

BMJ Open Measures used to assess interventions for increasing patient involvement in Danish healthcare setting: a rapid review

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ABSTRACT

Objective To identify measures used within Denmark evaluating any type of intervention designed to facilitate patient involvement in healthcare.

Design Environmental scan employing rapid review methods.

Data sources MEDLINE, PsycInfo and CINAHL were searched from 6–9 April 2021 from database inception up to the date of the search.

Eligibility criteria Quantitative, observational and mixed methods studies with empirical data on outcomes used to assess any type of intervention aiming to increase patient involvement with their healthcare. Language limitations were Danish and English.

Data extraction and synthesis Two independent reviewers extracted data from 10% of the included studies and, due to their agreement, the data from the rest were extracted by first author. Data were analysed with reference to existing categories of measuring person-centred care; findings were synthesised using narrative summaries. Adapted Preferred Reporting Items for Systematic Reviews and Meta-Analyses 2020 guidelines were used to guide reporting.

Results Among 3767 records, 43 studies met the inclusion criteria, including 74 different measures used to evaluate interventions aimed at increasing patient involvement within healthcare in Danish hospital and community settings. Generic measures assessed: patient engagement (n=3); supporting self-management (n=8); supporting shared decision-making (n=9); patient satisfaction and experiences of care (n=11); health-related patient-reported outcome (n=20).

Conclusions Across Denmark, complex interventions designed to improve patient involvement with healthcare vary in their goals and content. Some targeting healthcare professionals, some patient health literacy and some service infrastructure. A plethora of measures assess the impact of these interventions on patient, professional and service delivery outcomes. Few measures assessed patient involvement directly, and it is unclear which proxy measures capture indicators of perceived involvement. Lack of conceptual clarity between intervention goals, the components of change and measures makes it difficult to

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This study used rigorous methods for a rapid review in the search strategies and for reporting of methods and findings.
- ⇒ A narrative synthesis of measures was used across different types of patient involvement interventions evaluated in the Danish healthcare setting.
- ⇒ A steering group of health service researchers and quality improvement leads were actively involved as collaborators to ensure that the study was relevant to their needs as end-users.
- ⇒ The research benefits from adopting a multiple stakeholder framework to link measures with evaluations of complex interventions developed and evaluated in healthcare.
- ⇒ Only quantitative intervention studies were included, though qualitative methods of evaluation are likely to help understanding of associated concepts.

see what types of intervention can best support change in services to ensure patients are more effectively involved in their healthcare.

INTRODUCTION

Patient involvement interventions within health settings aim to support the active engagement of patients in the process of securing appropriate, effective, safe and responsive healthcare.^{1–3} They are designed to improve a range of outcomes associated with increasing patient health literacy, clinical decision-making, self-management, experience of care and engagement with services.⁴ Their content, structure and delivery are underpinned by different theoretical and conceptual frameworks,⁵ such as: person-centred communication⁶; supported self-management; informed or⁷; shared decision-making (SDM)^{8 9}; and health and illness behaviour change.^{10–13} The terms



person-centred and patient-centred care tend to be used interchangeably in patient involvement interventions as they have an overall mutual focus, however in part because they have a different purpose.¹⁴ There is a lack of consensus on the components within these active ingredients, the actual meaning, and the interpretation of the terms involvement and engagement⁴ as well as a classification of which measures capture meaningfully changes to patient experience and service are missing.^{15 16} The consequences are that the outcomes selected to evaluate these disparate interventions are varied,^{8 17 18} making it challenging to synthesise findings and ascertain which type of intervention facilitates patient involvement in what context, and for whom.^{12 15 19 20}

Involving patients in healthcare is a legal requirement of service delivery in Denmark²¹ and increasing patient involvement through national quality improvement programmes is an explicit goal.²² Since 2014, several patient involvement interventions have been developed for Danish services²³ to increase patient health literacy, decision-making and management of health including: the User-Involving Hospital programme,²⁴ SDM, patient-centred care, patient involvement in healthcare surveys and patient-reported outcomes (PRO).^{25 26} Patient self-report questionnaires of their healthcare experiences are increasingly seen as a key component of healthcare quality monitoring and improvement. The national survey of patient experiences ("Landsdækkende Undersøgelse af Patientoplevelser", LUP) consists of five generic questions developed by researchers to address patient perceptions of their satisfaction with services and involvement in healthcare.²⁷ The questions have been used in a yearly survey in all Danish hospitals. The Danish programme 'PRO' recommended disease-specific patient-reported outcome measures to be developed,^{25 26} and integrated within healthcare practice to help patients and professionals discuss what is important to patients about their illness when managing healthcare.²⁸ Both the User-Involving Hospital programme²⁴ and research programmes²⁹ have started translating measures from international research to evaluate health literacy, decision quality and SDM outcomes.^{10 18 30}

