

#### The implementation, use and impact of patient reported outcome measures in value-based healthcare programmes: A scoping review

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The implementation, use and impact of patient reported outcome measures in value-based
healthcare programmes: A scoping review
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#### 27

#### 28 Abstract

#### 29 Background

Value-Based Healthcare (VBHC) focuses on the value of patient outcomes and is achieved by ensuring resources already available are managed to realise the best possible individual and population health outcomes. Patient reported outcome measures (PROMs) measure the impact of illnesses from the patient perspective. We conducted a scoping review to understand how PROMs were implemented and used, and their impact in the context of VBHC.

#### 36 Methods

Arksey and O'Malley's overarching framework supplemented by principles from mixed-methods Framework Synthesis were used. CINAHL, Cochrane Library, EMBASE, MEDLINE, PsycINFO, Web of Science, Google Scholar and reference lists were searched. An a priori data extraction framework was created using the review question and objectives as key domains against which to extract data. Mixed-methods data were organised, integrated and preserved in original format and reported for each domain.

#### 43 **Results**

Forty-three studies were included with 60,200 participants. Few studies reported a welldeveloped programme theory and we found little robust evidence of effect. PROMs were universally considered to have the potential to increase patient satisfaction with treatment and services, enhance patient awareness of symptoms and self-management, and improve health



outcomes such as quality of life and global health status. Evidence is currently limited on how
PROMs work and how best to optimally implement PROMs to achieve the target outcome.
Implementation challenges commonly prevented the realisation of optimal outcomes and
patients generally needed better and clearer communication about why PROMs were being
given and how they could optimally be used to support their own self-management.

#### 53 Conclusion

54 PROMSs have yet to demonstrate their full potential in a VBHC context. Optimal 55 PROMs implementation is poorly understood by clinicians and patients. Future studies should 56 explore different models of PROM implementation and use within VBHC programmes to 57 understand what works best and why for each specific context, condition, and population.

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#### 59 Keywords

Value-Based Healthcare, Patient Reported Outcome Measures, PROMs, VBHC, scoping
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#### 68 Introduction

69 Value-Based Healthcare (VBHC) is a delivery model with the overarching goal of 70 maximising value for patients and healthcare providers [1]. VBHC is achieved through the 71 equitable, sustainable, and efficient use of resources to achieve better outcomes for every 72 patient [1,2]. With growing demand being placed on finite health resources, the concept of 73 VBHC has become increasingly important [2–4].

74 VBHC models are focused on patient-centred care, using outcomes that matter most to patients rather than relying solely on clinical measures [5,6]. Such metrics include mental and 75 social functioning, health-related quality of life, disease symptoms and patient views on their 76 health. Patient-reported outcome measures (PROMs) are a set of questions that seek to 77 comprehensively capture these important metrics and are commonly used in research contexts 78 79 [7]. PROMs are implemented within a VBHC setting with the aim of enabling healthcare providers to understand what matters most to patients, to better monitor, detect and if necessary, 80 81 act-upon patient symptoms, and to facilitate shared patient-clinician decision making [7]. From the patient perspective, the aim of PROMs is to improve quality of care and health outcomes, 82 improve patient understanding of their health, and promote active patient engagement with 83 84 their own self-care and management [7].

PROMs have been established in healthcare for over a decade and are often an essential component in the delivery of person-centred care. However, there is a dearth of evidence on how to implement and use PROMs within a VBHC setting to maximise value for patients and health providers. Additionally, whether PROMs are effective in improving patient and health systems outcomes is also unclear. Addressing these questions is essential to help inform current and future PROMs interventions within a VBHC setting. Therefore, the aim of this scoping



91 review was to identify and describe studies on the implementation, use and effectiveness of

92 PROMs as part of a VBHC programme or a similar routine practice context.

93

### 94 Material and methods

95 The methodology was guided by Arksey and O'Malley's [8] five stage framework for96 scoping reviews:

- Stage 1: identifying the research question (i.e., defining the scope and review protocol)
- Stage 2: identifying relevant studies
- Stage 3: study selection
- Stage 4: charting the data
- Stage 5: collating, summarizing, and reporting the results
- 102

To manage and interpret a wide range of study designs, we incorporated principles of mixed-methods framework synthesis to extract, map, chart, categorise and aggregate study findings [9]. An a priori protocol was developed. In line with scoping review methodology, the level of synthesis was low with the output largely descriptive.

#### 107 Identifying the research question

108 A Setting, Perspective, Intervention/Phenomenon of Interest, Comparator, Evaluation
109 (SPICE) framework was followed to structure the research question, objectives, and subsequent
110 search strategy [10], as follows:

111

Setting: High income countries with similar health systems to the UK NHS. Primarily hospitalbased VBHC programmes that used PROMS.

115	Perspectives: Patients, carers, implementers, service providers, healthcare professionals, other				
116	key stakeholders. Any patient group or condition. In addition, we specifically looked at four				
117	diverse tracer services in greater depth:				
118	- A surgical intervention (cataract surgery),				
119	- A chronic disease with a large cohort of young adults (epilepsy),				
120	- A chronic disease affecting a predominantly elderly and sometimes frail cohort				
121	(Parkinson's disease), and				
122	- A long-term chronic condition that is most common in older people but can affect				
123	people at any age (heart failure).				
124					
125	Intervention/phenomena of interest:				
126	1. What PROMs are used and what evidence is there that PROMs work?				
127	2. How are PROMs used by patients, professionals, carers, the health service,				
128	and stakeholders?				
129	3. How are PROMs intended to work to bring about specific outcomes?				
130	4. How are PROMS implemented in four specific tracer conditions (cataract				
131	surgery, epilepsy, heart failure, Parkinson's disease)?				
132	5. What are the factors that create barriers and facilitators to PROMs				
133	implementation?				
134	6. What (if any) are the unintended consequences of PROMs?				
135	7. What are the experiences of patients and carers in using PROMs?				
136	8. Are there differences in experiences or demographics across different				
137	services?				

138	9. How are PROMs used with people (including family members and carers)
139	with multiple co-morbid conditions?
140	10. Do PROMs raise any equity issues?
141	11. Are PROMs sustainable?
142	12. How translatable is this evidence?
143	13. What is the economic cost of developing or implementing PROMs
144	programmes?
145	Comparison: Differences in experiences, perspectives and outcomes between groups and

146 different ages, conditions, groups, contexts, ethnicity etc.

