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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.

Contents

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1. Background

In the Danish context, the purposes and functionalities of patient-reported outcomes (PROs) are currently expanding, particularly due to PROs digitalization and widespread integration into clinical practice [1]. The hypothesised effect of PROs on patient participation, patient empowerment, and self-management are focal features reflected in healthcare policies and academia [2–7].

The reasons PROs and patient participation should hold a more prominent position are many. PROs may alter clinician-patient interactions from the more traditional paternalistic approach that emphasises control and compliance to an empowering and egalitarian partnership [8,9] with a positive effect on adherence, patient outcomes, patients' experience with their disease, information-seeking behaviours, and patient confidence [10–12]. Another issue pertains to the development of outcome reporting that has traditionally been conducted by clinicians alone [13], even though studies have shown that healthcare professionals and patients may have discrepant views on the type of outcomes that are most important to patients [14–16]. Moreover, "'*patient report' suggests a patient-centred approach, and the policy discourse around* [patient-reported outcome measures] *PROMs reinforces the impression that outcomes are patient defined*" [13]; additionally, patients are the main consumers of healthcare [17], thus there are several reasons why patient participation should be mandatory in the development of PROs. The validity of PROs, the data quality, and the response rates might be improved by patient engagement; in other words, *"PROs are only as useful as the quality of the data collected, which makes the patient, by definition, the most important stakeholder to engage in the data collection process"* [18]. This is underscored by findings showing that continuously engaged patients in some cases are in better health compared to those who cease to participate [19].

Digitalization plays a major role as it allows tracking disease progression over time, potentially enabling and improving patients' self-management [5,20,21]. Increasing numbers of the chronically ill, demographic developments in Western countries, and continual technological and medical innovations are constraining and pressuring healthcare systems economically, making knowledge concerning patient participation, self-management, and empowerment tools warranted [2,11].

Hence, the link between patient participation and PROs is relevant to investigate, especially in relation to how patient participation specifically influences the functionality of PROs [22] and how it might affect patient participation [22]; in other words, it is relevant to examine the reciprocity between the two phenomena in the context of chronic care. Therefore, based on current scientific evidence, this review provides an overview of the association between PROs and patient participation in chronic care.

2. Methods

2.1. Research design

This review is a 'scoping review', which is an appropriate approach when little is known on a subject or when the topic is complex and/or heterogeneous. A scoping review aims to broadly map key concepts and the research activity within a research area, providing an overview of a subject field and identifying relevant knowledge gaps. What particularly distinguishes the scoping approach from a systematic review is the aim and execution of the analysis. Thus, the quality of the included research results are not assessed and ranked; instead, the review offers a thematic and descriptive analysis of relevant findings following the nature of a scoping approach [23,24]. Besides following theoretical guidelines, the review was conducted according to PRISMA-ScR standards [25]. In this case, the scoping approach was a natural choice as the subject field—the association between PROs and patient participation—is a complex and broad topic.

2.2. Research question

The scoping review functions as a first step to identify and map associations between PROs and patient participation in chronic care, subsequently revealing knowledge gaps and enabling evidence-based stakeholder discussions on the matter. The research question—*'What is known from existing scientific literature about the relationship between PROs and patient participation in chronic care?'*—is investigated through three sub-questions: a) *In what areas is there a relation between PROs and patient participation in chronic care?* b) *What scientific knowledge exists on the subject field within the identified areas?* and c) *What barriers/enablers influence the relationship between PROs and patient participation in the identified areas?*

2.3. Initial steps

The scoping review started on 16 March 2018 when the first of two meetings with a professional librarian was held. The meetings helped select relevant databases, determine suitable search terms, and elucidate the query logic in each database.

The first search was conducted during March and April 2018, followed by searches based on the same criteria on 23 November 2018 and 4 November 2019 to update the empirical material.

2.4. Eligibility criteria pre-search

Because it is unclear in what way PROs and patient participation are linked, the outcomes included are those within chronic care in which: a) the functionality of PROs is affected by patient

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Table 1
Inclusion/exclusion criteria – articles were included/excluded if they regarded.

Inclusion criteria	Exclusion criteria
PRO interventions in adult healthcare.	Research concerning children.
Areas with associations between PRO and patient participation.	Primary care studies.
HRQoL-issues relevant to the research question.	Validation studies.
Use of PRO in a hospital, outpatient context.	Placebo studies.
PROs functionality.	PRO as a secondary endpoint in research and RCT studies.
The substance of PROs.	Guidelines on the implementation of PROs.
The purpose of PRO.	How to ensure standardization of PRO measures.
The use of PRO in	Acute care.
Chronic care areas.	

participation or b) PROs are supposed to promote patient participation or related concepts. In this context, patient participation is interpreted as "a process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change" [26, p. 10]. A broad definition facilitating the explorative approach applied in the present review.

Aligned with the scoping review's explorative nature, studies were not excluded due to specific methods or disease areas. Literature was only eligible if in English or Danish, and articles were not excluded based on year, as PRO was conceptualized relatively recently, making this factor less relevant. The review consists of published research articles exclusively, mainly studies; however, commentaries/discussions providing novel insights were also deemed eligible. In greater detail, studies were excluded/included according to the following criteria in Table 1:

2.5. Search strategy and key terms

The literature stems from four electronic databases: Embase, PubMed, CINAHL, and SCOPUS. These databases were selected in consultation with the professional librarian. Keywords included patient-reported outcome (PRO), terms covering aspects of patient participation, patient empowerment, and patient recognition. The search engines seemed to treat the terms PRO and PROM as similar; therefore, both terms are used in this review. Patient participation was, besides 'patient participation', operationalized as 'patient engagement', 'patient involvement', and 'patient-centredness'. Specific concepts identified as relevant to patient participation were 'shared decision-making', 'partnership', 'dialogue' and 'communication'. The terms 'patient recognition' and 'patient empowerment' were included based on the assumption that empowerment and recognition of patients are fundamental if PRO-based systems are to promote patient participation. 'Patient recognition', 'recognition', 'patient acknowledgement' and 'acknowledgement' were linked to 'screening', 'visitation', and 'health literacy'. 'Patient empowerment' was operationalized as 'education' and 'self-management'. The search terms had to appear in either the title or the abstract of a paper to be deemed eligible. Overview of the search terms, the different facets of the search and examples of exact search strings are accessible online in Appendices A–E.

