

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

Bente Skovsby Toft ,¹ Lotte Rodkjaer,^{1,2} Anne Bendix Andersen,³ Annette de Thurah,⁴ Berit Nielsen,⁵ Camilla Palmhøj Nielsen,⁵ Jens Thusgård Hørlück,⁶ Lisbeth Kallestrup,⁷ Liv Marit Valen Schougaard,⁸ Mette Spliid Ludvigsen,^{9,10} Mette Terp Hoybye,¹¹ Trine Ellegaard,¹² Hilary Bekker¹³

To cite: Toft BS, Rodkjaer L, Andersen AB, *et al.* Measures used to assess interventions for increasing patient involvement in Danish healthcare setting: a rapid review. *BMJ Open* 2022;**12**:e064067. doi:10.1136/bmjopen-2022-064067

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2022-064067>).

Received 20 April 2022
Accepted 08 December 2022



© Author(s) (or their employer(s)) 2022. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

For numbered affiliations see end of article.

Correspondence to

Dr Bente Skovsby Toft;
betoft@rm.dk

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)

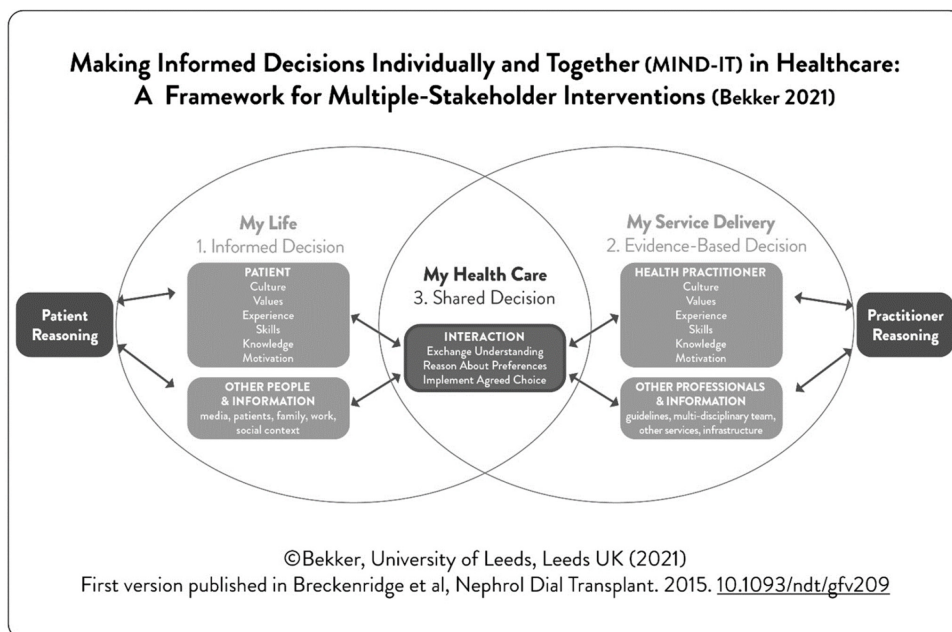


Figure 1 The MIND-IT framework. This figure is reproduced from reference 31 (Breckenridge K, Bekker HL, Gibbons E, van der Veer SN, Abbott D, Briçon S, *et al*. How to routinely collect data on patient-reported outcome and experience measures in renal registries in Europe: an expert consensus meeting.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

Types 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.

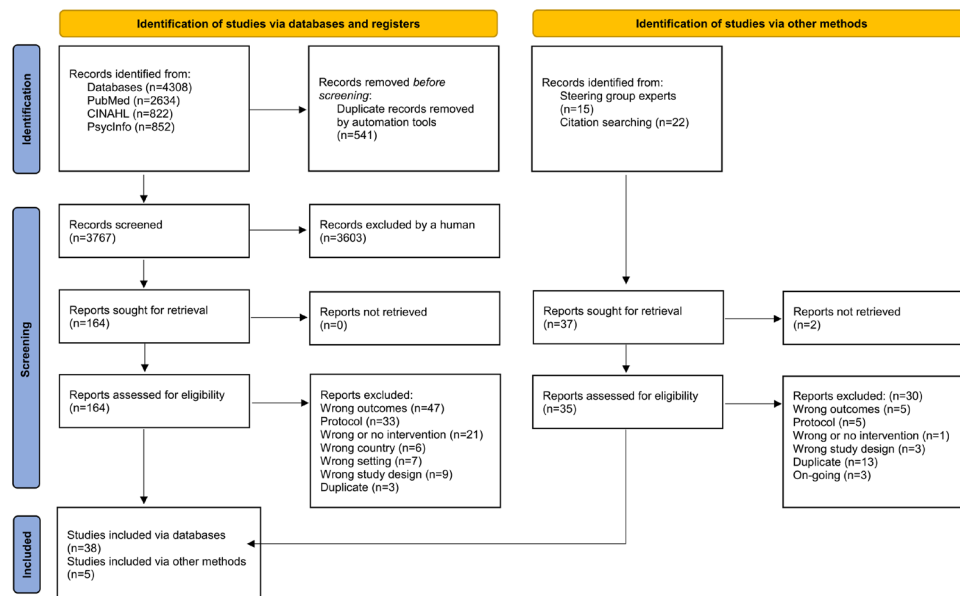


Figure 2 Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram of information through the different phases of the rapid review.

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.

Author affiliations

¹Research Centre of Patient Involvement, Århus Universitetshospital, Aarhus, Denmark

²Infectious Diseases, Aarhus University, Aarhus, Denmark

³Research Centre of Health and Welfare Technology, Viborg Regional Hospital, Viborg, Denmark

⁴Department of Rheumatology, Aarhus Universitetshospital, Aarhus, Denmark

⁵Department of Public Health, DEFACTUM - Public Health and Quality Improvement, Aarhus N, Denmark

⁶Social and Health Services and Labour Market, Defactum, Aarhus, Midtjylland, Denmark

⁷Department of Quality and Patient Involvement, Aarhus University Hospital, Aarhus, Denmark

⁸AmbuFlex/WestChronic, Occupational Medicine, Regional Hospital West Jutland, Herning, Denmark

⁹Department of Clinical Medicine, Randers Regional Hospital, Randers, Midtjylland, Denmark

¹⁰Faculty of Nursing and Health Sciences, Nord University, Bodo, Nordland, Norway

¹¹Interdisciplinary Research Unit, Elective Surgery Center, Regionshospitalet Silkeborg, Silkeborg, Midtjylland, Denmark

¹²Psychosis Research Unit, Aarhus University, Aarhus, Denmark

¹³Leeds Institute of Health Sciences, University of Leeds, Leeds, UK

Acknowledgements We thank research librarian Anne Vils Møller (AVM), Aarhus University Library, for supporting the literature search methods for this rapid review.

Contributors HB and LR led the collaboration. BST carried out the review with LR and HB. ABA, AdT, BN, CPN, JTH, LK, LMVS, MSL, MTH and TE contributed to the study idea, research design and methods, interpretation of findings, write-up and final article. BST was the overall guarantor of the content and accepts full responsibility for the finished work and/or the conduct of the study. She had access to the data, and controlled the decision to publish.

Funding This work was supported by The Research Centre for Patient Involvement (ResCenPI)—Central Denmark Region, Denmark (no award/grant number).

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement No data are available.