Identifying valid and reliable measures is necessary to ensure researchers and service innovators develop a shared understanding of what to use when assessing patient involvement interventions to practice change.^{8 15} We drew on a major review by the Health Foundation (UK) identifying over 200 surveys and scales used to assess person-centred care,⁸ to guide this review of measures assessing patient involvement interventions. The following informs our identification and categorisation of measures associated with the underlying goals of different patient involvement interventions: (1) Patient engagement, measuring the extent to which people feel a part of, or actively participating in the care process; (2) Supported self-management, measuring the decisions and behaviours patients undertake to care for themselves; (3) SDM, measuring the patient-professional

communication process about choosing between healthcare options, considering risks, benefits and preferences, and agreeing about the care plan; (4) Patient satisfaction with care, measuring patient reports of their experiences of healthcare services; 5) PROs, measuring reports of their health status and impact on their life.⁸

A challenge for evaluating patient involvement interventions within healthcare is they tend to be complex interventions with several interacting components, and involve multiple stakeholders with different viewpoints. The Making Informed Decisions Individually and Together (MIND-IT) framework by Bekker (see figure 1)³¹ represents the role of two, or more people are approaching the same health problem, each with different goals, values, skills and knowledge and needs.³² The MIND-IT framework helps patient involvement intervention developers think proactively about (1) the decision context for each individual when thinking about the health problem, (2) the factors associated with each stakeholder's reasoning and actions and differential needs and (3) the points within healthcare pathways enabling interaction between multiple stakeholders. The Medical Research Council (MRC) framework for research to develop and evaluate complex interventions³³ provides guidance to carry out research that informs the components and 'active ingredients' of interventions, identify factors associated with change, and requirements supporting the integration of the interventions to find evidence of which components worked for whom, when and in what context.

Due to the lack of consensus on assessing patient involvement, this review provides an overview of measures used to evaluate patient involvement interventions carried out in Denmark to explore the common ground between quality improvement and applied health research programmes that can be used to change practice.

Objective and research questions

The objective is to identify measures used within Denmark evaluating any type of intervention designed to facilitate patient involvement in healthcare.

Research questions:

- ▶ What measures are used to evaluate interventions designed to increase patient involvement in healthcare within Denmark?
- ▶ What type of population and interventions are assessed and with which measurement tools?
- ▶ Which measures provide evidence of patients' self-report of involvement in their healthcare?

METHODS

Design

An environmental scan³⁴ of quantitative and survey-based measures used in Denmark to assess clinical patient involvement interventions using the rapid review method,³⁵ which is a thorough review method that accelerates systematic review processes.^{36 37} The method followed the steps for rapid reviews as defined by the WHO: (1)

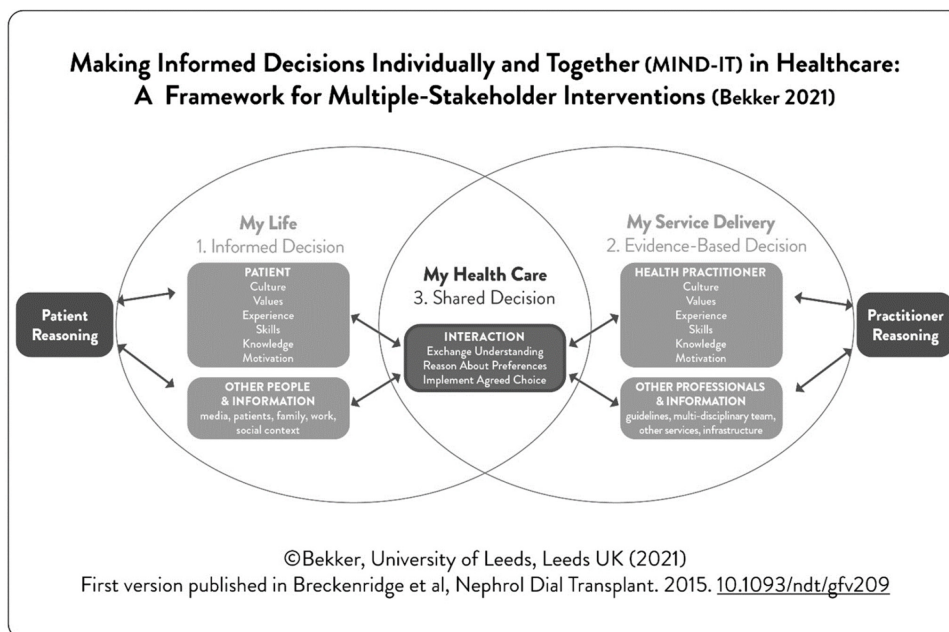


Figure 1 The MIND-IT framework. This figure is reproduced from reference 31 (Breckenridge K, Bekker HL, Gibbons E, van der Veer SN, Abbott D, Briçon S, *et al*. How to routinely collect data on patient-reported outcome and experience measures in renal registries in Europe: an expert consensus meeting. *Nephrology Dialysis Transplantation*. 2015; 30 (10): 1605–14).³¹