147 **Evaluation:** Scoping review to aggregate, describe and understand the evidence.

### 148 Identifying relevant studies

The search protocol was developed and refined with the help of an expert librarian using 149 a rigorous iterative process. Pilot searches were conducted to refine the search terms and assess 150 the feasibility of the initial criteria. A systematic search for published studies was carried out 151 in August to November 2022. The primary searches were conducted in CINAHL, Cochrane 152 Library, EMBASE, MEDLINE, PsycINFO and Web of Science, and included relevant studies 153 154 found via key word searches on Google Scholar. We also searched the VHBC study repository at a local health organisation. In addition, a non-comprehensive 3-word search targeting 155 specific conditions was performed independently by two authors (MSB, EC), and each author 156 157 used two different databases (PubMed and Google Scholar). The reference lists of all the identified systematic reviews were screened, with all potentially eligible studies subsequently 158 159 assessed independently by two authors (MSB, EC) against the inclusion criteria.



160 The search was not designed to be exhaustive and was conducted iteratively in 161 accordance with scoping review guidance [11]. A pilot search was performed to refine the 162 Medical Subject Headlines (MeSH) terms and Boolean phrasing with the help of an experience 163 librarian. The final search terms were inserted as keywords into all 9 databases were:

164

PROMS AND Patient Reported Outcome Measures AND VBHC AND Value Based HealthCare AND Implementation Evaluation

#### 167 Study selection

We imported all searches to Mendeley (Elsevier, Amsterdam, Netherlands) for screening. Titles and abstracts of identified articles were screened by two people (EW, BC) independently to determine eligibility for inclusion. We included studies investigating the implementation, use, and impact of PROMs applied within the context of VBHC (i.e., the use of PROMs in healthcare to focus on outcomes that are important for patients, and/or used to increase value for patients and healthcare providers) (Table 1).

#### 174 **Table 1.** Inclusion and exclusion criteria

Inclusion	Exclusion
Full text peer-reviewed studies or grey	Abstracts or no full text available
literature	
Studies in the English language, unless a	Studies not available in English
translation is readily available	
PROMs used in a Value-Based Health Care,	Psychometric studies involving the development,
implementation study, service improvement	validation, or reliability of PROMs
or service evaluation setting.	
Studies in adult populations (>18 years)	Studies with children
Published after 2010 onwards	Studies published prior to 2010



Any methodology or design	Non-human or animal studies
Any clinical condition	

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176	Full texts were retrieved and assessed independently by two authors (EW, MSB, BN,
177	EC) against the eligibility criteria. Papers not meeting the inclusion criteria were excluded and
178	the reasons for exclusion noted. Any disagreement between screeners was resolved by a third
179	person until a consensus was reached.

#### 180 Charting the data

All papers were uploaded as PDF files and managed in Mendeley. A data extraction form which served as the a priori framework was developed using the phenomena of interest as key headings.

#### 184 Collating, summarizing, and reporting the results

An a priori data extraction framework was created using the review question and objectives 185 as key domains against which to extract data. Using a process of familiarisation, studies were 186 first marked up with notes and memos and key text of interest highlighted and then extracted 187 into the a priori framework on an excel spreadsheet (S1 Table). Supplementary information for 188 each study was obtained where available and when necessary primary study authors were 189 190 consulted to obtain or confirm data. Having extracted all data of interest into the framework, mapping and charting was undertaken to visualise and interpret each element of 191 interest. PROMs were first viewed as a cross-disciplinary general intervention. Mixed-methods 192 data were organised, integrated and preserved in original format and reported for each domain 193 in the a priori framework that corresponded to the review question and objectives. Then 194



evidence was sought and configured on PROMs specifically for the four tracer
conditions. Through this process we developed descriptive level findings and explanations.
Findings were shared and discussed with a wider group of researchers and discussed with key
stakeholders. The review was reported using the relevant domains of the Preferred Reporting
items for Systematic Review and Meta-Analysis for scoping reviews (PRISMA-ScR) (S2
Table) [12].

#### 201 **Quality assessment**

All included studies were independently appraised by two reviewers (AJ, BN, EC, GR, JN, LM, MSB) using the Quality Assessment for Diverse Studies (QuADS) tool [13]. The tool was designed to appraise mixed or multi-methods studies in complex systematic reviews in health services research. The QuADS tool [12] is reported to demonstrate strong inter-rater reliability (k=0.66), and substantial content validity, and is composed of 13 domains [12]. Two reviewers (EC & MSB) piloted the tool on five studies encompassing different designs prior to assessment.

The checklist usually includes a final score for quality assessment, which we did not 209 calculate. This is because total quality scores are considered unhelpful as the domains assessed 210 do not impact equally on the quality of the study. What is more important is the identification 211 212 of methodological limitations in primary studies and how these limitations may impact on the interpretation of findings [14]. We used the checklist to assess the level of methodological 213 concerns rather than calculate a total quality numeric score. All studies were appraised 214 according to the level of methodological concern: 'no/minor', 'moderate', 'serious', or 'very 215 serious' concerns. Studies were not excluded based on their methodological limitations, but 216 findings from studies with serious and very serious methodological concerns were interpreted 217

with caution. All disagreements were discussed and resolved, and a third review author wasconsulted when necessary. All assessments were transparently recorded using Microsoft Excel.