2.6. Data synthesis

The next step was how to chart and analyse the included materials. The output of the review is best described as falling between a 'thematic synthesis' and a 'narrative synthesis'. The thematic approach was chosen as the initial strategy, as it allows identifying and analysing topics across studies to facilitate a more thorough understanding of a phenomenon [27]. In practice, 256 articles were read and notes were extracted systematically, resulting in a 304-page document. Areas of interest pertained to the studies' purpose, method, results, and conclusion, and PROs' functionalities and purposes, with particular focus on patient participation. Next, the extracted empirical data were systematically analysed and sorted into categories focusing on the association between PRO and patient participation, resulting in the identification of seven overall categories. The included areas on the association between PRO and patient participation were those that occurred most frequently based on the assumption that those areas also hold the most value scientifically and in practice. The narrative approach was the last step of the analysis, chosen to provide a textual descriptive overview of the included material [27]. Thus, the empirical material is presented narratively, complemented by tabular presentations that provide a more holistic, aggregate, and simple overview of the link between PROs and patient participation.

3. Results

This section first presents an aggregate overview of the included literature describing the number and type of articles and the selection process (3.1–3.3). Second, scientific literature on the seven areas identified as having particular importance regarding the association between PROs and patient participation in chronic care is elaborated upon (3.4–3.10).

3.1. Number of articles and flow chart

Based on the inclusion/exclusion criteria, studies were identified and selected by the first author, resulting in 6895 articles (Appendix F). All entries were imported into Mendeley and duplicates were removed, resulting in 4343 articles. The articles were then screened according to the inclusion/exclusion criteria, generating 199 articles for a full reading. Two subsequent searches added 57 for a total of 256 articles deemed eligible for a full read. Reading resulted in the inclusion of 84 articles for qualitative synthesis. The process is detailed in Fig. 1.

3.2. Type of articles

To the extent possible, the included articles have been sorted according to method/study/article type, disease area, country, and year. The top three distributions in each area are as follows: *method/study/article type*: a) review study (n = 18), b) discussion/commentary (n = 14), and c) feasibility study (n = 12); *disease area*: a) cancer (n = 26), b) across conditions (n = 20), and c) rheumatology/arthritis (n = 5); *country*: a) USA (n = 35), b) UK (n = 18), and c) Canada (n = 13); *year*: a) 2018 (n = 23), b) 2017 (n = 10), and c) 2012 (n = 10) (Table 5).

3.3. PRO development

In four studies, various PROMs were reviewed, and results indicated that lack of patient participation was often an issue during the PROM development process [14,28–30]. Based on twelve studies,

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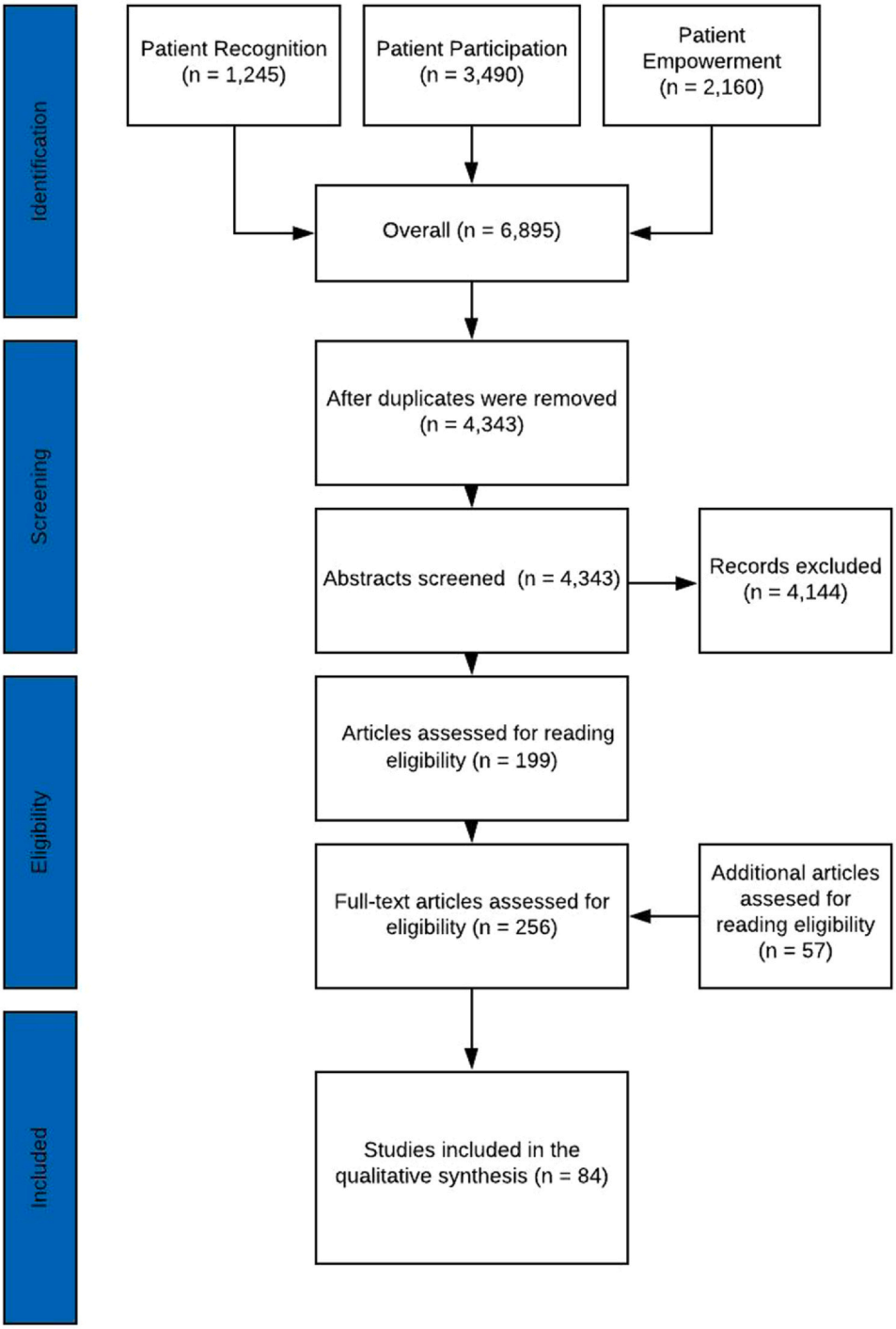

Fig. 1. Flow chart diagram displaying the selection process.