form and refine the research question and PICO (Patient population, Intervention, Comparator, Outcomes); (2) definition of search terms and literature search; (3) screening and study selection; (4) data extraction; (5) knowledge synthesis; (6) risk of bias assessment; (7) report production and dissemination.³⁸ The PICO were adapted to include Timing and Setting to become PICOTS³⁹ in order to provide a more comprehensive analytical framework for reviewing complex interventions.⁴⁰ The protocol was incorporated as a part of the review process and therefore not registered or published⁴¹ as the content is equivalent to the content of the methods described in this paper. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidance⁴² were used and adapted to the needs of the rapid review³⁹ as the PRISMA-RR has not yet been published.⁴³

Search strategy

The search strategy was developed and refined in cooperation with a research librarian (AVM) to identify studies reporting outcome measures used by researchers in a Danish context with reference to the objectives of this study.

The Cochrane Library was searched to ensure that no existing reviews existed or was planned on this topic. An initial search was undertaken in PubMed to identify index terms of appropriate Medical Subject Headings (MeSH) terms and keywords for the search in the MeSH browser. A second search using MeSH terms/thesaurus/heading in combination with free text was undertaken across the three databases: PubMed, PsycInfo and CINAHL. The search strategy was broad in nature with a limited and controlled vocabulary related to the terms: ‘patient involvement OR engagement OR activation

AND Danish’. The detailed search strategy and search terms entered into the electronic databases is presented in online supplemental appendix A. The searches were performed from 6–9 April 2021 from database inception up to the date of the search. Reference lists and citations of all included articles were hand searched for additional studies, and grey literature was provided by a steering group of experts. Language was limited to Danish and English.

Inclusion and exclusion criteria

The primary focus of this review was to identify quantitative, mixed methods, observational and survey-based measures used to evaluate patient involvement intervention in empirical studies.

Type of participants: People who participated in a patient involvement intervention research project within a health-care setting, including health professionals, patients, carers and relatives.

Types of intervention: Any published intervention designed to increase patient involvement in healthcare, for example, self-management, decision support; patient-centred communication, health-related quality of life; health literacy; health and illness behaviours.

Types of comparison: Any comparison group in studies with an experimental or observational design.

Types of outcomes: Any measure used to capture patient involvement in healthcare as either primary or secondary outcomes. The measurement tools needed to be quantitative or survey-based including self-report questionnaires and/or analysis of consultations.

Types of timing: No time limit was set for publication year of the studies.

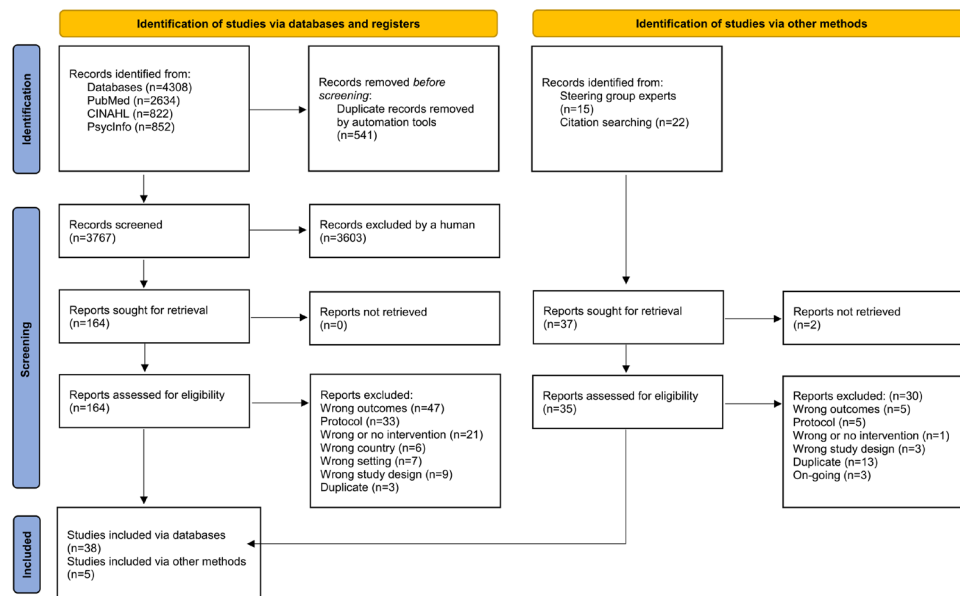


Figure 2 Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram of information through the different phases of the rapid review.