Supplemental material This content has been supplied by the author(s). It has not been vetted by BMJ Publishing Group Limited (BMJ) and may not have been peer-reviewed. Any opinions or recommendations discussed are solely those of the author(s) and are not endorsed by BMJ. BMJ disclaims all liability and responsibility arising from any reliance placed on the content. Where the content includes any translated material, BMJ does not warrant the accuracy and reliability of the translations (including but not limited to local regulations, clinical guidelines, terminology, drug names and drug dosages), and is not responsible for any error and/or omissions arising from translation and adaptation or otherwise.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

ORCID iD

Bente Skovsby Toft <http://orcid.org/0000-0003-3107-1699>

REFERENCES

- Coulter A, Ellins J. Effectiveness of strategies for informing, educating, and involving patients. *BMJ* 2007;335:24–7.
- Kitson A, Marshall A, Bassett K, *et al*. What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing. *J Adv Nurs* 2013;69:4–15.
- Santana MJ, Manalili K, Jolley RJ, *et al*. How to practice person-centred care: a conceptual framework. *Health Expect* 2018;21:429–40.
- Nolte E, Merkur S, Anell A. *Achieving person-centred health systems: evidence, strategies and challenges*. Cambridge University Press, 2020.
- O’Cathain A, Croot L, Duncan E, *et al*. Guidance on how to develop complex interventions to improve health and healthcare. *BMJ Open* 2019;9:e029954.
- Ahmed N, Ellins J, Krelle H, *et al*. *Personcentred care: from ideas to action (bringing together the evidence on shared decision making and self-management support)*. London, England: The Health Foundation, 2014.
- Bekker H, Thornton JG, Airey CM, *et al*. Informed decision making: an annotated bibliography and systematic review. *Health Technol Assess* 1999;3:1–156.
- De Silva D. *Helping measure person-centred care: a review of evidence about commonly used approaches and tools used to help measure person-centred care*. Health Foundation, 2014.
- Patel D, Centre E. *Helping people share decision making. A review of evidence considering whether shared decision making is worthwhile the health Foundation evidence: helping people share decisions*. Health Foundation, 2012: 90.
- Bomhof-Roordink H, Gärtner FR, Stiggelbout AM, *et al*. Key components of shared decision making models: a systematic review. *BMJ Open* 2019;9:e031763.
- Atkins L, Francis J, Islam R, *et al*. A guide to using the theoretical domains framework of behaviour change to investigate implementation problems. *Implement Sci* 2017;12:77.
- Gültzow T, Hoving C, Smit ES, *et al*. Integrating behaviour change interventions and patient decision AIDS: how to accomplish synergistic effects? *Patient Educ Couns* 2021;104:3104–8.
- Leventhal H, Bodnar-Deren S, Breland JY, *et al*. *Modeling health and illness behavior: the approach of the commonsense model*, 2012.
- Håkansson Eklund J, Holmström IK, Kumlin T, *et al*. "Same same or different?" A review of reviews of person-centered and patient-centered care. *Patient Educ Couns* 2019;102:3–11.
- Mockford C, Staniszewska S, Griffiths F, *et al*. The impact of patient and public involvement on UK NHS health care: a systematic review. *Int J Qual Health Care* 2012;24:28–38.
- Beresford P, Russo J. *Patient and public involvement in research. achieving person-centred health systems*. Cambridge University Press Cambridge, 2020: 149–52.
- NHS. Measuring supported self-management. five steps to help teams choose approaches, 2021. Available: https://www.nwcpwd.nhs.uk/attachments/article/507/Measuring_and_evaluation_within_supported_self_management.pdf
- Kjærside B, Lomborg K, Munch-Hansen T. *Indikatormål for 'patientinddragelse'-teoretiske og metodiske overvejelser [Indicator goals for patient involvement]*. CFK Folkesundhed og Kvalitetsudvikling. Aarhus: Region Midtjylland, 2015.
- Hall J, Peat M, Birks Y, *et al*. Effectiveness of interventions designed to promote patient involvement to enhance safety: a systematic review. *Qual Saf Health Care* 2010;19:e10.
- Collins A. *Measuring what really matters. towards a coherent measurement system to support personcentred care*. London: The Health Foundation, 2014: 1–20.
- Vrangbaek K. Patient involvement in Danish health care. *J Health Organ Manag* 2015;29:611–24.
- Health Ministry, KL and Danish Regions. *Nationale mål for sundhedsvæsenet [National goal for the health care system]*, 2021. Available: <https://sum.dk/Media/637697073524473744/Nationale%20M%C3%A5l%20for%20Sundhedsv%C3%A6senet%202021.pdf>
- Dahl Steffensen K, Hjelholt Baker V, Vinter MM. Implementing shared decision making in Denmark: first steps and future focus areas. *Z Evid Fortbild Qual Gesundheitswes* 2017;123-124:36–40.
- Jørgensen MJ, Pedersen CG, Martin HM, *et al*. Implementation of patient involvement methods in the clinical setting: a qualitative study exploring the health professional perspective. *J Eval Clin Pract* 2020;26:765–76.
- Jensen A, Lomborg K, Hjøllund N, *et al*. DiabetesFlex™ – the effect of PRO-based telehealth and user involvement in care management of patients with type 1 diabetes: trial protocol for a non-inferiority randomised controlled study. *Med Res Arch* 2020;8.
- Friis RB, Hjøllund NH, Pappot H, *et al*. Patient-Reported outcome measures used in routine care predict for survival at disease progression in patients with advanced lung cancer. *Clin Lung Cancer* 2021;22:e169–79.
- DEFACTUM. Måling af patienters oplevelse af inddragelse [Measurement of patients experiences of involvement]: Central Region Denmark, 2016. Available: <https://www.defactum.dk/om-DEFACTUM/projektsite/indikatorer-for-patientinddragelse/maling-af-patientinddragelse2-Test/>
- Sundhedsdatastyrelsen. Hvad er PRO? [What is PRO?], 2017. Available: https://sundhedsdatastyrelsen.dk/-/media/subsites/pro/filer/pro/hvad_er_pro/pro_pjece.pdf?la=da
- Finderup J, Dam Jensen J, Lomborg K. Evaluation of a shared decision-making intervention for dialysis choice at four Danish hospitals: a qualitative study of patient perspective. *BMJ Open* 2019;9:e029090.
- Gärtner FR, Bomhof-Roordink H, Smith IP, *et al*. The quality of instruments to assess the process of shared decision making: a systematic review. *PLoS One* 2018;13:e0191747.
- Breckenridge K, Bekker HL, Gibbons E, *et al*. How to routinely collect data on patient-reported outcome and experience measures in renal registries in Europe: an expert consensus meeting. *Nephrol Dial Transplant* 2015;30:1605–14.
- von Winterfeldt D. Bridging the gap between science and decision making. *Proc Natl Acad Sci U S A* 2013;110 Suppl 3:14055–61.
- Skivington K, Matthews L, Simpson SA, *et al*. *A new framework for developing and evaluating complex interventions: update of medical Research Council guidance*, 2021.
- Graham P, Evitts T, Thomas-MacLean R. Environmental scans: how useful are they for primary care research? *Can Fam Physician* 2008;54:1022–3.
- Garrity C, Gartlehner G, Nussbaumer-Streit B, *et al*. Cochrane rapid reviews methods group offers evidence-informed guidance to conduct rapid reviews. *J Clin Epidemiol* 2021;130:13–22.
- Akers J, Aguiar-Ibáñez R, Baba-Akbari A. *Systematic reviews: CRD's guidance for undertaking reviews in health care*, 2009.
- Hartling L, Guise J-M, Kato E, *et al*. *Epc methods: an exploration of methods and context for the production of rapid reviews*, 2015.
- Tricco AC, Langlois E, Straus SE. *Rapid reviews to strengthen health policy and systems: a practical guide*. World Health Organization, 2017.
- Guise J. Rapid review guidance document.
- Butler M, Epstein RA, Totten A, *et al*. AHRQ series on complex intervention systematic reviews-paper 3: adapting frameworks to develop protocols. *J Clin Epidemiol* 2017;90:19–27.
- Polisena J, Garrity C, Kamel C, *et al*. Rapid review programs to support health care and policy decision making: a descriptive analysis of processes and methods. *Syst Rev* 2015;4:1–7.
- Page MJ, McKenzie J, Bossuyt P, *et al*. *Updating guidance for reporting systematic reviews: development of the PRISMA 2020 statement*, 2020.