Table 2
Potential effects of patient participation during the development process.

Enables a more holistic picture of patients disease situation [33,34]
Enhanced validity, meaningfulness, relevance and acceptability of measures [14,28,29,31,33,35–38]
Enhanced sensitivity [35,37]
Enhanced reliability [29]
Improved response rates [28,31,35]
Easier interpretable data [14,37,39]
Genuine reflection of the patient perspective [17,28,35]
Generation of health outcome measures that matter the most to patients –based on patient preferences [17,28,29,36]
Prevent waste of resources [36]

Table 2 lists potential effects of patient participation during the development process. Results in this section are based on: Discussions/commentaries (5), reviews (3), scoping reviews (2), mixed methods and feasibility study (1), individual and focus group interviews (1), telephone interviews (1) and narrative review (1).

In one study in which patient participation was operationalized as a meaningful contribution to the identification of domains/items, patient participation was absent in 17 of 26 PROM development processes [14]. A second study identified patient participation in 25.9% of the development processes (193 PROMs), with patient participation occurring mostly during item development (58.5%) or as part of comprehensibility testing (50.8%). Involvement in the

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Table 3
Potential barriers and enablers regarding compliance/response.

The patient is not interested [40]
Patient burden: multiple diseases [39], too ill [39,40], lengthy questionnaires [17], amount and frequency of PROMs [56,57]
The patient is too distressed [40]
The patient dislikes computers [40]
Respondent fatigue – relevant when an iterative process [48]
Notifications and personal reminders [42,45,58]
Need for adequate time to complete the questionnaire [45,58]
Forgetfulness [45,59]
Proper understanding of PROs benefits [60,61]
Technologic issues: accessibility, connectivity issues, technological familiarity [17,39,45,59,62,63]
The administration of PROs [32,59]
Not receiving the questionnaires or thinking it is spam [45]
Data security: who might access data - confidentiality [61]
Negative prior questionnaire experiences - lack of feedback [32]
Questionnaires not reflecting patients disease situation [64]
Lack of use and clinician feedback [38,60,64]
Too intimate questions [65]
Trust between patients and clinicians [61]
Fear that IT might replace physical consultations, preference for normal consultations, PRO perceived as intrusive [20,45,65]
Health literacy issues [38,62,66]
Lack of language alternatives [43,50,62]
Lack of cultural validation [67]
Physical limitations: visual, fine motor skills [62]
Comprehension of personal benefits, expression of health issues, patient perspective, the value in consultation [32,33,68]
Encouragement by clinicians for patients to participate [21]
The chance to help other patients in a similar situation [32]
Financial incentives [66]
Assistance from friends and family or healthcare professionals [45]
Real-time monitoring of non-responders – enabling intervention [42]
Proper communication and information [32,45,46]
Acceptable and meaningful questionnaires [20,21,46,59]
Computer Adaptive Testing (CAT)/tailored solutions [38,46,66,67]
Short-form PROs, easy to complete [48,67–69]
Multiple options, availability via different channels [56]
Guidelines [20,38,59,66]

entire development process took place in just 6.7% of the cases [28]. Another study found that patient involvement was lacking in 17 of 26 PROM developing processes; 12 development processes were not assessable due to lack of information, five did not provide any evidence on patient engagement, two merely consulted patients during the concept elicitation, and in one study, patients participated solely in validating the psychometric properties of the measures. Thus, in only six of 26 development processes were patients part of both concept elicitation and subsequent cognitive interviews [29]. In the fourth included study, patient participation was identified in just three of 41 development processes, with only one containing a post hoc evaluation [30].

Especially people with low literacy skills are excluded from the development processes, either by active exclusion in the eligibility process or due to recruitment materials and administrative methods not being adjusted to the patients' reading levels and cognitive abilities [31]; consequently, the accessibility and validity of PROMs concerning this patient group seem problematic [32].

3.4. Response rates and patient burden

Four studies presented the following ranges of response rates: 54–70% [40]; 81–98% [41]; 85–95% [42]; and 55% [43], response rates referring to the number of participants who completed a PRO questionnaire, likely affected by some of the enablers/barriers, identified in the 28 studies, displayed in Table 3. Evidence in this section is based on: Discussions/commentaries (9), feasibility studies (8), readability assessments (5), workshops (2), scoping reviews (2), semi-structured interviews (2), mixed methods (1), individual and focus group interviews (1), feasibility study and semi-structured interviews (1), participant observation and semi-structured interviews (1), individual interviews (1), survey (1), case studies (1), systematic review (1), consensus panels (1) and longitudinal study (1).

According to Black (2013), appropriate response rates are a challenge, especially "*among older, sicker, more deprived, and non-white patients who tend to be underrepresented*" [44]. Studies included in this review found that response rates vary with age, gender, ethnicity, socioeconomic status, and procedure type [45], influenced by health literacy, reading level, visual ability, language fluency, familiarity with touch-screens, access to computers and the internet, manual dexterity, and eyesight [46]. Patients with advanced disease are likely to have unique needs, an issue exacerbated by lower cognitive abilities [47]—a focal point, as those patients are also the ones reporting symptoms most frequently [48]. Participation seems to be higher among younger patients, males, and the socially advantaged [40].

Five studies examined health literacy and readability on a number of PROs questionnaires, revealing that in most cases the included PROs questionnaires required too high a reading-level, typically that of a seventh- to ninth-grader, exceeding the recommended fifth- to sixth-grade level [49–53].

Six studies considered the mediation of PROs and/or location of completion [18,32,38,45,54,55]. For example, in the US context, mediation preferences vary by insurance status, since email delivery is more acceptable to patients with private or Medicare insurance (68%) compared to patients with marketplace plans (21%), leading the authors to conclude that "*lower socioeconomic status is associated with less electronic access and health engagement*" [45]. The location of completion also differed—some patients prefer to complete a PRO questionnaire at home, as it shortens the time spent at an appointment, reduces time pressure during completion, and offers flexibility as to when to fill out the questionnaire; others prefer completion on site as it allows their healthcare-related tasks to be done at one time [45] and makes professional assistance available [38]. Especially patients with low health literacy value their privacy highly; therefore, in cases for which support from familiar relations is an option, home completion seemed popular [32]. This means that some patients might benefit from completing PROMs in-office while others prefer the pre-visit option [54]; in sum, to reduce patient burden, the location of completion should be tailored to the individual patient [18].