#### 220 Stakeholder engagement

Stakeholders with experience using PROMs as health care professionals or working 221 with relevant health conditions, staff working in relevant third sector organisations and 222 established stakeholder and patient advocacy groups were invited to participate in engagement 223 sessions (i.e., St. David's Hospice Care, British Heart Foundation, Digital Wales, Epilepsy 224 Action, Digital Communities Wales, Parkinson's UK Cymry, Race Equality First, Aneurin 225 Bevan Community Health Council and VBHC Patient Reference Group). Engagement sessions 226 with stakeholders were planned strategically and the discussions were tailored for each group 227 according to their background and lived experience. Stakeholder input was primarily used to 228 provide context and inform the interpretation of findings and help identify gaps in evidence. 229 230 For example, stakeholder engagement helped with the interpretation of facilitation and barriers factors for PROM implementation, disease-specific aspects of PROMs and digital literary and 231 issues related to equality, inclusion and diversity. 232

#### 233 **Results**

Forty-three studies were included in total. Among these, 39 studies reported a total of 60,200 participants aged between 18 to 103 years; and 31 studies reported that 56.8% of participants were female (n = 18,845) (Fig 1. and S3 Table). Included studies investigated various PROMs interventions, across 13 countries, and across a wide range of conditions (Table 2). Twentyfour studies specified investigating the use of PROMs specifically in a VBHC program [15– 38], while the other 19 studies [39–56], investigated aspects of PROMs implementation in

240	routine practice that were relevant to our research questions (language barriers, multiple
241	comorbidities, tracer conditions etc.).
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244	Fig 1. PRISMA flow-chart.
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Health Condition / Topic	Author & year	PROMs used	PROM delivery method	Response rates [%]
Asthma $(n = 4)$	Peters et al (2013)	Generic:	Paper questionnaire	30.0%
	Peters et al (2014)	• EuroQoL EQ-5D		
	Peters et al & Croker et al	Disease specific:		
	(2014)	• Mini Asthma Quality of Life Questionnaire (mini- AQOL)		
	Porter et al (2021)	Generic:	Delivered in general	100%
		<ul><li>EuroQoL EQ-5D</li><li>Patient Generated Index (PGI)</li></ul>	practice. Specific method not provided	
		Disease specific:		
		• Mini Asthma Quality of Life Questionnaire (mini- AQOL)		
Cancer $(n = 8)$	Ashley et al (2013)	Illness Perception Questionnaire-Revised EuroQol-5D, Version 2	Digitally	55.21% overall, 61.4% face-to-face, 48.8%
		Medical Outcomes Study 36-Item Short-Form Health Survey, Version 2		over the phone, 41% via letter
		Social Difficulties Inventory		
		European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire		
		Quality of Life in Adult Cancer Survivors Scale		
	Basch et al (2016)	PROM questionnaire adapted from the National Cancer Institute's Common Terminology Criteria for Adverse Events regarding 12 common symptoms reported during chemotherapy	Digitally	73%
	Demedts et al (2021)	EORTC Core Quality of Life questionnaire (EORTC QLQ- C30)	Digitally	92%

**Table 2**. Patient Reported Outcome Measures [PROMs] per condition and response rates [n= 39 studies]



	EORTC QLQ-LC13: A 13-item lung cancer-specific questionnaire		
Nguyen et al (2019)	The European Organisation for Research and Treatment of Cancer Quality of Life questionnaire (EORTC QLQ-C30)	Paper questionnaire	100% at baseline, 93.8% during therapy, 100% at the end of therapy and 100, 85.7, 83.3 and 66.7% every 3 months until 1 year after therapy, respectively
Schuler et al (2017)	EuroQoL EQ-5D The European Organisation for Research and Treatment of Cancer Quality of Life questionnaire (EORTC QLQ-C30)	Digitally	34.2% at admission and 17.3% at discharge
van Egdom et al (2019)	The European Organisation for Research and Treatment of Cancer Quality of Life questionnaire (EORTC QLQ-C30) The European Organisation for Research and Treatment of Cancer Quality of Life for Breast Cancer (EORTC-QLQ B23) BREAST-Q pre-operative and post-operative modules EQ-5D-5L Distress Thermometer The Reproductive Concerns Scale (RCS-NL) The CarerQoL-7D	Paper questionnaires	83.3% at baseline, 65.7% at 6 months and 55.1% at 12 months
Wheelock et al (2015)	Short Form Health Survey (SF-36) Personal Health Questionnaire Depression Scale (PHQ-8) Symptom questions modified from the Memorial Symptom Assessment Scale	Digital	Not reported
Devlin et al (2010)	EuroQoL EQ-5D	Paper questionnaire	Not reported



Cataract Surgery (n = 7 studies)		The Visual Focus Index 14 (VF-14)		
	Fung et al (2016)	EuroQoL EQ-5D EQ-VAS visual analogue scale National Eye Institute Socioemotional Scale (NEI-SES) The Short-form Visual Function Index (VF-8R)	Paper questionnaire delivered by post	67.2% at 3 weeks after surgery, 61.8% at 3 months after surgery. 30% non-response rate
	Queir <mark>ó</mark> s et al (2021)	CATQUEST-9SF	Paper questionnaire in clinic	Not reported
	Sparrow et al (2018)	CATQUEST-9SF CAT-PROM5	Not reported	Not reported
	Sparrow et al (2020)	CAT-PROM5	Digitally	94.3% at pre-operative time point and 36.4% post-operative
	Tognetto et al (2021)	CATQUEST-9SF	Not provided	Not reported
	Zijlmans et al (2021)	CATQUEST-9SF	Not provided	Not reported
Chronic Obstructive Pulmonary Disease (COPD) (n = 4)	Peters et al (2013) Peters et al (2014) Peters et al & Croker et al (2014)	<ul> <li>Generic:</li> <li>EuroQoL EQ-5D</li> <li>Disease specific:</li> <li>Clinical COPD questionnaire (CCQ)</li> </ul>	Paper questionnaire delivered by post	49.2%
	Porter et al (2021)	<ul> <li>Generic:</li> <li>EuroQoL EQ-5D</li> <li>Patient Generated Index (PGI)</li> <li>Disease specific:</li> <li>Clinical COPD Questionnaire (CCQ)</li> <li>MRC breathlessness scale</li> </ul>	Delivered in general practice. Specific method not provided	100%



