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Patients' reasons for non-use of digital patient-reported outcome concepts

A scoping review

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Abstract

Data from digitally administered patient reported outcomes (PROs) is used more and more in routine healthcare for long-term conditions as a part of daily clinical practice. This literature study reviews empirical studies of digital PRO to examine patients' reasons for non-use of digitally administered PRO data in routine care. This scoping review searched through PubMed, Embase, Web of Science and PsycINFO databases, reporting on study population, intervention, duration of intervention and motivational factors alongside stated reasons for nonparticipation or dropout for each study. The patients' reasons for not participating, either from study start or by dropout, were analysed through a thematic approach.

Fifty-one studies were included, published from 2010 to 2019, mostly from Europe and the Unites States covering different long-term conditions. The reasons for non-use are manifold and cover the themes of ability to use PRO, engagement, emotional distress and technical barriers.

Several reasons are given explaining why patients with long-term conditions are not using digitally administered PRO as intended. This should be taken into account in the design phase of digital PRO interventions and considered in conversations with patients during the intervention.

Keywords

ehealth, human factors, IT design and development methodologies, mhealth, telehealth

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Introduction

Digital patient-reported outcomes in routine care

Patient-reported outcome (PRO) data are being increasingly used in routine care of long-term conditions.[1] Discussion continues about their definition but, for the purposes of this study, PROs are defined as standardized, typically validated, generic or disease-specific questionnaires completed by patients to assess their perceptions of their health situation (including health status and quality of life).[2,3] Numerous PRO concepts were originally developed for research or general evaluation purposes.[3,4] Currently, PROs are gradually applied in clinical practice[5] and serve as screening tools anticipated to detect disease complications or as clinical monitoring tools to assess the impact of treatment.[6,7] PROs are expected to facilitate patient involvement, support patients in self-managing long-term conditions and increase health literacy.[6,8] However, a limitation to PROs is that all patients do not benefit equally from their use; in fact, some patients do not engage with PROs at all.[7,9,10] As the healthcare system becomes more digitalized, so do PROs, allowing patients to complete questionnaires on a computer or smartphone without a healthcare worker present.[11] This digitalization creates additional risks to patient engagement and of increasing inequality in the healthcare system.[12]

Reviews exist of factors affecting enrolment in and engagement with digital health interventions.[13] Similarly, reviews of facilitators and barriers to implementation of PROs have been conducted.[14] However, to the best of our knowledge, no reviews exist of the patients' reasons for non-use of digital PROs in routine healthcare.

The purpose of this study is to review empirical studies of the use of digitally administered PROs in routine care and examine the stated reasons for patients' non-use of digital PRO.

Research questions

The research questions are as follows: (1) what are the characteristics of patients who decline to participate in digital PRO (nonparticipation), and (2) what are the patients' reasons for non-use (nonparticipation from the beginning of the intervention and dropout during intervention) of digitally administered PROs in empirical studies of routine healthcare for outpatients with long-term conditions?

Method

A scoping review was conducted using the framework of Arksey and O'Malley[15] and PRISMA-ScR reporting.[16] A scoping review is a quick way to synthesize existing knowledge, with the aim of mapping key concepts and main sources of available evidence in a research area. It differs from a systematic review by addressing a broader research question, including more study designs, structuring data extraction differently and typically synthesizing evidence qualitatively.[15]

Eligibility criteria

The focus of this scoping review is digitally administered PROs used in routine outpatient care for adult patients with long-term conditions, defined as any somatic or psychiatric disease requiring ongoing regular treatment or monitoring at a hospital or medical clinic (Figure 1).

We included primary studies using digital PROs as part of or as an entire intervention in routine care or routine care like settings, published in English in peer-reviewed journals from January 2008

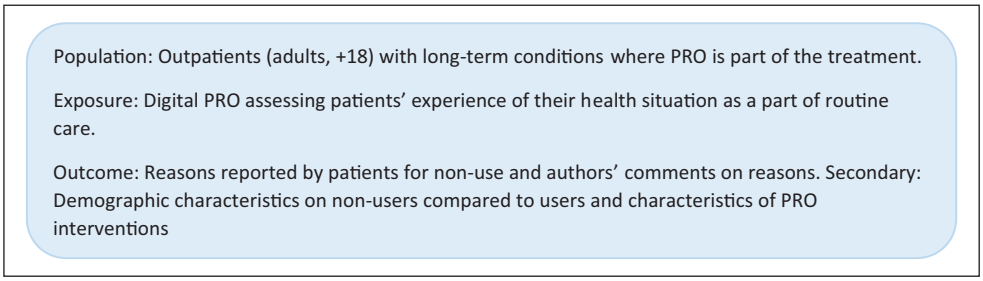

Figure 1. Population, exposure and outcome of study.

to January 2019. We defined routine use as incorporating individual patients' PRO data into clinical practice as a part of their treatment or care.[10,17,18] Studies using PROs only as outcome measures for another clinical intervention are not included.