Regarding patient burden in completing PROs questionnaires, scientific knowledge is scarce; however, one study shows that evening completion is favoured over morning, weekly is less burdensome than daily, and twice-a-day more burdensome than once-a-day [55].

3.5. Display and quality of data

Eight studies specifically scrutinised patient and clinician preferences concerning the display of PROs data [63,70–76]; overall, 35 studies provided inputs to the area (Table 4). Findings in this section are based on: Discussions/commentaries (10), systematic reviews (3), workshops (3), feasibility studies (2), individual interviews (2), reviews (2), semi-structured interviews (2), focus group interviews (2), mixed methods (2), participant observation and semi-structured interviews (1), consensus panels (1), case studies (1), scoping review (1), structural interviews (1), human-centered design process (1) and cross-sectional mixed methods evaluation (1).

Results showed that simple linear graphs, display of disease progression over time, detailed information conveying the meaning of scores, proper label explanations on the Y-axis, indications on severity levels of symptoms, and marking potential attention points are advisable when presenting individual PROs data [63,70,71,73–76]. One study also found that patients prefer housing

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Table 4
Clinician and patient concerns and preferences on PRO-data regards.

Clinicians	Patients
Validity [16,21,36,39,47,54,56,58–60,66,68,69,77,78]	Accessibility [63]
Reliability [16,21,36,39,54,58,66,68,69,78]	Tracking of progression [38,63,75]
Interpretability [16,36,39,45–47,56,63,69,71]	Meaningfulness [75]
Timely data [38,54,66]	Display of data: simple graphs (line or bar graphs) [54,70,73–75], show via traffic light or housing icons/star rating displays [72]
Tracking of progression[38,63,75]	Free text options [54,74]
Display of data: simple graphs (line or bar graphs)[54,70,75]	Comparability over time [38]
Value in daily practice [17,54]	Comprehensiveness [38,66]
Relevance [16,17,36–38,54]	Information on the probability of treatment outcomes [38]
Complementarity to other types of data [21]	Contextual information [74]
Actionability [33,38,66,68,79]	Marking of relevant attention points [71]
Relevant and standardized MIDs [36,75]	The honesty of answers? [61]
Responsiveness [16,36,39,47,77,80]	Simple lay language [76]
Sensitivity [66,77]	
Comparability to former collected PRO-data [54]	
The forming of a comprehensive report [64]	
How easy it is to use [18,39,54,66,69,80]	
The honesty of answers [61,81]	
Usability [17,47]	

icons/star ratings and that traffic-light symbols were considered the second-best option [72]. Patients emphasised the importance of written text and required well-explained and contextual information [74]. Clinicians requested more detailed information on the results, that is, displays of confidence intervals, p-values, and directionality to assess whether a patient is doing better or worse and displaying clinical versus statistical significance [63,70,71]. Results from one study supported the use of simple linear graphs as this format ensures correct interpretation of data 85–98% of the time, irrespective of age or educational level [73].

3.6. Patient empowerment and self-management

Ten studies provided input on patient empowerment and self-management [5,11,34,60,64,82–86]. The studies showed that PROs offer a more holistic approach, highlighting the issues that matter most to patients [11,34,64]. Evidence in this section is based on: Mixed methods and feasibility studies (2), workshops (1), structured review (1), RCT study (1), mixed methods (1), individual interviews (1), participant observation and semi-structured interviews (1), integrative review (1) and prospective cohort study (1).

PROs equip patients with an improved understanding of their condition, treatment, and health and increase their awareness of psychosocial issues and symptoms by encouraging disease-related reflections [60,64,82,84]. Furthermore, PROs enable patients to separate general symptoms from disease-specific symptoms [60], help them acquire the vocabulary needed when addressing disease-related issues, and encourage them to verbalise formerly neglected psychosocial issues regarding, for example, sadness, anxiety, and sexual functionality [64].

PROs involve and empower patients during consultations [34], due to useful PROM feedback [83], improved decision-making [84], and by structuring patients' thinking when discussing sensitive issues [85]. Thus, PROs positively affect patient autonomy and their sense of control [11,34,64,85], adherence to the drug regime [82], disease-related goal-setting [84], patient ownership [34], patient motivation [34,84], emotional well-being [34], and self-perceived health [82], consequently, enhancing disease activity and self-management [34,60,64,82].

PROs' effects on patient empowerment and participation seem to be affected by complementary patient education [5,11,82–84,86]; advice on behavioural changes, joint fitness programmes [82], and introducing coping strategies [83] are examples of educative efforts supplementing PROs intervention. PRO-based patient empowering interventions might be improved by multidisciplinary teams [5], confidence-building, engaging encouragement of treatment adherence by clinicians [11], coaching, adequate communication skills, commitment from the involved actors [86], and useful PROs feedback to patients can improve patient-clinician collaboration [84].

3.7. Patient-clinician communication

Sixteen studies reported that in most cases, the use of PROs improves and/or increases communication with clinicians during consultations [11,20,34,58–60,65,78,85,87–93]. PROs ensured patient-centred communication [60] and more patient-driven consultations [84] from the patients' perspective [11] and based on their disease experiences [65,87]. Hence, PROs enabled a shared understanding of the patient's disease situation [11,34]. Results in this section are based on: Systematic reviews (4), RCT studies (2), mixed methods and feasibility studies (2), workshop (1), feasibility study (1), scoping review (1), participant observation and semi-structured interviews (1), feasibility study and semi-structured interviews (1), feasibility study and RCT study (1), survey (1) and content analysis of consultations (1).

PROs help identify unmet needs and previously omitted concerns [34,85] and detect unrecognised problems [90] by prompting broader and patient-relevant discussions concerning topics that might otherwise have been overlooked [59].

During consultations, PROs provide specific disease information [65], open the question of psychosocial issues [60], and promote discussions of symptoms [20,58,86], medication adjustments [87], emotional functioning [20,89], social and sexual functioning [89], and other health-related quality of life (HRQoL) and/or sensitive issues [20].

Furthermore, PROs might streamline consultations as a result of more efficient and productive talks [59], enhancing interprofessional communication [59] and supporting doctors' treatment decisions [92].

Improvements in patient-clinician communication and patient participation during consultations can be facilitated by such strategies as a printed symptom summary for patients [87], jointly reviewing PROs answers [88], patient-encouraging computer screen

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Table 5
Overview of the empirical studies included in the scoping review.