- 43 Stevens A, Garritty C, Hersi M, *et al.* Developing PRISMA-RR, a reporting guideline for rapid reviews of primary studies (protocol). EQUATOR network, 2018. Available: <https://www.equator-network.org/wp-content/uploads/2018/02/PRISMA-RR-protocol.pdf>
- 44 Popay J, Roberts H, Sowden A, *et al.* Guidance on the conduct of narrative synthesis in systematic reviews. A product from the ESRC methods programme version 2006;1:b92.
- 45 Kasper J, Hoffmann F, Heesen C, *et al.* MAPPIN'SDM--the multifocal approach to sharing in shared decision making. *PLoS One* 2012;7:e34849.
- 46 Durand M-A, Bekker HL, Casula A, *et al.* Can we routinely measure patient involvement in treatment decision-making in chronic kidney care? A service evaluation in 27 renal units in the UK. *Clin Kidney J* 2016;9:252-9.
- 47 Adellund Holt K, Hansen DG, Mogensen O, *et al.* Self-Assessment of goal achievements within a gynecological cancer rehabilitation counseling. *Cancer Nurs* 2019;42:58-66.
- 48 Skorstengaard MH, Brogaard T, Jensen AB, *et al.* Advance care planning for patients and their relatives. *Int J Palliat Nurs* 2019;25:112-27.
- 49 Berthelsen CB, Kristensson J. The SICAM-trial: evaluating the effect of spouses' involvement through case management in older patients' fast-track programmes during and after total hip replacement. *J Adv Nurs* 2017;73:112-26.
- 50 Carlsen K, Houen G, Jakobsen C, *et al.* Individualized infliximab treatment guided by Patient-managed eHealth in children and adolescents with inflammatory bowel disease. *Inflamm Bowel Dis* 2017;23:1473-82.
- 51 Castensøe-Seidenfaden P, Husted GR, Jensen AK, *et al.* Testing a smartphone APP (young with diabetes) to improve self-management of diabetes over 12 months: randomized controlled trial. *JMIR Mhealth Uhealth* 2018;6:e141.
- 52 Dalum HS, Waldemar AK, Korsbek L, *et al.* Participants' and staffs' evaluation of the illness management and recovery program: a randomized clinical trial. *J Ment Health* 2018;27:30-7.
- 53 de Thurah A, Stengaard-Pedersen K, Axelsen M, *et al.* Tele-Health followup strategy for tight control of disease activity in rheumatoid arthritis: results of a randomized controlled trial. *Arthritis Care Res* 2018;70:353-60.
- 54 Moils RE, Hald M, Vistisen HS, *et al.* Nurse-Led motivational telephone follow-up after same-day percutaneous coronary intervention reduces readmission and contacts to general practice. *J Cardiovasc Nurs* 2019;34:222-30.
- 55 Erlang AS, Schjødt K, Linde JKS, *et al.* An observational study of older patients' experiences of involvement in discharge planning. *Geriatr Nurs* 2021;42:855-62.
- 56 Enggaard H, Laugesen B, DeJonckheere M, *et al.* Impact of the guided Self-Determination intervention among adolescents with co-existing ADHD and medical disorder: a mixed methods study. *Issues Ment Health Nurs* 2021;42:87-98.
- 57 FINDERUP J, Lomborg K, Jensen JD, *et al.* Choice of dialysis modality: patients' experiences and quality of decision after shared decision-making. *BMC Nephrol* 2020;21:330.
- 58 FINDERUP J, Jensen JKD, Lomborg K. Developing and pilot testing a shared decision-making intervention for dialysis choice. *J Ren Care* 2018:160-1.
- 59 Gabel P, Edwards A, Kirkegaard P, *et al.* The lead trial-The effectiveness of a decision aid on decision making among citizens with lower educational attainment who have not participated in FIT-based colorectal cancer screening in Denmark: a randomised controlled trial. *Patient Educ Couns* 2020;103:359-68.
- 60 Holt KA, Mogensen O, Jensen PT, *et al.* Goal setting in cancer rehabilitation and relation to quality of life among women with gynaecological cancer. *Acta Oncol* 2015;54:1814-23.
- 61 Husted GR, Thorsteinsson B, Esbensen BA, *et al.* Effect of guided self-determination youth intervention integrated into outpatient visits versus treatment as usual on glycemic control and life skills: a randomized clinical trial in adolescents with type 1 diabetes. *Trials* 2014;15:321.
- 62 Hørdam B, Boolsen MW. Patient involvement in own rehabilitation after early discharge. *Scand J Caring Sci* 2017;31:859-66.
- 63 Jensen SB, Dalum HS, Korsbek L, *et al.* Illness management and recovery: one-year follow-up of a randomized controlled trial in Danish community mental health centers: long-term effects on clinical and personal recovery. *BMC Psychiatry* 2019;19:65.
- 64 Kargo AS, Jensen PT, Lindemann K, *et al.* The PROMova study comparing active and passive use of patient-reported outcome measures in ovarian cancer follow-up: effect on patient-perceived involvement, satisfaction with care, and usefulness. *Acta Oncol* 2021;60:434-43.
- 65 Khoury LR, Møller T, Zachariae C, *et al.* A prospective 52-week randomized controlled trial of patient-initiated care consultations for patients with psoriasis. *Br J Dermatol* 2018;179:301-8.
- 66 Knudsen MV, Petersen AK, Angel S, *et al.* Tele-rehabilitation and hospital-based cardiac rehabilitation are comparable in increasing patient activation and health literacy: a pilot study. *Eur J Cardiovasc Nurs* 2020;19:376-85.
- 67 Korfage LJ, Carreras G, Arnfeldt Christensen CM, *et al.* Advance care planning in patients with advanced cancer: a 6-country, cluster-randomised clinical trial. *PLoS Med* 2020;17:e1003422.
- 68 Lavesen M, Ladelund S, Frederiksen AJ, *et al.* Nurse-initiated telephone follow-up on patients with chronic obstructive pulmonary disease improves patient empowerment, but cannot prevent readmissions. *Dan Med J* 2016;63:A5276.
- 69 Loos S, Clarke E, Jordan H, *et al.* Recovery and decision-making involvement in people with severe mental illness from six countries: a prospective observational study. *BMC Psychiatry* 2017;17:38.
- 70 Maindal HT, Sandbæk A, Kirkevoeld M, *et al.* Effect on motivation, perceived competence, and activation after participation in the "Ready to Act" programme for people with screen-detected dysglycaemia: a 1-year randomised controlled trial, Addition-DK. *Scand J Public Health* 2011;39:262-71.
- 71 Maindal HT, Carlsen AH, Lauritzen T, *et al.* Effect of a participant-driven health education programme in primary care for people with hyperglycaemia detected by screening: 3-year results from the ADDITION-Denmark study. *Diabet Med* 2014;31:976-86.
- 72 Marcussen M, Nørgaard B, Borgnakke K, *et al.* Improved patient-reported outcomes after interprofessional training in mental health: a nonrandomized intervention study. *BMC Psychiatry* 2020;20:236.
- 73 Mertz BG, Dunn-Henriksen AK, Kroman N, *et al.* The effects of individually tailored nurse navigation for patients with newly diagnosed breast cancer: a randomized pilot study. *Acta Oncol* 2017;56:1682-9.
- 74 Nielsen JD, Palshof T, Mainz J, *et al.* Randomised controlled trial of a shared care programme for newly referred cancer patients: bridging the gap between general practice and hospital. *Qual Saf Health Care* 2003;12:263-72.
- 75 Pedersen SS, Schmidt T, Skovbakke SJ, *et al.* A personalized and interactive web-based health care innovation to advance the quality of life and care of patients with heart failure (ACQUIRE-HF): a mixed methods feasibility study. *JMIR Res Protoc* 2017;6:e96.
- 76 Puschner B, Becker T, Mayer B, *et al.* Clinical decision making and outcome in the routine care of people with severe mental illness across Europe (cedar). *Epidemiol Psychiatr Sci* 2016;25:69-79.
- 77 Riis CL, Jensen PT, Bechmann T, *et al.* Satisfaction with care and adherence to treatment when using patient reported outcomes to individualize follow-up care for women with early breast cancer - a pilot randomized controlled trial. *Acta Oncol* 2020;59:444-52.
- 78 Schougaard LMV, Mejdahl CT, Christensen J, *et al.* Patient-Initiated versus fixed-interval patient-reported outcome-based follow-up in outpatients with epilepsy: a pragmatic randomized controlled trial. *J Patient Rep Outcomes* 2019;3:1-14.
- 79 Simonsen SM, Strømberg C, Zoffmann V, *et al.* About me as a person not only the disease - piloting Guided Self-Determination in an outpatient endometriosis setting. *Scand J Caring Sci* 2020;34:1017-27.
- 80 Smidth M, Olesen F, Fenger-Grøn M, *et al.* Patient-experienced effect of an active implementation of a disease management programme for COPD - a randomised trial. *BMC Fam Pract* 2013;14:147.
- 81 Søndergaard SR, Madsen PH, Hilberg O, *et al.* The impact of shared decision making on time consumption and clinical decisions. A prospective cohort study. *Patient Educ Couns* 2021;104:1560-7.
- 82 Søndergaard SR, Madsen PH, Hilberg O, *et al.* A prospective cohort study of shared decision making in lung cancer diagnostics: impact of using a patient decision aid. *Patient Educ Couns* 2019;102:1961-8.
- 83 Sørensen CA, Lisby M, Olesen C, *et al.* Self-Administration of medication: a pragmatic randomized controlled trial of the impact on dispensing errors, perceptions, and satisfaction. *Ther Adv Drug Saf* 2020;11:204209862090461.
- 84 Trads M, Deutch SR, Pedersen PU. Supporting patients in reducing postoperative constipation: fundamental nursing care - a quasi-experimental study. *Scand J Caring Sci* 2018;32:824-32.
- 85 Varming AR, Rasmussen LB, Husted GR, *et al.* Improving empowerment, motivation, and medical adherence in patients with poorly controlled type 2 diabetes: a randomized controlled trial of a patient-centered intervention. *Patient Educ Couns* 2019;102:2238-45.