This review focuses on digitally administered PROs that assessed patients' self-reported health situation including well-being. They included both digital versions of PROs that were originally designed for administration on paper and new PRO instruments specifically developed for digital media. We excluded studies of home monitoring with medical equipment generating clinical data to limit the diversity of technology and focus on patients' experiences of their health. However, we included studies adding PRO data to existing home monitoring (e.g. ongoing blood glucose measurement self-monitoring).

Furthermore, this review is limited to research regarding adult patients, to avoid any risk of different characteristics relating to children, for example, parent involvement.

Exclusion

Studies were excluded if the PROs component of the intervention was trivial in comparison with the main purpose of the intervention, no clinicians reviewed PRO data, no results were reported (e.g. study protocols) or the focus was on healthcare professionals, not patients or on prevention in otherwise healthy individuals (we viewed obesity and physical inactivity as risk factors, not as long-term conditions themselves). In addition, we excluded studies that did not report on non-participation or dropout rates and those collecting PRO data only from paper-based instruments.

Search and screening

Relevant studies were identified by searching PubMed, Embase, Web of Science and PsycINFO databases. Search terms: (Patient Reported Outcome OR Self-monitoring OR home-monitoring) AND (digital OR online OR web-based OR app OR internet OR m-health OR e-health) within the last 10 years (January 2009–January 2019). A PRISMA screening process[16] followed (Figure 2).

Data

We collected data on nonparticipant and dropout rates, reasons for nonparticipation or dropout and characteristics of nonparticipants and dropouts. We also reviewed study population, intervention, type of PROs, intervention duration and use of reminders.

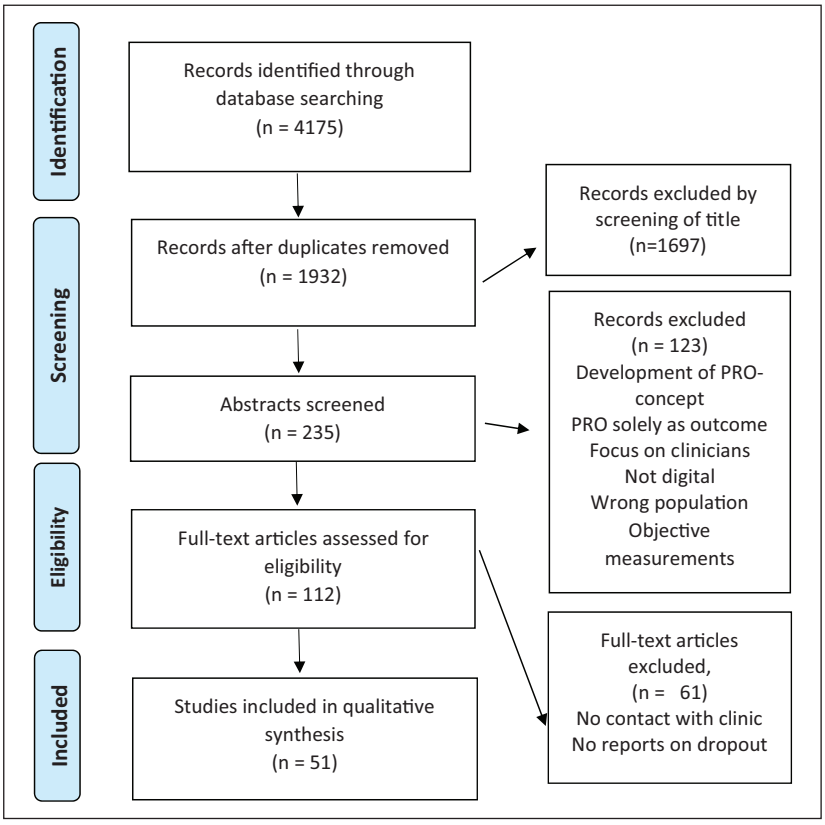

Figure 2. PRISMA diagram.

Analysis and reporting

Study population, intervention and duration and use of reminders are reported in Table 1, along with reasons for nonparticipation or dropout for each study. Patients' reasons for non-use, either from study start or by dropout, were analysed using a thematic approach.[70] All reported reasons were (1) recorded as worded in the article, (2) categorized based on close similarities (e.g. 'language barriers' and 'language problems') and (3) grouped into broad themes based on overall influence on patients' interaction with digital PROs. After removing reasons reflecting clinicians' or organizational perspectives, the remaining themes were labelled as shown in Table 4.

