digital transformation of PRO may enable new functionalities.

Firstly, when PRO is digitally mediated it allows real-time monitoring of patients and timely-data becomes available during patient-clinician consultations; potentially, leading to tailored patient management, improved decision making, more accurate diagnosing and better treatment [11].

Secondly, accessibility of PRO-data changes when digitalized as it enables patients to access data from at home; allowing them to follow their disease progression systematically over time. Therefore, the completion of ePRO-questionnaires potentially initiates a learning process as patients are confronted with issues pertaining to their condition; thus, PRO-data might empower and engage patients [12]. This feature, coupled with patients opportunity to track their disease progression over time and, e.g. set disease-related goals, are focal reasons why PRO-data is perceived as a self-management tool [13]. Thus, ePROs increased accessibility potentially improves patient

participation and self-monitoring as part of patients everyday life [13][14]. Moreover, ePROs might also affect patients’ ability to engage more actively in conversations with healthcare professionals; potentially, enhancing shared-decision making in clinical practice [11].

Furthermore, improved accessibility also means that PRO can be used as a coordination tool as it supports organizational information flows on both a vertical and horizontal level. In other words, the digitalization of PRO potentially enables healthcare teams and providers on different organizational levels to share data. As a result, stakeholders are able to base decisions on timely data, while patients’ avoid having to complete similar questionnaires over and over again, as they progress through the healthcare system [7]. However, this feature of PRO-data arguably relies heavily on adequate digital infrastructures [15] and regulations like, e.g. GDPR.

Thirdly, the systematic digital collection of PRO-data offers stakeholders an opportunity to plan and execute healthcare based on population data; exemplified by the value-based healthcare (VBHC) approach, where the reduction of health care costs and efficient use of resources are central aspects [16]. Thus, VBHC, via the use of digital PRO-data, might enable benchmarking, reimbursement and accountability of healthcare providers based on values pertaining to patient preferences and economic efficiency [14]. Moreover, this application of PRO-data might be used to improve systematic knowledge sharing among healthcare providers [14].

Lastly, PRO, as part of a triage system, is an example of a more recent application. The system is based on algorithms, which sorts patients into different categories (green, yellow and red) according to their health status; subsequently, determining who needs to show up for a patient-clinician consultation. Hence, some patients are able to skip unnecessary routine consultations, which ensures that those patients who are in need of medical attention, are prioritized [17].

Table 1. PROs functionality on an individual and population level pre and post its digitalization.

Stakeholders ²	Functionality	Pre digitalization (PRO)	Post digitalization (ePRO)
C	Decision-making and treatment [11]	x	x
C	Diagnosing [18]	x	x
CP	Patient perspective [4][6]	x	x
CP	Shared-decision making (SDM) [6]	x	x
CI	Drug testing [19]	x	x
CI	Research [14]	x	x
CPM	Patient-centred healthcare [14][20]	x	x
CP	Communication/dialogue [13][20]	x	x
C	Screening [11][20]	x	x
CPM	Patient satisfaction [6]	x	x
P	Patient participation [6]		x
P	Self-management [6][13][14][17]		x
M	Health policy development [21]		x
CPM	Quality of care [1][14][20]		x
CM	Best practice [14]		x
CP	Adherence [6][15]		x
M	Reduce health care costs/efficient use of resources [22]		x
CM	Triage system based on algorithms [17]		x

² Stakeholder terminology: C – clinicians, P – patients, M – managers/politicians, I -industry

P	Patients goals [15]	x
M	Monitor population health/preventive tool [7]	x
C	Monitoring and patient management [22]	x
M	Value-based healthcare (VBHC)/ Benchmarking/Reimbursement/ Accountability [16]	x
CM	Coordination tool/ Interdisciplinary/multidisciplinary communication [20]	x
P	Patient Empowerment [23]	x
P	Self-monitoring [24]	x

Table 1. Demonstrates how the digitalization of PROs has altered its functionality. Thus, PRO has changed from mainly being a tool used by clinicians and industry for research and drug testing, to now also being a tool used by patients, healthcare managers and politicians, e.g. facilitating systematic patient participation, patient management and VBHC.

