



Perceived benefits and limitations of using patient-reported outcome measures in clinical practice with individual patients: a systematic review of qualitative studies

Rachel Campbell¹ · Angela Ju¹ · Madeleine T. King¹ · Claudia Rutherford^{1,2}

Accepted: 17 September 2021 / Published online: 27 September 2021
© The Author(s), under exclusive licence to Springer Nature Switzerland AG 2021

Abstract

Purpose Patient-reported outcome measures (PROMs) are increasingly used in clinical settings to inform individual patient care. In-depth understanding of end-users' experiences may help identify factors that promote or hinder their use in clinical decision-making. We aimed to examine stakeholder perceptions of the utility of using PROMs in clinical practice based on real-life experience.

Methods Systematic review searching Medline, Embase and PsychINFO from inception to May 2021. Qualitative studies examining patients' and/or clinicians' experiences of using PROMs in clinical settings were included. Study screening and data extraction were performed by two independent reviewers. Qualitative data from included studies was analysed thematically.

Results Of 2388 abstracts retrieved, 52 articles reporting 50 studies met eligibility. Five key benefits were identified: (1) promotes active patient involvement (enables goal setting and discussion of sensitive topics); (2) enhances the focus of consultations (prioritizes patient needs); (3) improves quality of care (enables tailored, holistic care and prompts action); (4) enables standardized monitoring of patient outcomes; and (5) enhances the patient–clinician relationship (provides reassurance). Perceived limitations included the capacity of PROMs to shift the focus of consultations; inaccurately estimate problems; raise unrealistic expectations for care; inhibit patient–clinician interaction; lack clinically meaningful information; and not be suitable for all patients.

Conclusion Both patients and clinicians reported benefits of using PROMs across diverse health conditions and clinical settings, but also highlighted several limitations. These limitations shed some light on why PROM use may not always improve patient outcomes and provide considerations for the design and implementation of future PROM initiatives.

Keywords Patient-reported outcomes · Clinical practice · Qualitative research · Patient centered care

Introduction

Traditionally, patient-reported outcomes (PROs) such as health-related quality of life (HRQL) have been most commonly used as endpoints in clinical trials where aggregated PRO data is used to guide improvements in clinical care.

More recently, there is increasing momentum internationally for using patient-reported outcome measures (PROMs) in routine clinical practice to support and inform the management of individual patients [1, 2]. PROMs provide unique information about the impact of disease and treatment from patients' perspectives that can complement conventional clinical measures (e.g. blood tests, functional tests, imaging) [3] and are increasingly viewed as a key component of patient-centered care [4].

Although there is variation in how PROMs are used in clinical settings with individual patients, typically this involves a patient completing a questionnaire (or set of questionnaires) that assess health-related outcomes and results are provided to the treating healthcare professional for review [5]. In clinical practice, PROMs can be used to

✉ Rachel Campbell
r.campbell@sydney.edu.au

¹ The University of Sydney, Faculty of Science, School of Psychology, Sydney Quality of Life Office, Sydney, Australia

² The University of Sydney, Susan Wakil School of Nursing and Midwifery, Cancer Nursing Research Unit (CNRU), Faculty of Medicine and Health, Sydney, Australia

screen for and detect problems (e.g. symptoms of depression or anxiety), monitor changes in patient outcomes over time, and promote patient-centered care by incorporating the patient's perspective into clinical decision-making [6].

Despite proven benefits for patient–clinician communication and patient satisfaction [7], several systematic reviews indicate mixed evidence regarding whether routine assessment of PROs in clinical practice improves patients' health outcomes [7–11]. Given these variable findings, a better understanding of end-users' experiences of using PROMs to inform patient care is needed to improve their future utility. Previous reviews have identified barriers and facilitators to using PROMs in clinical practice [12–14] and examined how PROMs support patient care [15]. A deeper understanding of how patients and clinicians perceive the clinical utility of PRO data based on their own experiences may provide unique insights into specific factors that promote or hinder their use in clinical decision-making. To explore this issue in-depth, we conducted a systematic review of the qualitative literature to examine end-users' perceptions of the utility of using PROMs in diverse medical contexts. Psychiatric settings were excluded from this review as use of PROMs in these settings has been comprehensively reviewed elsewhere [16]. Our specific objective was to examine the perceived benefits and limitations of using PROMs in medical clinical practice settings from both patient and clinician perspectives, based on their real-life experience.

Methods

This review focused on qualitative studies of experiences of using PROMs in clinical practice. We chose to limit our review to qualitative studies because qualitative designs allow for more in depth exploration of patient and clinician perspectives on the benefits and limitations of using PROMs “in clinic”. From hereon, we use the term “in clinic” to refer to use of PROMs in clinical practice to support individual patient management. This systematic review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (see Supplementary File 1) and Centre for Reviews and Dissemination (CRD's) guidance for undertaking reviews in health care [17].

Electronic searches

We searched MEDLINE, EMBASE, and PsychInfo databases from inception to May 25th 2021. Our search strategy included terms for “patient-reported outcome”, or “quality of life” or “symptom report” and “clinical setting”, or “practice”, and qualitative methods (see Supplementary File 2 for full search strategy). We also checked reference lists of

included studies and relevant review articles for potentially relevant studies.

Study selection and eligibility criteria

Eligibility criteria were:

- qualitative study design (i.e. interviews, focus groups or open-ended survey questions); mixed method studies were considered if qualitative data collection was included; and
- focus was on using PROMs in clinic and explored patient and/or clinician perceptions of the benefits and/or limitations of PROMs in managing individual patient care.

Studies were excluded if they:

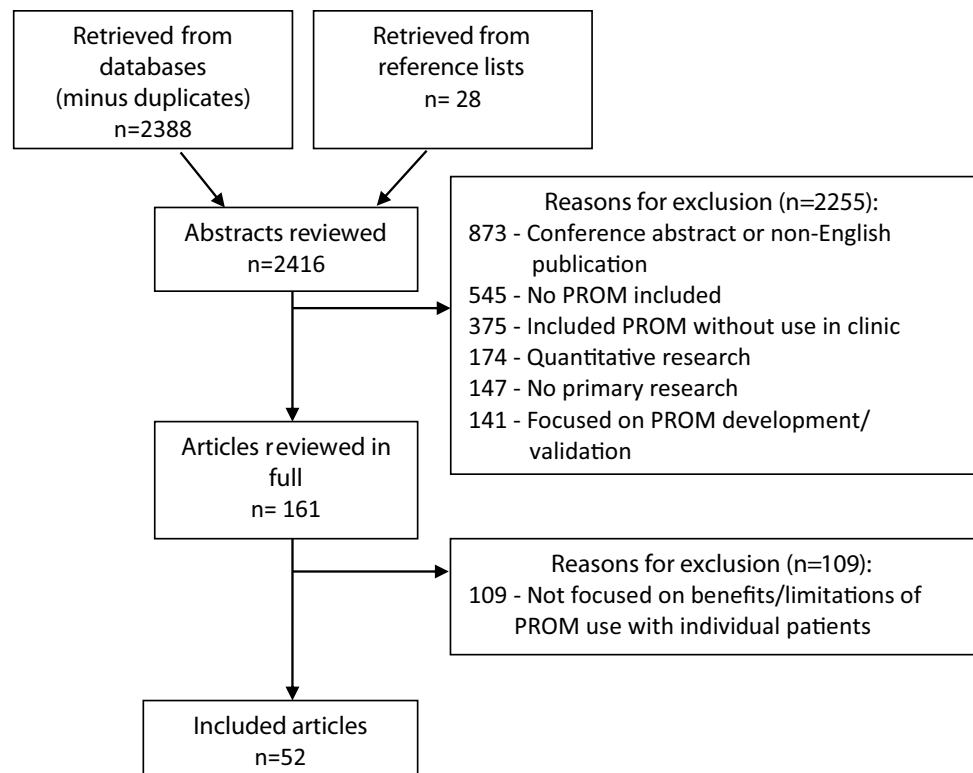
- used quantitative methods;
- focused on PROM development, validation, or selection for use in clinic;
- used patient-reported experience measures for quality improvement purposes;
- only asked about hypothetical benefits/limitations, not based on actual experience;
- were non-English or conference abstracts; or
- were in psychiatric settings.

All retrieved titles and abstracts were screened for eligibility by one reviewer (RC)¹ and 25% cross-checked at random by a second reviewer (AJ) [18]. If abstracts met eligibility criteria or relevance was unclear, full texts were obtained and reviewed independently by two reviewers (RC and AJ). Disagreements were resolved through team discussion.

Quality assessment

The quality of the reporting of included studies was assessed using the Consolidated Criteria for Reporting Qualitative research (COREQ) checklist [19]. The COREQ checklist includes 32 items, grouped into three domains: (i) research team and reflexivity; (ii) study design; and (iii) data analysis and findings. Each item was scored as 0 = not reported, 1 = partially reported, and 2 = fully reported, with each article receiving a total quality score out of 64, converted into a percentage (see Supplementary File 3 for scoring rules for each COREQ item). Thus, higher scores indicate higher quality reporting. Two reviewers (RC and AJ) independently assessed three articles, compared assessments, and discussed discrepancies until consensus was reached. Given minimal

¹ XX, YY, ZZ used throughout to replace author initials for blind manuscript.

Fig. 1 Flow chart of study inclusion

discrepancies, the remaining articles were assessed by one reviewer (RC or AJ) and a second reviewer (RC or AJ) cross-checked assessments against original articles.

Data extraction

A data extraction form was developed that included study aim, patient characteristics (e.g. population/disease type, sample size, age, gender), clinician characteristics (e.g. specialty, sample size, gender, age, years of experience), study design (e.g. focus groups, interviews, mixed methods), PROM used, purpose of PROM use, mode of administration (i.e. paper or electronic), and textual data regarding perceived benefits and limitations of using PROMs in clinic from patient and clinician perspectives. One author extracted data (RC or AJ) and a second author (RC or AJ) cross-checked extractions against the original article for accuracy.