Diabetes (n = 5 studies)	Peters et al (2013) Peters et al (2014) Peters et al & Croker et al (2014)	<ul> <li>Generic:</li> <li>EuroQoL EQ-5D</li> <li>Disease specific:</li> <li>The Diabetes Health Profile (DHP)</li> </ul>	Paper questionnaire delivered by post	40%
	Porter et al (2021)	<ul> <li>Generic:</li> <li>EuroQoL EQ-5D</li> <li>Patient Generated Index (PGI)</li> <li>Disease specific:</li> <li>The Diabetes Health Profile (DHP)</li> </ul>	Delivered in general practice. Specific method not provided	100%
Epilepsy (n = 8 studies)	Clary et al (2022)	QOLIE-10 Generalized Anxiety Disorder (GAD-7) scale Neurological Disorders Depression Inventory for Epilepsy (NDDI-E)	Telephone or online via electronic health records portal	66.7% for 6 months for patients using electronic health record and 100% for telephone PROMs collection
	Moura & Magliocco et al (2016)	Patient-Reported Outcome Measurement Information System–10 (PROMIS-10) Quality of Life in Epilepsy ii Inventory (QOLIE-31)	Digitally in clinic	49.3%
	Moura & Schwamm et al (2019)	Newly developed questionnaire for medication adherence & side-effects, seizure frequency, and driving. This questionnaire included the Patient-Reported Outcome Measurement Information System–10 (PROMIS-10) measure	Digitally in clinic	44.8% at epilepsy clinic. Response rates were 12.3%, 51.1%, and 36.6 for the first, second, and third months of data collection, respectively
	Peters et al (2013)	Generic:	Paper questionnaire delivered by post	34%
	Peters et al (2014)	• EuroQoL EQ-5D		
	Peters & Croker et al (2014)	<ul><li>Disease specific:</li><li>Quality of Life in Epilepsy ii Inventory (QOLIE-31)</li></ul>		



	Sajobi et al (2021)	Quality of Life in Epilepsy (QOLIE10-P) measure. Epilepsy Comorbidity Index (for depression and anxiety)	Not provided	Prospective data from the Calgary Comprehensive Epilepsy Program
Heart Failure (n = 7 studies)	Kane et al & Daveson (2017) Kane & Ellis-smith et al et al (2017)	Kansas City Cardiomyopathy Questionnaire (KCCQ) Patient Health Questionnaire-8 (PHQ-8) A quality-of-life visual analogue scale	Telephone questionnaire	66%
	Pennucci et al (2020)	Kansas City Cardiomyopathy Questionnaire-12 (KCCQ-12) Self-Care Heart Failure Index (SCHFI) (Italian translation)	Questionnaire by phone or email	64% at baseline, 61% at 1 month, 49% at 7 months and 31% at 12 months. Response rate was higher when patients gave only a caregiver contact (80% vs 64.2%)
	Peters et al (2013) Peters et al (2014) Peters et al & Croker (2014)	<ul> <li>Generic:</li> <li>EuroQoL EQ-5D</li> <li>Disease specific:</li> <li>Minnesota Living with Heart Failure Questionnaire (MLHFQ)</li> </ul>	Paper questionnaire delivered by post	50%
	Porter et al (2021)	<ul> <li>Generic:</li> <li>EuroQoL EQ-5D</li> <li>Patient Generated Index (PGI)</li> <li>Disease specific:</li> <li>Minnesota Living with Heart Failure Questionnaire (MLHFQ)</li> </ul>	Delivered in general practice. Specific method not provided	100%
	Bernstein et al (2019)	The Patient-Reported Outcomes Measurement Information System (PROMIS) questionnaire including items on physical function, pain interference, and depression	Digitally in-clinic	Not reported



Orthopaedic Conditions (n = 5 studies)	Devlin et al (2010)	EuroQoL EQ-5D Oxford Knee Score (for knee replacements) Oxford Hip Score (for hip replacements) Short form heath survey (for hip replacements)	Paper questionnaire	92% for hip replacement
	Liu et al (2018)	PROMIS Global Health measure Hip Disability and Osteoarthritis Outcome Score Knee Injury and Osteoarthritis Outcome Score	In person paper questionnaire	Not reported
	Malhotra et al (2016)	EuroQoL EQ-5D EQ-VAS visual analogue scale	Digital	85.9%
	Papuga et al (2017)	<ul> <li>PROMIS computer adaptive test (CAT) instruments:</li> <li>Physical function</li> <li>Pain interference</li> <li>Depression</li> </ul>	Digitally	Not reported
	Porter et al (2021)	<ul> <li>Generic:</li> <li>EuroQoL EQ-5D</li> <li>Patient Generated Index (PGI)</li> <li>Disease specific:</li> <li>Oxford Hip Score (for knee replacements)</li> <li>Oxford Knee Score (for knee replacements)</li> </ul>	Delivered in general practice. Specific method not provided	100%
Stroke (n = 5 studies)	Groeneveld et al (2019)	EuroQoL EQ-5D Stroke Impact Scale (SIS) Stroke and Aphasia Quality of Life Scale (SAQOL-39NL) HADS Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-P) Fatigue Severity Scale (FSS)	Paper or digital	60% response rates for inpatients and 43.3% response rates for outpatients
	Oemrawsingh et al (2019)	EuroQoL EQ-5D	Telephone or in person interviews	Prospective data



	Peters et al (2013)	Generic:	Paper questionnaire	36.4%
	Peters et al (2014)	• EuroQoL EQ-5D	delivered by post	
	Peters et al & Croker (2014)	Disease specific:		
		• Stroke Impact Scale (SIS)		
Varicose vein surgery	Devlin et al (2010)	EuroQoL EQ-5D	Paper questionnaire	75%
Groin hernia repair		Short form heath survey (SF-36) (for groin hernia repair)		
		Aberdeen Varicose Vein Symptom Severity questionnaire (for varicose vein surgery)		
Bariatric surgery	Goretti et al (2020)	Bariatric Analysis and Reporting Outcome System (BAROS)	In person interview	82% response rate at
		Questionnaire for physical activity, work capability, dressing, and sexual activity	by clinicians	calls), and 83.4% seven days and 1-year follow- up after surgery
Pregnancy & childbirth	Laureij et al (2020)	Patient-Reported Outcome Measurement Information System–10 (PROMIS-10) to track perceived quality of life.	Digitally	39%
		Depression during pregnancy or postpartum, screened with Patient Health Questionnaire-2 (PHQ-2)		
		Breastfeeding Self-Efficacy Scale-Short Form (BSES-SF)		
		International Consultation on Incontinence Questionnaire- Short Form (ICIQ-SF) or PROMIS SFFAC102 to measure incontinence and pain with intercourse		
		Mother-Infant Bonding Scale (MIBS)		
		Birth Satisfaction Scale-Revised (BBS-R)		
Advanced chronic kidney disease (CKD)	van der Willik et al (2019)	PROMs questionnaire developed for chronic kidney disease (CKD) symptoms	Digitally	Not reported
Implementation of PROMs tool for wide range of conditions	O'Connell et al (2018)	<ul> <li>Developed generic PROM tool with three components:</li> <li>The EQ-5D-5L questionnaire</li> <li>The Work Productivity and Activity Impairment (WPAI) tool</li> </ul>	Digitally	Not reported



