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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**

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

36 **Methods**

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

43 **Results**

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

48 outcomes such as quality of life and global health status. Evidence is currently limited on how
49 PROMs work and how best to optimally implement PROMs to achieve the target outcome.
50 Implementation challenges commonly prevented the realisation of optimal outcomes and
51 patients generally needed better and clearer communication about why PROMs were being
52 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.

58

59 **Keywords**

60 Value-Based Healthcare, Patient Reported Outcome Measures, PROMs, VBHC, scoping
61 review

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

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

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

102

103 To manage and interpret a wide range of study designs, we incorporated principles of
104 mixed-methods framework synthesis to extract, map, chart, categorise and aggregate study
105 findings [9]. An a priori protocol was developed. In line with scoping review methodology, the
106 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

112 **Setting:** High income countries with similar health systems to the UK NHS. Primarily hospital
113 based VBHC programmes that used PROMS.

114

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**

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

167 **Study selection**

168 We imported all searches to Mendeley (Elsevier, Amsterdam, Netherlands) for
 169 screening. Titles and abstracts of identified articles were screened by two people (EW, BC)
 170 independently to determine eligibility for inclusion. We included studies investigating the
 171 implementation, use, and impact of PROMs applied within the context of VBHC (i.e., the use
 172 of PROMs in healthcare to focus on outcomes that are important for patients, and/or used to
 173 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 literature	Abstracts or no full text available
Studies in the English language, unless a translation is readily available	Studies not available in English
PROMs used in a Value-Based Health Care, implementation study, service improvement or service evaluation setting.	Psychometric studies involving the development, validation, or reliability of PROMs
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	

175

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**

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

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

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

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

201 **Quality assessment**

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

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

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

220 **Stakeholder engagement**

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

233 **Results**

234 Forty-three studies were included in total. Among these, 39 studies reported a total of 60,200
 235 participants aged between 18 to 103 years; and 31 studies reported that 56.8% of participants
 236 were female (n = 18,845) (Fig 1. and S3 Table). Included studies investigated various PROMs
 237 interventions, across 13 countries, and across a wide range of conditions (Table 2). Twenty-
 238 four studies specified investigating the use of PROMs specifically in a VBHC program [15–
 239 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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243

244 **Fig 1. PRISMA flow-chart.**

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

Health Condition / Topic	Author & year	PROMs used	PROM delivery method	Response rates [%]
Asthma (n = 4)	Peters et al (2013) Peters et al (2014) Peters et al & Croker et al (2014)	Generic: <ul style="list-style-type: none">EuroQoL EQ-5D Disease specific: <ul style="list-style-type: none">Mini Asthma Quality of Life Questionnaire (mini-AQOL)	Paper questionnaire delivered by post	30.0%
	Porter et al (2021)	Generic: <ul style="list-style-type: none">EuroQoL EQ-5DPatient Generated Index (PGI) Disease specific: <ul style="list-style-type: none">Mini Asthma Quality of Life Questionnaire (mini-AQOL)	Delivered in general practice. Specific method not provided	100%
Cancer (n = 8)	Ashley et al (2013)	Illness Perception Questionnaire-Revised EuroQol-5D, Version 2 Medical Outcomes Study 36-Item Short-Form Health Survey, Version 2 Social Difficulties Inventory European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Quality of Life in Adult Cancer Survivors Scale	Digitally	55.21% overall, 61.4% face-to-face, 48.8% over the phone, 41% via letter
	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%

		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
	Queiros 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)	Generic: • EuroQoL EQ-5D Disease specific: • Clinical COPD questionnaire (CCQ)	Paper questionnaire delivered by post	49.2%
	Porter et al (2021)	Generic: • EuroQoL EQ-5D • Patient Generated Index (PGI) Disease specific: • Clinical COPD Questionnaire (CCQ) • MRC breathlessness scale	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)	Generic: <ul style="list-style-type: none"> EuroQoL EQ-5D Disease specific: <ul style="list-style-type: none"> The Diabetes Health Profile (DHP) 	Paper questionnaire delivered by post	40%
	Porter et al (2021)	Generic: <ul style="list-style-type: none"> EuroQoL EQ-5D Patient Generated Index (PGI) Disease specific: <ul style="list-style-type: none"> The Diabetes Health Profile (DHP) 	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) Peters et al (2014) Peters & Croker et al (2014)	Generic: <ul style="list-style-type: none"> EuroQoL EQ-5D Disease specific: <ul style="list-style-type: none"> Quality of Life in Epilepsy ii Inventory (QOLIE-31) 	Paper questionnaire delivered by post	34%