4. Discussion

The paper elucidates how the digitalization of PROs has changed their functionality and purpose. However, even though the digitalization has improved and innovated PROs functionality, certain issues pertaining to the application and implementation of PROs still persist.

Therefore, even when ePROs, in some cases, might increase data accessibility, the use of PROs in healthcare can also exclude particular groups of patients. Thus, low health/eHealth literacy [25][26] and lack of technological access [19][22][27], are factors which potentially exclude patients; subsequently, creating a barrier towards patient participation. Hence, clinicians and managers need to be aware of the patient burden PROs might entail [22][27], to make sure that the use of PROs enables patient empowerment and not turns into patient work [28].

Furthermore, it is essential to make sure that PRO-data is actionable [6] and actually used in clinical practice since this is not always the case [29]. Therefore, to secure the use of PRO-data in clinical practice PRO measures need to be clinically relevant [22][29], and clinicians should be trained regarding the application and interpretation of PRO-data [29][30]. Whereas, on an organizational level, attention to how workflows are affected [27] and whether sufficient time is allocated for meaningful use of PROs [30] is needed.

Hence, even after PROs digital transformation, there is still a lot of work to be done to make sure that PRO fulfil its potential, which is why further research within this area is recommended. However, as the overview in table 1. Demonstrates, ePROs have the potential to further a more personalized and actively engaging approach in healthcare.

References

- [1] M. Korzeniowski et al., "Piloting prostate cancer patient-reported outcomes in clinical practice," *Support. Care Cancer*, vol. 24, no. 5, pp. 1983–1990, May 2016.
- [2] D. Desantis et al., "A clinical perspective on collecting patient-reported outcomes at the point-of-care for urinary incontinence," *Can. Urol. Assoc. J.*, vol. 10, no. 5–6, p. S87, 2016.
- [3] U. S. Department of Health and Human Services, Food and Drug Administration (FDA), "Guidance for Industry Use in Medical Product Development to Support Labeling Claims Guidance for Industry," no. December, pp. 1–39, 2009.