- 86 Wolderslund M, Kofoed P-E, Holst R, *et al.* Digital audio recordings improve the outcomes of patient consultations: a randomised cluster trial. *Patient Educ Couns* 2017;100:242–9.
- 87 Zoffmann V, Lauritzen T. Guided self-determination improves life skills with type 1 diabetes and A1c in randomized controlled trial. *Patient Educ Couns* 2006;64:78–86.
- 88 Zoffmann V, Vistisen D, Due-Christensen M. Flexible guided self-determination intervention for younger adults with poorly controlled Type 1 diabetes, decreased HbA1c and psychosocial distress in women but not in men: a real-life RCT. *Diabet Med* 2015;32:1239–46.
- 89 Øksnebjerg L, Woods B, Vilsen CR, *et al.* Self-management and cognitive rehabilitation in early stage dementia - merging methods to promote coping and adoption of assistive technology. A pilot study. *Aging Ment Health* 2020;24:1894–903.
- 90 Coulter A, Fitzpatrick R, Cornwell J. *The point of care: measures of patients' experience in hospital: purpose, methods and uses.* London: The Kings Fund, 2009.
- 91 Siebinga VY, Driever EM, Stiggelbout AM, *et al.* Shared decision making, patient-centered communication and patient satisfaction - A cross-sectional analysis. *Patient Educ Couns* 2022;105:2145–50.
- 92 Sepucha KR, Abhyankar P, Hoffman AS, *et al.* Standards for universal reporting of patient decision aid evaluation studies: the development of SUNDAE checklist. *BMJ Qual Saf* 2018;27:380–8.
- 93 Stacey D, Légaré F, Lewis K, *et al.* Decision AIDS for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 2017;4:CD001431.
- 94 Ishaque S, Karnon J, Chen G, *et al.* A systematic review of randomised controlled trials evaluating the use of patient-reported outcome measures (PROMs). *Qual Life Res* 2019;28:567–92.
- 95 El-Hussuna A, Rubio-Perez I, Millan M, *et al.* Patient-Reported outcome measures in colorectal surgery: construction of core measures using open-source research method. *Surg Innov* 2021;28:560–6.
- 96 Skovsgaard CV, Kruse M, Hjollund N, *et al.* Cost-Effectiveness of a telehealth intervention in rheumatoid arthritis: economic evaluation of the telehealth in RA (TeRA) randomized controlled trial. *Scand J Rheumatol* 2022:1–11.
- 97 Iversen ED, Wolderslund M, Kofoed P-E, *et al.* Communication skills training: a means to promote time-efficient patient-centered communication in clinical practice. *J Patient Cent Res Rev* 2021;8:307–14.
- 98 Svendsen ML, Ellegaard T, Jeppesen KA, *et al.* Family involvement and patient-experienced improvement and satisfaction with care: a nationwide cross-sectional study in Danish psychiatric hospitals. *BMC Psychiatry* 2021;21:190.
- 99 Skovlund PC, Ravn S, Seibaek L, *et al.* The development of PROMunication: a training-tool for clinicians using patient-reported outcomes to promote patient-centred communication in clinical cancer settings. *J Patient Rep Outcomes* 2020;4:1–11.
- 100 Schougaard LMV, Larsen LP, Jessen A, *et al.* AmbuFlex: tele-patient-reported outcomes (telePRO) as the basis for follow-up in chronic and malignant diseases. *Qual Life Res* 2016;25:525–34.
- 101 Skovlund PC, Vind Thaysen H, Schmidt H, *et al.* Effect of patient-reported outcomes as a dialogue-based tool in cancer consultations on patient self-management and health-related quality of life: a clinical, controlled trial. *Acta Oncol* 2021;60:1668–77.
- 102 Bekker H, Stiggelbout A, Kunneman M, *et al.*, eds. *Psychometric Testing of SHARED—a patient reported outcome measure of shared decision making. Book of Abstracts: Oral Sessions for the 10th International Shared Decision Making Conference.* Leeds, 2019.
- 103 Légaré F, Kearing S, Clay K, *et al.* Are you sure?: assessing patient decisional conflict with a 4-item screening test. *Can Fam Physician* 2010;56:e308–14.
- 104 Ferron Parayre A, Labrecque M, Rousseau M, *et al.* Validation of sure, a four-item clinical checklist for detecting decisional conflict in patients. *Med Decis Making* 2014;34:54–62.
- 105 CPI. Spørgeskemaerne anvendt i den Landsdækkende Undersøgelse af Patientoplevelser (LUP) [Questionnaires used in LUP] Center for Patientinddragelse, 2021. Available: <https://www.regionh.dk/patientinddragelse/LUP/aktuel-undersogelse/Sider/Spoergeskemaer-LUP-2021.aspx>
- 106 Munch-Pedersen M. *Guide til måling af individuel inddragelse [Guide for measuring individual involvement.* Copenhagen: ViBIS, 2021.

Appendix A: PICOTS and search string in MeSH terms/thesaurus/heading and free text

Popula- tion	Intervention	Compa- rator	Outcome	Type of studies	Setting
Health profes- sionals Patients Carers Relatives	MeSH: Decision Making, shared Decision Support Techniques Self-Management Patient-Centered Care Patient Participation Patient reported outcome measures Free text: decision support patient decision making shared decision making self-management patient-cent* patient involv* patient engag* patient participat* patient activat* patient reported outcome*	Usual care	To be identified	Surveys and question- naires	Denmark Danish health care

No filters or limitations were used in the search.