Data synthesis

Thematic analysis [20] was conducted using NVivo 12. Two authors (RC and AJ; both post-doctoral researchers with expertise in PRO methodology) coded the textual data extracted from the results sections of included studies line by line to inductively identify preliminary concepts, annotating whether textual data was specific to clinician or patient perceptions. Following initial coding, both authors looked for similarities and differences between concepts and grouped

them into descriptive hierarchical themes (i.e. subthemes and themes). A third author (CR) also read the articles and reviewed the descriptive themes to ensure they accurately reflected data reported in included studies. Aggregated findings across studies were grouped and summarized under each descriptive theme.

Results

Summary of included studies

Searches yielded 2388 abstracts, of which 161 were potentially relevant and 52 articles reporting on 50 studies met inclusion criteria (see Fig. 1). Included studies used focus groups ($n=15$), interviews ($n=24$), a combination of interviews and focus groups ($n=7$), mixed methods ($n=2$), or qualitative data from open-ended survey questions ($n=2$) (Table 1). Studies were conducted in primary care ($n=22$), hospital ($n=9$), outpatient clinics ($n=9$), palliative care ($n=4$) or multiple settings ($n=5$) and reported clinicians' ($n=26$), patients' ($n=7$) or both patient and clinician experiences ($n=17$). PROMs were administered electronically ($n=26$), via paper ($n=12$) or either ($n=4$); eight studies did not report mode of administration. Total sample size across studies was 1256 clinicians and 375 patients; four studies did not report sample size for patients, clinicians or both. Studies used PROMs in diverse patient groups, including cancer,

Table 1 Characteristics of the included qualitative studies

First author (year); country	Clinical setting	Patient and/or clinician perspective	Patient group; sample size (n); age; gender	Clinician group; sample size (n); age; gender; years of experience	Method	Patient group PROM used in	PROM used	Purpose PROM was used for	Mode of administration
Ahluwalia (2018); USA	Veteran affairs rural and urban, community, and hospital-based primary care clinics	Clinician	NA	Primary care providers and clinic staff; n = 60; NR; NR; NR	Focus groups	Veterans	PROM not specified	Routine pain screening	Electronic
Baker (2017); USA	Hospital; Medical-surgical inpatient unit	Clinician	NA	Nurses; n = 63; NR; NR; NR	Focus groups	Medical surgical patients	RDOS	To assess dyspnea	Electronic
Baker (2020); USA	Intensive care unit (ICU)	Clinician	NA	Nurses; n = 7 at first focus group; n = 10 at second focus group; NR; NR; NR	Focus groups	ICU patients	Numeric rating scale from 0 to 10	To assess dyspnea	Paper
Bendtsen (2003); Sweden	Outpatient hospital-based clinic	Clinician	NA	Physicians; n = 7 at first focus group; n = 9 at second focus group; NR; NR; NR	Focus groups	Chronic obstructive pulmonary disease	SF-36	To assess HRQL	Electronic
Bouvette (2002); Canada	Multiple settings	Clinician	NA	Nurses; n = 42; NR; NR; NR	Focus groups	Patients in palliative care	PSAR	To assess symptoms	Paper
Callaly (2006); Australia	Mental health services	Clinician	NA	Nurses, allied health staff and medical staff; n = 83; NR; NR; NR	Focus groups and interviews	Patients attending mental health services	BASIS-32; K-10+; MHI-38	To assess treatment effectiveness	Electronic
Colquhoun (2010); Canada	Older person's rehabilitation unit	Clinician	NA	Occupational therapists; n = 3; Mean age = 15, age range = 6–31; all female; NR	Qualitative data from open ended questions	Mixed (orthopedic and neurological diagnoses)	COPM	To assess performance in everyday living over time	NR
Cranley (2004); Canada	Acute teaching hospital	Clinician	NA	Nurses; n = 29; NR; NR; NR	Semi structured interviews	Mixed (not specified)	Unspecified	To assess activities of daily living, symptoms, and readiness for discharge	NR
Delgadillo (2017); UK	Psychological therapies stepped care service	Patient and clinician	Patients accessing mental health services; n = 6; NR; NR	Therapists; n = 15; NR; NR; NR	Semi structured interviews	Patients accessing mental health services	PHQ-9; GAD-7	To monitor response to treatment	Electronic

Table 1 (continued)

First author (year); country	Clinical setting	Patient and/or clinician perspective	Patient group; sample size (n); age; gender	Clinician group; sample size (n); age; gender; years of experience	Method	Patient group PROM used in	PROM used	Purpose PROM was used for	Mode of administration
Deutscher (2008); Israel	Outpatient rehabilitation clinics	Clinician	NA	Therapists; n = 114; mean age = 37.7, age range = 24–63; male = 37.7%; mean years experience = 11.9	Qualitative data solicited during a series of informal meetings	Neuromusculoskeletal diagnosis	8 body part-specific CATs to assess functional status of cervical, shoulder, elbow, wrist, hand, lumbar, hip, knee, foot and ankle	To assess functional outcomes	Electronic
Dowrick (2009); England	General practice	Patient and clinician	Mixed patient group; n = 24; mean age = 47, age range = 20–77; Male = 38%	General practitioners; n = 34; mean age = 44, age range = 31–62; male = 56%; mean years experience = 14	Semi structured interviews	Mixed patient group	PHQ-9; HADS	To assess severity of depression	NR
Dronker (2020); The Netherlands	Outpatient clinic	Patient	Patients with head and neck cancer, n = 15; NR; NR	NA	Semi structured interview	Patients with head and neck cancer	EORTC QLQ-C30; EORTC H&N35 module; HADS; EAT1; VHI; EQ-5D-5L	To measure physical problems, psychosocial problems and HRQL	Electronic
Eilander (2016); The Netherlands	Diabetes clinics	Clinician	NA	Pediatrician, Diabetes nurse, psychologist, dietician; n = 26; NR; male = 15.40%; NR	Semi structured interviews	Adolescents with type 1 diabetes	MY-Q	To assess HRQL related to diabetes	Electronic
Evans (2020); Canada	Eight in-facility hemodialysis units	Patient and clinician	Patients receiving long-term hemodialysis; n = 9; mean age = 64; male = 44%	Nephrologists, nurses, pharmacists, dieticians, social workers, other staff; n = 48; NR; NR; NR	Semi structured interviews	Patients receiving long-term in-facility hemodialysis	ESAS-r; Renal	To assess physical and psychosocial symptom burden in patients treated with maintenance dialysis	Electronic and paper

Table 1 (continued)

First author (year); country	Clinical setting	Patient and/or clinician perspective	Patient group; sample size (<i>n</i>); age; gender	Clinician group; sample size (<i>n</i>); age; gender; years of experience	Method	Patient group PROM used in	PROM used	Purpose PROM was used for	Mode of administration
Greenhalgh (2005); UK	Outpatient clinics	Patient	Multiple sclerosis; <i>n</i> = 13; mean age = 43, age range = 30–66; Male = 23%	NA	Semi structured interviews	Multiple sclerosis	MSSID	To monitor symptoms and assess HRQL	Paper
Greiner (2015); UK and Canada	Home based completion	Patient	Multiple sclerosis; <i>n</i> = 12; NR; NR	NA	Telephone interview	Multiple sclerosis	MSQoL	To assess weekly health reports	Electronic
Hughes (2004); England	Non specialist palliative care settings	Patient and clinician	Patients in palliative care; <i>n</i> = 3; NR; NR	Nurses; <i>n</i> = 13; NR; all female; mean years experience = 3	Semi structured interviews	Patients in palliative care	POS	To assess physical, psychological and spiritual domains of HRQL	Paper
Kettis-Lindblad (2007); Sweden	Hospital	Patient and clinician	Gastrointestinal cancer; <i>n</i> = 20; mean age = 60.5; male = 50%	Oncologists; <i>n</i> = 6; NR; male = 66.67%; NR	Semi structured interviews	Gastrointestinal cancer	SEIQoL-DW; SEIQoL-DR	To assess HRQL	Electronic
Klein (2006); USA	Primary care clinic	Clinician	NA	Staff at primary care practice; <i>n</i> = 11; NR; NR; NR	Focus groups	Mixed patient group	PRIME-MD; PHQ-9	To screen for depression	Paper
Knudsen (2018); Denmark	Rheumatology clinic	Patient	Rheumatoid arthritis; <i>n</i> = 15; mean age = 56, age range = 28–77; male = 53.55%	NA	Semi structured interviews	Rheumatoid arthritis	Flare-RA	To monitor disease activity and determine if a patient needs an outpatient visit	Electronic
Korzeniowski (2015); Canada	Ambulatory cancer center	Patient and clinician	Prostate cancer; NR; NR; All male	Radiation oncologists, nurses, resident; <i>n</i> = 10; NR; male = 50%; NR	Semi structured interviews and brief informal debriefing	Prostate cancer	EPIC-26	To assess bowel, bladder, sexual functioning and impacts of hormone therapy	Electronic

Table 1 (continued)