	• 'About You' questions on height, weight smoking history, exercise levels, alcohol consumption and medically diagnosed comorbidities		
Rutherford et al (2021)	Patient-Reported Outcome Measurement Information System–10 (PROMIS-10) Depression Anxiety Stress Scales (DASS21) (only available at specific sites) Chronic obstructive pulmonary disease Assessment Test	Digitally	69% at baseline and 55.6% at follow-up
	(CAT) (only available at specific sites)		



#### 250 Methodological strengths and limitations of included studies

The majority of included studies were judged to have no or minor methodological 251 concerns 79% (n=33), followed by 14% (n=6) moderate methodological concerns and 7% 252 (n=3) serious methodological concerns. No study was judged to have very serious 253 methodological concerns (S4 Table). For most studies, methodological concerns were due to a 254 lack of reporting rather than methodological limitations. For example, the lack of recruitment 255 information was the second most common limitation encountered. The main limitation 256 encountered was the absence of stakeholder involvement in research design or conduct. Data 257 collection and analysis were mostly well designed and conducted across the studies. 258

# 259 Factors that created barriers and facilitators to optimal 260 implementation

Thirty-one studies described factors that created barriers and facilitators to PROMs implementation. Many of the factors described were bi-directional, acting as either facilitators or barriers depending on the context and whether the factor was present or not. We identified four groups of factors in the implementation of PROMs (Table 3). These groups included digital and technology factors, factors associated with patients and carers, factors associated with healthcare staff and stakeholders, and structural & organisational factors.

267

268	Table 3. Factors that cre	ated barriers and	facilitators at different	stages of PROMs i	mplementation
				0	

	Preparation for implementation	Implementation in practice	Sustainability in the long term
Digital and technology factors	Electronic PROM systems that are integrated with patient medical records* [15,18,22,26,29,30,34,35,37– 40,49,53]	Reliable internet [18,34,35,37,38] Electronic PROMs systems that are integrated with patient medical records <sup>*</sup>	Reliable internet [18,34,35,37,38]. Electronic PROMs systems that are integrated with patient medical records*

	IT support staff <sup>#</sup> [18,34,35,37,38] Costs for software and digital	[15,18,22,26,29,30,34,35,37– 40,49,53]	[15,18,22,26,29,30,34,35,37– 40,49,53]
	equipment such as tablets, computers, software etc <sup>4</sup> [24,39,49]	Accessible and well-functioning digital systems that require limited effort from clinical staff with data collection, analysis, and reporting <sup>*</sup> [15,22,29,34,38,39,49] Automated PROMs pathways <sup>*</sup> [18,38,42,49] IT support staff <sup>#</sup>	Accessible and well-functioning digital systems that require limited effort from clinical staff with data collection, analysis, and reporting* [15,22,29,34,38,39,49] Automated PROMs pathways* [18,38,42,49] IT support staff <sup>#</sup> [18,34,35,37,38]
		[18,34,35,37,38]	
Factors associated with patients &	Planning for dedicated time to complete PROMs for patients <sup>#</sup> [15,34,39,46]	Providing dedicated time to complete PROMs for patients <sup>#</sup> [15,34,39,46]	Providing dedicated time to complete PROMs for patients <sup>#</sup> [15,34,39,46]
carers	<ul> <li>Planning for hybrid delivery [digital / paper PROM] to allow for patient preference and requirements, and to improve retention<sup>#</sup> [8,12,24,27,28]</li> <li>Planning provisions for patient with poor language proficiency in the main healthcare language, particularly in multicultural locations<sup>#</sup> [22,34,39,49]</li> <li>Carefully developing PROM content with stakeholder engagement to ensure it is acceptable and feasible to target population i.e., not too long, well explained, understandable, captures what is important<sup>#</sup> [15,30,34,46,50]</li> </ul>	Length and difficulty to complete PROMs <sup>®</sup> [15,30,34,46,50] Caregivers helped patients with language, technology, or physical/mental impairment barriers, resulting in improved accessibility of PROMs to often excluded groups] <sup>#</sup> [4,11,13,16– 20,26] Patient not understanding the content of the PROMs questions or becoming upset over being confronted by their condition <sup>®</sup> [6,8,15] Poor patient understanding about what PROMs are and how they are used in their healthcare <sup>9</sup> Clear communication about PROMS with patients and carers is very important <sup>#</sup> [15,30,34,37,46] Digital literacy, particularly for patients with cognitive impairments <sup>®</sup> [18,34,37,41,46,50] Hybrid delivery [digital / paper PROM] to allow for patient preference and requirements, and to improve retention <sup>#</sup> [8,12,24,27,28] Digital literacy <sup>®</sup> [18,21,34,37,41,52]] Reminders to complete PROMs <sup>#</sup>	Caregivers helped patients with language, technology, or physical/mental impairment barriers, resulting in improved accessibility of PROMs to often excluded groups <sup>#</sup> [4,11,13,16– 20,26]] Patient understanding about what PROMs are and how they are used in their healthcare <sup>1</sup> Clear communication about PROMS with patients and carers is very important <sup>#</sup> [15,30,34,37,46] Digital literacy, particularly for patients with cognitive impairments <sup>1</sup> [18,34,37,41,46,50]. Hybrid delivery [digital / paper PROM] to allow for patient preference and requirements, and to improve retention <sup>#</sup> [8,12,24,27,28]. Poor language proficiency in the main healthcare language <sup>1</sup> [22,34,39,49] Reminders to complete PROMs <sup>#</sup> [29,38,59] Digital literacy <sup>1</sup> [18,21,34,37,41,52] Physical and mental health impairments <sup>4</sup> [25,29,46]
		[29,38,59]	