Setting: Danish healthcare settings where questionnaire-based surveys were used to evaluate patient involvement interventions.

Only articles published in English and Danish were included.

The review excluded qualitative studies, reviews, protocols and non-research articles as well as studies without empirical data on outcome measurement or use of measurement tools. Studies conducted outside a healthcare setting were excluded.

Evidence selection

EndNote computer software was used to manage references and to remove duplicate articles; the software tool Covidence was used for screening and managing the references in the selection process. After removing duplicates, the main reviewer (BST) performed a screening of titles and abstracts and selected studies on the basis of the inclusion criteria. Potentially relevant articles were retrieved in full text and screened by the main reviewer (BST) and a second reviewer (LR). Agreement was reached on which articles met the inclusion criteria. Reasons for exclusion of full-text articles that did not meet the inclusion criteria were recorded and reported in a flow diagram (figure 2) (PRISMA-SR).⁴²

Data extraction

A data extraction sheet was developed for the review to elicit the following: author; publication year; study aim; intervention; name of measurement tool; number of measures; and conclusion (see online supplemental appendix B). In the mixed methods studies, only data related to the quantitative measurement was extracted as qualitative data was not relevant for the purpose of this study. Two independent reviewers (BST and LR) extracted data from 10% of the included studies and

measured their agreement. The kappa coefficient was calculated, revealing 94% agreement; differences were a consequence of extracting different amounts of text or details on the population group. Due to the level of agreement the remaining data extraction was conducted by the first reviewer (BST), and decisions checked by the second reviewer (LR). There was no need to consult a third reviewer. Due to the rapid review methodology the included studies did not undergo a formal quality appraisal process or an evaluation of the validity of findings and their psychometric qualities of measures were not assessed.

Data analysis

The data analysis steps were informed with reference to the Economic and Social Research Council narrative synthesis framework⁴⁴: textual description; grouping; tabulation; vote-counting; translating data in a thematic analysis and a content analysis. The review purpose was methodological to classify measures used, therefore no analysis was carried out to synthesise the study results (ie, common statistical rubrics, data pooling and intervention effectiveness).⁴⁴ Findings were mapped and presented in tabular forms and figures to provide an overview and a summary of the included studies. The categorisation of the data was divided into generic or disease specific measures, and synthesis were informed by the categories by the Health Foundation.⁸ Moreover, the theoretical background for the analysis was based on frameworks developed from other person-centred measurement reviews,^{8 37 45 46} and the MIND-IT,³¹ for example, identifying the purpose of the measure (active ingredient) and the agency of the participant (professional, patient or family member).

Patient and public involvement

None.

RESULTS

The electronic search identified 3767 records of which 164 full-text studies were screened for eligibility and 43 studies were included in this rapid review^{47–89} (see flow-chart, figure 2).

Brief descriptions of the study aim, intervention, measures and conclusion provided in online supplemental appendix B. Table 1 summarises the study characteristics, population, intervention type and delivery, healthcare context and measures used.

The table shows that 86% of the studies (37/43) were published in 2015 or later and spanned over 13 medical specialities. The population in 74% (32/43) of the studies was adults and elderly participants (range 26–75 years), 12% (5/43) were paediatric or adolescents and in one study was the population of a mean age above 75 years. Six studies (14%) were with women only.

The interventions were delivered in different ways, mainly in hospitals (49%) or in outpatient clinics (27%). The providers of the interventions were most often nurses (44%) or an interdisciplinary team of staff (40%). The aims of the interventions were targeted service changes and most often focused on improved self-management and disease control. Most interventions were designed to target supported self-management, with or without PRO. Although most employed a randomised controlled trial design, less than 30% referred to a reporting guideline, and only one study reported involving a patient partner in their research governance.

In total, 74 named measures were used (see table 2 and online supplemental appendix C for abbreviations). Of these, the majority were completed by patients, whereas five were completed by relatives/carers and six by both patient and staff (-S).