First author (year); country	Clinical setting	Patient and/or clinician perspective	Patient group; sample size (n); age; gender	Clinician group; sample size (n); age; gender; years of experience	Method	Patient group PROM used in	PROM used	Purpose PROM was used for	Mode of administration
Krawczyk (2019); Canada	Palliative care	Patient and clinician	Patients with life limiting illness in palliative care; n = 3; age = 55 and older; NR	Nurses; NR; NR; NR; NR	Focus groups and interviews	Patients with life limiting illness in palliative care	ESAS; MQOL; CANHELP Lite	To assess HRQL	Electronic
Litchfield (2021); The UK	Primary care	Clinician	NA	GPs; n = 25; NR; 52% male; years of experience range 2–33	Semi structured interviews	Patients attending GP clinics	Not specified	To assess perceptions about the impact of disease and treatment on symptoms, functioning and HRQL	Electronic and paper
Locker (2015); Germany	Palliative care ward	Patient and clinician	Advanced cancer patients; n = 3; mean age = 68.67, age range = 55–86; male = 33.3%	Doctors and nurses; n = 5; NR; NR; A total of 50 years experience between clinicians	Interviews	Advanced cancer patients	SEIQoL-DW; QLQ-C15-PAL; RSCL; POS	To assess HRQL	Paper
Mark (2008); USA	Community oncology clinics	Clinician	NA	Physicians, nurse practitioners, physician assistants; n = 16; NR; NR; NR	Interviews	Mixed cancer patients	PCM	To assess symptoms	Electronic
Mason (2008); UK	Primary care	Clinician	NA	Nurses and midwives; n = 19; NR; NR; range in years experience = 15 months–28 years	Semi structured interviews	Women with postnatal depression	EPDS	To assess/ screen for postnatal depression	Paper
McHorney (2002); USA	Asthma clinic	Patient and clinician	Asthma; n = 39; NR; male = 31%	Physicians; n = 30; NR; male = 80%; NR	Focus groups and semi structured interviews	Asthma	SF-36; HOI Asthma 10.1	To assess functional health	Paper
Meehan (2006); Australia	Various	Clinician	NA	Mental health staff; n = 324; NR; NR; NR	Focus groups	Adults using mental health services	MHI-38	To monitor treatment effectiveness	Electronic
Mejdahl (2018); Denmark	Outpatient clinics	Clinician	NA	Nurses and physicians; n = 13; NR; male = 3%; NR	Interviews	Epilepsy patients	AmbuFlex/epilepsy PROM	To identify patients in need of clinical attention	Electronic and paper

Table 1 (continued)

First author (year); country	Clinical setting	Patient and/or clinician perspective	Patient group; sample size (n); age; gender	Clinician group; sample size (n); age; gender; years of experience	Method	Patient group PROM used in	PROM used	Purpose PROM was used for	Mode of administration
Mitchell (2011); UK	General practice clinic	Clinician	NA	General practice staff; n = 38; NR; NR; NR	Focus groups	Patients with diabetes, heart disease, new-onset depression	PHQ-9	To screen for depression	Electronic
Monroe (2018); USA	Urban HIV clinic	Patient and clinician	HIV positive; n = 11; mean age = 51%, age range = 33–61; male = 64%	Physicians, nurse practitioners, physician assistants; n = 11; NR; NR; NR	Interviews	HIV positive patients	AUDIT-C; ASSIST; PHQ-8; GAD-7; “measures of quality of life”	To assess self-reported substance use and mental health	Electronic
Neff (2018); USA	Hospital	Patient and clinician	Parkinson’s disease; n = 8; NR; NR	Neurologist, physical therapist, occupational therapist, speech pathologist, medical assistants, nurse; n = 11; NR; NR; NR	Focus groups and interviews	Parkinson’s disease	PDQ-39	To assess difficulties across 8 dimensions of daily living	Paper
Nyirenda (2019); USA	Home-based completion	Clinician	NA	“Clinicians” exact role not specified; n = 6; NR; NR; NR	Interviews	Mixed patient group	PROMIS self-efficacy for managing symptoms, daily activities, and global health	To assess health status and self-efficacy for managing symptoms	Electronic
O’Connor (2017); Australia	Hospital	Clinician	NA	Nurses, social workers, physiotherapist; n = 6; NR; NR; NR	Mixed methods	Gynaecologic cancer	DT; Problem Checklist	To assess distress and problems	NR
Porter (2021); UK	Primary care practices	Patient and clinician	Patients with multimorbidity; n = 10; NR; NR	Nurses; n = 4; NR; NR; NR	Semi structured interviews	Patients with multimorbidity	EQ-5D-5L; mini-AQLQ; RCP 3 asthma questionnaire; CCQ; MRC Breathlessness scale; PHQ-9; MLHFQ; OHS; OKS; PGI	To assess aspects of health status	Paper

Table 1 (continued)

First author (year); country	Clinical setting	Patient and/or clinician perspective	Patient group; sample size (n); age; gender	Clinician group; sample size (n); age; gender; years of experience	Method	Patient group PROM used in	PROM used	Purpose PROM was used for	Mode of administration
Primdahl (2019); Denmark	Rheumatologic care (exact setting not specified)	Patient	Patients with inflammatory arthritis; n = 32; mean age = 60, age range = 32–80; male = 34%	NA	Focus groups	Patients with inflammatory arthritis	HAQ; 3 items from the MD-HAQ assessing pain, fatigue and global health scores	To assess functional status and symptoms	Electronic
Ryan (2016); USA	Burns outpatient clinic	Patient and clinician	Young adult burn survivors; n = 11; age range = 19–30; NR	Doctors and nurses; n = 11; NR; 1 > years experience	Qualitative data from open ended questions	Young adult burn survivors	YABOQ	To assess symptoms, functioning and HRQL	Electronic
Schick-Makaroff (2017); Canada	Home dialysis clinic	Clinician	NA	Clinic nurses, n = 11, mean age = 46; all female; between 1 and 10 years experience	Mixed methods	Adult patients receiving home dialysis	ESAS for renal patients; KDQOL-36; comox valley nursing centre client PROM	To assess symptoms and HRQL	Electronic
Schmidt (2016); Germany	Hospital	Patient and clinician	Mixed cancer; n = 71; mean age = 61.3; male = 55%	Physicians, nurses, medical technicians, social workers, nutritional consultant; n = 39; NR; NR; NR	Focus groups and interview	Mixed cancer	EORTC QLQ-C30; DT; MDASI; EORTC single items	To screen and monitor symptoms	Electronic
Scholle (2018); NR	Federally Qualified Health Center; Academic Health Centre	Patient and clinician	Type 2 diabetes; NR; NR; NR	Clinicians and/or care managers; NR; NR; NR; NR	Semi-structured interviews	Type 2 diabetes	PROMIS-29	Used in care planning to improve quality of care	Paper
Schulman-Green (2017); USA	Hospice	Clinician	NA	Hospice staff; n = 24; NR; NR; NR	Semi-structured interviews	Patients in hospice	ESAS	To assess symptoms	NR
Schwartz (2005); USA	Hospice, home health and palliative care	Clinician	NA	Exact roles not specified, referred to as "staff"; NR; NR; NR	Interviews	Advanced chronic illness	MVQOLI-R	To assess HRQL	Paper

Table 1 (continued)

First author (year); country	Clinical setting	Patient and/or clinician perspective	Patient group; sample size (n); age; gender	Clinician group; sample size (n); age; gender; years of experience	Method	Patient group PROM used in	PROM used	Purpose PROM was used for	Mode of administration
Tai (2020); Canada	Falls prevention clinic	Patient	Patients attending the falls prevention clinic; n = 21; mean age = 81.1; age range = 66–93; male = 25%	NA	Focus groups	Patients attending a falls prevention clinic following a trauma fall in the previous 12 months	EQ-5D-5L	To assess health status	NR
Talib (2018); USA	Primary care	Patient	Patients experiencing poor sleep, pain, anxiety, depression and fatigue; n = 23; mean age = 56, age range = 24–77; male = 52%	NA	Individual interviews	Patients experiencing poor sleep, pain, anxiety, depression and fatigue	PROMIS-29	To assess symptoms	Electronic
Tavabie (2009); The UK	Primary care practice	Clinician	NA	General practitioners; n = 16; NR; Male = 56.25%; range in years experience = 0–10 years	Semi-structured interview and focus groups	Patients attending a GP practice	PHQ-9	To screen for depression	Electronic
Thestrup Hansen (2019) 1; Denmark	Hematology outpatient clinic	Patient	Chronic Hematologic Cancer; n = 16; age range = 68–86; male = 62.5%	NA	Focus groups and individual interviews	Chronic Hematologic Cancer	EORTC QLQ-C30; OEQ	To assess HRQL	Electronic or paper
Thestrup Hansen (2019) 2; Denmark	Hematology outpatient clinic	Clinician	NA	Hematologists; n = 14; NR; male = 71.4%; NR	Individual interviews	Chronic Hematologic Cancer	EORTC QLQ-C30; OEQ	To assess HRQL	Electronic or paper
Thestrup Hansen (2021); Denmark	Hematology outpatient clinic	Clinician	NA	Nurses; n = 9; NR; All female; NR	Focus groups and individual interviews	Chronic Hematologic Cancer	EORTC QLQ-C30; OEQ	To assess HRQL	Electronic or paper
Trautmann (2016); Germany	Comprehensive Cancer Centre	Clinician	NA	Nurses and Physicians, n = 5; NR; NR; NR	Group interview	Mixed cancer patients	EORTC QLQ-C30; DT; HSI MNA; CPS; BPI	To assess symptoms and HRQL	Electronic

Table 1 (continued)

First author (year); country	Clinical setting	Patient and/or clinician perspective	Patient group; sample size (n); age; gender	Clinician group; sample size (n); age; gender; years of experience	Method	Patient group PROM used in	PROM used	Purpose PROM was used for	Mode of administration
Unsworth (2012); UK	Hospital and a counseling service	Patient and clinician	Clients of occupational health therapist; n = 10; NR; NR	Occupational health therapists, trainee physiotherapists, primary care counseling therapists; n = 13; NR; NR; mean years experience = 6.5–9	Focus groups and interviews	Clients of occupational health therapist	CORE-OM	To assess well-being, social functioning, symptoms, risk to self/others	Electronic
Wheat (2018); UK	Various institutional settings	Clinician	NA	Commissioner or practitioner, program or network manager; n = 26; NR; NR; NR	Interviews	Mixed patient group	Various (exact PROMs not specified)	To assess patient outcomes	NR
Wressle (2009); Sweden	Hospital	Clinician	NA	Physiotherapists; occupational therapists, physician, social worker, assistant nurse; n = 7; NR; NR; NR	Interviews	Rheumatoid arthritis	COPM	To assess occupational performance and satisfaction with performance in areas of self-care, productivity and leisure	NR

