Hvad er PRO?
Hvad kan PRO?
(Hvad skal PRO?)

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Review article

The association between patient-reported outcomes (PROs) and patient participation in chronic care: A scoping review

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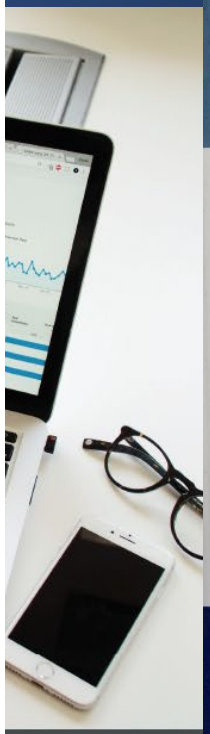
ABSTRACT

Objectives: Patient-reported outcomes (PROs) are increasingly applied in chronic care due to their many functionalities and synergies with current healthcare policies. The participatory potential of PROs is especially emphasised in the Danish context. This review scrutinises the association between PRO and patient participation in chronic care.
Methods: This scoping review adheres to PRISMA-ScR guidelines, and the synthesis is based on narrative and thematic analyses.
Results: Eighty-four articles were deemed eligible. The association between PRO and patient participation regards seven themes: PRO development, response rates and patient burden, patient empowerment and self-management, display and quality of data, patient-clinician communication, shared decision-making, and organisational and attitudinal aspects. Lack of knowledge, actor attitudes, organisational setup, and technological infrastructure act as the main barriers.
Conclusion: The connection between PROs and patient participation is dialectic and unfolds in three phases—before, during, and after patient-clinician consultation. Knowledge regarding the last phase is particularly scarce. Henceforth, studies should address how to include a broader segment of patients, PROs participatory effects over time and PROs impact on patients' everyday lives.
Practice implications: The review provides knowledge concerning the association between PROs and patient participation to enhance future chronic care, research, and discussions in the area.



PURPOSE, FUNCTIONALITY AND RECONCEPTUALISATION OF PATIENT-REPORTED OUTCOME

A PATIENT PARTICIPATION PERSPECTIVE ON PRO IN CLINICAL PRACTICE POST ITS DIGITALISATION

BY
JEPPE ERIKSEN

DISSERTATION SUBMITTED 2021

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DENMARK

Hvad er PRO?

The American Food and Drug Administration (FDA): *"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"* (U. S. Department of Health and Human Services, 2009).

Program PRO: *"PRO-data (Patient Reported Outcome Data) er data om patientens helbredstilstand, herunder fysiske og mentale helbred, symptomer, helbredsrelateret livskvalitet og funktionsniveau. PRO-data bliver rapporteret direkte af patienten"* (ViBIS, 2016).

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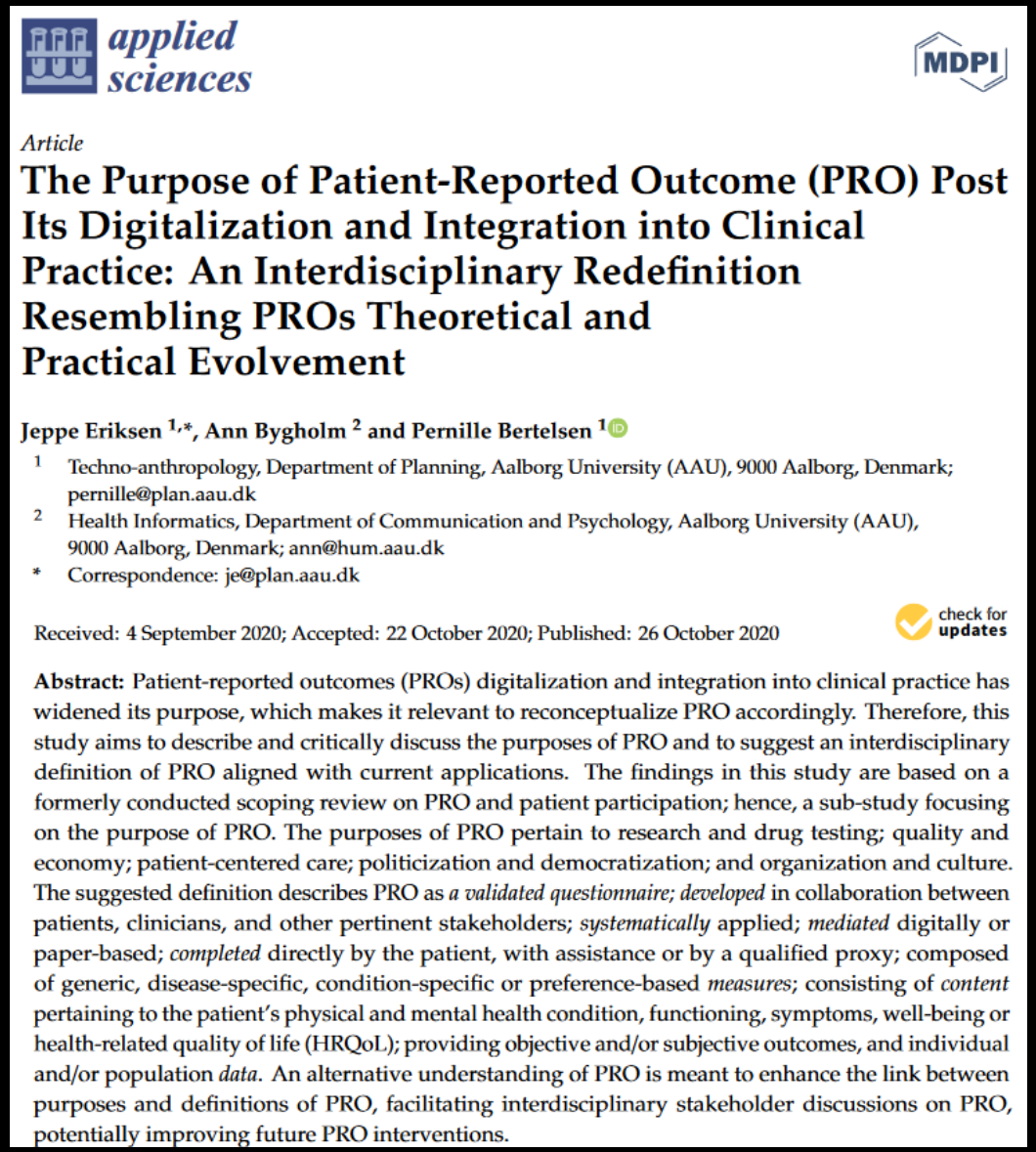