Factors associated with healthcare staff & stakeholders	Leadership and staff resistance <sup>1</sup> [30,34,35,39] Management of staff capacity and responsibility in relation to the additional clinical burden of PROMs <sup>*</sup> [6,8,15,24,27,30,33] Provision of dedicated PROMs support staff <sup>#</sup> [8,12,17] Staff motivation, engagement and ownership in implementation and delivery of PROMs <sup>*</sup> [22,30,34,35,37,44,60] Staff training and support for clinicians and staff. This is essential in ensuring PROMs are implemented as intended and that staff understand the purpose of PROMs, helping to consolidate engagement. It also provides space for staff to voice concerns and find collaborative solutions <sup>*</sup> [17,27–29,34,35,38,49,53,60,61]	Physical and mental health impairments <sup>®</sup> [25,29,46] Poor language proficiency in the main healthcare language <sup>®</sup> [22,34,39,49] Leadership and staff resistance <sup>®</sup> [30,34,35,39] Management of staff capacity and responsibility in relation to the additional clinical burden of PROMs <sup>*</sup> [6,8,15,24,27,30,33] Provision of dedicated PROMs support staff <sup>#</sup> [8,12,17] Disruption to clinical flow <sup>®</sup> [27,30,34] Ongoing staff training and support for clinicians and staff <sup>*</sup> [17,27– 29,34,35,38,49,53,60,61] Staff motivation, engagement, and ownership in delivery of PROMs <sup>#</sup> [22,30,34,35,37,44,60]	Leadership and staff resistance <sup>4</sup> [30,34,35,39] Staff ownership, teamwork, and collaboration <sup>*</sup> [22,30,34,35,37,44,60] Staff understanding of PROMs <sup>*</sup> Provision of dedicated PROMs support staff <sup>#</sup> [8,12,17] Administrative assistance for clinical staff <sup>#</sup> Ongoing staff training and support for clinicians and staff <sup>*</sup> [17,27– 29,34,35,38,49,53,60,61] Staff motivation, engagement, and ownership in delivery of PROMs <sup>#</sup> [22,30,34,35,37,44,60] Disruption to clinical flow <sup>4</sup> [27,30,34]
Structural and organisational factors	System wide institutional support [managerial, IT, financial] <sup>*</sup> [24,38,39,49] Well thought through planning, incorporating engagement with key stakeholders at all stages <sup>#</sup> [24,29,34,42,52] Availability of multilingual valid translated PROMs <sup>#</sup> [39,49] System wide implementation can be more efficient in terms of scalability and costs <sup>#</sup> [22,38] Communication within and between services <sup>#</sup> [15,38,49] Dedicated time and resources to implement and deliver PROMs <sup>#</sup> [15,29,34]	Resource availability [staff, digital, financial]* [15,24,34,35] System wide institutional support [managerial, IT, financial]* [24,38,39,49] Well thought through delivery, incorporating engagement with key stakeholders at all stages <sup>#</sup> [24,29,34,42,52] Ongoing evaluation and iterative refinement of PROMs systems. Small incremental changes may be a better approach <sup>#</sup> [37,38] Communication within and between services <sup>#</sup> [15,38,49]	Resources availability [staff, digital, financial]* [15,24,34,35] System wide institutional support [managerial, IT, financial]* [24,38,39,49] Ongoing evaluation and iterative refinement of PROMs systems <sup>#</sup> Small incremental changes may be a better approach. Stakeholders should be incorporated <sup>#</sup> [37,38] Communication within and between services <sup>#</sup> [15,38,49] Data management capacity <sup>#</sup> [27] Flexibility to change over time <sup>#</sup> [21] Co-production design <sup>#</sup> [37]

269 <sup>#</sup>Predominantly facilitator

270 \*Bidirectional, can be both a barrier and facilitator

271 <sup>e</sup>Predominately barrier



#### 272 **Programme theory**

We have identified two main programme theories explaining the mechanisms by which PROMs were thought to improve patient outcomes. These theories are not mutually exclusive, and analysis of included studies suggested multiple mechanistic pathways associated with PROM interventions.

# Theory 1: PROMs promote proactive communication and positive health behaviours in patients

One possible mechanism is that by completing PROMs patients were prompted to 279 reflect on their symptom, thereby improving awareness of their health and wellbeing. PROMs 280 helped to validate patients' concerns and empowered them to raise these issues with clinicians, 281 thus improving patient-clinician communication. Additionally, enhanced patient awareness 282 regarding their own health potentially increased their engagement in positive health-related 283 284 behaviours [15,17,21,23,29–31,33]. We found evidence that PROMs promoted self-reflection [18,24,46,49], helped patients to identify their needs and priorities [18,34,46,49], and promoted 285 more active engagement from patients in managing their own health [18,34,46,50,55]. 286

#### 287 Theory 2: PROMs increase clinician awareness of patient symptoms

PROMs provided regular feedback to clinicians highlighting undetected issues or symptoms, and/or changes in symptoms. Improved symptom detection subsequently enhanced the quality of appointments and benefited patient health outcomes [38,42,49]. Better symptom awareness and detection promoted quicker treatment and tailoring of care according to the needs of patients [13,15,17,19,29,37]. Clinicians reported that PROMs enabled them to prioritise topics for discussion during appointments, which resulted in better shared decisionmaking [18,37,38,42,46,49,50,52].



#### 295 Effectiveness of PROMs interventions

#### 296 Health Outcomes

Two studies showed statistically significant improvements in health outcomes in cancer 297 patients as a result of a VBHC PROM intervention [18,42]. In these studies, PROMs data was 298 collected regularly and used to automatically alert the healthcare team when a predefined 299 threshold indicated need of clinical attention [18,42]. Patients receiving the PROMs had higher 300 301 survival, a lower decrease in health-related quality of life and remained on chemotherapy for longer compared to the treatment-as-usual group [18,42]. Additionally, patients receiving 302 PROMs also had less emergency care visits, were less frequently hospitalised, and had shorter 303 lengths of stay in clinic compared to those in usual care [18,42,23,29,42]. 304

#### 305 Patient Health-Related Behaviours

306 Several studies demonstrated that PROMs positively influenced health-related 307 behaviours in patients, such as symptom reporting and more active engagement in their own 308 healthcare and management.