	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)	Kansas City Cardiomyopathy Questionnaire (KCCQ)	Telephone questionnaire	66%
	Kane & Ellis-smith et al et al (2017)	Patient Health Questionnaire-8 (PHQ-8) A quality-of-life visual analogue scale		
	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)	Generic: <ul style="list-style-type: none"> EuroQoL EQ-5D Disease specific: <ul style="list-style-type: none"> Minnesota Living with Heart Failure Questionnaire (MLHFQ) 	Paper questionnaire delivered by post	50%
	Porter et al (2021)	Generic: <ul style="list-style-type: none"> EuroQoL EQ-5D Patient Generated Index (PGI) Disease specific: <ul style="list-style-type: none"> Minnesota Living with Heart Failure Questionnaire (MLHFQ) 	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 health 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)	PROMIS computer adaptive test (CAT) instruments: <ul style="list-style-type: none"> Physical function Pain interference Depression 	Digitally	Not reported
	Porter et al (2021)	Generic: <ul style="list-style-type: none"> EuroQoL EQ-5D Patient Generated Index (PGI) Disease specific: <ul style="list-style-type: none"> Oxford Hip Score (for knee replacements) Oxford Knee Score (for knee replacements) 	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) Peters et al (2014) Peters et al & Croker (2014)	Generic: <ul style="list-style-type: none"> EuroQoL EQ-5D Disease specific: <ul style="list-style-type: none"> Stroke Impact Scale (SIS) 	Paper questionnaire delivered by post	36.4%
Varicose vein surgery Groin hernia repair	Devlin et al (2010)	EuroQoL EQ-5D Short form health survey (SF-36) (for groin hernia repair) Aberdeen Varicose Vein Symptom Severity questionnaire (for varicose vein surgery)	Paper questionnaire	75%
Bariatric surgery	Goretti et al (2020)	Bariatric Analysis and Reporting Outcome System (BAROS) Questionnaire for physical activity, work capability, dressing, and sexual activity	In person interview by clinicians	82% response rate at follow-up (phone 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. 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)	Digitally	39%
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)	Developed generic PROM tool with three components: <ul style="list-style-type: none"> The EQ-5D-5L questionnaire The Work Productivity and Activity Impairment (WPAI) tool 	Digitally	Not reported

		<ul style="list-style-type: none"> 'About You' questions on height, weight smoking history, exercise levels, alcohol consumption and medically diagnosed comorbidities 		
	Rutherford et al (2021)	<p>Patient-Reported Outcome Measurement Information System–10 (PROMIS-10)</p> <p>Depression Anxiety Stress Scales (DASS21) (only available at specific sites)</p> <p>Chronic obstructive pulmonary disease Assessment Test (CAT) (only available at specific sites)</p>	Digitally	69% at baseline and 55.6% at follow-up

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249

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

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

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

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

267

268 **Table 3.** Factors that created barriers and facilitators at different stages of PROMs implementation

	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*	Reliable internet [18,34,35,37,38]. Electronic PROMs systems that are integrated with patient medical records*