applied sciences

MDPI

Article

The Purpose of Patient-Reported Outcome (PRO) Post Its Digitalization and Integration into Clinical Practice: An Interdisciplinary Redefinition Resembling PROs Theoretical and Practical Evolvement

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check for updates

Abstract: Patient-reported outcomes (PROs) digitalization and integration into clinical practice has widened its purpose, which makes it relevant to reconceptualize PRO accordingly. Therefore, this study aims to describe and critically discuss the purposes of PRO and to suggest an interdisciplinary definition of PRO aligned with current applications. The findings in this study are based on a formerly conducted scoping review on PRO and patient participation; hence, a sub-study focusing on the purpose of PRO. The purposes of PRO pertain to research and drug testing; quality and economy; patient-centered care; politicization and democratization; and organization and culture. The suggested definition describes PRO as *a validated questionnaire; developed* in collaboration between patients, clinicians, and other pertinent stakeholders; *systematically* applied; *mediated* digitally or paper-based; *completed* directly by the patient, with assistance or by a qualified proxy; composed of generic, disease-specific, condition-specific or preference-based *measures*; consisting of *content* pertaining to the patient's physical and mental health condition, functioning, symptoms, well-being or health-related quality of life (HRQoL); providing objective and/or subjective outcomes, and individual and/or population *data*. An alternative understanding of PRO is meant to enhance the link between purposes and definitions of PRO, facilitating interdisciplinary stakeholder discussions on PRO, potentially improving future PRO interventions.

Hvad er PRO?

"…a PRO is defined as a: validated questionnaire; developed in collaboration between patients, clinicians, and other pertinent stakeholders; systematically applied; mediated digitally or paper-based; completed directly by the patient, with assistance or by a qualified proxy; composed of generic, disease-specific, condition-specific or preference-based measures; consisting of content pertaining to the patient's physical and mental health condition, functioning, symptoms, well-being or health-related Quality of life (HRQoL); providing objective and/or subjective outcomes, and individual and/or population data" (Eriksen, Bygholm and Bertelsen, 2020)

Hvad er PRO?

Validated questionnaire

Developed in collaboration between patients, clinicians, and other pertinent stakeholders

Completed directly by the patient, with assistance or by a qualified proxy

Providing objective and/or subjective outcomes

Hvad kan PRO? - funktionalitet

Digital Personalized Health and Medicine
L.B. Pape-Haugaard et al. (Eds.)

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

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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, systematical 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

Metoder:
Dokumentanalyse.

Forskningsspørgsmål:
Hvad er PROs funktionaliteter?

Resultater:

- 33 forskellige funktionaliteter.
- Digitaliseringen af PRO har ført til en øget mængde af funktionaliteter.
- PRO er i stigende grad blevet et patient- og ledelsesværktøj.

Hvad kan PRO? - funktionalitet

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

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

(Eriksen J, Bertelsen P and Bygholm A, 2020)

Stakeholders	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
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

Hvad kan PRO? - Borgerens perspektiv

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SAGE journals

Original Research

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

Jeppe Eriksen [1], Ann Bygholm [2], Signe Hudtloff Nielsen [3], and Pernille Bertelsen [1]

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

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

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

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

Metoder:
Semistrukturerede interviews og deltagerobservation.

10 borgere. 30-79 år.