Results

Included studies

A total of 51 studies published from 2010 to 2019 were included (Table 2). In all, 31 studies were from Europe, 14 from North America, 3 from Australia and 3 from Asia.

Interventions in included studies were digital questionnaires or web-based diaries and mobile phone applications or text messages, using a 'bring your own device' approach or a provided smartphone/tablet. Intervals for completing questionnaire varied from daily to half yearly. The duration of interventions was 2–3 weeks to 2 years.

Table 1. Overview of literature.

Name, country	Methods	Population	Intervention	Type of PROs	Duration	Reminders	Reasons for nonparticipation or drop out	Nonparticipation from study start	Drop out during study	Demographics
Andikyan et al.,[19] **USA**	Prospective, single-arm pilot study	Women scheduled for laparotomy (n = 49)	Weekly web-based questionnaire (STAR)	(NCI CTCAE 3.0 and EORTC QLQ-C30)	6 weeks	N/A	N/A	6%	26.5% (end of study) 18% (four out of seven sessions)	Use internet (94%) High school or less (6%) Median age (56)
Anne-Marieke Wiggers et al.,[20] Netherlands (abstract)	Questionnaire	Cardiac rehabilitation (n = 94)	Online questionnaire	(Not reported)	N/A	N/A	Health problems	48% never used	72.3 %	Mean age (64.7)
Ashley et al.,[21] **UK**	Feedback questionnaire	Breast, colorectal, and prostate cancer (n = 1152)	Online PRO system (ePOCS) at three points in time	Not reported	15 months	Email reminders	Age, IT reasons (e.g. no computer) Technical errors Death	44.8%	42.4 %	Mean age (61.3)
Bakker and Rickard,[22] Australia	Feedback questionnaire	Depression and anxiety, MoodPrism users (n = 1349)	App-based daily assessment of mood (MoodPrism)	Mood questionnaire	30 days	N/A	Mental health literacy	83% (did not complete first questionnaire and not in the study)	N/A	Mean age (34.8)
Baron et al.,[23] **UK**	Recruitment data from mixed-methods RCT	Diabetes (n = 1360, recruited n = 81)	Mobile telehealth	Diabetes-related parameters	N/A	N/A	Too busy Does not want additional stress Satisfaction with current care IT reasons Health problems Does not want to be monitored Does not want to complete questionnaires Relatives disagree with participation	94% (73% of 300 patients due to patient-related constraints or refusal)	N/A	
Basch et al.,[24] **USA**	Multicenter trial	Cancer, (invited n = 361, recruited n = 285)	Tablet in waiting room	Symptomatic adverse events (e.g. nausea)	N/A	N/A	Not interested Too anxious Death Too sick Do not want to use computer Too busy Do not like research Institutional errors Internet connectivity	21%	15% of recruited participants at visit 5	Median age (57) Use internet (64.7%) High school or less education (26.8%)
Bauer et al.,[25] **USA**	Usability and satisfaction surveys, semi-structured interviews	Collaborative care patients (invited n = 38, eligible n = 32, recruited n = 17)	Daily app-based questionnaire	PHQ9/GAD7	8 weeks	N/A	Too busy Concerns about passive data collection	44%	65% (no sustained use at 8 weeks)	
Benze et al.,[26] Germany	Prospective feasibility trial	Cancer (n = 40)	Daily app-based PRO system (meQoL)	Perceived distress (NCCN Distress Thermometer®), pain intensity, pain episodes, Edmonton Symptom Assessment Scale	110 days	Push notifications	Personal reasons Uncertainty regarding device and technology	N/A	15%	Mean age (57)

(Continued)

Table 1. (Continued)