The self-report questionnaires varied in lengths and with a range of rating scales; some developed coding frames to classify interview, or consultation data. Most studies used more than one self-report measure. The majority (n=51) of the measures were generic, that is, able to be used across care settings for people with any health problem; the rest were disease specific (n=23) (see table 2). The generic measures were divided into the five categories by De Silva⁸ based on the main purpose of the questionnaire. Although these questionnaires are classified under these different categories, many questionnaires have items within them that assess similar concepts.

We classified the following three measures in category 1 (Patient engagement) the Health Literacy Questionnaire (HLQ); Patient Activation Measure (PAM); and the Participation Subscale (PS) (developed for the LUP-survey) assessing patient involvement in healthcare. These measures were used in six studies: HLQ^{66 78} PAM^{66 70 71 78 79} and PS.⁵⁵ Patient engagement was the primary aim and outcome of one study,⁵⁵ patient involvement was the

primary aim of three studies,^{62 74 84} and self-management, or patient activation, in two studies.^{66 78}

We classified the following eight measures in category 2 (Supporting self-management): Bangor Goal Setting Interview; Goal Attainment Scale; General Self-efficacy Scale (GSE), Perceived Competence Scale (PCS); Rosenberg's Self-Esteem Scale; Treatment Self-Regulation Questionnaire (TSRQ); Brief Cope (assessing effective and ineffective ways to cope with a stressful life event) and Carers Assessment of Difficulties (CADI). The measures were used in three studies as primary outcome measures.^{47 70 89} Primary outcomes included disease development, adherence to medicine, functioning, hospital contacts or quality of life. Six studies employed these measures as secondary outcomes.^{49 53 54 67 78 88}

We classified the following nine measures in category 3 (Supporting SDM): Clinical Decision Making Style patient/staff; Clinical Decision Making Involvement and Satisfaction Scale patient/staff (CDIS-P and CDIS-S); CollaboRATE (assessing the core dimensions of SDM); Decisional Conflict Scale; Decision Regret Scale; OPTION (observing patient involvement in SDM); and Shared Decision-Making Questionnaire (assessing effectiveness of interventions aimed at the implementation of SDM). The measures were used in four studies as primary outcome measures^{69 76 81 82} and in one study as a secondary outcome measure.⁵⁹ More studies used more than one of these measures.^{69 81 82} Two of the studies did not report a patient decision aid component in their intervention.^{69 76}

We classified the following 11 measures in category 4 (Patient satisfaction and experience of care): Camberwell Assessment of Need Short Appraisal Schedule patient/staff; Carers Assessment of Satisfaction Index (CASI); Client Satisfaction Questionnaire; Helping Alliance Scale patient/staff; Healthcare Climate Questionnaire; Patient Assessment of Chronic Illness Care (PACIC); Patient Experience Questionnaire; Perception of Parents Scale (POPS) and Usefulness, Satisfaction and Ease of use. The measures were used in 6 studies as primary outcome measures^{49 56 69 76 77 80} and 11 studies as secondary outcome measures.^{51 61 63–65 71 72 85 87–89} One study used patient and staff measures to capture a multiple stakeholder perspective.⁶⁹

We classified 20 measures in category 5 (PRO). The measures were used in 32 studies to measure the impact of symptoms and illness on quality of life. Although PRO can be used as components within patient involvement interventions, these measures are patient-reported health-related outcomes, and outside the remit of this rapid review.

The number of measures used in each study varied from 1 (n=7) to 12 (n=1). The majority of studies used two measures (n=16) in different combinations (see table 1 and online supplemental appendix B).

In category 1 most studies used two or more measures to evaluate their interventions, for example, PAM and HLQ^{66 78}; patient satisfaction and patient participation⁵⁵ or self-management (GSE, PCS, TSRQ); patient

Table 1 Overview of studies included (n=43), their population, intervention and measurement tools