NA not applicable, NR not reported, ASSIST alcohol, smoking and substance involvement screening test, AUDIT-C alcohol use disorders identification test alcohol-consumption, BASIS-32, behavior and symptom identification scale-32, BPI brief pain inventory, CANHELP Canadian health care evaluation project, COPM Canadian occupational performance measure, CORE-OM clinical outcomes in routine evaluation, CPS control preference scale, DHP diabetes health profile, DT distress thermometer, EAT10 eating assessment tool, EORTC-QLQ-C15-PAL European Organization for Research and Treatment of Cancer-Quality Core 15 Quality of Life Questionnaire, EORTC-QLQ-C30 European Organization for Research and Treatment of Cancer-Quality of Life Questionnaire, EPDS Edinburgh postnatal depression scale, EPIC-26, expanded prostate cancer index composite-26, ESAS Edmonton symptom assessment scale, ESAS-r:RENAL Edmonton symptom assessment system revised: Renal, Flare-RA flare in rheumatoid arthritis questionnaire, GAD-7 general anxiety disorder-7, HADS Hospital anxiety and depression scale, HAQ health assessment questionnaire, HSI Hornheider screening instrument, HOI Asthma 10.1 Health Outcomes Institute 10.1, K-10+ Kessler-10 Plus, KDQOL-36 kidney disease quality of life questionnaire-36, MDASI M.D. Anderson symptom inventory, MDHAQ multidimensional health assessment questionnaire, MHI-38 mental health inventory-38, mini-AQLQ mini quality of life questionnaire, MLHFQ Minnesota living with heart failure questionnaire, MNA mini nutritional assessment, MQOL McGill quality of life questionnaire, MS-Qol multiple sclerosis-quality of life, MSSID MS symptom and impact diary, MVQOLI-R Missoula-VITAS quality of LIFE index-revised, MY-Q MIND youth-questionnaire, OEQ outcomes and experiences questionnaire, OHS Oxford hip score, OKS, Oxford knee score, PCM patient care monitor, PDQ-39, Parkinson disease questionnaire-39, PGI patient generated index, PHQ-8 patient health questionnaire-8, PHQ-9 patient health questionnaire-9, POS palliative care outcomes scale, PRIME-MD primary care evaluation of mental disorders, PROMIS-29 patient-reported outcomes measurement information system-29, PSAR pain and symptom assessment record, RCP Royal College of Physicians, RDO5 respiratory distress observation scale, RSCL Rotterdam symptom checklist, SEIQoL-DR schedule for the evaluation of the individual quality of life-disease related, SEIQoL-DW schedule for the evaluation of the individual quality of life-direct weighting, SF-36 short-form-36, VHI voice handicap index, YABOQ young adult burn outcome questionnaire

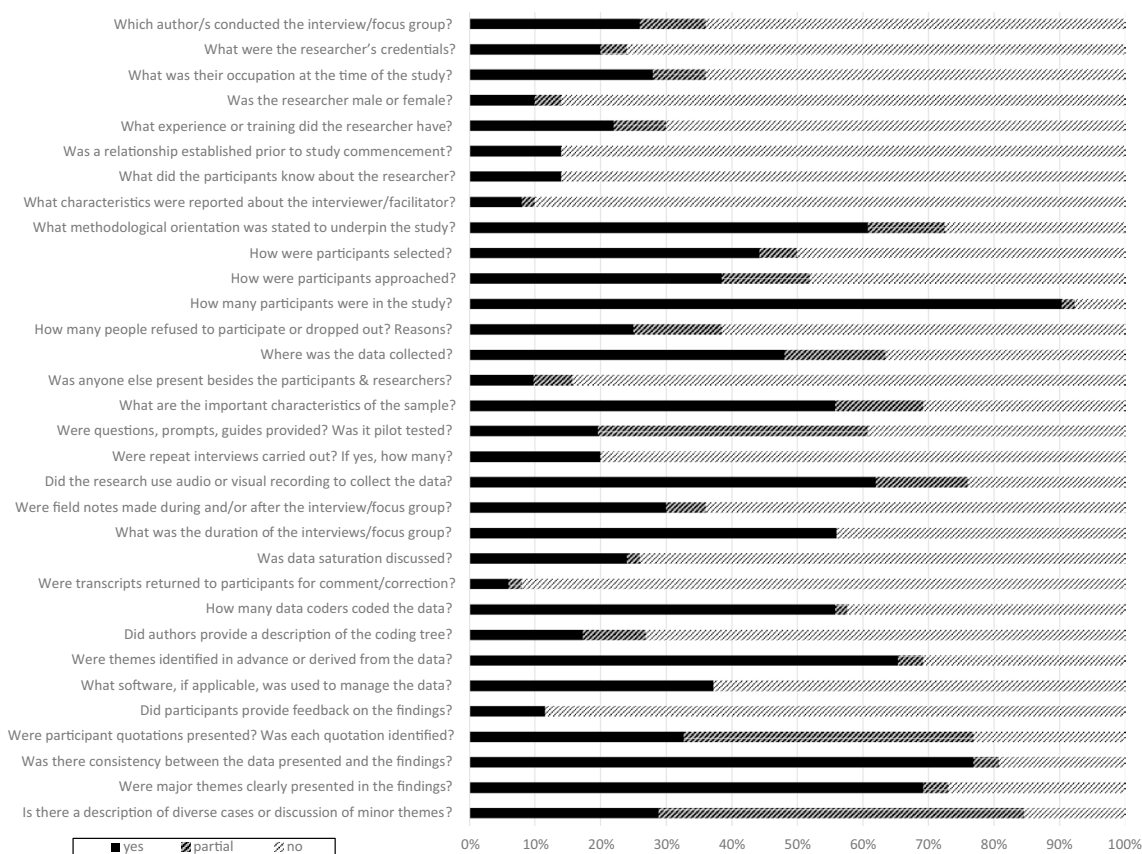


Fig. 2 Quality of reporting across included articles ($n=52$) per COREQ item

diabetes, arthritis, HIV, asthma, Parkinson's disease, kidney disease, among others. PROMs most commonly used (i.e. in three or more studies) included the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30), the Patient Health Questionnaire-9 (PHQ-9), and the Edmonton Symptom Assessment Scale (ESAS).

Methodological quality of included studies

The quality of included studies was highly variable with quality scores ranging from 8 [21] to 69% [22]. Notably, none of the COREQ items were fully reported in all studies (see Fig. 2). However, the majority of studies reported the number of participants (90%) and methodological orientation underpinning the study (60%); displayed consistency between data presented and findings (77%); and clearly presented major themes (69%). Few studies included interviewer characteristics such as gender, possible bias, and nature of the relationship with interviewee (8%); whether anyone else was present during the interview/focus groups besides the researcher (10%); and whether transcripts were returned to participants for comment (6%).

Synthesis

Seven themes were identified: Active patient involvement and partnership; Focus of consultation; Quality of care; Standardized monitoring of patient outcomes; Patient–clinician relationship; Lack of valuable information; and Suitability for all patients. Below we describe the subthemes pertaining to each theme, which cover perceived benefits and limitations of using PROMs in clinic, or a mixture of both. Illustrative quotes are included in Table 2.

Active patient involvement and partnership

Enables greater awareness and reflection

Both patients and clinicians reported completing PROMs helped patients identify their needs and symptoms [23–29]. Some patients reported PROM completion increased their self-awareness by “forcing them to think” and identify specific problem areas [22, 30–34], whereas clinicians reported PRO data helped reflect on patients' progress and improved their understanding and awareness of patients' physical and mental health [35–38].

Table 2 Illustrative quotes

Theme	Benefit, limitation or mixed	Illustrative quotations	Sources
Active patient involvement and partnership Enables greater awareness and reflection	Benefit	I think that [completing the questionnaire] helped me in my head as well ... Well I started to think, you know about why I was getting depressed and that [29] (P) I think it brings an awareness to them in that moment and makes them think about each individual thing so it's like right at the front of their brain when they go in to talk to the nurse. [22] (C)	[22–38]
	Benefit	I think it's good in the way that if you have something like this [QOL results], then you can actually tell the doctor that, 'I would like to talk to you about this and that,' and then he'll have to listen [31] (P) It was good that I could put the information in for myself and I thought that it was really good that at the end of it we could have a look at it and go through it [43] (P)	[24, 27, 29, 31, 32, 39–43]
Facilitates goal setting Influences honesty	Benefit	It's good for setting your goals on your treatment plan [24] (P)	[21, 24, 28, 34, 35, 44]
	Mixed	You're more likely to lie, well I found I'm more likely to lie ... Because I still find a lot of stigma attached to depression [29] (P) You know they all just seemed incredibly anxious to please the nurses really, and ticked the response they thought were correct [45] (C) When they're sitting in the waiting room, filling in [the ePROs], they can be a bit more honest with themselves and then that is very revealing to the healthcare providers [22] (C)	[22, 25, 27, 29, 40, 45–47]
Permits discussion of sensitive topics	Benefit	Gives patients permission [to talk] and includes questions not usually asked (sexual concerns) [48] (C) Some people don't talk to their doctor very well. So, [the PRO measure] certainly would help that process. [26] (C)	[22, 24, 26, 38, 46, 48, 49]
	Benefit	Physicians can see [before the visit] okay, there are some things here that we need to take care of and can identify things about their disease [42] (C) When I have these data in advance, I have a better impression if there is a problem, so I am ready ... In that way PROMs are quite positive [50] (C)	[22, 42, 50, 51]
Focus of consultation Helpful as a screening tool			

Table 2 (continued)