Name, country	Methods	Population	Intervention	Type of PROs	Duration	Reminders	Reasons for nonparticipation or drop out	Nonparticipation from study start	Drop out during study	Demographics
Berry et al.,[27] **USA**	RCT	Cancer (n = 374)	Web-based self-report system (ESRA-C)	Symptoms and quality of life (SxQOL)	N/A	Push tips	Software error Different clinical services	N/A	37.7% (never used)	
Bilderbeck et al.,[28] **UK**	RCT follow up questionnaires	Bipolar disorder (n = 121)	Weekly online mood tracking	Quick Inventory of Depressive Symptomology (QIDS-SR16) and Altman Self-Rating Mania scale	12 months	N/A	Receiving treatment elsewhere	N/A	4% (group MIMM) 18% (group FIMM less than five sessions)	Mean age (44)
Blocker et al.,[29] **UK**	Interviews	Hip and knee arthroplasty (n = 31, included n = 17)	Text messaging PROM system (2 questions)	Oswestry Very Short Form	N/A	Text messages	Wrong phone number Poor eyesight Personal reasons Phone not charged Prefer to report in person	53% (of included pt)	11%	Mean age (70)
Brochmann et al.,[30] Denmark	Questionnaire + focus groups	Myeloproliferative neoplasms (invited n = 135, recruited n = 118)	Internet-based PRO system (pen and paper version chosen by 9%)	Quality of Life Questionnaire-Core 30, Myeloproliferative Neoplasm Symptom Assessment Form, Brief Fatigue Inventory and Short Form 36 Health Survey	6 months	SMS or email reminder	Too busy Need distance from disease Lack of energy Too old No personal benefit Death	13%	10% of recruited, online participants	Mean age (62)
Chen et al.,[31] Taiwan	Pre- and post-measures of blood glucose and behaviour	Diabetes (n = 184, intervention group = 59)	Daily diary at online diabetes self-management system and glucose measurement (allowed to use own glucometer)	Dietary information, physical activity, blood glucose level	18 months	Telephone calls or text reminders by clinicians	Age Not used to smartphones with camera (photo upload of dietary intake) Technological difficulties Too busy	N/A	10% never logged in	Mean age (51.3)
Cowan et al.,[32] **USA (Poster)**	Web-based questionnaire	Gynecologic cancer (n = 120)	Web-based questionnaire	National Cancer Institute's CTCAE 3.0 and EORTC QLQ-C30 3.0.	N/A	Alerts	Clinicians do not find it useful	N/A	42.5% (less than 4 of 7 sessions)	N
Cummings et al.,[33] **Australia**	RCT	Chronic obstructive pulmonary disease (n = 106)	Daily diary of symptoms in paper (n = 51) or electronic (n = 55) form	Symptoms and psycho-social data	12 months	Regular telephone contact	Death	N/A	36%	Mean age of Intervention group (70.2) 20% of intervention group chose to use IT diary IT users completed diary more frequently

(Continued)

Table 1. (Continued)

Name, country	Methods	Population	Intervention	Type of PROs	Duration	Reminders	Reasons for nonparticipation or drop out	Nonparticipation from study start	Drop out during study	Demographics
Drion et al.,[34] The Netherlands	RCT	Type 1 diabetes (n = 395, intervention group = 32)	Diary	Blood glucose values, medication, physical exercise	3 months	N/A	N/A	9% declined to participate (35% of non-excluded patients), 50% excluded for having no smartphone	0%	Age (33)
Due J. et al.,[35] Denmark	Interviews by telephone	Cancer (n = 55)	Online portal for patients to self-report adverse effects	Adverse effects	N/A	N/A	Too ill System too complicated	N/A	27%	Median age (61) Average e-health literacy (3.9 on 5-pt scale)
Echarri et al.,[36] Spain	N/A	Crohn's disease (n = 219)	Mobile application with diary	General well-being, pain, stools per day, abdominal mass, extra-intestinal symptoms	4 months	N/A	N/A	N/A	24% did not attend scheduled appointment at month 4	Mean age (36)
Elves et al.,[37] **UK**	N/A	Urological cancer follow-up (n = 120, recruited n = 65)	Web-based app for self-reporting of disease	Disease/treatment effect	10 months	N/A	Clinician concerns about disease progression No Internet No device	45%	32%	66% older than 69 years
Engelhard et al.,[38] **USA**	Questionnaire	Multiple sclerosis (n = 31)	Monthly web-based PRO questionnaire	MS-related symptoms	6 months	N/A	Technical difficulties	13%	N/A	Median age (48) 93.5% female
Faurholt-Jepsen et al.,[39] Denmark		Bipolar disorder (n = 21)	Android smartphone with app for daily self-monitoring	Depression symptoms	3 months	Prompts	Preference for different technical solution	19%	0%	Mean age (33.4)
Girgis et al.,[40] Australia	Web-based evaluation surveys and interviews	Cancer (n = 205)	Digital Pro system for follow-up every 4 weeks	Distress Thermometer, Edmonton Symptom Assessment Scale, and Supportive Care Needs Survey-Screening Tool 9 (SCNS-ST9)	3 months	N/A	Health issues Change in personal circumstances	83%	37% completed only one assessment	Mean age (62)
Gossec et al.,[41] France	RCT	Rheumatoid arthritis (n = 320)	Self-assessment website (Sanoia)	Perceived Efficacy in Patient-Physician Interactions (PEPPI-5)	12 months	None	Poorly organized site Technical issues Fear of Internet Remission Lost interest in self-assessment	N/A	25.7% (never accessed platform)	Mean age (57)

(Continued)

Table 1. (Continued)