Forskningsspørgsmål:
Hvordan opfatter og oplever nyligt diagnosticerede borgere med type 2-diabetes PRO ved anvendelse i kommunal sundhedspraksis?

Resultater:

- Ambivalent oplevelse.
- PRO-skema og -data er brugbart, men kræver justeringer ift. nydiagnosticerede.

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Hvad kan PRO? - Borgerens perspektiv

”Det mest interessante jeg har lavet de sidste 14 dage, det er dét her spørgeskema” (griner) (Informant G)

(Eriksen J., et al., 2022)

Hvad kan PRO? - Borgerens perspektiv

PRO-spørgeskemaet

Meningfuldt, relevant og relativt klart formål

- **Manglende svarmuligheder:** *'ikke relevant' ville være vildledende, 'Det må være relevant, hvorfor spørger de mig ellers om det?'*
- **Manglende sygdomshistorik:** holistisk syn, betydning af nuværende skavanker og 'misvisende sammenhæng'.

Længde: for langt vs. passende – acceptabelt pga. relevans.

Lokation og distribution: digitale PRO (hjemme) var acceptable og foretrukket pga. komfort, privatliv, tid og fleksibilitet.

Bekymrings-/motivationsdilemma:

- **Manglende + ny viden:** Hvad skal jeg svare? Er mine svar korrekte? Kommer jeg ned af den forkerte vej?
- **Påvirkning af borgeren:** nervøs, bekymret, motiverende, vigtigheden af egenhåndtering.

Læring/empowerment:

- Direkte adspurgt: nej…
- …men borgerne havde en række aha-oplevelser ift. diabetes påvirkning af sexliv, fødder, syn, hjerte og søvn.

(Eriksen J., et al., 2022)

Hvad kan PRO? - Borgerens perspektiv

"Altså vi snakkede jo om nogle ting, spørgeskemaet gav mig ikke nogen viden, udover at der, udover at jeg med sikkerhed kunne sige, "der er ting jeg ikke ved jeg bør vide", men når jeg sidder og udfylder det, gør det mig ikke klog på noget udover at jeg kan se, at med de spørgsmål der er, så må man gå ud fra, at der forventes at man kan svare på det, og der måtte jeg bare sige, "jamen, det kan jeg ikke med den viden jeg har"" (Informant D)

"Jo, jo, men altså, jeg skrev jo det der med, at det virker da lidt bekymrende, fordi, "kan du styre dit blodsukker?", hvis ikke man ved at man skal styre sit blodsukker, ikke også, og man bliver spurgt om man kan, så kan man da godt sådan sidde og tænke, okay, så det burde jeg så vide, hvordan jeg gør…altså hvad skal jeg have af remedier for at kunne gøre det her, ikke også, altså, "har du problemer med dine fødder?", nej jeg går på dem" (Informant D)

(Eriksen J., et al., 2022)

Hvad kan PRO? - Borgerens perspektiv

”Jeg følte mig en lille smule mere bekymret da jeg havde [udfyldt skemaet], fordi der også var spørgsmål om hvordan man sprøjter sig selv…for mig var der nogle ”uh ha, godt det ikke er mig der er der”” (griner lettet) (Informant B)

”Eh, altså ikke lige ift. med læring, jeg tror mere som bekymring fordi jeg blev jo lidt bekymret hvor der stod blodprop eller (griner nervøst)…den ene var ift. det med hjerterytme eller hjertesmerter og åndenød, det var det ene spørgsmål og det var jo hvor man skulle krydse af, det var sådan en lang liste over hvad man gerne ville ind på og så stod der blodprop…det var de to ting fordi det er jo nogle sygdomme som man ikke har lyst til at have selvfølgelig og er dem man ligesom tænker lidt mere over, ja…det gør jo også at jeg tænker, okay nu skal jeg virkelig også tage mig sammen og så lige få sat mig ind i det her og så lige gøre noget ved det fordi det er jo ikke dér jeg vil ende…” (Informant H)

(Eriksen J., et al., 2022)

Hvad kan PRO? - Borgerens perspektiv

PRO-data under konsultationen

Tid: passende.

Beslutningsstøtte, deltagelse, anerkendelse og kontrol:

- Blev informeret, men traf selv valgene.
- Forskelle på hvem, der kontrollerede samtalen (tilpasset individuelt).

Effekt af data:

- Strukturer samtalen
- Fælles udgangspunkt
- Effektivisering af samtale (forberedt)
- Individualiseret og relevant.

Kategorisering og visning af data:

- Brugbar, let at forstå (online)
- Forvirrende (fysisk).

Synliggør mentale, fysiske og seksuelle symptomer:

- Identificerede symptomer vs. symptomerne ville være italesat uanset.

(Eriksen J., et al., 2022)

Hvad kan PRO? - Borgerens perspektiv

Foreslåede forbedringer

- Inklusion af tekstbokse
- Adaptivt spørgsskema
- Kort foldud-spørgeskema
- To spørgeskemaer

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(Eriksen J., et al., 2022)

Tak for jeres tid og opmærksomhed

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