Study		Population		Intervention		Measurement tools	
Publication year	n=	Age groups (mean age)	n=	Type of delivery	n=	Type	n=
≤2009	2	0–25 (paediatric and adolescent)	5	Face-to-face by healthcare professional	19	Generic	51
2010–2014	4	26–50 (adults)	8	Patients plus relatives	5	Disease specific	23
2015–2019	25	51–75 (elderly)	24	Including group sessions	7		
≥2020	12	75–100 (older adults)	1	Including telecom	7		
		Combined adult ages	5	Mainly web-based	5		
Questionnaires used in study		Gender (female)		Setting		Outcomes assessed	
1	7	0–25%	3	Hospital department	23	Engagement	3
2 or 3	22	26–50%	20	Outpatient clinic	13	Self-management	8
4 or 5	9	51–75%	13	Primary care/general practitioner	3	Shared decision-making	9
6 or more	5	76–100%	6	Community healthcare centre	3	Satisfaction	11
		Unknown/missing	1	Other	1	Patient-reported outcome	20
Study design		Education level reported		Provider		Frequency of data collection	
Cohorte	2	Yes	20	Nurse	19	Single time point	6
Observational	5	Partly	11	Physician	2	Multiple time points	37
Quasi experimental	2	Missing	12	Interdisciplinary group	17		
Interventional	4			Investigator/coordinator	3		
Mixed methods	4			Others	2		
Randomised controlled trial (cluster, multicentre)	24						
Non-randomised	2						
Use of reporting guidelines		Ethnicity reported		Stated staff training			
Yes	12	Yes	5	Yes	19		
No	30	No	38	No	23		
Use of patient partners in research		Medical speciality					
Yes	1	Cardiology	4				
No	42	Dermatology	1				
		Endocrinology	6				
		Internal medicine	1				
Theoretical framework							
Yes	37	Neurology	2				
No	6	Nephrology	2				
		Obstetrics and gynaecology	1				
		Oncology	11				
		Orthopaedics	3				

Continued

Table 1 Continued

Study	Population	Intervention	Measurement tools
	Psychiatry	5	
	Paediatrics	4	
	Respiratory medicine	2	
	Rheumatology	1	

satisfaction (PACIC) and/or PROs related to well-being and quality of life. Some used measures within the same category, but usually the measures were combined with measures from other categories, such as Supporting self-management (CASI, CADI and POPS) or Supporting SDM (CDIS-P/CDIS-S/OPTION scale).^{67 69 76 81}

Most interventions included components targeting the actions of multiple stakeholders (patient, relatives, health professional, interactions and infrastructure). Most evaluated mechanism of change associated with the intervention goal, such as health literacy, satisfaction with care or health professional communication (online supplemental appendix B). Some studies included measures assessing the impact of the intervention on more than one stakeholder: patient and relatives^{48 49}; patient and consultation^{57 58 64}; patient and health professional^{52 63}; or patient, health professional and consultation^{80 81}. Most of the measures used to evaluate impact of the intervention on multiple stakeholders tended to be completed by one stakeholder perspective of another stakeholder's contribution, for example, a patient rating the quality of their own decision-making and their perception of health professional communication skills or family support.

DISCUSSION

The measures used to evaluate interventions designed to increase patient involvement in a Danish healthcare setting, showed that most studies investigated patient involvement interventions in services for people with long-term or chronic health conditions. Some focused on enabling health professionals to increase patient engagement within existing care pathways, through innovating resources and communication practices,^{64 75} others on changing the care-delivery infrastructure^{70 71 85}. The majority of the measures were generic (51/74), of which few measures assessed patient involvement directly, and no measures were used across all studies.

Our findings are in keeping with those from established reviews of person-centred measurement^{6 8} indicating that supported self-management (plus PRO) interventions are researched independently from SDM (plus patient decision aids) interventions and person-centred care; there are seldom common measures used across intervention types.^{6 8 30 90} Different active components of these intervention types are assessed with measures aligned to their theoretical framework (eg, activation, decisional conflict, health professional communication), and judgements made about their effectiveness.⁴⁵ However, these measures

are not capturing patient perception of involvement in healthcare.^{46 91} Further, only one-third of the studies used measures assessing intervention impact on multiple stakeholder outcomes, or mechanisms of change, suggesting evaluations are not capturing findings to inform integration within healthcare pathways.

It was encouraging to see that more studies are drawing on reporting guidelines to inform their evaluations of these complex interventions in practice. The methods associated with the application of these guidelines, and conceptual frameworks, are likely to lead to more robust evaluations of the design, implementation and assessment of patient involvement interventions, and more meaningful results to impact practice.^{5 33 92}

Our review is a reminder of the need to reflect critically on the purpose, content and measurement of developing interventions to innovate patient involvement with healthcare. A common narrative for health policy quality improvement programmes is to implement SDM, self-management support or person-centred care.^{1 6 8 22} Using an outcome measure to label an initiative signals the goal for an organisation's culture but it hides the components, stakeholders and mechanisms needed to facilitate change in patient experiences, professional practices and systems.^{5 33} Further, although health policy initiatives draw from evidence, for example, adding patient decision aids⁹³ or patient-reported outcomes⁹⁴ within care pathways to improve patient involvement in care, the evidence does not always explain all mechanisms associated with implementation. Research evaluating complex interventions tend to vary in their description of the study context and integration or delivery within usual care; the actions of stakeholders, infrastructure and factors within these complex and dynamic systems supporting access, management and involvement may be under-reported. As with previous reviews,^{8 10 19 30 94} our findings illustrate the challenge for quality improvement programmes and sustainability of innovation to investigate how best to integrate patient self-report measures within usual care⁹⁵ enabling services to assess (1) routine practices carried out by stakeholders that facilitate, or hinder, patient involvement, (2) individual patient need within clinics and (3) variations across services to identify future innovations, or biases in the system.