Name, country	Methods	Population	Intervention	Type of PROs	Duration	Reminders	Reasons for nonparticipation or drop out	Nonparticipation from study start	Drop out during study	Demographics
Howard et al.,[42] **USA**	Longitudinal cohort	Knee surgical patients (n = 59)	Digital questionnaire every 2 or 4 weeks	Questions related to rehabilitation and questions from standard PRO measures	24–26 weeks	Max. two reminders	No internet access No email Not willing Technical problems Discontinuation of therapy Symptom resolution Disinterest	11%	28%	Average age (35.4)
Jaeger et al.,[43] Switzerland (Poster)	Three-arm study	Rheumatic disease (n = 329)	App with questionnaires weekly	Symptoms reporting	1–16 months	N/A	N/A	N/A	50% after 1 month	
Jamilloux et al.,[44] France	Prospective cohort study, feasibility	Sjögren's syndrome or inflammatory bowel disease (n = 149)	Electronic questionnaire sent by email	SF36, Hospital Anxiety and Depression scale, and an analogue symptom scale	6 months	Reminder after 5 days	Too busy Away from home internet access No internet access	14%	18%	Mean age (42)
Jiang et al.,[45] **USA**	Cross-sectional correlation design	Lung transplant recipients (n = 96)	Smartphone application for daily health monitoring	Health (not reported)	12 months	None	Death Too sick: Don't want reminder of deteriorating status Lack of satisfaction with training Too big a burden	N/A	42.7% (low use at 12 months)	Mean age (57)
Kim et al.,[46] Korea	Prospective observational study	Crohn's disease (n = 309)	Weekly assessment on smartphone	Symptom diary (CDSD): number of bowel movements, pain, general well-being, abdominal mass, complication	44 months	N/A	N/A	1.3%	12% no recorded data for at least two months	
Kjær et al.,[47] Denmark	Web-based survey	HIV (n = 505)	Web-based questionnaire before scheduled appointment	Clinical symptoms	N/A	None	Language problems Time since diagnosis Too sick	45%	5%	Average age respondents (52), nonrespondents (47)
Koevoets et al.,[48] The Netherlands	Analysis of use of registry	Rheumatoid arthritis (n = 214)	Online assessment of disease activity from home or in waiting room	Disease activity, patient's global assessment of disease activity or pain and the HAQ	N/A	In waiting room	Inexperience with computers or Internet Lack of time Do not want to perform disease assessment	24%	36%	Median age (56)
Lauritsen et al.,[49] Denmark	Single-arm observational	Depression (n = 89)	Smartphone app for daily mood and symptoms tracking (DayBuilder)	Sleep, mood, activity and medication	4 weeks	Text messages	Readmission to hospital Worsening of symptoms	51%	24%	Mean age (35.9)

(Continued)

Table 1. (Continued)

Name, country	Methods	Population	Intervention	Type of PROs	Duration	Reminders	Reasons for nonparticipation or drop out	Nonparticipation from study start	Drop out during study	Demographics
Li et al.,[50] **USA**	Online survey	Rheumatoid arthritis (n = 1078) (Online n = 775)	Online survey	(PROMIS) physical function form	N/A	N/A	Time constraints Dissatisfaction with online tool Lack of integration into routine care Technical frustrations	28%	72% of those who activated account (activated online account but never filled out a questionnaire)	Mean age (58)
Maier et al.,[51] Germany	Questionnaire	ALS (n = 162)	Weekly self-assessment on website	ALS Functional Rating Scale (ALSFRS-R) and other established self-assessment questionnaires	52 weeks	None	Lack of Internet access Insufficient technical requirements Discomfort with submitting data	11%	36% of patients that met criteria for analysis (n = 127)	Mean age (58) 22.4% of online surveys completed by caregiver
Melissant et al.,[52] The Netherlands	Pretest-posttest survey + semi-structured telephone interviews	Breast cancer (n = 101)	E-health self-management application based on PROMs (OncoKompas) two times after surgery	Clinical factors and health-related quality of life (HRQOL)	N/A	N/A	Too burdensome Want to forget about the cancer Intervention offered too late in treatment process No symptoms Recent development in condition Family circumstances Forgot about the intervention	19%	10.5 %	Mean age (56)
Michaud et al.,[53] **USA (Poster)**	Analysis of passive data and questionnaire	Rheumatoid arthritis (n = 700)	Smartphone application with daily questionnaire	Pain and global disease assessment and Patient Activity Scale-II (PAS-II)	2 months	N/A	High pain Old age	73%	27%	Mean age (53.6)
Miller et al.,[54] **USA**	RCT	Multiple sclerosis (n = 220)	Web-based electronic messaging system with graphical feedback (MCCO) to self-monitor quarterly and before consultations	Well-being	12 months	Prompt to email	Typing and computer skills Change in health status Difficulty using system Moved from area Patient preference	N/A	19%	Mean age (48.1)
Min et al.,[55] Korea	Questionnaire and interviews	Breast cancer (n = 38)	Smartphone application for daily sleep disturbance-related data collection (Pit-a-Pat)	Sleep patterns, anxiety severity, and mood status	90 days	Push notifications	App incompatible with smartphone No smartphone Language barrier Not interested in research No symptoms to report Technical issues Forgetting to assess Too sick Don't think it is useful 'Didn't feel like it'	9%	21%	Mean age (45) None responded 'too busy' or 'it was inconvenient'