	<p>IT support staff[#] [18,34,35,37,38]</p> <p>Costs for software and digital equipment such as tablets, computers, software etc[§] [24,39,49]</p>	<p>[15,18,22,26,29,30,34,35,37–40,49,53]</p> <p>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]</p> <p>Automated PROMs pathways* [18,38,42,49]</p> <p>IT support staff[#] [18,34,35,37,38]</p>	<p>[15,18,22,26,29,30,34,35,37–40,49,53]</p> <p>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]</p> <p>Automated PROMs pathways* [18,38,42,49]</p> <p>IT support staff[#] [18,34,35,37,38]</p>
<p>Factors associated with patients & carers</p>	<p>Planning for dedicated time to complete PROMs for patients[#] [15,34,39,46]</p> <p>Planning for hybrid delivery [digital / paper PROM] to allow for patient preference and requirements, and to improve retention[#] [8,12,24,27,28]</p> <p>Planning provisions for patient with poor language proficiency in the main healthcare language, particularly in multicultural locations[#] [22,34,39,49]</p> <p>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[#] [15,30,34,46,50]</p>	<p>Providing dedicated time to complete PROMs for patients[#] [15,34,39,46]</p> <p>Length and difficulty to complete PROMs[§] [15,30,34,46,50]</p> <p>Caregivers helped patients with language, technology, or physical/mental impairment barriers, resulting in improved accessibility of PROMs to often excluded groups[#] [4,11,13,16–20,26]</p> <p>Patient not understanding the content of the PROMs questions or becoming upset over being confronted by their condition[§] [6,8,15]</p> <p>Poor patient understanding about what PROMs are and how they are used in their healthcare[§]</p> <p>Clear communication about PROMS with patients and carers is very important[#] [15,30,34,37,46]</p> <p>Digital literacy, particularly for patients with cognitive impairments[§] [18,34,37,41,46,50]</p> <p>Hybrid delivery [digital / paper PROM] to allow for patient preference and requirements, and to improve retention[#] [8,12,24,27,28]</p> <p>Digital literacy[§] [18,21,34,37,41,52]</p> <p>Reminders to complete PROMs[#] [29,38,59]</p>	<p>Providing dedicated time to complete PROMs for patients[#] [15,34,39,46]</p> <p>Caregivers helped patients with language, technology, or physical/mental impairment barriers, resulting in improved accessibility of PROMs to often excluded groups[#] [4,11,13,16–20,26]]</p> <p>Patient understanding about what PROMs are and how they are used in their healthcare[§]</p> <p>Clear communication about PROMS with patients and carers is very important[#] [15,30,34,37,46]</p> <p>Digital literacy, particularly for patients with cognitive impairments[§] [18,34,37,41,46,50].</p> <p>Hybrid delivery [digital / paper PROM] to allow for patient preference and requirements, and to improve retention[#] [8,12,24,27,28].</p> <p>Poor language proficiency in the main healthcare language[§] [22,34,39,49]</p> <p>Reminders to complete PROMs[#] [29,38,59]</p> <p>Digital literacy[§] [18,21,34,37,41,52]</p> <p>Physical and mental health impairments[§] [25,29,46]</p>

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

269 [#]Predominantly facilitator

270 ^{*}Bidirectional, can be both a barrier and facilitator

271 [‡]Predominately barrier

272 **Programme theory**

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

277 **Theory 1: PROMs promote proactive communication and positive health**
 278 **behaviours in patients**

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

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

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

295 **Effectiveness of PROMs interventions**

296 **Health Outcomes**

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

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.

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

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

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

321 **Patient Perspectives on PROMs**

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

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

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

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

342 **PROMs and Service Monitoring**

343 Ten studies described PROMs helped to critically appraise, evaluate, and improve
 344 service provision to better meet patient and staff needs [21,33,34,38,56]. This often entailed
 345 using longitudinal PROMs data to track, inform, and refine services [21,24,29,34,37,38,49],
 346 leading to improved efficiency, better management of resources, and improved patient care
 347 [21,24,29,33,34,37,38,49]. For instance, a VBHC service in Wales used longitudinal PROM
 348 data to inform high-level decision making, which resulted in continued improvement of
 349 services [38].

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

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

359

360 **Transferability and generalisability**

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

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

371 **Cost-effectiveness**

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

378 **Tracer conditions**

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

382

383 **Discussion**

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

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

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

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

420 **Strengths and limitations**

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

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

435 be additional useful evidence of PROMs use outside of VBHC programmes to further enhance
 436 understanding [13].

437 **Gaps and future research**

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

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

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

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

477 **Conclusion**

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

483

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484

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485

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486

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701 **Supporting Information**

702 **S1 Table. Framework.** Framework used for data analysis.

703 **S2 Table. PRISMA checklist results**

704 **S3 Table. Characteristics of included studies.** Characteristics of 43 studies.

705 **S4 Table. Quality appraisal.** Quality Appraisal of all included studies using the
706 Quality Assessment for Diverse Studies checklist.

707 **S5 Text. Findings for tracer conditions.** Findings related to the implementation and
708 use of PROMs in Epilepsy, Heart Failure, Parkinson's disease and Cataract surgery.

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