Reference	Number of Participants/articles/ subject field	Method/Study/Article type	Disease area	Year	Country	Theme
[30]	N = 12 articles	Scoping review	Subarachnoid haemorrhage	2019	Canada	PRO development
[28]	N = 189 studies	Scoping review	Across conditions	2016	Netherlands	PRO development
[35]	N = 24 PROM developers	Telephone interviews	Across conditions	2017	Netherlands	PRO development
[14]	N = 26 PROMs	Narrative review	Cardiovascular	2018	Australia/USA	PRO development
[32]	N = 20 patients, 10 clinicians	Individual and focus group interviews	COPD	2012	UK	PRO development
[31]	N = 12 PROMs	Review	COPD	2013	UK	PRO development
[29]	N = 26 PROMs	Review	Cross-sectional	2018	USA	PRO development
[36]	N[a]	Review	Chronic heart failure	2014	Australia	PRO development/ Display and quality of data
[37]	PROMs in clinical practice	Discussion/commentary	Across conditions	2018	Australia	PRO development/Attitudes, experiences and structures
[41]	N = 8.256 patients	Feasibility study	Cross-sectional	2016	Denmark	Response rate and patient burden
[49]	N = 4 PROMs	Readability assessment	Swallowing disorders	2011	USA	Response rate and patient burden
[50]	N = 12 PROMs	Readability assessment	Dysphonia	2012	USA	Response rate and patient burden
[51]	N = 10 PROMs	Readability assessment	Oral conditions	2012	USA	Response rate and patient burden
[57]	N = 275 patients	Survey	Cancer	2018	USA	Response rate and patient burden
[42]	N = 271 patients	Longitudinal study	Cancer	2019	Denmark	Response rate and patient burden
[55]	N = 61 volunteers	Feasibility study	Across conditions	2019	Canada/UK/USA	Response rate and patient burden
[53]	N = 10 PROMs	Readability assessment	Rheumatology	2013	UK	Response rate and patient burden
[52]	N = 15 PROMs	Readability assessment	Tinnitus	2011	USA	Response rate and patient burden
[44]	PRO in healthcare	Discussion/commentary	Across conditions	2013	UK	Response rate and patient burden
[43]	N = 277 patients	Feasibility study	HIV	2018	Denmark	Response rate and patient burden
[18]	PROs integration into EHRs	Discussion/commentary	Cross-sectional	2018	USA	Response rate and patient burden
[67]	PRO, PROM, PREM and PPI	Discussion/commentary	Across conditions	2013	UK/Australia	Response rate and patient burden
[48]	N = 31 patients	Feasibility study	Multiple sclerosis	2017	USA	Response rate and patient burden
[45]	N = 51 patients	Semi-structured interviews	Arthritis	2018	USA	Response rate and patient burden
[62]	N = 1.418 self-assessments	Feasibility study	Cardiac surgery	2013	USA	Response rate and patient burden
[40]	N = st.1: 272 patients, st.2: 1.291 patients	Feasibility study	Cancer	2003	UK	Response rate and patient burden
[47]	N = 60 articles	Scoping review	Cross-sectional	2018	UK/Portugal	Response rate and patient burden
[58]	N = 107 patients	Feasibility study	Cancer	2007	USA	Response rate and patient burden/ Patient-clinician communication
[38]	PRO as information technology in healthcare	Discussion/commentary	Across conditions	2015	Israel	Response rate and patient burden/Display and quality of data
[20]	N = 30 articles	Scoping review	Cancer	2015	Canada	Response rate and patient burden/Organizational and attitudinal aspects
[17]	PRO in chronic illness care	Discussion/commentary	Chronic conditions	2018	USA	Response rate and patient burden/Display and quality of data
[75]	N[a]	Review	Cancer	2018	Austria/Italy	Display and quality of data
[39]	PRO in breast cancer	Discussion/commentary	Cancer	2018	USA	Display and quality of data
[63]	N = 27–28 participants	Consensus Panels	Cancer	2018	USA/Austria/Canada	Display and quality of data
[76]	N = 45 patients, 12 providers	Human-centered design process	Arthritis	2019	USA	Display and quality of data
[71]	N = 39 patients, 40 clinicians	Mixed methods	Cancer	2016	USA	Display and quality of data
[16]	PPI in PRO development	Discussion/commentary	Across conditions	2012	UK	Display and quality of data
[72]	N = 45 patients	Focus group interviews	Elective surgery	2012	UK	Display and quality of data
[70]	N = 50 patients, 20 clinicians	Cross-sectional mixed methods evaluation	Cancer	2015	USA/Canada	Display and quality of data
[73]	N = 198 patients	Structural interviews	Cancer	2005	Canada	Display and quality of data
[66]	N = 3 case studies	Case studies	Across conditions	2012	USA/Sweden	Display and quality of data
[74]	N = 6 meetings, 3–7 patients each time	Focus group interviews	Cancer	2003	Canada	Display and quality of data
Reference	Number of Participants/articles/ subject field	Method/Study/Article type	Disease area	Year	Country	Theme
[56]	N = 50 + stakeholders	Workshop	Chronic conditions	2017	Canada/USA	Display and quality of data
[78]	N = 22 studies	Systematic review	Cross-sectional	2018	Australia	Display and quality of data/Patient-clinician communication
[54]	Real-time PRO in clinical practice	Discussion/commentary	Cancer	2011	USA	Display and quality of data/Organizational and attitudinal aspects

(*continued on next page*)

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Table 5 (*continued*)