(Continued)

Table 1. (Continued)

Name, country	Methods	Population	Intervention	Type of PROs	Duration	Reminders	Reasons for nonparticipation or drop out	Nonparticipation from study start	Drop out during study	Demographics
Montserrat et al.,[56] Spain (Poster)	Feasibility study	Obstructive sleep apnea syndrome (n = 66)	Web-based follow-up with weekly questionnaires	Symptoms, sleep quality, potential CPAP side effects, physical activity and body weight	12 weeks	N/A	N/A	N/A	18%	
Pedersen et al.,[57] Denmark	Prospective pilot study	Crohn's disease (n = 27)	Webpage (constant-care) for weekly assessment	Disease activity	52 weeks	N/A	Pregnancy (ex. criteria) Surgery	N/A	37% (at follow-up at 52 weeks) 78% (completed less than 26 weeks)	Median age (38)
Peltola et al.,[58] Finland	Prospective pilot study	Head and neck oncology (n = 9)	ePRO application (Kaiku®) during and 1 month after radiotherapy	Treatment and side effects (CTCAE) and quality of life (15D and EORTC QLQ-H&N35)	1 month	None	Difficulty in using Internet	44%	N/A	Median age (63)
Pittman et al.,[59] **UK**	Evaluation of use of website	Chronic kidney disease (n = 84)	Online (web-page) PRO for daily use	Well-being, pain, sleep, breathing, energy, appetite	30 days	None	Death Transplant N/A	5%	20%	Average age (59.6)
Rasschaert et al.,[60] Belgium	Evaluation of use of tool	Oral cancer (n = 11)	Smartphone with interactive electronic self-report tool (RemeCoach) for daily report	Side effects (CTCAE)	4 weeks	Auditory and visual reminder	N/A	0	55%	Median age (57)
Robotham et al.,[61] **UK**	Feasibility study, survey and interviews	Severe mental illness (n = 58)	Electronic questionnaire (myhealthlocker)	Mental Wellbeing (WEMWBS)	12 months	N/A	Lack of support technical and clinically	70%	45%	
Seng et al.,[62] **USA**	Naturalistic longitudinal cohort study	Headache (n = 1561)	Mobile application for headache diary (Curelator Headache®)	Headache symptoms and anxiety ratings	90 days	N/A	People who paid for the app had higher adherence than people who did not Feeling 'nervous'	N/A	67.6%	Mean age (39)
Sevick et al.,[63] **USA**	Single-centre RCT	Type II diabetes (n = 378, intervention group = 123)	PDA-based dietary self-monitoring, daily (BalanceLog®)	Diet	6 months	N/A	Adherence declined over time. 'The most powerful predictor of adherence is prior adherence'	N/A	19.5% did not participate in final 6 months measurement	Average age (54.7)
Steele Gray et al.,[64] Canada	Pilot study	Complex chronic disease and disability (n = 11)	Smartphone with mobile app ePRO for daily reporting (My Goal Tracker)	PROMIS: General health scale, Pain Interference scale, Health Assessment questionnaire	4 weeks	None	Health issues Data entry became a tedious task Life stresses Increased anxiety due to reporting symptoms	8% (one participant)	27%	Average age (58)

(Continued)

Table 1. (Continued)

Name, country	Methods	Population	Intervention	Type of PROs	Duration	Reminders	Reasons for nonparticipation or drop out	Nonparticipation from study start	Drop out during study	Demographics
Steinert et al.,[65] Germany	Questionnaire after 1 year plus usage data	Lipid metabolism disorder (n = 100)	Smartphone application (MyTherapy)	Not known	12 months	Reminders	Lack of time Health problems Lack of motivation Technical problems Not perceived useful Too much effort to use the system Forgot Disruptive in daily life	53%	15%	Average age (52.6)
Torbjørnsen et al.,[66] Norway	Three-arm RCT (RENEWING HEALTH) (HeiQ and SUTAQ measures)	Type II diabetes (n = 101)	Diary app for smartphone		1 year		Skills to manage symptoms, skills to make use of equipment	N/A	26% lost to follow-up at 1 year	Median age (59)
van der Meer et al.,[67] The Netherlands	RCT	Asthma (n = 200)	Internet-based weekly monitoring (n = 101)	Effect (Asthma Control Questionnaire)	1 year	N/A	Reduced need for monitoring with controlled disease	N/A	9%	Mean age (36.3)
Wintner et al.,[68] Austria	Questionnaire	Cancer (n = 166)	Home ePRO by website (n = 55) or phone interview (n = 51)		N/A	N/A	Scepticism about the questionnaire itself Reservation about digital device Poor health Speech problems Language barriers Technical barriers Treatment discontinuation Death	36%	18%	Mean age (58.7)
Wright et al.,[69] **UK (Oral Abstract)**	Evaluation	Cancer (n = 1184, recruited n = 636)	Electronic PRO at three time points (6, 9, 15 months)	Quality of life (EORTC QLQ-C30)	15 months	Reminders	Technical issues Lack of Internet access Lack of Internet usage	54%	19% (at 6 months) 39% (at 15 months)	