Theme	Benefit, limitation or mixed	Illustrative quotations	Sources
Prioritizes patients' needs	Benefit	<p>It didn't necessarily change what I asked patients, but maybe the order. It helped me to prioritize my patient's needs and I could see they appreciated that... You never felt like you were leaving something important to the end and rushing as a result [52] (C)</p> <p>I look at it [ePROs] before I start the interview. I focus on it first—those are the things that are important to the patient, rather than focus on what's important to me [22] (C)</p> <p>I like knowing where they're at but sometimes I think it puts the focus of my visit on that rather than maybe their other medical conditions that probably I need to focus more on [44] (C)</p>	[22, 28, 29, 31, 33, 37, 40, 42, 44, 46, 48, 51–54]
Provides one piece of the picture	Limitation	<p>Each personality has varying situations and, like, a questionnaire is not going to necessarily give you the full picture of what that person's circumstances are. It might gloss over some areas that would turn out to be more important than others, I think [29] (C)</p> <p>A score on a scale tells you very little about the person... how that person lives... sees the world and so forth [54] (C)</p>	[29, 31, 53–55]
Structures consultations and improves efficiency	Benefit	<p>It's a good way to structure my time; it allows me to take care of the ones who need me the most. [37] (C)</p> <p>It would make the appointment go quicker and the doctor's time go quicker because he doesn't really need to ask about these things that are [rated] "never" or "rarely". The ones that are "sometimes to always" are the areas he'd want to look into [27] (P)</p>	[25, 27, 31, 32, 37, 46, 48]
Quality of care	Benefit	<p>I was really surprised by some patient scores. Some men had significant urinary symptoms, but did not seem bothered by them, as indicated by their scores ... knowing the meaning symptoms have for a patient can really affect your clinical decision-making [52] (C)</p> <p>I didn't understand how you could ask somebody questions and think whether they were depressed or not.. but then.. more recently I did it with the (measure) ... it had a lot more questions and they did it on the computer and it was a lot better and more methodical [29] (C)</p>	[21, 25, 29, 51–54, 56]
Assists diagnosis and enables tailored care	Benefit		

Table 2 (continued)

Theme	Benefit, limitation or mixed	Illustrative quotations	Sources
Ensures holistic care	Benefit	<p>The usefulness of things like this is to remind me to ask patients more about what is going on in their life and not just focus on the lab numbers. So, you've got to get into the meat of how it [disease] affects them. What's the point of doing a major heart operation, you know, if quality of life isn't better? [26] (C)</p> <p>We all assess out patients every time we see them, but we don't always think outside the box...about quality of life and depression. We look more at the medical elements [38] (C)</p> <p>The great thing I liked about the PROM was that there were so many different questions that it provided opportunity to bring out all kinds of stuff that you wouldn't normally have caught in the first visit sometimes with people [57] (C)</p>	[26, 36, 38, 42, 48, 57, 58]
Can inaccurately estimate the problem	Limitation	<p>They're eating 25%, but their experience is: no my appetite is fine. I don't have a problem. But you know they are not fine, so the data you get is not really that useful in terms of assessing the improvement in symptom management [49] (C)</p> <p>There's a lot of people I know just want to get in there, get it over with, and get out. They may have other things on their mind so if you're forcing them to fill it out, they may just go sit down and start putting checks down and not pay any attention. So that's false information into the system which wouldn't be good [27] (C)</p>	[25, 27, 29, 40, 44, 49, 55, 59, 60]
Prompts appropriate action	Mixed	<p>Hopefully he is going to come away with some solution as to help you not feel that way. Either with some medicine, diet, or exercise [27] (P)</p> <p>I can think of at last 4 [patients] right off ... that I helped into pain management because they had pain going on but nobody ever asked about it really [57] (C)</p> <p>If we ask patients all these questions with PROMs, patients might think that I can help them solve all sorts of things [50] (C)</p> <p>I think we would all feel compelled to that oh, now I've seen this, I really need to do something about this [40] (C)</p>	[26, 27, 29, 31, 32, 37–41, 45, 46, 49, 50, 55, 57]
Standardized monitoring of patient outcomes over time			

Table 2 (continued)

Theme	Benefit, limitation or mixed	Illustrative quotations	Sources
Helps determine effectiveness and side-effects of treatment	Benefit	There were a couple of occasions where it highlighted to both of us really that the treatment we were doing –although it was useful for them– it wasn't as effective as it could be, so it meant that we could change very quickly what we were doing [35] (C)	[33, 35, 42, 51, 52, 61, 62]
	Mixed	It's great to finally have some site-specific information about our prostate cancer patients while they are on treatment. Often time they are well otherwise and I am most curious about their bowel, bladder and sexual functioning [52] (C) They can see then whether things have improved or not ...by looking at those [previous results] [29] (P) If changes in scores on treatment stabilize after follow-up, we can ascertain the score changes were a result of acute side effects and that we don't need to investigate symptoms further [52] (C)	[23, 24, 26, 29, 49, 52, 61, 63]
Patient–clinician relationship Provides reassurance that clinicians care	Benefit	It can be perceived as you're being taken more seriously I suppose. It's probably something the doctor should have asked a long time ago you know cause blokes especially are never going to come in and say oh I'm depressed it's like come back with a proper illness you know [29] (P)	[26, 29, 32, 35, 36, 40, 42, 46, 53]
	Limitation	I want to see us go back to the days when the doctors are concerned about human beings rather than computerized graphs and managing their patient population by the numbers [26] (P) I think that the patients are relatively uncomplicated, so why introduce a questionnaire between the patient and me? That does not make sense to me. Clinicians, both nurses and haematologists, have the ability to recognize personalities, and we talk to our patients in relation to that ability as we use our skills ... I wish that we could get rid of these PROMs and focus on our work [50] (C)	[26, 29, 35, 37, 40, 47, 49, 50, 52, 64]
Inhibits interaction and rapport			
Lack of valuable information			

Table 2 (continued)

Theme	Benefit, limitation or mixed	Illustrative quotations	Sources
PRO data is not specific enough to be clinically meaningful	Limitation	<p>[Generic survey] certainly don't measure anything that I can treat. How they fill out [Generic survey] may have a great deal more to do with events outside what you are interested in – the medical care. I suspect that there are a great many other things that are out of our control, out of our purview that affect these answers [26] (C)</p> <p>Having the full set of questions and responses available would be even more specific and detailed and would help to assess and identify the exact parameters that are changing for a patient [52] (C)</p>	[25, 26, 39, 46, 52, 57, 59]
Provides redundant information	Limitation	<p>I've got a reasonable amount of experience in mental health... I feel reasonably confident in assessing depression anyway. If you've got people who are less happy about their abilities in assessing depression this would be a useful tool [29] (C)</p> <p>Having the scores didn't change what I asked a patient during review. I found myself still inquiring about the same anticipated side-effects in the manner that I normally would without EPIC [52] (C)</p>	[26, 29, 47, 51, 52, 54]
Suitability for all patients	Limitation	<p>I think the problem with palliative patients is that by the time we get them, they are so sedated or their disease process is such that they can't understand the questions [54](C)</p> <p>I couldn't help but think what would happen to a person who is limited in English proficiency who got one of these? Or someone who struggled with basic reading skills. There seems to be some vocabulary that might be a challenge for some people in society [26] (P)</p>	[26, 31, 33, 44, 45, 53, 55, 56, 58, 65]

Identifiers in brackets after the quote: *P* patient, *C* clinician

Encourages patient involvement

Both patients and clinicians reported PROM completion improved communication by helping patients recall symptoms to discuss with their clinician [27, 31, 32, 39] and clinicians to pinpoint issues to discuss with their patients [40, 41]. This enhanced communication was reported by both as encouraging patients' to work collaboratively with clinicians and be more involved in their care [24, 29, 42, 43].

Facilitates goal setting

PRO data was reported to facilitate short- and long-term goal setting by patients and clinicians [24, 44]. Clinicians found patient-reported functional data particularly useful for setting functional goals throughout treatment [21]. Both patients and clinicians reported PRO data helped to motivate and "reinforce positive change when patients' symptoms were on track" [34, 35]. Some clinicians stated individual items (rather than domain scores) were especially useful for setting goals with patients [28].

Influences honesty

Patients and clinicians had mixed opinions about patients' honesty when completing PROMs. Some patients reported the impersonal nature of PROMs promoted honesty whereas others reported it facilitated dishonesty [25, 27, 29, 45]. The degree of honesty may be dependent on the type of PROM, with some patients expressing they were more dishonest when completing PROMs assessing depression, to avoid unwanted treatment or being judged [29]. Clinicians similarly expressed mixed views, with some reporting patients were more honest because they did not need to please clinicians directly while others reported patients hid symptoms and responded in socially desirable ways [22, 40, 45–47].

Permits discussion of sensitive topics

PROMs were reported to help patients and clinicians discuss difficult or embarrassing topics during the clinical encounter (e.g. sexual or mental health issues) [24, 38, 46]. Some clinicians reported completing PROMs gave patients "permission to talk" about sensitive issues because PROMs covered questions not usually asked by clinicians [48]. Others stated using PROMs helped patients with communication difficulties to express concerns in numbers rather than words [22, 49].

Focus of consultation

Helpful as a screening tool

Receiving PRO data before the consultation helped some clinicians better prepare by providing an overall impression of their patient's condition and identifying issues to focus on during the consultation [22, 50]. This reduced time needed to take detailed histories, allowing them to focus immediately on patient priorities [42].

Prioritizes patients' needs

Many patients and clinicians reported using PROMs helped prioritize patients' needs and identify problems that may have otherwise been overlooked [22, 29, 33, 37, 40, 42, 44, 46, 48, 51–53]. It also helped clinicians identify areas in which patients were doing well, enabling them to focus on other issues important to the patient [52]. Some clinicians stated PRO data did not change the questions they asked, but rather the order in which they asked questions [22, 52], preventing important issues from being left till last [28, 33, 52].

PRO data was reported to trigger conversations about patients' priorities for care and treatment [31]. This was appreciated by patients, because patients and clinicians can differ in what they perceive as most important in relation to care [31, 42]. One clinician described patients as looking "relieved we're talking about what is most important to them" [28]. Some clinicians reported PRO data captured information essential for shared decision-making and helped clinicians understand patients' treatment preferences [42].

Conversely, some clinicians reported using PROMs negatively shifted the focus of consultations away from the patient's main health complaint, towards other less important symptoms, particularly when PROMs were symptom-specific (e.g. focused on pain) [44]. Those clinicians felt this resulted in them having to manage lower priority problems and reduced the time to deal with other important issues [44, 54].