The strength of this review is that it followed rigorous methods³⁸ to provide a snapshot of measures employed across patient involvement interventions in Denmark.^{96–100} Our regional steering group of experts

Table 2 Measurement tools identified in included studies

Category	Named tools	Generic (G)/ disease specific (D)	No. of items in tool
(1) Patient engagement, n=3	Health Literacy Questionnaire (HLQ)	G	44
	Patient Activation Measure (PAM)	G	13
	Participation subscale (PS) (by DEFACTUM)	G	5
(2) Supporting self-management, n=11	Bangor Goal Setting Interview (BGSi)	G	–
	The European Heart Failure Self-Care Behaviour (EHFScB)	D	9
	Goal Attainment Scale (GAS)	G	–
	General Self-efficacy Scale (GSE)	G	10
	Perceived Competence in Diabetes Scale (PCD)	D	3
	Perceived Competence Scale (PCS)	G	4
	Rosenberg's Self-Esteem Scale (RSES)	G	10
	Summary of Diabetes Self-Care Activities (SDSCA)	D	6
	Treatment Self-Regulation Questionnaire (TSRQ)	G	21
	Brief Cope	G	28
	Carers Assessment of Difficulties (CADI)	G	15 of 30
(3) Supporting shared decision-making, n=10	Clinical Decision Making Style patient/staff (CDMS-P and CDMS-S)	G	20
	Clinical Decision Making Involvement and Satisfaction Scale patient/staff (CDIS-P and CDIS-S)	G	7
	CollaboRATE	G	3
	Decisional Conflict Scale (DCS)	G	16
	Decision Quality Measure (DQM)	D	12
	Decision Regret Scale (DRS)	G	5
	OPTION	G	12
	Shared Decision-Making Questionnaire (SDM-Q9)	G	9
(4) Patient satisfaction/ experience of care, n=13	Camberwell Assessment of Need Short Appraisal Schedule patient/staff (CANSAS-P and CANSAS-S)	G	22+22
	Carers Assessment of satisfaction Index (CASI)	G	30
	Client Satisfaction Questionnaire (CSQ)	G	8
	FAMCARE-P and FAMCARE	D	19+16
	Helping Alliance Scale patient/staff (HAS-P and HAS-S)	G	6+5
	Healthcare Climate Questionnaire (HCCQ)	G	5
	Patient Assessment of Chronic Illness Care (PACIC)	G	20/26
	Patient Experience Questionnaire (PEQ)	G	25
	Perception of Parents Scale (POPS)	G	42
	Usefulness, Satisfaction and Ease of use (USE)	G	30
(5) Patient-reported outcomes, n=37	Adult (State) Hope Scale (AHS)	G	6
	Bayer-Activities of Daily Living Scale (B-ADL)	G	25
	Beliefs about Medicines Questionnaire (BMQ)	G	18
	Bristol Stool Scale	D	–
	Constipation Risk Assessment Scale (CRAS)	D	25