Reference	Number of Participants/articles/ subject field	Method/Study/Article type	Disease area	Year	Country	Theme
[21]	N = 24 patients, 14 nurses, 15 neurologists	Feasibility study	Multiple Sclerosis	2014	USA	Display and quality of data/Organizational and attitudinal aspects
[68]	Patient-reported outcomes in cancer care	Discussion/commentary	Cancer	2017	USA	Display and quality of data/Response rate and patient burden/ Shared decision-making (SDM)/Organizational and attitudinal aspects
[5]	N = 31 patients	Mixed methods	Chronic Heart Failure	2018	Australia	Patient empowerment and self-management
[64]	N = 29 patients	Individual interviews	Epilepsy	2018	Denmark	Patient empowerment and self-management
[85]	N = 13–20 patients	Mixed methods and feasibility study	Cancer	2018	UK	Patient empowerment and self-management
[83]	N = 142 patients	Prospective Cohort study	Osteoarthritis	2018	Netherlands	Patient empowerment and self-management
[82]	N = 147 patients	RCT study	Arthritis	2012	Egypt	Patient empowerment and self-management
[34]	N = 18 patients, 4 nurses	Mixed methods and feasibility study	Chronic heart failure	2018	UK	Patient empowerment and self-management
[84]	N = 26 articles	Integrative review	Cancer	2015	Netherlands	Patient empowerment and self-management
[11]	N = 17 experts	Workshops	Multiple sclerosis	2015	International	Patient empowerment and self-management
[60]	N = 9 consultations, 12 patients	Participant observation and semi-structured interviews	Chronic kidney disease	2016	Denmark	Patient empowerment and self-management
[93]	N = 213 patients	RCT study	Cancer	2007	USA	Patient-clinician communication
[91]	N = 213 patients	RCT study	Lung-transplant patients	2010	Canada/USA	Patient-clinician communication
[87]	N = 112 patients	Feasibility study and RCT-study	Cancer	2016	USA	Patient-clinician communication
[65]	N = 10 clinicians	Feasibility study and semi-structured interviews	Cancer	2016	Canada	Patient-clinician communication
[88]	N = 323 patients	Survey	Neurology	2017	USA	Patient-clinician communication
[100]	N[a]	Multidisciplinary consensus process	Cancer	2012	USA	Patient-clinician communication
[89]	N = 26 articles	Systematic review	Cancer	2014	UK	Patient-clinician communication
[59]	N = 43 articles	Systematic review	Cancer	2017	Canada	Patient-clinician communication
[90]	N = 27	Systematic review	Cancer	2013	Australia	Patient-clinician communication
[92]	N = 22 consultations, 22 patients, 16 doctors	Content analysis of consultations	Cancer	2012	UK	Patient-clinician communication
[86]	N = 146 articles	Structured review	Across conditions	2005	UK	Patient-clinician communication
[98]	N = 17	Systematic review	Across conditions	2013	Ireland	Shared decision-making (SDM)
[8]	Patient empowerment as a PRO	Discussion/commentary	Chronic conditions	2012	UK	Shared decision-making (SDM)
[94]	N = 85 patients	Survey	Carpal Tunnel Release	2014	Korea	Shared decision-making (SDM)
[33]	PRO into health care	Discussion/commentary	Across conditions	2016	USA	Shared decision-making (SDM)
[96]	N 63.931 responses	Panel survey	Cross-sectional	2018	USA	Shared decision-making (SDM)
[99]	PROMs for quality improvements	Discussion/commentary	Across conditions	2017	International	Shared decision-making (SDM)
[97]	N = 39 articles	Cochrane review	Across conditions	2014	International	Shared decision-making (SDM)
[95]	N = 126 patients	Cross-sectional survey	Cancer	2017	Germany	Shared decision-making (SDM)
[79]	N = 50 + stakeholders	Workshop	Chronic conditions	2017	Canada/USA	Organizational and attitudinal aspects
[77]	N = 16 articles	Systematic review	Across conditions	2014	Ireland/UK	Organizational and attitudinal aspects
[46]	N[a]	Workshop	Across conditions	2009	Germany/Canada	Organizational and attitudinal aspects
[80]	N[a]	Discussion/commentary	Across conditions	2007	Denmark	Organizational and attitudinal aspects
[61]	N = 19 patients, 11 providers	Semi-structured interviews	HIV	2018	USA	Organizational and attitudinal aspects
[69]	N = 63 articles, 7 experts	Mixed methods	Cross-sectional	2018	UK	Organizational and attitudinal aspects
[81]	N = 13 clinicians	Individual interviews	Epilepsy	2018	Denmark	Organizational and attitudinal aspects
[101]	N = 678 patients	Cross-sectional survey	Atopic Dermatitis	2017	USA	Organizational and attitudinal aspects
[102]	N[a]	Review	Cancer	2018	USA	Organizational and attitudinal aspects

[a] Number of included participants/articles is unclear.

Table 6
Organisational and attitudinal barriers and enablers on the use of PROs in chronic care.

Theme	Barriers/enablers
Knowledge and education	– Knowledge on how to use and/or interpret PROs data, enabling clinical actions and preventing improper or non-use of PROs [40,60,92,93,100–102]. – PRO-data can steer discussions into areas clinicians have little control over and are uncertain how to address [60,92,100]. – Educational initiatives helping clinicians get accustomed to PROs and recognise their purpose and clinical value improve acceptance of PROs measures [18,40,46,101,102] – Patients must be informed and motivated by clinicians on the use of PROs to ensure compliance [46].
Attitudes and expectations	– Doctors might avoid engaging in PRO-based conversations by offering the patient a logical explanation, downplaying the issue, or normalising the patient's experience [92]. – Uncertainty whether the PROs data are being applied during patient-clinician consultations might affect patient attitudes negatively[60]. – Patient efforts exerted in completing the questionnaire should correspond with the actual use of the information in chronic care[61]. – Clinicians express ambivalence towards PROs as some believe they improve patient-centredness and the quality of follow-ups while others perceive them as limiting the nursing practice, impairing the patient-clinician relationship, negatively affecting the quality of care, reducing interpersonal contact, and preventing the exercise of 'real nursing' [61,81]. – If patients do not perceive PROs as a patient-oriented tool but rather as a data-collection or time-saving instrument, their desire to actively engage might decrease [60]. – PROs' ability to improve patient outcomes is critical to convince clinicians of PROs clinical value [8,54].
Organisational issues	– The organisational setup is important to promote systematic education, training, and support for clinicians and patients [18,20,21,64,75,77,79]. – The culture in the healthcare system is a potential barrier [11,77]. Hence, successful integration of PROs depends on whether the functionalities of PROs match current demands in healthcare [99], on the stakeholders' engagement, and on whether joint ownership emerges[37–39,43,54,68,81]. – Appropriate technological infrastructures are required if clinicians are to accept the use of PROs [69,79]. – The quality of logistical structures, support systems, and how PROs are mediated and administered are essential [17,46]. – The balance between workflow and PROs interventions affects their utility in chronic care [39,54,66,81]. On the one hand, workflow modifies how PROs are applied and administered [20,54] and on the other hand, PROs may impact the workflow by increasing the workload and the burden on clinical staff [33,77,81], an attention point in a busy working environment [39,102]. Therefore, data availability needs to be attuned to existing workflows [54,68]; the system should assist rather than present barriers when clinicians exhibit PRO-based referrals or consider treatment options [77]. – Lack of time and resources is a potential barrier [20,39,58,61,81,91,102]. Accordingly, resources determine the time clinicians are given to interpret data [33]. Adequate time and resources are required to enable thorough scrutiny of PROs data to ensure a holistic understanding of the patient's disease situation and avoid important details/information being omitted [58,81]. Hence, there seems to be a trade-off between available resources and the quality of the reporting of a patient's health status [75]. Nonetheless, some studies indicate that consultation times may not necessarily increase when applying PROs [20,91]. The time aspect seems particularly relevant when PRO is part of a triage system, since the distribution of patients presumably results in fewer 'easy patients' showing up for consultation, potentially increasing the clinicians' burden and eroding job satisfaction [81]. – Functional multidisciplinary teams to ensure proper responses to PRO scores [80,100].

positioning [60], positive PROs interactions by clinicians [59], and recognition of patients as genuine partners [34].