Provides one piece of the picture

PROMs were perceived by some patients and clinicians to reduce complex conditions to numeric scores and only provide one piece of the picture [29, 54]. Several clinicians emphasised the importance of using PRO data in combination with clinical skills and questioning patients further about their broader life context [55].

Structures consultations and improves efficiency

PRO data helped several clinicians structure consultations by highlighting areas to focus on Refs. [27, 37, 46, 48]. PROMs administered electronically were reported especially efficient because they provided information at a glance, enabling clinicians to prepare for consultations time-effectively [25, 27, 31, 46]. The process of completing PRO assessments also helped patients feel better prepared, resulting in a more efficient consultation [32].

Quality of care

Assists diagnosis and enables tailored care

PRO data assisted some clinicians to make accurate diagnoses by identifying exactly where problems lay [29, 54]. Others reported it helped determine goals of treatment, resulting in more individualised care plans [21, 25, 51, 53, 56]. Patients similarly believed that reporting symptoms systematically assisted their healthcare team to make decisions about their care [52].

Ensures holistic care

Several clinicians stated PROMs covered issues essential for holistic care such as patients' quality of life [36, 42]. By providing information about different aspects of quality of life (e.g. emotional, social and spiritual), PRO data helped clinicians understand patients' lives more holistically [26, 38, 48, 57, 58].

Can inaccurately estimate the problem

Some clinicians reported PRO data inaccurately estimated patients' problems by over- or underestimating symptoms [27, 29, 40, 44, 55]. Some were concerned PRO data led to "false positives" and encouraged patients to "find" a complaint, pushing clinicians to intervene even if treatment was not a priority [44]. Others were concerned PRO data underestimated patients' problems and reported cases of patients scoring low on symptoms (e.g. dyspnea) even though they exhibited signs of more severe symptom burden [49, 59, 60]. Several patients also expressed difficulty quantifying the level of their symptoms [25].

Prompts appropriate action

Many patients expected PRO data to prompt clinicians to take action to manage their symptoms [27, 32, 39]. When PRO scores did not prompt any action, patients wanted reassurance their scores had been considered when developing

treatment plans [26, 31, 39]. Conversely, other patients were not aware that their PRO data could inform treatment decisions [39].

Many clinicians reported PRO data prompted them to address symptoms [29, 31, 46, 55], while others expressed concern that patients may expect PRO scores to prompt action. Some found it difficult to act on PRO data and worried they were expected to address all the issues reported, even though they were not equipped with adequate resources to manage them [38, 40, 41, 45, 46, 49, 50]. Others reported the demands induced by PROMs was a stress factor that had a negative bearing on their job satisfaction [37, 38].

Standardized monitoring of patient outcomes over time

Helps determine effectiveness and side-effects of treatment

Routinely assessing PROs in clinic helped some clinicians assess whether treatment was achieving desired outcomes, resulting in modifications to treatment plans if symptoms were not improving [33, 35, 42, 51, 52, 61]. Others reported it helped monitor acute and late effects of treatment [52, 61] and determine whether supportive care was required [62].

Useful for monitoring changes and tracking progress

Regular PRO assessment helped clinicians monitor changes and track progress in patient outcomes over time [49, 61]. Some clinicians reported showing patients trends in their PRO scores over time helped illustrate improvements in their condition [24, 26]. Patients reported seeing their PRO data helped to "see how far they've come and how far they needed to go" [63]. While some patients found it encouraging to see symptoms improve over time, others found it distressing when symptoms worsened [23].

Patient–clinician relationship

Provides reassurance that clinicians care

Some patients reported completing PROMs helped improve the patient–clinician relationship by reassuring patients that clinicians cared [32, 40]. It helped some patients feel they were being taken seriously and induced a feeling of not being left alone [29]. Several clinicians reported using PROMs improved the patient–clinician relationship by demonstrating clinicians' interest in all aspects of patients' well-being [26, 35, 36, 42, 46, 53].

Inhibits interaction and rapport

Others expressed the opposing view, namely that PRO assessment inhibits interaction and rapport. Some patients found PROM assessment impersonal because it gave the impression clinicians were too busy to talk to them [26]. As a result, one patient stated they wanted to “go back to the days when doctors were concerned about human beings and not numbers” [26]. Others worried PROM assessment would reduce the time available to talk with the clinician [35, 52].

Several clinicians were similarly concerned PROM assessment would be perceived as impersonal and harm the patient–clinician relationship [37, 40, 47, 49, 64]. One clinician argued that “patient-centered care should rely on conversation and focus on knowing the human, not data” [50]. Others feared using PROMs would lead to a de-skilling of clinicians and produce a “generation of doctors driven by ticking boxes” [29].

Lack of valuable information

PRO data is not specific enough to be clinically meaningful

Generic PROMs (e.g. the SF-36) were reported by some clinicians to be less clinically meaningful than disease-specific PROMs because they provided information on outcomes outside clinicians’ control [26]. Some clinicians were also critical of how PRO data was reported, stating that scores of individual items were more clinically meaningful than aggregated multi-item scores because items enabled identification of specific issues of concern [52].

Both clinicians and patients reported patients had difficulty answering questions in some PROMs because questions were unclear or irrelevant [25, 39, 46, 57, 59]. Some patients also struggled to choose a response because options provided were not specific enough [25, 39].

Provides redundant information

Some clinicians stated PROMs provided redundant information because they covered questions already asked by clinicians and added no new information [52]. Perceived usefulness of PROMs was somewhat dependent on clinicians’ years of experience; PROMs were considered most useful for less experienced or less confident clinicians [26, 29, 47, 51, 54].

Suitability for all patients

Several clinicians and patients believed PROM assessment was not universally suitable for all patients [26, 31, 44]. Some clinicians reported very sick or highly distressed

patients were unable to concentrate on completing PROMs [45, 55, 58]. Others felt patients in palliative care were so used to their symptoms they had difficulty quantifying them, or so heavily sedated they were unable to reliably respond to questions in PROMs [56]. Several clinicians reported PROM completion was too complex for elderly, cognitively impaired or low literacy patients [26, 33, 53, 65].

Discussion

This review identified 52 articles reporting on patient and clinician experiences of using PROMs in clinical practice to inform the management of individual patients. Synthesized evidence indicated both patients and clinicians reported many benefits of using PROMs in clinic. These include five key benefits: (1) promoting active patient involvement in their care by facilitating goal setting, and permitting discussion of sensitive topics; (2) enhancing the focus of consultations by prioritizing care around patient needs; (3) improving quality of care by enabling tailored, holistic care and prompting appropriate action; (4) enabling standardized monitoring of outcomes over time to monitor PRO changes and track progress; and (5) enhancing the patient–clinician relationship by reassuring patients that clinicians care. A number of limitations were also identified such as the capacity for PROMs to negatively shift the focus of consultations and reduce quality of care by inaccurately estimating symptoms and raising expectations for care that exceed clinicians’ resources. In some studies, PROMs were reported to inhibit the patient–clinician relationship, lack clinically meaningful information and were not considered suitable for all patients.

Although patients and clinicians tended to converge on the perceived benefits of using PROMs, several limitations were uniquely reported by clinicians (e.g. PROMs provide redundant information and negatively impact on the focus of consultations). Given that clinicians play a key role in the utilization of PRO data, these negative perceptions may hinder the potential for PRO data to drive clinical decision-making and improve patient outcomes. These findings suggest that shifting clinician attitudes by providing training and education on the added value of PRO data, may help to improve the effectiveness of using PROMs in clinic. They further highlight the importance of emphasising that PROMs administration is intended to promote high quality standardized patient-centered care and enhance communication with patients’ about their needs and concerns rather than replace patient–clinician conversations.

The themes identified were remarkably consistent across diverse health conditions and clinical settings. The most common themes identified across ten or more health conditions were enabling greater awareness and reflection, useful for monitoring changes and tracking progress, influencing

honesty in disclosure and inhibiting interaction and rapport. The least common themes, emerging across only five or fewer health conditions, were helpful as a screening tool, structures the consultation and improves efficiency and provides redundant information. The consistency of themes across clinical settings was also noteworthy, with all themes emerging across three or more different clinical contexts. The biggest discrepancies were observed within palliative care settings, where several themes did not emerge (i.e. facilitates short & long term goal setting, helps determine effectiveness of treatment, helpful as a screening tool, PRO data not specific enough to be clinically meaningful, and provides redundant information).

Importantly, the identified limitations highlight why use of PROMs in clinical settings may not always improve patient outcomes and indicate important considerations to be addressed in the design and implementation of future PROM initiatives. In line with the International Society for Quality of Life Research (ISOQOL) guidance [66], these findings emphasize the importance of choosing appropriate PROMs for the patient group and clinical context, reporting PRO results to clinicians in an easily interpretable and clinically meaningful format, and developing feasible strategies or guidance for responding to issues identified by PROMs. It is essential that PROMs support clinicians to provide enhanced care, rather than add to job demands. While patient engagement with PROMs is critical, clinicians are responsible for using PRO data to inform patient care and require adequate support and training to realize their full potential. Co-designing PROM initiatives with patients and clinicians may help ensure clinical relevance and feasibility.

A key strength of this review is that it synthesizes qualitative evidence on the clinical utility of PROMs among a range of patient groups, across diverse clinical settings and countries, from both patient and clinician perspectives. Although other qualitative reviews have also examined end-users' experiences of using PROMs in clinical practice, they focused mainly on barriers and facilitators to PROM implementation either from clinicians' perspectives [12] or within a particular clinical setting [13]. The themes identified in our review closely align with key findings from a realist synthesis of qualitative and quantitative data [15], which also found PROMs facilitated reflection and gave patients permission to raise issues with clinicians but could sometimes constrain rather than support communication [15]. This review supports and extends these findings by also identifying several additional themes common across diverse health conditions and clinical settings such as facilitating short and long term goal setting and influencing honesty during consultations. This review also provides some insight into findings from quantitative systematic reviews [7–9, 11, 12] which found mixed evidence for the effectiveness of using PROMs in clinic by identifying several limitations such as the capacity

of PROMs to underestimate problems or lack clinically meaningful information, which may have contributed to variability in patient outcomes across studies.