Continued

Table 2 Continued

Category	Named tools	Generic (G)/ disease specific (D)	No. of items in tool
	Disease Activity Score (DAS28)	D	28
	Dermatology Life Quality Index (DLQI)	D	10
	Endometriosis Health Profile 30 (EHP-30)	D	30
	Quality of Life Questionnaire for cervical cancer module (EORTC QLIQ-CX24)	D	24
	Quality of Life Questionnaire for ovarian cancer module (EORTC QLIQ-OV28)	D	28
	Quality of Life Questionnaire for endometrial cancer module (EORTC QIQ-En24)	D	24
	EORTC Quality Of Life Questionnaire - SATisfaction with IN-PATient cancer care (EORTC QLQ-IN-PATSAT32)	D	32
	Quality of Life Questionnaire Core 30(EORTC QLQ-C30)	D	30
	Quality of Life Questionnaire Core 15 Palliative questionnaire (EORTC-QLQ-C15-PAL)	D	5
	EuroQol five-dimensional version (EQ-5D-5L)	G	5
	Rheumatoid Arthritis Flare tool (Flare-RA)	D	11
	Generalised Anxiety order scale (GAD-7) (c)	G	7
	Global Assessment of Symptoms or Functioning (GAF-s and GAF-f)	G	–
	General Self-efficacy Scale (GDS-15)	G	15
	Hospital Anxiety and Depression Scale (HADS)	G	14
	Health Assessment Questionnaire (HAQ)	G	30
	Hip disability and Osteoarthritis Outcome Score (HOOS)	D	40
	ICEpop CAPability index of older people (ICEPAP-O)	G	5
	Health-related quality of life in paediatric inflammatory bowel disease (IMPACT-III)	D	35
	Illness Management and Recovery scales (IMRS-P and IMRS-S)	G	15
	Kansas City Cardiomyopathy Questionnaire (KCCQ)	D	12
	Manchester Short Assessment of Quality of Life (MANSA)	G	16
	Mental Health Recovery Measure (MHRM)	G	30
	Outcome Questionnaire-45 (client progress throughout therapy and following termination) (OQ-45.2)	G	45
	Problem Areas In Diabetes (PAID)	D	5/20
	Symptom Checklist 92-item version (SCL-92)	G	92
	Short Form-12 or 36 questionnaire (SF12 or SF36)	G	12/36
	Stages of Recovery Inventory (STORI)	G	30
	WHO-5 Well-Being Index (WHO-5)	G	5
	Young Mania Rating Scale (YMRS)	D	11

from across patient experience, quality improvement and research organisations, contributed to our study methods from inception to dissemination. This review afforded our steering group a chance to step back from their focused

approaches and revisit definitions of patient-centred care, reflect on components included within our patient involvement interventions and consider our assessment approaches from multiple stakeholder perspectives.³⁷

We are aware that adopting a rigorous methodology has limited our exploration of the area, as every step affects the likelihood of identifying meaningful measures to evaluate patient involvement interventions. Studies were omitted from the review either because they were not published at the time of the search,^{25 101} or the intervention was not categorised as patient-centred via electronic indexing systems (eg, SDM only indexed in 2020 and PRO Measures in 2017). We are aware many measures used to evaluate patient involvement interventions^{8 10} are: (1) not yet translated for use in Danish healthcare settings, for example, SHARED¹⁰²; (2) used in research associated with the development, feasibility or implementation phases of interventions, for example, qualitative methods and SURE^{103 104}; (3) used as quality improvement and service evaluation, for example, national patient experience,¹⁰⁵ and the Danish Patient Association's (ViBIS) guidance.¹⁰⁶

The main finding of this review is that there is no common measure used across evaluations of quality improvement and research programmes in Denmark assessing patient self-report of involvement in healthcare. The implications for research and health service innovation are that it is unclear which patient involvement interventions, or their components, are perceived by patients to increase their engagement with healthcare. This methodological limitation makes it difficult to explore the differential impact of, or similarities between, different types of patient involvement interventions on multiple stakeholder outcomes, and find evidence to guide innovation in services. It might be useful for research to revisit concepts around patient involvement and explore with multiple stakeholders which are considered meaningful measures of patient engagement in healthcare.

We suggest the following may support the development of an evidence base to inform patient involvement innovation in healthcare:

- ▶ Use a multiple stakeholder framework (eg, MIND-IT) to design, implement or evaluate the patient involvement intervention, describing explicitly the components needed to support change, for the people involved along the care pathway, and measures assessing impact.
- ▶ Use the complex intervention research framework (MRC)³³ to identify different types of methods and measures for use during different phases of development, feasibility testing and implementation.
- ▶ Reflect on the different types of patient involvement interventions, and their underpinning theoretical frameworks, to explore what goals, components and measures they have in common to help with generating evidence for synthesis across interventions, contexts and populations.
- ▶ Use more than one measure to assess the integrity of the intervention with its theoretical goal, impact on multiple stakeholders and association with patient involvement in healthcare. For example, from discussion with our steering group, we can see value in using the PS questions from the LUP survey for a generic

measure of patient involvement with SHARED as a measure of patient experience of SDM, or SURE as a measure of patient experience of informed decision-making.

CONCLUSION

This review described measures used to evaluate patient involvement interventions in the Danish healthcare setting. It aimed to identify a common approach, or shared understanding, of how to evaluate interventions that innovate. Our findings suggest there is no common measure of patient involvement used systematically to evaluate patient involvement interventions in Denmark.

The key findings indicate a disconnect between outcomes selected to evaluate interventions facilitating patient involvement in healthcare with measures of patient involvement, and little evidence of a measure common to patient involvement intervention evaluations. It seems unlikely that findings captured the current measures used that can be synthesised to inform policy about what types of interventions facilitate patient involvement, for whom, when, and how to integrate them within healthcare systems.

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