PubMed search: (((((((((((("Decision Making, Shared"[Mesh]) OR ("Decision Support
Techniques"[Mesh])) OR ("Self-Management"[Mesh])) OR ("Patient-Centered Care"[Mesh])) OR
("Patient Participation"[Mesh])) OR (decision support[Title/Abstract])) OR (patient decision
making[Title/Abstract])) OR (shared decision making[Title/Abstract])) OR (patient
involv*[Title/Abstract])) OR (patient engag*[Title/Abstract])) OR (patient
participat*[Title/Abstract])) OR (patient activat*[Title/Abstract])) OR (patient
cent*[Title/Abstract])) OR ("Patient Reported Outcome Measures"[Mesh])) AND (((Danish) OR
(Denmark)) OR (Denmark))

Appendix B: Data extraction sheet

Author, year	Aim of study	Intervention (patient components) procedure, aids	Name of measurement instrument (outcome)	Instruments (n=)	Conclusion
Adellund, 2019	To evaluate whether (1) nurse-led supported goal setting and assessment of goal achievement were feasible in a clinical setting and (2) there was a positive association between women's goal achievement and their self-assessed global health status	Two face-to-face rehabilitation sessions ≤1 hour, each occurring 1 and 3 months after discharge and 2 phone calls 1 month after each rehabilitation session. Use of pamphlets.	EORTC QLQ-C30 and QLQ-CX24/QLQ-En24/QLQ-OV28 (QoL with cervical/endometrial /ovarian cancer)	2	Goal measurement is feasible in cancer rehabilitation, in both goal setting and goal achievement.
Bendstrup, 2019	To investigate the effects of advanced care planning (ACP) among patients with lung, heart and cancer diseases with an estimated life-span of up to 12 months.	A single discussion of 45 min between researcher and patient and one or more relatives.	EORTC-QLQ-C15-PAL (QoL palliative) and SCL-92 (symptoms of anxiety and depression) and <u>FAMCARE scale</u> and <u>FAMCARE-patient scale</u> (patient satisfaction with palliative care)	4	No significant effect of ACP among patients and their relatives regarding HRQoL, anxiety, depression, and satisfaction with health care.
Berthelsen, 2017	To evaluate the effect of spouses' involvement in older patients' care trajectories, using case management as intervention in total hip replacement through fast-track programmes.	Usual care with additional mandatory information meetings: pre-admission interview, individual discharge meeting during admission and the follow-up telephone call and the final meeting at discharge with possibility of additional information meetings during admission.	<u>CASI (spouses' satisfaction)</u> and HOOS (hip dysfunction) and GDS-15 (geriatric depression) and CADI (carers' assessment of difficulties) and GAD-7 (spouses' anxiety)	5	The case management intervention seemed to have an effect in patient and spousal groups.
Carlsen, 2017	To individualize timing of infliximab (IFX) treatment in children and adolescents with inflammatory bowel disease (IBD) using a patient-managed eHealth program	Patients were instructed individually face-to-face in how to use the program (45 min.) and families were instructed to consult the IBD team anytime alarm symptoms appeared.	IMPACT III (HRQoL) and <u>patient-parent tandem</u> evaluation questionnaire	2	Self-managed, eHealth-individualized timing of IFX treatments was accompanied by no significant development of IFX antibodies. Patients reported better control and improved knowledge of their IBD.
Castensøe-Seidenfaden, 2018	To assess whether the mHealth app "Young with Diabetes" (YWD) improved young people's self-management measured by glycated haemoglobin (HbA1c) and three self-reported psychometric scales.	Patients and parents downloaded YWD on their smartphone/tablet during a 10-minute initial face-to-face/telephone session. Only patient got the Chat Room function and were encouraged to use YWD as a stand-alone resource and in collaboration with their parents and HCP.	PCD (perceived competence in diabetes) and HCCQ (perception of autonomy support) and PAID-20 (problem areas in diabetes)	3	Patients did not improve HbA1c, but it may be a useful complement to self-management.

Dalum, 2018	To investigate the benefits and harms of the Illness Management and Recovery (IMR) program among people with severe mental illness.	TAU and an IMR program was provided in a group format with ten participants in each group and each group. It lasted nine months with one weekly session 1 hour/day.	<u>(IMRS-P)</u> and <u>(IMRS-S)(staff illness and self-management)</u> and AHS (hope) and Mental Health Recovery Measure and CSQ	5	IMR appears not to be better than TAU in any of the outcomes.
De Thurah, 2018	To test the effect of PRO-based tele-health follow-up for tight control of disease activity in patients with rheumatoid arthritis (RA), and the differences between tele-health follow-up performed by rheumatologists or rheumatology nurses.	PRO-based telehealth (PRO-TR/PRO-TN) follow-up were scheduled for a telephone consultation every 3–4 months following a predefined consultation checklist.	DAS28 (changes in disease) and Flare-RA (detect disease) and HAQ (physical functioning and EQ-5D (HRQoL) and GSE (self-efficacy)	5	Tele-health follow-up for control of disease activity in RA can achieve similar disease control as conventional outpatient follow-up. The degree of disease control did not differ between patients seen by rheumatologists or nurse.
Elmose, 2019	To investigate whether nurse-led telephone follow-up influenced patients' self-management post-PCI	A 15-minute telephone consultation within 2-5 days post-PCI and usual discharge procedure.	HADS (anxiety and depression) and GSE (self-efficacy)	2	Telephone follow-up did not influence adherence to antiplatelet medical therapy after PCI, but positively influenced self-management of angina pectoris and reduced readmissions and contacts to GPs and hospitals.
Erlang, 2021	To describe older medical patients' experiences of involvement in discharge planning.	Standard discharge was assessed (face-to-face)	One questionnaire with questions from the PS, Danish National Health Survey and questions to measure patient participation.	1	The older patients in general felt well informed regarding the discharge planning, which facilitated the opportunity for involvement.
Enggaard, 2020	To evaluate how the Guided Self-Determination intervention impacted 10 adolescents with ADHD and a co-existing medical disorder	18 semi-structured reflection sheets and professional communication used in five sessions: four with adolescents (and parents) and one session with parents alone within 3 months.	<u>HCCQ (perception of autonomy support)</u> and <u>POPS (perceived parental support)</u>	2	Adolescents' management of co-existing ADHD and MD improved by enhancing self-insight and support from nurses as prerequisites for developing self-management strategies. Offering parents a single session had no impact on perceived parental support, and that some adolescents reported no improvement in their management of co-existing ADHD and MD.

Finderup, 2020	To evaluate the implementation of an intervention designed to achieve SDM for dialysis choice, patients' knowledge, readiness and achieved preferences; and to determine if patients experienced SDM.	Patient and the relative(s) had meeting(s) with a dialysis coordinator. Videos describing other patients' experiences of making this decision was presented. The modality and the development of the intervention was made by the patient and the relatives together with the dialysis coordinator. Paper format PDA; a decision map, an overview of symptoms and options and a Decision Guide.	<u>SDM-Q9 (shared decision making)</u> and <u>DQM (decision quality)</u>	2	80% of participants exposed to the intervention and responded to the surveys experienced SDM and reached a high-quality decision. Both participants who chose home and hospital-based treatment experienced the intervention as SDM and made a high-quality decision.
Finderup, 2018	To develop the PDA meeting all the Patient Decision Aid Standards (IPDAS) criteria	Three meetings about: 1) the choice talk using the decision map and the overview of symptoms 2) option talk using one tool with an overview of options and two videos. 3) decision talk using a Decision Guide.	<u>SDM-Q9 (shared decision making)</u> and <u>DQM (decision quality)</u>	2	The intervention supported by PDA seemed to increase the number of patients choosing home dialysis. The SDM Q9 and DQM were feasible evaluation tools.
Gabel, 2019	To evaluate the effectiveness of a web-based decision aid (DA) for colorectal cancer screening on components of informed choice among previous non-participants in colorectal cancer screening.	A web-based DA was sent by a mail with a link with information about CRC and CRC screening focusing on the benefits and harms of screening participation. Information was presented primarily in figures and charts with a minimum of text and pop-up boxes with more information and a "read-more"-function.	A seven-item scale (developed and validated by the research group) (knowledge) and a four item scale developed by Marteau et al., 2007) (Attitudes/informed choice) and <u>DCS (patients' uncertainty and internal conflicts about a course of action)</u>	3	The web-based DA offers a feasible way to provide individualised screening information in a "one size fits all" approach that may hold the potential to increase informed CRC screening uptake.
Holt, 2015	To analyse rehabilitation goals defined during hospital-based rehabilitation in patients with gynaecological cancer, with regard to number, category, changes over time, and differences between cancer diagnosis, and 2) analyse the association between health-related quality of life and goals defined for rehabilitation.	Two rehabilitation sessions of 1 hour at one and three months after discharge following surgery. Women were asked to summarise current problems and to formulate goals in any categories and prioritise if more than three goals. No ranking of the goals was conducted. A photocopy of these goals was given to the women.	EORTC QLQ-C30 and QLQ-En24/QLQ-OV28/QLQ-CX24 (Quality of life).	2	Goal setting seemed feasible in all problem areas. The EORTC questionnaires were helpful during the process although expectations of the sub-scores being predictive of which areas to address were not convincing.