RCT: randomized controlled trial; PRO: patient-reported outcome.

Table 2. Diagnosis of patients in the included studies.

Long-term conditions	Studies	Patients
Cancer	16	3947
Diabetes	5	2418
Mental health	5	1638
Rheumatoid arthritis	5	2641
Inflammatory bowel disease	4	704
Other	16	3364

Use of reminders. Seven studies did not use reminders because the aim was to explore how patients interacted with the system without being reminded of it.[41,45,47,51,58,59,64] This included a French study of a self-assessment website for patients with rheumatoid arthritis (RA),[41] 25.7 per cent of whom never accessed the website.

In all, 17 studies used written reminders such as email, SMS or push notifications.[21,26,27,29–33,39,42,44,49,54,55,60,65,69] Two studies used telephone reminders, and one reminded people when they arrived at the clinic.[48]

Nonparticipation and dropout rates. Nonparticipants were defined as patients who were invited to participate in the study or the intervention but never did for patient-related reasons. Nonparticipants reflect both people who do not want to be part of the intervention and those who do not want to join a study. Dropouts are defined as patients beginning the study or the intervention and then dropping out as defined in the study. The included studies variously defined nonparticipants and dropouts. Table 3 summarizes nonparticipation and dropout rates and underlying definitions.

Characteristics of nonparticipants

Only four studies described the characteristics of nonparticipants;[47,30,53,61] no studies included characteristics of dropouts. Robotham et al. reported no difference between active participants and nonparticipants. In the work by Brochman et al., participants and nonparticipants were of similar age, but nonparticipants included more women, were better educated and were less likely to live alone (6% vs 22% of participants). In the work by Kjær et al., both groups were again of similar age and more likely to be women (41% vs 28% of participants). Michaud et al. found that the average age of nonparticipants was slightly less than that of participants (53.6 vs 55.7), but the proportions of women and educational levels were the same.

Reasons for nonparticipation and dropout

Reasons for nonparticipation and dropout are summarized in Table 4 and presented in detail.

Ability to use PRO. A total of 13 studies reported that patients did not use the intervention because of 'health problems' or 'health issues' affecting their ability to engage in the intervention. However, most studies did not provide a definition of health problems. Five studies defined 'health problem' as patients feeling 'too ill' to participate.[24,35,45,47,55] Death was a reported reason for dropout in seven studies. Four studies reported 'old age' as a reason for patients to decline participation[11,21,30,53] without defining an age limit or explaining how age hindered engagement.

Three studies found that language barriers were a reason for dropout.[47,55,68] Several other studies used lack of sufficient language skills as exclusion criteria. An English study of a digital

Table 3. Nonparticipation and dropout rates in included studies.

STUDY	DROPOUT (%)	DROPOUT DEFINITION	NONPARTICIPANTS (%)	NONPARTICIPATION DEFINITION
ANDIKYAN ET AL.[19]	26.5	No use after 6 weeks	6	Never used
ANNE-MARIEKE WIGGERS ET AL.[20]	72.3	Did not complete final questionnaire	48	Never used
BAKKER AND RICKARD[22]	–	N/A	83	Did not complete first questionnaire
BARON ET AL.[23]	2.4	No use in previous 2 months	73	Appointment nonparticipation, refusal, unreturned questionnaire for randomization
BAUER ET AL.[25]	65	No sustained use at 8 weeks	44	Declined participation
BASCH ET AL.[24]	15	Nonadherence at visit 5	21	N/A
BENZE ET AL.[26]	25	Feedback at study end	29	N/A
BERRY ET AL.[27]	37.7	No use	–	N/A
BILDERBECK ET AL.[28]	4	Used less than five sessions	3	Withdrew after randomization
BLOCKER ET AL.[29]	11	Did not complete	53	Did not engage
BROCHMANN N. E AL.[30]	10	Not still enrolled after 6 months	13	Declined participation
CHEN ET AL.[31]	10	Did not log in once	–	N/A
COWAN ET AL.[32]	42.5	Used less than four of seven sessions	–	N/A
DRION ET AL.[34]	–	N/A	35	Declined participation
ECHARRI ET AL.[36]	24	Did not attend final scheduled appointment	–	N/A
FAURHOLT-JEPSEN ET AL.[39]	0	Did not attend 3-month follow-up	19	Declined participation or no-show
GIRGIS ET AL.[40]	37	Only completed one assessment	83	Did not consent or withdrew before starting
GOSSEC ET AL.[41]	25.7	Never accessed platform	–	N/A
HOWARD ET AL.[42]	28	No completed surveys	11	Declined participation
JAEGER ET AL.[43]	50	No use after 1 month	–	N/A
JIANG ET AL.[45]	42.7	Low use at 12 months	–	N/A
KIM ET AL.[46]	12	No recorded data for 2 months	1.3	No recorded data at all
KJÆR ET AL.[47]	5	Failed to submit questionnaire	45	Did not respond