This review also has some limitations. Our search strategy did not include terms for PROMs often used in the field of psychiatry and clinical psychology, such as routine outcome monitoring (ROM), clinical feedback (CF), measurement feedback system, and feedback-informed treatment. As such our findings may not be generalizable to these settings. A systematic review of qualitative studies examining patient experiences of ROM/CF systems as part of psychological therapies within mental health settings found some benefits similar to those identified in this review, such as empowering patients to be more involved in their care, encouraging a collaborative practice by helping patients to set goals, track progress, reflect and become more self-aware [16]. However, that review also identified some negative perceptions that did not emerge in our review, such as suspicion towards service providers including concerns about confidentiality and fears that patients' PRO data could be used against them to limit or deny access to services [16]. Privacy concerns were reported in two studies included in our review [26, 31], with some patients expressing fear about whether insurance companies would have access to their data. However, as this concern only emerged in two studies it did not warrant inclusion as a major theme or subtheme in our review.

We acknowledge that our search strategy may also have missed other relevant papers. This arises due to different terminology heritages and conventions across disciplines, creating a complex problem for cross-disciplinary systematic reviews. Arguably this problem could be solved by identifying an exhaustive multidisciplinary set of terms for PROMs, but its use would likely retrieve thousands of abstracts to screen, a task which may not be feasible for many research teams due to resource constraints. Another limitation is that the methodological quality of included studies was highly variable. Several studies lacked detail about their methods which may affect the credibility of some findings. In addition, it was not possible to synthesise data by sample characteristics, either because patient and clinician characteristics were poorly reported or findings were not reported by sample characteristics in the original studies. This is a missed opportunity as it prevents gaining insight into specific patient and/or clinician characteristics that promote or hinder the use of PRO data in clinical decision-making. We also did not assess inter-rater consistency during screening and full text review but any discrepancies were discussed until consensus was reached. Finally, this review was also limited to full text articles published in English and may have excluded informative studies published in other languages and formats.

This review identified some critical gaps in evidence. Only one study reported on the experiences of ethnic

minorities [57] and few studies included patients with low socio-economic status or low literacy. As a result, the potential benefits and limitations of using PROMs in clinic is not well known from the perspective of these vulnerable patient groups. Further qualitative research is needed to gain insights into the unique experiences of these and other more socially disadvantaged patient groups to ensure future PROM initiatives are designed to be equitable and inclusive.

In sum, the present review identified many benefits but also highlighted several limitations of using PROMs in clinical practice from both patient and clinician perspectives. Although patients and clinicians agreed on many of the perceived benefits, several of the limitations such as concerns about the validity of existing PROMs, clinical relevance or added burden on job demands were only reported by clinicians. In order for PRO data to be useful and improve patient outcomes, it is essential that these limitations are addressed in the design and implementation of future PROM initiatives.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s11136-021-03003-z>.

Data availability Requests for access to qualitative data will be considered, and made available if deemed reasonable.

Code availability Requests for qualitative software coding will be considered, and made available if deemed reasonable.

Declarations

Conflict of interest The authors report no conflicts of interest.

References

- Agency for Clinical Innovation. (2019). Patient reported measures: Outcomes that matter to patients. Retrieved from <https://www.aci.health.nsw.gov.au/make-it-happen/prms>. Accessed Jan 11 2021
- NHS England. (2019). The National Patient Reported Outcome Measures (PROMs) Programme. Retrieved from <https://www.england.nhs.uk/wp-content/uploads/2018/08/proms-guide-aug-18-v3.pdf>. Accessed Jan 11 2021
- Mercieca-Bebber, R., King, M. T., Calvert, M. J., Stockler, M. R., & Friedlander, M. (2018). The importance of patient-reported outcomes in clinical trials and strategies for future optimization. *Patient Related Outcome Measures*, 9, 353–367.
- Øvretveit, J., Zubkoff, L., Nelson, E. C., Frampton, S., Knudsen, J. L., & Zimlichman, E. (2017). Using patient-reported outcome measurement to improve patient care. *International Journal for Quality in Health Care*, 29(6), 874–879.
- Gonçalves Bradley, D. C., Gibbons, C., Ricci-Cabello, I., Bobrovitz, N. J. H., Gibbons, E. J., Kotzeva, A., et al. (2015). Routine provision of information on patient-reported outcome measures to healthcare providers and patients in clinical practice. *Cochrane Database of Systematic Reviews*. <https://doi.org/10.1002/14651858.CD011589>
- Greenhalgh, J. (2009). The applications of PROs in clinical practice: What are they, do they work, and why? *Quality of Life Research*, 18(1), 115–123.
- Chen, J., Ou, L., & Hollis, S. J. (2013). A systematic review of the impact of routine collection of patient reported outcome measures on patients, providers and health organisations in an oncologic setting. *BMC Health Services Research*, 13, 211.
- Greenhalgh, J., & Meadows, K. (1999). The effectiveness of the use of patient-based measures of health in routine practice in improving the process and outcomes of patient care: A literature review. *Journal of Evaluation in Clinical Practice*, 5(4), 401–416.
- Valderas, J. M., Kotzeva, A., Espallargues, M., Guyatt, G., Ferrans, C. E., Halyard, M. Y., et al. (2008). The impact of measuring patient-reported outcomes in clinical practice: A systematic review of the literature. *Quality of Life Research*, 17(2), 179–193.
- Boyce, M. B., & Browne, J. P. (2013). Does providing feedback on patient-reported outcomes to healthcare professionals result in better outcomes for patients? A systematic review. *Quality of Life Research*, 22(9), 2265–2278.
- Ishaque, S., Karnon, J., Chen, G., Nair, R., & Salter, A. B. (2019). A systematic review of randomised controlled trials evaluating the use of patient-reported outcome measures (PROMs). *Quality of Life Research*, 28(3), 567–592.
- Boyce, M. B., Browne, J. P., & Greenhalgh, J. (2014). The experiences of professionals with using information from patient-reported outcome measures to improve the quality of healthcare: A systematic review of qualitative research. *BMJ Quality & Safety*, 23(6), 508–518.
- Antunes, B., Harding, R., & Higginson, I. J. (2014). Implementing patient-reported outcome measures in palliative care clinical practice: A systematic review of facilitators and barriers. *Palliative Medicine*, 28(2), 158–175.
- Lewis, C. C., Boyd, M., Puspitasari, A., Navarro, E., Howard, J., Kassab, H., et al. (2019). Implementing measurement-based care in behavioral health: A review. *JAMA Psychiatry*, 76(3), 324–335.
- Greenhalgh, J., Gooding, K., Gibbons, E., Dalkin, S., Wright, J., Valderas, J., et al. (2018). How do patient reported outcome measures (PROMs) support clinician-patient communication and patient care? A realist synthesis. *Journal of Patient-Reported Outcomes*, 2(1), 42.
- Solstad, S. M., Castonguay, L. G., & Moltu, C. (2019). Patients' experiences with routine outcome monitoring and clinical feedback systems: A systematic review and synthesis of qualitative empirical literature. *Psychotherapy Research*, 29(2), 157–170.
- Centre for Reviews and Dissemination (CRD). (2008). *Systematic reviews. CRD's guidance for undertaking reviews in health care*. CRD UoY.
- McDonagh, M., Peterson, K., Raina, P., Chang, S., & Shekelle, P. (2008). *AHRQ Methods for effective health care avoiding bias in selecting studies. Methods guide for effectiveness and comparative effectiveness reviews*. Agency for Healthcare Research and Quality (US).
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349–357.
- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8(1), 45.
- Deutscher, D., Hart, D. L., Dickstein, R., Horn, S. D., & Gutvirtz, M. (2008). Implementing an integrated electronic outcomes and electronic health record process to create a foundation for clinical practice improvement. *Physical Therapy*, 88(2), 270–285.
- Schick-Makaroff, K., & Molzahn, A. E. (2017). Evaluation of real-time use of electronic patient-reported outcome data by