Husted, 2014	To evaluate the impact of GSD-Y after it was integrated into paediatric outpatient visits versus treatment-as-usual, focusing on glycaemic control and the development of life skills in adolescents with type 1 diabetes.	Eight sessions of one hour over an 8- to 12-month-period in an individual setting. Prior to intervention 18 semi-structured reflection sheets for adolescents, five for parents were used. If visiting a dietician: min. two sessions and six reflection sheets were added.	PCD (competences in diabetes) and <u>HCCO (perception of autonomy support)</u> and TSRQ (treatment motivation) and PAID (problem areas in diabetes) and WHO-5 (wellbeing) and <u>POPS (perceived parental support)</u>	6	Compared with treatment-as-usual, GSD-Y did not improve HbA1c levels, but it did decrease adolescents' amotivation for diabetes self-management.
Hørdam, 2017	To involve and coach older adults with a hip replacement to self-care after early discharge in transition between hospital and home.	Semi-structured interview guide was used by coach at 1, 3 and 7 weeks after discharge. Tele-care intervention with patients 1 and 7 weeks after hip replacement and a face-to-face intervention was performed 3 weeks after hip replacement and early discharge.	SF-36 (overall health)	1	Our three RCTs showed improvements for older adults undergoing hip replacement when nurses used the model 'coaching to self-care'.
Jensen, 2019	To evaluate whether participants in the Illness Management and Recovery (IMR) program exhibited improved clinical and personal recovery and illness management postintervention and at the one-year follow-up	The IMR course in addition to TAU (1-year follow-up) (group-based IMR). 9 months with weekly group sessions, and each closed-enrolment group included ten patients. Educational hand-outs were used.	<u>GAF-S (staff)</u> and <u>GAF-F (follow-up)</u> (symptomatology and social functioning) and YMRS (mania) and <u>IMRS (illness self-management)</u> and MHRM (perceived recovery for individuals with a serious mental illness) and AHS (hope) and CSQ (patients' satisfaction)	7	The trial showed no significant effect on clinical and personal recovery at the 1-year follow-up. The effect of IMR on symptom severity is unclear, which raises questions regarding the impact of IMR on functioning. IMR did not affect personal recovery.
Kargo, 2021	To investigate the effect of active use of PROMs on patient-perceived involvement in decisions made during the clinical encounter. Secondary aims were satisfaction with care, unmet needs, patient-perceived usefulness of PROMs, and QoL during follow-up after primary ovarian cancer treatment	Aim: to actively use PROMs the clinician had access to the patient's present and previous patient scores during the clinical encounter. The clinicians were encouraged to use the results actively together with the patients.	EORTC QLQ C-30 and QLQ-OV-28 (quality of life) and <u>CollaboRATE (patient's sense of collaboration in decision making)</u> and <u>PEQ (patients' satisfaction)</u>	4	Active use of PROMs did not improve patients' experience of involvement in follow-up care as compared to passive use.

Khoury, 2018	To investigate the efficacy and safety of PICC for patients with psoriasis compared with routinely scheduled consultations with a dermatologist.	One annual consultation with a dermatologist (but were able to initiate consultations when needed) with individual, face-to-face information on patient safety and to recognize difficulties and access appropriate help through the helpline.	DLQI (HRQoL) and HAS (anxiety and depression)	2	PICC offers additional clinical benefits over routine care, making patients less dependent on clinical visits. The intervention adds no harm to monitoring systemic treatment, and patients report high quality of life and satisfaction with healthcare.
Knudsen, 2020	To evaluate patient activation and health literacy in tele-rehabilitation compared to hospital-based cardiac rehabilitation.	A 12-week tele-rehabilitation programme with exercise training, dietary advice, educational sessions and psychosocial support. Patients entered their dietary intake in an online tool. Patients were supervised through weekly tele-consultations (phone, email or text message).	PAM (Patients' knowledge, skills and confidence in relation to self-management) and HLQ (health literacy)	2	Tele-rehabilitation and hospital-based cardiac rehabilitation seemed to be equally successful in improving patient activation and health literacy.
Korfage, 2020	To test the implementation of Advanced Care Planning (ACP) in patients with advanced cancer.	The ACTION RC ACP for patients and relatives, which includes 3 components: (1) facilitated structured ACP conversations, (2) the My Preferences form, and (3) information leaflets.	EORTC QLQ-C15-PAL and EORTC IN-PATSAT (quality of life) and Brief COPE (coping)	3	Quality of life effects did not change with intervention. The increased use of specialist palliative care and AD inclusion in hospital files is meaningful. Alternative approaches to support patient-centred end-of-life care in this population are needed.
Lavesen, 2016	To explore whether telephone follow-up after discharge may reduce readmission rates, lower mortality and improve disease management in patients with chronic obstructive pulmonary disease (COPD).	Usual care and nurse-initiated telephone follow-up consisting of two telephone follow-up calls on day 2 and day 30 after discharge. Within this period, additional telephone calls were offered if either the nurse or the patient found that this was required.	SF-12 (overall health)	1	Nurse-initiated telephone follow-up does not reduce readmission rates, but does empower patients with COPD.
Loos, 2017	To investigate the impact of decision-making experience on recovery.	Patients nominated a clinician closely involved in their treatment. Both completed baseline measures. Bi-monthly, they were asked about context, content and implementation of clinical decision making. They wrote down the most important decision made at their last meeting. A list of predefined topics with three possible responses was presented to indicate what was discussed in general in the selected meeting.	CANSAS-P and -S (need) and STORI (stages of recovery) and OQ-45.2 (mental health functioning) and MANSA (quality of life) and GAF (staff) (symptomatology and social functioning) and CDIS-P and -S (involvement and satisfaction) and CDMS-P and -S (preferences for decision making) and HAS-P and -S (therapeutic alliance)	12	Patient-rated decision-making involvement and change in stage of recovery are associated. Joint consideration of decision practise within the recovery process between patient and clinician is supposed to be a useful strategy to improve clinical practice.

Maindal, 2011	To investigate the reach of the “Ready to Act” programme and the 1-year effects on psychological determinants of healthy behaviour: motivation, perceived competence, and activation level.	Usual treatment and additionally two individual counselling interviews and eight group sessions with 8–14 participants (total 18 hours) within a period of 3 months. Eight themes within the fields of action competence, cardiovascular risk, and dysglycaemia. The group sessions consisted of lectures of 2–3 hours with practical interactive exercises. At the end of the programme all participants had a second individual session.	TSRQ (treatment motivation) and PCS (perceived competences) and PAM (patients' knowledge, skills and confidence in relation to self-management)	3	The programme is a promising health-promoting component in prevention and care for people with screen-detected dysglycaemia, as it attracted four of 10 people and had effects on motivation and perceived competence.
Maindal, 2014	To assess whether a 12-week participant-driven health education programme offered to individuals with screening-detected hyperglycaemia in Danish primary care would lead to improvements in cardiovascular risk factors, health behaviour and patient-reported outcomes after 3 years	A 12-week participant-driven health education programme with two individual counselling interviews and eight group sessions (18 hours) over a 3-month period.	PAM (patients' knowledge, skills and confidence in relation to self-management) and EuroQoL-5D (quality of life) and <u>PACIC (quality of care)</u>	3	For patients with screening-detected hyperglycaemia, a participant-driven health education programme was not associated with improvements in most clinical, behavioural and patient-reported outcomes after 3 years of follow-up.
Marcussen, 2020	To assess impacts on patient satisfaction, self-reported psychological distress and mental health status in a psychiatric ward.	At the start of the hospitalization, the goals of the treatment were agreed on by the patient and the team. Weekly team conferences were held to ensure the patients' progress and, if required, to adjust their treatment plans. The patients' active participation in the teamwork was a key feature of the intervention	SF-36 (overall health) and CSQ-8 (patients' satisfaction)	2	Patients reported higher scores regarding mental health status and satisfaction than did comparison group patients. As IPE interventions have rarely involved patients and fewer have taken place in practice settings.
Mertz, 2017	To determine the feasibility and effectiveness of an individual, nurse-navigator intervention for relieving distress, anxiety, depression and HRQoL in women who have been treated for breast cancer and are experiencing moderate-to-severe psychological and physical symptoms.	Individual, manual-based counselling based on strategies from cognitive therapy and psychoeducation to motivate and support patients in self-managing their symptoms, and using existing rehabilitation services.	HADS (anxiety and depression) and EORTC QLQ-C30 (quality of life)	2	Promising feasibility of the individually tailored nurse-navigation intervention is shown. No significant effects were observed after 6 months. No statistically significant effects on distress, anxiety and depression 12 months after diagnosis.