- [4] S. Dean, et al., “‘The patient is speaking’: Discovering the patient voice in ophthalmology,” *Br. J. Ophthalmol.*, vol. 101, no. 6, pp. 700–708, 2017.
- [5] C. A. McHorney, “HEALTH STATUS ASSESSMENT METHODS FOR ADULTS: Past Accomplishments and Future Challenges,” *Annu. Rev. Public Health*, vol. 20, no. 1, pp. 309–335, 2002.
- [6] M.-J. Santana and D. Feeny, “Framework to assess the effects of using patient-reported outcome measures in chronic care management,” *Qual. Life Res.*, vol. 23, no. 5, pp. 1505–1513, Jun. 2014.
- [7] Munch-Petersen et al., “Program PRO” VibIS, p. 70, 2016, located at: <https://danskepatienter.dk/vibis/om-vibis/vores-projekter/program-pro>.
- [8] J. Eriksen et al. “Associations between Patient-Reported Outcomes and Patient Participation - a systematic search and review.” Forthcoming, 2020.
- [9] S. P. McKenna and J. Wilburn, “Patient value: its nature, measurement, and role in real world evidence studies and outcomes-based reimbursement,” *J. Med. Econ.*, vol. 21, no. 5, pp. 474–480, 2018.
- [10] H. Fagerlind et al., “Patients’ understanding of the concepts of health and quality of life,” *Patient Educ. Couns.*, vol. 78, no. 1, pp. 104–110, 2010.
- [11] M. Y. Halyard, “The use of real-time patient-reported outcomes and quality-of-life data in oncology clinical practice,” *Expert Rev. Pharmacoeconomics Outcomes Res.*, vol. 11, no. 5, pp. 561–570, 2011.
- [12] W.G. Groen et al., “Empowerment of Cancer Survivors Through Information Technology: An Integrative Review,” *J. Med. Internet Res.*, vol. 17, no. 11, p. e270, Nov. 2015.
- [13] C. Trillingsgaard et al., “Use of patient-reported outcomes in outpatient settings as a means of patient involvement and self-management support – a qualitative study of the patient perspective,” *Eur. J. Pers. Centered Healthc.*, vol. 4, no. 2, p. 359, 2016.
- [14] M. C. Wang and J. Bellows in M. R. Helton and T. Daaleman, *Chronic Illness Care*. 2018.
- [15] L. M. Philpot et al., “Barriers and Benefits to the Use of Patient-Reported Outcome Measures in Routine Clinical Care: A Qualitative Study.,” *Am. J. Med. Qual.*, p. 1062860617745986, Dec. 2017.
- [16] M. E. Porter, “What Is Value in Health Care?,” *Perspective*, vol. 363, no. 1, pp. 1–3, 2010.
- [17] C. T. Mejdahl et al., “PRO-based follow-up as a means of self-management support – an interpretive description of the patient perspective,” *J. Patient-Reported Outcomes*, vol. 2, no. 1, p. 38, 2018.
- [18] K. Haywood et al., “Patient participation in the consultation process: A structured review of intervention strategies,” *Patient Educ. Couns.*, vol. 63, no. 1–2, pp. 12–23, 2006.
- [19] L.E. Strong, “The past, present, and future of patient-reported outcomes in oncology,” *Am. Soc. Clin. Oncol. Educ. Book*, pp. e616–e620, 2015.
- [20] J. Greenhalgh, “The applications of PROs in clinical practice: What are they, do they work, and why?,” *Qual. Life Res.*, vol. 18, no. 1, pp. 115–123, 2009.
- [21] N. Black, “Patient reported outcome measures could help transform healthcare,” *BMJ*, vol. 346, no. 7896, pp. 1–5, 2013.
- [22] C. Chang, “Patient-reported outcomes measurement and management with innovative methodologies and technologies,” *Qual. Life Res.*, vol. 16, no. SUPPL. 1, pp. 157–166, 2007.
- [23] M. McAllistar et al., “Patient empowerment: the need to consider it as a measurable patient-reported outcome for chronic conditions,” *BMC Health Serv. Res.*, vol. 12, no. 1, p. 157, Jun. 2012.
- [24] L. Segan et al., “Enhancing self-care strategies in heart failure through patient-reported outcome measures.,” *Intern. Med. J.*, vol. 48, no. 8, pp. 995–998, Aug. 2018.
- [25] J. Øvretveit et al., “Using patient-reported outcome measurement to improve patient care,” *Int. J. Qual. Heal. Care*, vol. 29, no. 6, pp. 874–879, 2017.
- [26] J. S. Blumenthal-Barby, “‘That’s the doctor’s job’: Overcoming patient reluctance to be involved in medical decision making,” *Patient Educ. Couns.*, vol. 100, no. 1, pp. 14–17, 2017.
- [27] S. E. Tevis et al., “Patient-Reported Outcomes for Breast Cancer,” *Ann. Surg. Oncol.*, vol. 25, no. 10, pp. 2839–2845, 2018.
- [28] A. Bygholm and P. Bertelsen, “Patient at Work - In the Era of PRO.,” *Stud. Health Technol. Inform.*, vol. 241, pp. 115–121, 2017.
- [29] J. Greenhalgh et al., “How do doctors refer to patient-reported outcome measures (PROMS) in oncology consultations?,” *Qual. Life Res.*, vol. 22, no. 5, pp. 939–950, Jun. 2013.
- [30] D. Howell et al., “Patient-reported outcomes in routine cancer clinical practice: A scoping review of use, impact on health outcomes, and implementation factors,” *Ann. Oncol.*, vol. 26, no. 9, pp. 1846–1858, Sep. 2015.