In two studies, the authors pointed out that findings lacked statistically robust evidence [78,89], that not all patients experience PROs as having any effect on patient-clinician communication/consultation [58,60], and that effects on patient management also were seen as limited [91–93].

3.8. Shared decision-making (SDM)

In ten studies, the connection between PROs and SDM was examined [37,38,64,68,94–99]. Findings in this section are based on: Discussions/commentaries (4), Cochrane review (1), systematic review (1), individual interviews (1), cross-sectional survey (1), survey (1) and panel survey (1).

Results reflected that patients vary in their interest in taking an active role in the decision-making process [64,94,95], although the majority of patients prefer to share treatment responsibility [95]. Therefore, PRO-based follow-up might be most suiting in patient cases in which there is a preference for an active patient role [64].

Interestingly, when patients' preferences on decision-making involvement matched their actual involvement, subjective outcomes were better; identifying patients' decision-making preferences pre-consultation [94,95] is essential as it allows clinicians to tailor their approach to the individual patient [95].

During consultations, PRO-based patient participation was strengthened if clinicians actively encouraged, motivated, and engaged patients, providing proper information/feedback, and facilitating patients' engagement in SDM and shared goal-setting [37,38,68,99].

Positive effects of SDM include increased patient satisfaction, better healthcare delivery and improved quality of patient-reported outcomes [96], meaning that SDM might improve how patients' perceive subjective health outcomes. Conversely, poor SDM may result in deteriorating patient-reported health outcomes [96], while divergence between real and preferred patient involvement may result in worse subjective outcomes [94].

In two included studies, the authors underscored that evidence is still quite scarce and relatively weak statistically [97,98].

3.9. Organisational and attitudinal aspects

Wang and Bellows (2018) stated that "*challenges associated with collecting and using PROs data in routine clinical practice are well-documented and pertain to providers, patients, and healthcare practices and organisations*" [17]. Hence, Table 6 displays attitudinal and organisational barriers and enablers on the use of PROs in chronic care, which are included as they may mitigate PRO-based patient participation. Table 6 are based on inputs from 33 papers [8,11,17,18,20,21,33,37–40,43,46,54, 58,60,61,64,66,68,69,75,77,79–81,91–93,99–102], indicating that barriers/enablers mainly concern knowledge and education, attitudes and expectations and organisational issues. Evidence in this section is based on: Discussions/commentaries (11), feasibility studies (4), workshops (3), individual interviews (2), reviews (2), RCT studies (2), semi-structured interviews (1), mixed methods (1), participant observation and semi-structured interviews (1), case studies (1), scoping review (1), content analysis of consultations (1), multidisciplinary consensus process (1), systematic review (1) and cross-sectional survey (1).

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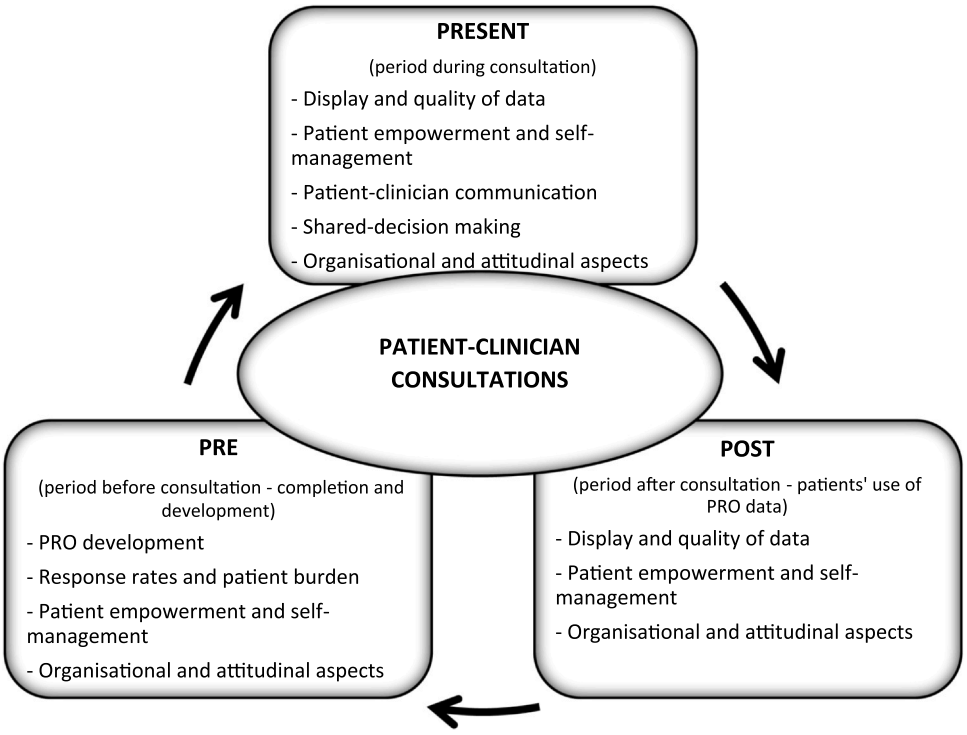

Fig. 2. The timewise association between PROs and patient participation in chronic care with patient-clinician consultations as the reference point.

4. Discussion and conclusion

4.1. Discussion

The three sub-questions formulated to answer the research question concerning the association between PROs and patient participation in chronic care must be dealt with. Results were elaborated upon and discussed timewise with patient-clinician consultations as the reference point.