Nielsen, 2003	To determine the effect of a shared care programme (SCP) on the attitudes of newly referred cancer patients towards the healthcare system and their health related quality of life and performance status, and to assess patients' reports on contacts with their GP.	Patients received oral and as written information about the information package to their GP. The patients were encouraged to contact their GP when facing problems, they assumed could be solved in this setting. The SCP was launched when the patient left the hospital.	EORTC QLQC30 (quality of life)	1	An intersectoral SCP in which GPs and patients are actively involved has a positive influence on patients' attitudes towards the healthcare system. Young patients and men particularly benefit from the programme.
Pedersen, 2017	To examine the feasibility of engaging patients to use patient-centred and personalized tools coupled with a Web-based, shared care and interactive platform in order to empower and enable them to live a better life with their disease.	Use of the CGI's modular and cloud-based CommunityCare360 (CC360) platform makes it possible for patients and HCPs to access, monitor, and update personal health data	KCCQ (health status) and EHFScB (patients' self-care behaviour)	2	The intervention seems feasible and will help educate, empower, and engage patients more in their own disease management for some patients. Nursing staff found it beneficial as a communication tool with patients but were reticent to use it as a replacement for the personal contact in the outpatient clinic.
Puschner, 2016	To examine preferred and experienced clinical decision making from the perspectives of patients and staff, and how these affect treatment outcome	Patients' and staffs' perception of clinical Decision Making and Outcome in Routine Care for People with Severe Mental Illness.	<u>CDIS-P and CDIS-S (involvement and satisfaction)</u> and <u>CANSAS-P (need) and GAF (staff)(symptomatology and social functioning)</u>	4	Decision making style of staff is a prime candidate for the development of targeted intervention. This could pave the ground for a shift from shared to active involvement of patients including changes to professional socialization through training in principles of active decision making.
Riis, 2020	To evaluate the patients' satisfaction with the care provided, when using electronic patient reported outcomes (ePROs) to individualize follow-up care in women with early breast cancer receiving adjuvant endocrine therapy.	ePROs every third month were used actively as (1) a screening tool to assess the patient's problems and requirements; (2) a dialogue tool to map symptoms and concerns in order to focus the discussion on what mattered most to the individual patient. The results of the PROs was the focus of the dialogue.	<u>PEQ</u> (patients' satisfaction) and EORTC QLQ-C30 (quality of life)	2	A significant reduction in consultations was observed for the intervention group without compromising satisfaction, quality of life or adherence to treatment. The implementation of ePROs to individualize follow-up care was feasible.

Schougaard, 2019	To evaluate the effects of patient-initiated outpatient follow-up in patients with epilepsy utilization, quality of care, and the patient perspective.	When feeling the need patients were asked to contact the outpatient clinic by filling in a disease-specific questionnaire on the website 'My Epilepsy'. The patients could also phone the outpatient clinic.	WHO-5 (wellbeing) and SF-36 (overall health) and HLQ (health literacy) and GSE (self-efficacy) and PAM (patients' knowledge, skills and confidence in relation to self-management)	5	The study did not find less use of health care resources, improved patient self-management or satisfaction in intervention group. The interventions may be used as an alternative to fixed-interval PRO-based follow-up in patients who prefer this approach.
Simonsen, 2020	To assess if the implementation of the Guided Self Determination (GSD) method targeted women with complex endometriosis appeared feasible and supported self-management.	Preparatory semi-structured reflection sheets were completed by the patients before face-to-face conversations with the HCP. The patient and the HCP together create a common knowledge that provides the basis for further problem-solving of the issues that the patient considered to be particularly important in accordance with their values and needs.	EHP-30 (HRQoL regarding endometriosis) and PAM (patients' knowledge, skills and confidence in relation to self-management)	2	The GSD method appeared feasible and developed self-management skills in relation to endometriosis and its symptoms by increasing insight into patients' needs and behaviours and gaining new knowledge about the disease itself. The before-and-after assessment suggested benefit of the intervention.
Smidth, 2013	To examine the effect of an evidence-based, planned and proactive implementation of a disease management programme (DMP) compared to the usual implementation strategy	Smoking cessation, yearly follow-up, flu and bronchitis vaccination, advice on comorbidities, diet, exercise and end-of-life care were targeted self-management support for patients to cope with exacerbations of the disease. Action card with advice to patients on management of sputum and exacerbations were used.	<u>PACIC (quality of care)</u>	1	Reinforcing the role of general practice as coordinator for care-and self-management-support with an active implementation of a DMP for COPD made patients score higher on the PACIC instrument, which indicates a better experience of the received healthcare.
Søndergaard, 2020	To evaluate consultation length and decisions made when using an in-consult patient decision aid (PtDA).	Use of a developed patient decision aids in a four step approach to SDM: choice talk, preference talk, option talk, and decision talk.	<u>OPTION 12 (observing patient involvement)</u> and <u>DRS (regret after healthcare decisions)</u>	2	SDM did not take significantly longer time and led to slightly more conservative decisions.
Søndergaard, 2019	To describe the impact on patient-reported outcomes of introducing Shared Decision Making (SDM) and a Patient Decision Aid (PtDA) in the initial process of lung cancer diagnostics.	Consultations with SDM using in-consult PtDA focusing on: choice talk, preference talk, option talk, and decision talk.	<u>DCS (patients' uncertainty and internal conflicts about a course of action)</u> and <u>CollaboRATE (patient's sense of collaboration in decision making)</u> and <u>DRS (regret after healthcare decisions)</u>	3	The use of SDM and a PtDA had significant positive impact on patient-reported outcomes. Our results may encourage the increased uptake of SDM in the initial process of lung cancer diagnostics.

Sørensen, 2020	To investigate whether self-administration of medication (SAM) during hospitalization affects the number of dispensing errors, perceptions regarding medication, and participant satisfaction when compared with nurse-led medication dispensing.	Participants in the intervention group self-administered their medication during hospitalization, with the exception of medication unsuitable for self-administration	BMQ (patients' perceptions regarding medication)	1	The reduced number of dispensing errors in the intervention group, indicate that SAM is safe. SAM had a positive impact on (a) perceptions regarding medication, thus suggesting increased medication adherence, (b) deviations in medication list after discharge, and (c) participant satisfaction related to medication management at the hospital.
Trads, 2018	To test the efficacy of a nursing intervention based on active patient involvement including individualised nursing care plans and daily dialogues for patients with hip fractures in preventing constipation after surgery.	Admission interview was conducted a personal care plan was created together with the patients. At least once a day, the nurse participated in a dialogue with the patient to discuss issues related to defecation, bloating, stomach ache etc., and to teach and counsel the patient in increasing fibre and fluid intakes, and individual needs regarding constipation.	CRAS (constipation risk) and Bristol Stool Scale (stool consistency)	2	Patients with hip fractures that were actively involved in their own care in preventing constipation were significantly less constipated 30 days after surgery than control patients. Increases in fluid and fibre intakes had significant effects on reducing the risk of developing constipation.
Varming, 2019	To test whether an intervention consisting of four patient-centred consultations improves glycaemic control and self-management skills in patients with poorly regulated type 2 diabetes (T2DM), compared to a control group receiving usual care.	Four one-on-one and one telephone consultations in which the Empowerment, motivation, and medical adherence (EMMA) tools to promote dialogue and informed choices about T2DM self-management through reflection, diabetes-specific knowledge and learning and facilitate goal setting and brief telephone consultation.	<u>HCCQ (perception of autonomy support)</u> and <u>TSRQ (treatment motivation)</u> and PCD (perceived competences in diabetes) and SDSCA (Patients practiced self-care activities in diabetes) and WHO-5 (wellbeing) and PAID-5 (problem areas in diabetes)	6	Despite increased autonomy support and individual goal-setting, the intervention was not superior to usual care in terms of glycaemic control.
Wolderslund, 2017	To investigate the effects on patients' outcome of the consultations when provided with: a Digital Audio Recording (DAR) of the consultation and a Question Prompt List (QPL).	Consultations with digital Audio Recording (DAR) enabled the patients to replay their consultation. A Question Prompt List included information about the importance of being prepared for the consultation and asking questions during the consultation.	PrePerEx: A two-part patient administered questionnaire developed for this study. Preparation (6 items), Perception (12 items), and <u>Experience of outpatient consultation</u> .	1	Providing outpatients with a QPL and DAR of their consultation positively influences the patients' perception of having adequate information after the consultation.