- nurses with patients in home dialysis clinics. *BMC Health Services Research*, 17(1), 439.
23. Greenhalgh, J. (2005). An assessment of the feasibility and utility of the MS symptom and impact diary (MSSID). *Quality of Life Research*, 14(5), 1363–1374.
 24. Callaly, T., Hyland, M., Coombs, T., & Trauer, T. (2006). Routine outcome measurement in public mental health: Results of a clinician survey. *Australian Health Review*, 30(2), 164–173.
 25. Primdahl, J., Jensen, D. V., Meincke, R. H., Jensen, K. V., Ziegler, C., Nielsen, S. W., et al. (2020). Patients' views on routine collection of patient-reported outcomes in rheumatology outpatient care: A multicenter focus group study. *Arthritis Care and Research (Hoboken)*, 72(9), 1331–1338.
 26. McHorney, C. A., & Earl Bricker, D. (2002). A qualitative study of patients' and physicians' views about practice-based functional health assessment. *Medical Care*, 40(11), 1113–1125.
 27. Talib, T. L., DeChant, P., Kean, J., Monahan, P. O., Haggstrom, D. A., Stout, M. E., et al. (2018). A qualitative study of patients' perceptions of the utility of patient-reported outcome measures of symptoms in primary care clinics. *Quality of Life Research*, 27(12), 3157–3166.
 28. Neff, C., Wang, M. C., & Martel, H. (2018). Using the PDQ-39 in routine care for Parkinson's disease. *Parkinsonism & Related Disorders*, 53, 105–107.
 29. Dowrick, C., Leydon, G. M., McBride, A., Howe, A., Burgess, H., Clarke, P., et al. (2009). Patients' and doctors' views on depression severity questionnaires incentivised in UK quality and outcomes framework: qualitative study. *BMJ*, 338, b663.
 30. Eilander, M., de Wit, M., Rotteveel, J., Maas-van Schaaijk, N., Roeleveld-Versteegh, A., & Snoek, F. (2016). Implementation of quality of life monitoring in Dutch routine care of adolescents with type 1 diabetes: Appreciated but difficult. *Pediatric Diabetes*, 17(2), 112–119.
 31. Kettis-Lindblad, A., Ring, L., Widmark, E., Bendtsen, P., & Glimelius, B. (2007). Patients' and doctors' views of using the schedule for individual quality of life in clinical practice. *The Journal of Supportive Oncology*, 5(6), 281–287.
 32. Dronkers, E. A. C., de Jong, R. J. B., van der Poel, E. F., Sewnaik, A., & Offerman, M. P. J. (2020). Keys to successful implementation of routine symptom monitoring in head and neck oncology with "Healthcare Monitor" and patients' perspectives of quality of care. *Head & Neck*, 42(12), 3590–3600.
 33. Porter, I., Davey, A., Gangannagaripalli, J., Evans, J., Bramwell, C., Evans, P., et al. (2021). Integrating patient reported outcome measures (PROMs) into routine nurse-led primary care for patients with multimorbidity: A feasibility and acceptability study. *Health and Quality of Life Outcomes*, 19(1), 133.
 34. Tai, D., Li, E., Liu-Ambrose, T., Bansback, N., Sadatsafavi, M., & Davis, J. C. (2020). Patient-reported outcome measures (PROMs) to support adherence to falls prevention clinic recommendations: A qualitative study. *Patient Preference and Adherence*, 14, 2105–2121.
 35. Delgadillo, J., Overend, K., Lucock, M., Groom, M., Kirby, N., McMillan, D., et al. (2017). Improving the efficiency of psychological treatment using outcome feedback technology. *Behaviour Research and Therapy*, 99, 89–97.
 36. Krawczyk, M., & Sawatzky, R. (2018). Relational use of an electronic quality of life and practice support system in hospital palliative consult care: A pilot study. *Palliative Support Care*, 2018, 1–6.
 37. Mejdahl, C. T., Schougaard, L. M. V., Hjollund, N. H., Riiskjær, E., & Lomborg, K. (2018). Exploring organisational mechanisms in PRO-based follow-up in routine outpatient care—An interpretive description of the clinician perspective. *BMC Health Services Research*, 18(1), 546.
 38. Evans, J. M., Glazer, A., Lum, R., Heale, E., MacKinnon, M., Blake, P. G., et al. (2020). Implementing a patient-reported outcome measure for hemodialysis patients in routine clinical care: Perspectives of Patients and providers on ESAS-r:Renal. *Clinical Journal of the American Society of Nephrology*, 15(9), 1299–1309.
 39. Thestrup Hansen, S., Kjerholt, M., Friis Christensen, S., Brodersen, J., & Hølge-Hazelton, B. (2020). "I am sure that they use my PROM data for something important". A qualitative study about patients' experiences from a hematologic outpatient clinic. *Cancer Nursing*, 43(5), E273–E282.
 40. Monroe, A. K., Jabour, S. M., Peña, S., Keruly, J. C., Moore, R. D., Chander, G., et al. (2018). A qualitative study examining the benefits and challenges of incorporating patient-reported outcome substance use and mental health questionnaires into clinical practice to improve outcomes on the HIV care continuum. *BMC Health Services Research*, 18(1), 419.
 41. Thestrup Hansen, S., Kjerholt, M., Friis Christensen, S., Brodersen, J., & Hølge-Hazelton, B. (2021). Nurses' experiences when introducing patient-reported outcome measures in an outpatient clinic: An interpretive description study. *Cancer Nursing*, 44(2), E108–E120.
 42. Wheat, H., Horrell, J., Valderas, J. M., Close, J., Fosh, B., & Lloyd, H. (2018). Can practitioners use patient reported measures to enhance person centred coordinated care in practice? A qualitative study. *Health and Quality of Life Outcomes*, 16(1), 223.
 43. Unsworth, G., Cowie, H., & Green, A. (2012). Therapists' and clients' perceptions of routine outcome measurement in the NHS: A qualitative study. *Counselling and Psychotherapy Research*, 12(1), 71–80.
 44. Ahluwalia, S. C., Giannitrapani, K. F., Dobscha, S. K., Cromer, R., & Lorenz, K. A. (2018). "It encourages them to complain": A qualitative study of the unintended consequences of assessing patient-reported pain. *The Journal of Pain*, 19(5), 562–568.
 45. Hughes, R., Aspinall, F., Addington-Hall, J. M., Dunckley, M., Faull, C., & Higginson, I. (2004). It just didn't work: The realities of quality assessment in the English health care context. *International Journal of Nursing Studies*, 41(7), 705–712.
 46. Mark, T. L., Johnson, G., Fortner, B., & Ryan, K. (2008). The benefits and challenges of using computer-assisted symptom assessments in oncology clinics: Results of a qualitative assessment. *Technology in Cancer Research & Treatment*, 7(5), 401–406.
 47. Litchfield, I., Greenfield, S., Turner, G. M., Finnikin, S., & Calvert, M. J. (2021). Implementing PROMs in routine clinical care: A qualitative exploration of GP perspectives. *BJGP Open*. <https://doi.org/10.3399/bjgpopen20X101135>
 48. O'Connor, M., Tanner, P. B., Miller, L., Watts, K. J., & Musiello, T. (2017). Detecting distress: Introducing routine screening in a gynecologic cancer setting. *Clinical Journal of Oncology Nursing*, 21(1), 79–85.
 49. Schulman-Green, D., Cherlin, E. J., McCorkle, R., Carlson, M. D., Pace, K. B., Neigh, J., et al. (2010). Benefits and challenges in use of a standardized symptom assessment instrument in hospice. *Journal of Palliative Medicine*, 13(2), 155–159.
 50. Thestrup Hansen, S., Kjerholt, M., Friis Christensen, S., Hølge-Hazelton, B., & Brodersen, J. (2019). Haematologists' experiences implementing patient reported outcome measures (PROMs) in an outpatient clinic: A qualitative study for applied practice. *Journal of Patient-Reported Outcomes*, 3(1), 74.
 51. Cranley, L., & Doran, D. M. (2004). Nurses' integration of outcomes assessment data into practice. *Outcomes Management*, 8(1), 13–18.
 52. Korzeniowski, M., Kalyvas, M., Mahmud, A., Shenfield, C., Tong, C., Zaza, K., et al. (2016). Piloting prostate cancer patient-reported outcomes in clinical practice. *Supportive Care in Cancer*, 24(5), 1983–1990.

53. Locker, L. S., & Lübbe, A. S. (2015). Quality of life in palliative care: An analysis of quality-of-life assessment. *Progress in Palliative Care*, 23(4), 208–219.
54. Meehan, T., McCombes, S., Hatzipetrou, L., & Catchpoole, R. (2006). Introduction of routine outcome measures: Staff reactions and issues for consideration. *Journal of Psychiatric and Mental Health Nursing*, 13(5), 581–587.
55. Mason, L., & Poole, H. (2008). Healthcare professionals' views of screening for postnatal depression. *Community Practitioner*, 81(4), 30–33.
56. Bouvette, M., Fothergill-Bourbonnais, F., & Perreault, A. (2002). Implementation of the pain and symptom assessment record (PSAR). *Journal of Advanced Nursing*, 40(6), 685–700.
57. Scholle, S. H., Morton, S., Homco, J., Rodriguez, K., Anderson, D., Hahn, E., et al. (2018). Implementation of the PROMIS-29 in routine care for people with diabetes: Challenges and Opportunities. *Journal of Ambulatory Care Management*, 41(4), 274–287.
58. Schwartz, C. E., Merriman, M. P., Reed, G., & Byock, I. (2005). Evaluation of the Missoula-VITAS quality of life index—revised: Research tool or clinical tool? *Journal of Palliative Medicine*, 8(1), 121–135.
59. Baker, K. M., DeSanto-Madeya, S., & Banzett, R. B. (2017). Routine dyspnea assessment and documentation: Nurses' experience yields wide acceptance. *BMC Nursing*, 16(1), 3.
60. Baker, K. M., Vragovic, N. S., & Banzett, R. B. (2020). Intensive care nurses' perceptions of routine dyspnea assessment. *American Journal of Critical Care*, 29(2), 132–139.
61. Bendtsen, P., Leijon, M., Sofie Sommer, A., & Kristenson, M. (2003). Measuring health-related quality of life in patients with chronic obstructive pulmonary disease in a routine hospital setting: Feasibility and perceived value. *Health and Quality of Life Outcomes*, 1, 5.
62. Schmidt, H., Merkel, D., Koehler, M., Flechtner, H. H., Sigle, J., Klinge, B., et al. (2016). PRO-ONKO-selection of patient-reported outcome assessments for the clinical use in cancer patients—A mixed-method multicenter cross-sectional exploratory study. *Supportive Care in Cancer*, 24(6), 2503–2512.
63. Ryan, C. M., Lee, A. F., Kazis, L. E., Shapiro, G. D., Schneider, J. C., Goverman, J., et al. (2016). Is real-time feedback of burn-specific patient-reported outcome measures in clinical settings practical and useful? A pilot study implementing the young adult burn outcome questionnaire. *Journal of Burn Care & Research*, 37(1), 64–74.
64. Mitchell, C., Dwyer, R., Hagan, T., & Mathers, N. (2011). Impact of the QOF and the NICE guideline in the diagnosis and management of depression: A qualitative study. *British Journal of General Practice*, 61(586), e279–e289.
65. Colquhoun, H., Letts, L., Law, M., MacDermid, J., & Edwards, M. (2010). Feasibility of the Canadian occupational performance measure for routine use. *British Journal of Occupational Therapy*, 73(2), 48–54.
66. Snyder, C. F., Aaronson, N. K., Choucair, A. K., Elliott, T. E., Greenhalgh, J., Halyard, M. Y., et al. (2012). Implementing patient-reported outcomes assessment in clinical practice: A review of the options and considerations. *Quality of Life Research*, 21(8), 1305–1314.

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.