The first sub-question—"*In what areas is there a relation between PROs and patient participation in chronic care?*"—resulted in the identification of these seven areas: 1) PROs development, 2) response rates and patient burden, 3) patient empowerment and self-management, 4) data display and quality, 5) communication, 6) organisational and attitudinal aspects, and 7) shared decision-making.

Answers to the second and third sub-questions—"*What scientific knowledge exists on the subject field within the identified areas?*" and "*What barriers/enablers influence the relationship between PROs and patient participation in the identified areas?*"—are presented with the patient-clinician consultation as the reference point, since the literature reviewed indicated that the association between PROs and patient participation in chronic care timewise takes place in three phases: before consultation (pre), during consultation (present), and after consultation (post).

As Fig. 2 illustrates, the association between PROs and patient participation in chronic care is a three-phase iterative process. The review revealed that the character of the association between PROs and patient participation is dialectic and interdependent. Optimal PROs interventions require patient participation, whereas patient participation might be promoted and improved by the use of PROs.

The 'pre' phase, concerning the development and completion of PRO questionnaires, is quite extensively covered in the academic literature. Issues pertaining to *PROs development* processes with relatively low or no patient participation are typical, in which the exclusion of particular patient groups with learning disabilities, for example, or with very poor health persists. *Response rates* vary but might be improved by information, reminders, motivating encouragement, and by consistently applying PRO data during patient-clinician consultation. What is uncertain in the use of PRO in routine chronic care is how response rates evolve over a longer term. It is clear nevertheless that not all patients wish or are able to participate, making it interesting to further explore reasons behind non-participation and how initiatives such as mandatory completion and other types of PRO-mediation might have an impact. Knowledge of PRO-instigated *patient burden* is limited, requiring more attention, preferably with particular awareness of individuals with multiple chronic conditions, low health literacy, and/or cognitive challenges.

The 'present' phase, regarding the use of PRO data in patient-clinician consultations, signals that physical and mental engagement is required of all actors involved to bring about PRO-based patient participation. Empirical knowledge concerning this phase, in which PROs' participatory functionality guides patient-clinician consultations, was the focus. Several studies reported that PROs interventions improved *patient-clinician communication* by enabling more holistic, substantive, effective, relevant, and patient-engaged conversations. *Shared decision-making* may influence patient-reported outcomes, patient satisfaction, and the like, but studies on PROs' effects on SDM are lacking. However, the existing evidence indicates that patient preferences regarding their decision-making role vary along an active-passive continuum, adjusting patients' perception of being in control during the consultation. Clarification of patients' participatory preference before the application of PROs in general and in consultation might be useful and allow more individualised patient-clinician conversations. Further, PROs seem to have positive effects on *patient empowerment and self-management* in the 'pre' and 'present' phases that might mobilise and improve patients' knowledge, resources, and capabilities, resulting in an increased sense of autonomy. In this context, chances of success seem to increase if actors are motivated and engaged while being supported by appropriate educative intervention strategies. Little is known about the link between PROs and *patient empowerment and self-management* in the 'post' phase. Therefore, studies on patients' use of PRO data in homely settings as part of their everyday life are recommended.

Preferences and requirements regarding *display and quality of data* also received attention in the academic literature. Patients and clinicians require that PROs data be useful in every sense,

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statistically as well as clinically, and presented in a simple, informative, and clear way, flagging alarming issues and displaying progression over time. As most findings in this field are based on group/individual interviews, ethnographic studies on the use of PROs data in practice, at healthcare facilities or other places where patients access data would be beneficial. Moreover, it was frequently emphasised that PROs data as part of chronic care must adhere to scientific standards and practical requirements if clinicians and patients are to benefit from it. Knowledge on *organisational and attitudinal aspects* primarily applies to the 'pre' and 'present' phases but are also relevant in the 'post phase'. Thus, prerequisites concerning PRO-based patient participation in chronic care include clinician attitudes, functional technological infrastructure, contextual alignment with workflow, a patient-oriented culture, and adequate time and resources enabled by the necessary economic investment, multidisciplinary teams, and systematic education of users on PROs' functionality, application, and interpretation.

Based on the findings in the present review, four issues stand out regarding current knowledge on the association between PROs and patient participation in chronic care: a) the need for more research on the phenomena over a longer period; b) improved understanding of how different patient groups are affected, who is excluded from participating, and how they can be integrated appropriately; c) increased knowledge on the 'post' phase—empirical findings from patients' use of PRO data in natural settings between visits are very limited; d) awareness of organisational barriers relating to structure, technology, and culture. *Limitations* pertain to the shortage of explicit literature in the subject field, the filtering of articles having been done solely by the first author, and the scientific and 'only English' language criteria from four databases, thereby excluding other languages, alternate databases, unpublished papers, grey studies, and other materials. The acute care area is deliberately excluded and the palliative care area is potentially underrepresented in the present review; hence, future reviews examining patient participation in these specific areas of healthcare is encouraged. Similarly, studies on PRO and patient participation based on the vast amounts of validation studies excluded in this review hold great value as well.

4.2. Conclusion

The association between PROs and patient participation in chronic care consists of seven areas: 'PROs development', 'response rates and patient burden', 'patient empowerment and self-management', 'data display and quality', 'patient-clinician communication', 'organisational and attitudinal aspects', and 'shared decision-making'. Knowledge of the phenomena's association, which is dialectic, is extensive in the 'pre' and 'present' phases, but more research into the 'post' phase, in patient-relevant settings over a longer period and with a particular focus on potentially excluded patient groups is required in the near future. Barriers mainly pertain to organisational structures, actors' attitudes, time and resource constraints, technological setup, and cultural aspects.

4.3. Practice implications

This review contributes new knowledge on the association between PROs and patient participation in chronic care by consolidating current scientific knowledge on the subject, revealing in what areas the phenomena are associated, pinpointing knowledge gaps, and discussing them with patient-clinician consultation as a reference point resulting in a conceptual understanding of the connection between PROs and patient participation timewise. Findings may promote nuanced discussions on the subject, help target research within the field, and improve interventions in chronic care concerning PROs and patient participation.

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CRediT authorship contribution statement

Jeppe Eriksen: Conceptualization, Methodology, Formal analysis, Investigation, Resources, Original draft, Visualization. **Pernille Bertelsen:** Supervision, Writing – review & editing. **Ann Bygholm:** Supervision, Writing – review & editing.

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Conflicts of interest

The authors affirm having no actual or potential conflicts of interest to disclose.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.pec.2022.01.008.

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