Zoffmann, 2006	To report 1-year results of newly developed method, guided self-determination (GSD), applied in group training (GSD-GT) for Type 1 diabetes patients with persistent poor glycaemic control.	Groups of 10 members met over 8 weeks for 2 hours. Patient and professional worked out independent lists of issues that they each perceived to be difficult for the patient. Together they selected one to three issues. Patients examined their current strategies for approaching these issues and were challenged and supported by the nurse in order to develop alternative strategies. Self-determined goals for future diabetes care were set by patient. Three central worksheets comprising person-specific knowledge and agreements on strategies for problem solving were saved in a folder in the patient's medical record for 1-year follow-up.	<u>HCCQ (perception of autonomy support)</u> and <u>TSRQ (treatment motivation)</u> and PCD (perceived competence in diabetes) and PAID (problem areas in diabetes)	4	GSD was effective in improving life skills with diabetes over a period of 1 year.
Zoffmann, 2015	To report results from an 18-month randomized controlled trial (RCT) testing the effectiveness of a flexible guided self-determination (GSD) intervention on glycaemic control and psychosocial distress in younger adults with poorly controlled Type 1 diabetes.	Group-based or individual GSD sessions with 17 of 21 GSD reflections sheets were used and connected to seven conversations. The intervention took the participants' limited time and opportunities into account, allowing them to choose between seven individual 1-hour daytime sessions and 2.5-hour group sessions in the late afternoon. With preferably 14 days between sessions the intervention took ~ 3.5 months.	PAID (problem areas in diabetes) and WHO-5 (well-being) and RSES (self-esteem) and <u>HCCQ (perception of autonomy support)</u> and <u>TSRQ (treatment motivation)</u> and PCD (perceived competence in diabetes)	6	The flexible GSD intervention benefitted younger adult women by significantly improving glycaemic control and decreasing diabetes related distress. No effect was seen among men.

Øksnebjerg, 2020	To examine the feasibility and applicability of a group-based goal-oriented rehabilitation programme for people with early stage Alzheimer's disease, and to explore if such a programme can be a suitable and effective way to deploy and assistive technology was explored.	Two individual sessions with patient-caregiver dyads at baseline and one individual session at the end of the programme to identify the participants' individual goals. 1-3 individual goals were selected and discussed in relation to support and achievement with an introduction to the ReACT app. Group sessions based on self-management: psychoeducation related to living with early stage Alzheimer's disease and solution focused approaches to challenges in everyday life, including training of coping and compensation skills over 13 weeks.	Bangor Goal Setting Interview (BGSi)(Goal attainment) and ICECAP-O (capability-related well-being in older people) and B-ADL (deficits in the performance of everyday activities) and EQ-5D-5L (quality of life) and USE Questionnaire (Usefulness, Satisfaction, and Ease of use of the ReACT app).	5	The intervention is both feasible and applicable and can be an effective method to promote coping and adoption of assistive technology among people with early stage dementia.
------------------	-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	---	--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

Appendix C: Alphabetic list of abbreviations

Name abbreviated	Full name
AHS	Adult (State) Hope Scale
B-ADL	Bayer-Activities of Daily Living Scale
BGSI	Bangor Goal Setting Interview
BMQ	Beliefs about Medicines Questionnaire
CADI	Carers Assessment of Difficulties
CANSAS-P/-S	Camberwell Assessment of Need Short Appraisal Schedule patient/staff
CASI	Carers Assessment of satisfaction Index
CDIS-P/-S	Clinical Decision Making Involvement and Satisfaction Scale patient/staff
CDMS-P/-S	Clinical Decision Making Style patient/staff
CRAS	Constipation Risk Assessment Scale
CSQ-8	Client Satisfaction Questionnaire
DAS28	Disease Activity Score
DCS	Decisional Conflict Scale
DLQI	Dermatology Life Quality Index
DQM	Decision Quality Measure
DRS	Decision Regret Scale
ECOG	Eastern Cooperative Oncology Group
EHFScB	The European Heart Failure Self-Care Behaviour
EHP-30	Endometriosis Health Profile 30
EORTC	European Organization of Research and Treatment of Cancer
EQ-5D-5L	EuroQol five-dimensional-the five-level version
Flare-RA	Rheumatoid Arthritis Flare tool
GAD-7	Generalized Anxiety order scale
GAF-S/-F	Global Assessment of Symptoms or Functioning
GAS	Goal Attainment Scale
GDS-15	Geatric Depression Scale
GSE	General Self-efficacy Scale
HADS	Hospital Anxiety and Depression Scale
HAS-P/-S	Helping Alliance Scale patient/staff
HAQ	Health Assessment Questionnaire
HCCQ	Health Care Climate Questionnaire
HLQ	Health Literacy Questionnaire
HOOS	Hip dissability and Osteriosis Outcome Score
HRQoL	Health Related Quality of Life
ICEPAP-O	ICEpop CAPability index of older people
IMPACT-III	Health-related quality of life in pediatric inflammatory bowel disease
IMRS	Illness Management and Recovery scales
IN-PATSAT	Quality of Life Questionnaire in-patient-satisfaction with care measure
KCCQ	Kansas City Cardiomyopathy Questionnaire

MANSA	Manchester Short Assessment of Quality of Life
MHRM	Mental Health Recovery Measure
OPTION 12	Clinicians' involvement of patients in decisions
OQ-45.2	Outcome Questionnaire-45
PACIC	Patient Assessment of Chronic Illness Care
PAID (-5 or -20)	Problem Areas In Diabetes
PAM(-13)	Patient Activation Measure
PCD	Perceived Competence in Diabetes Scale
PCS	Perceived Competence Scale
PDA	Patient Decision Aid
PEQ	Patient Experience Questionnaire
POPS	Perception of Parents Scale
PS	Participation subscale
PrePerEx	Preparation, Perception, and Experience
QLQ-CX24	Quality of Life Questionnaire for cervical cancer module
QLQ-C30	Quality of Life Questionnaire Core 30
QLQ-C15-PAL	Quality of Life Questionnaire Core 15 Palliative questionnaire
QLQ-En24	Quality of Life Questionnaire for endometrial cancer module
QLQ-OV28	Quality of Life Questionnaire for ovarian cancer module
QoL	Quality of life
RSES	Rosenberg's Self-Esteem Scale
SCL-92	Symptom CheckList 92-item version
SDM-Q9	Shared Decision Making Questionnaire
SDSCA	Summary of Diabetes Self-Care Activities
SF-12 or 36	Short Form-12 or 36 questionnaire
STORI	Stages of Recovery Inventory
TSRQ	Treatment Self-Regulation Questionnaire
USE	Usefulness, Satisfaction and Ease of use
WHO-5	WHO-5 Well-Being Index
YMRS	Young Mania Rating Scale