*Symptom Reporting:* Patients on cancer treatment completing PROMs were more likely to report symptoms compared to those in usual care, particularly for symptoms not perceived as urgent by the patient [55]]. PROMs also helped patients with heart-failure to raise healthrelated problems with their clinician [46]. Specifically, patients described that PROMs provided the language to explain these issues and validated problems as worthy of reporting. PROMs also helped patients to raise symptoms associated with stigma such as pelvic dysfunction or mental health problems [22,46].

*Improved Patient Health Management*: PROMs helped patients to actively engage in managing
their own health [18,34,46,50,55]. Completing PROMs improved patient awareness of their



everyday functioning and of own health [37,41,46,52], which helped them take ownership of
managing their symptoms [46,47]. PROMs also helped patients prepare for appointments and
facilitated communication with clinicians [37,52].

321 **Patient Perspectives on PROMs** 

The response rate of PROMs completion varied from 30% to 100%. The lowest response rate was seen in asthma while diabetes, orthopaedic conditions and chronic obstructive pulmonary disease (COPD) had the highest response rates.

325 Seven studies reported that patients found PROMs helpful and using PROMs improved their quality of care [18,22,34,37,46,47,61]. More specifically, Porter [50] reported that 92% 326 of patients agreed that PROMs were easy to understand and helped during clinical 327 appointments, and 76% would like PROMs to be included as part of their routine care [50]. In 328 contrast, four studies reported that PROMs were not helpful, were overly bureaucratic, a waste 329 of resources, more for the benefit of clinicians/researchers than patients, and that they did not 330 adequately capture symptoms also voiced more critical patient perspectives regarding PROMs 331 [30,46,48,50]. 332

#### **Impact of PROMs on Healthcare Professionals and Clinical Practice**

Eleven studies reported clinicians used patient-reported data to better detect health 334 problems, and tailor treatment to the most appropriate care and support provision 335 [18,24,29,34,37,38,40,42,46,49,52,55]. PROMs were also used in clinical care as a triage tool 336 to signpost patients to the right service at the right time [34]. Additionally, several healthcare 337 professionals reported that PROMs enabled feedback of patient health status between 338 appointments [37,38,42,47,46,49]. Automated PROM systems allowed both clinicians and 339 patients to objectively track changes in health status and mental health over time without an 340 increase in workload [24,29,38,42,49]. 341



#### 342 **PROMs and Service Monitoring**

Ten studies described PROMs helped to critically appraise, evaluate, and improve service provision to better meet patient and staff needs [21,33,34,38,56]. This often entailed using longitudinal PROMs data to track, inform, and refine services [21,24,29,34,37,38,49], leading to improved efficiency, better management of resources, and improved patient care [21,24,29,33,34,37,38,49]. For instance, a VBHC service in Wales used longitudinal PROM data to inform high-level decision making, which resulted in continued improvement of services [38].

#### 350 **PROMs use with multiple co-morbid conditions**

There was a lack of evidence investigating the use of PROMs in patients with multiple 351 comorbidities. Patients with comorbid conditions were typically required to complete several 352 PROMs for each condition, which was perceived as time consuming and repetitive [50]. With 353 some notable exceptions, there was little linking across the PROMs used by the various 354 services. Porter [50] combined PROM administration to patients with co-morbidities to reduce 355 the overall number of PROMs that patients had to complete and avoid duplicate questions]. 356 Additionally, Withers [17] noted the importance of electronic systems to allow the integration 357 358 of multiple PROM pathways for patients with co-morbidities.

359

#### 360 Transferability and generalisability

Thirteen studies were large scale with sample sizes ranging from 822 to 17,892 participants [19,20,26–28,30–32,34,48,49,51,53,56,61], and fourteen studies evaluated the use of PROMs in more than one centre [17,19,21,22,26,30–32,34,38,40,41,46,47,53,56]. Studies evaluated the use of PROMs across 26 health care conditions. Factors that limited



365 transferability included studies conducted in single healthcare centres [15,18,20,28,37,42,43,45,52,54,55,61], the variety different health care models [e.g., private 366 healthcare], and the prominence of studies conducted in academic hospitals that may not be 367 sufficiently similar to hospitals not associated with academic institutions (e.g. resources, staff 368 patient ratios etc) [15,17,20,27,28,37,39,40,52,54,55,61]. It cannot therefore be assumed that 369 the results of these studies will extrapolate to global practice. 370

#### 371 Cost-effectiveness

We found limited evidence to inform the current understanding on the cost effectiveness of PROMs interventions [13]. PROMs interventions were reported to potentially reduce the need of resources indirectly as it resulted in a reduction of length of hospital stay, emergency department visits and hospitalisations [18,42]. However, not all studies found a significant reduction in appointments and medical tests between patients receiving PROMs compared to patients receiving standard care [55].

**Tracer conditions** 

Configuring the evidence for the four tracer conditions did not add anything to our overall understanding. For completeness, we present the studies organised by the four tracer conditions in S5 File.

382

#### 383 **Discussion**

We found 43 diverse study designs investigating the implementation, use and impact of PROMs in a broad range of disciplines and specialities. Although there were some



descriptions of how PROMs were intended to work, few studies reported a well-developed 386 programme theory. With some notable exceptions (such as early identification of symptoms in 387 cancer), we found little robust evidence of the effectiveness of PROMs. PROMs were 388 universally considered to have the potential to increase patient satisfaction with treatment and 389 services, enhance patient awareness of symptoms and self-management, and improve health 390 outcomes such as quality of life and global health status. PROMS were generally seen by 391 patients as providing information for healthcare professionals. Implementation issues 392 commonly prevented the realisation of optimal outcomes and patents generally needed better 393 394 and clearer communication about why PROMs were being given and how they could optimally be used by patients to support their own self-management. 395

Beyond a VBHC context, a Cochrane review [62] including 116 randomised controlled 396 trials that specifically included PROMs feedback as part of the intervention in a broader range 397 of settings and contexts found moderate evidence, calculated as measures of treatment effect 398 size, that PROM feedback improved quality of life, and increased patient-physician 399 communication, and disease control. However, this review also highlights the uncertainty 400 regarding the impact of PROMs on general health perception, pain, fatigue, and on physical, 401 402 mental, and social functioning [62]. In addition to the benefits associated with PROMs feedback, our scoping review suggested that PROMs longitudinal data helped to evaluate 403 404 health services and even led to updated models of service delivery. This is supported by the review by Gibbons [62], which demonstrated that PROMs data facilitated quality improvement 405 of services and were regarded as having substantial value beyond informing treatment. This 406 corroborated our finding that PROMs in VBHC can help to evaluate the provision of healthcare 407 408 and identify issues for improvement and inform the change within existing care pathways when 409 necessary. However, evidence of real-world PROMs implementation and specifically within a VBHC programme is still limited [63], or when available, aggregated PROMs data seemed to 410



411 be scarcely used to tailor treatments or improve services [44]. For instance, a recent review [64] reported little to no effect of aggregated PROM data on quality improvement methods in 412 healthcare and highlighted the need for more empirical research. Bureaucratic challenges and 413 the accessibility of IT systems integrated within current electronic health records was the main 414 barrier to optimal implementation and use of PROMs data identified in this review. This finding 415 is widely supported by other reviews [16,44,64-69]. For example, Gensheimer [66] 416 417 recommended that PROMs integration into electronic health records is context-dependent and should be guided by multidisciplinary expertise to balance the advantages and disadvantages 418 419 for each service [62].

420

#### Strengths and limitations

An a priori protocol was developed, and the scoping review was conducted using 421 systematic processes. The incorporation of different research designs and methods is 422 particularly relevant in health care research considering the complexity of some aspects of 423 424 health that cannot be readily quantified (e.g. lived experiences) [70]. The broad focus enabled a comprehensive understanding of the use, implementation, and impact of PROMs within a 425 VBHC setting involving a multidisciplinary team of seven core researchers. It is not a 426 requirement to assess methodological strengths and limitations of included studies in scoping 427 reviews, but we elected to do so. 428

Some limitations are worthy of note. Due to time constraints, the search strategy was not exhaustive. Therefore, some papers eligible for inclusion may not have been identified. Despite that, a considerable number of databases were searched, and a strategic 3-word search was also conducted. As this is a scoping review, we aimed to provide a broad overview on the use of PROMs within a VBHC or broadly similar setting. While this allowed us to have a detailed overview of the evidence, we had to compromise on depth and specificity. There may



be additional useful evidence of PROMs use outside of VBHC programmes to further enhanceunderstanding [13].

#### 437 Gaps and future research

Evidence about how PROMs work and how best to implement and deliver PROM interventions to optimise achievement of the target outcome within a VBCH and routine practice setting is currently limited. The routine practice and VBHC context are quite different to a time limited research context whereby patients usually complete a set number of PROMs over a defined period of time. It is clear that PROMs do not consistently translate from shortterm research to a long-term routine practice context and we need to understand why in order to address the implementation, feasibility and acceptability issues.

More empirical evidence is needed to demonstrate the value of PROMs and the benefits 445 to services and patients. Whilst there is a growing number of implementation, feasibility and 446 pilot studies, there is a lack of large-scale randomised controlled trials (RCTs) evaluating 447 PROMs in a VBHC setting. A recent Cochrane review [62] included RCTs where PROMs 448 449 were used for evaluation rather than the PROMs being the intervention. RCTs are however expensive and may not be the best way of evaluating PROMs in real world contexts as part of 450 a complex intervention in a complex health system. Addressing these gaps in evidence is 451 critical to help inform future strategies regarding the selection, implementation and use of 452 PROMs by patients, carers and healthcare professionals as part of a VBHC programme in 453 routine practice settings. VBHC programmes using PROMs are expensive and time consuming 454 for patients and health care professionals to use. PROMs need to work better and be more 455 highly valued in order to become a long-term sustainable component of routine practice. 456

457 More research is needed evaluating the impact of sustained implementation, delivery 458 and costs of PROMs within a healthcare service to understand the full potential of PROMs in



clinical practice. We need more understanding of how the proposed theoretical mechanisms of 459 PROMs work in practice. We also found a gap in the evidence about how disease-specific 460 factors might impact the implementation and use of PROMs, which is particularly important 461 for patients with multiple conditions. Indeed, no new findings were highlighted when we 462 configured and analysed the evidence for the four tracer conditions. Further research should 463 investigate the impact of disease-specific factors in the implementation and use of PROMs, 464 particularly in patients with multiple comorbidities. Additionally, building a broader evidence-465 base evaluating different models of PROM interventions is needed to understand what works 466 467 best for which conditions, healthcare settings and populations. This is essential for the future developments of evidenced-based, best-practice guidelines for PROMs. Few studies 468 investigated the role of caregivers in health care management [29,61]. Where appropriate, 469 470 future research should address whether PROMs are feasible and acceptable to caregivers and incorporate caregivers into the design and delivery of PROM interventions. Future studies 471 would also benefit from more integrated stakeholder and patient and public involvement when 472 developing and implementing PROMs in order to capture what is important to patients and 473 healthcare providers. We have subsequently embarked on a large scale realist evaluation and 474 social return on investment analysis to address some of the identified gaps to further support 475 optimal implementation of PROMs in VBHC programmes. 476

#### 477 Conclusion

This scoping review has mapped and described what is known and current evidence gaps and sets out a future research agenda. Value-Based healthcare programmes are being rolled out at scale in many different health systems and contexts. PROMs are commonly used in VBHC programmes but they have yet to demonstrate their full potential in a VBHC context. Optimal PROMs implementation is poorly understood by clinicians and patients.



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701		Supporting Information
702		S1 Table. Framework. Framework used for data analysis.
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		S2 Table. PRISMA checklist results
704		<ul><li>S2 Table. PRISMA checklist results</li><li>S3 Table. Characteristics of included studies. Characteristics of 43 studies.</li></ul>
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704 705 706		<ul> <li>S2 Table. PRISMA checklist results</li> <li>S3 Table. Characteristics of included studies. Characteristics of 43 studies.</li> <li>S4 Table. Quality appraisal. Quality Appraisal of all included studies using the Quality Assessment for Diverse Studies checklist.</li> </ul>
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