(Continued)

Table 3. (Continued)

STUDY	DROPOUT (%)	DROPOUT DEFINITION	NONPARTICIPANTS (%)	NONPARTICIPATION DEFINITION
KOEVOETS ET AL.[48]	16	Did not complete evaluation	24	Declined participation
LAURITSEN ET AL.[49]	24	Did not complete all 4 weeks	51	Declined participation
LI ET AL.[50]	72	Activated account but never completed questionnaire	28	Never activated account
MAIER ET AL.[51]	36	Stopped online assessment	11	Did not complete first online assessment
MELISSANT ET AL.[52]	10.5	Did not complete second survey	19	Declined participation
MICHAUD ET ALI.[53]	27	Did not complete 50% of surveys	73	Did not download app
MIN ET AL.[55]	21	Did not start using app	9	Declined participation
PEDERSEN ET AL.[57]	37	Did not attend follow-up at 52 weeks	–	N/A
PELTOLA ET AL.[58]	–	N/A	44	Declined participation
PITTMAN ET AL.[59]	20	Did not submit after 30 days	5	Did not submit once
RASSCHAERT ET AL.[60]	55	Did not use after 4 weeks	0	Withdrew before start
ROBOTHAM ET AL.[61]	70.6	Stopped using the site before 1 year	45	Did not use once
SENG ET AL.[62]	67.6	Did not complete 90 days of self-monitoring	–	N/A
SEVICK ET AL.[63]	19.5	Did not participate in final measurement	–	N/A
STEELE GRAY ET AL.[64]	27	Stopped using within 2 weeks	8	Could not be reached
STEINERT ET AL.[65]	15	Never used app	53	Did not register in app
TORBJØRNSEN ET AL.[66]	26	Lost to 1-year follow-up	–	N/A
WINTNER ET AL.[68]	18	Did not complete evaluation	36	Declined participation
WRIGHT ET AL.[69]	39	Did not complete at 15 months	54	N/A

questionnaire for people with severe mental illness found that lack of clinical support was regarded as a reason for dropout.[61]

Emotional distress. A Danish study of Internet-based questionnaires found that some patients did not want to engage in self-assessment because they needed distance from their disease.[30] A Canadian study of questionnaires for complex chronic diseases found that some patients dropped out

Table 4. Reasons for non-use.

Main topic	Categories of reasons for non-attending and dropout	Number of studies
Ability to use PROs	Old age	4
	Death	7
	Development in condition	2
	Other health issues	1
	Health problems	12
Engagement	No symptoms	2
	Symptoms resolved	2
	Data entry became a tedious task	1
	Disruptive to daily life	1
	Forgot	3
	Do not like research	1
	Do not want to	10
	Do not think it is useful	1
	Lack of energy	1
	Lack of motivation	3
	Lost interest	2
	No personal benefit	1
	Personal reasons	4
	Too burdensome	2
	Too busy	9
Emotional distress		7
Usability	Poor eyesight	1
	Language barriers	3
	Health literacy	2
Technical issue	Technical barriers	33
	Technical errors	9
Privacy and data security	Scepticism about the questionnaire itself	1
	Data security concerns	3
External factors	Moved	1
	Relatives disagreed with participation	1

because they felt an increased level of anxiety from reporting symptoms.[64] An American study of a smartphone application for lung transplant recipients found that patients did participate in daily health monitoring because they did not want a reminder of their deteriorating health status.[45] Similarly, a Dutch study of an e-health self-management application for breast cancer patients found that some patients wanted to forget about their cancer and felt that the constant assessment was a burdensome reminder.[52]

Engagement. Some studies found that patients did not participate because they were 'not sick enough'. A Korean study of a smartphone application for daily sleep disturbance for people with breast cancer[55] found that some patients did not use the intervention because they had no symptoms to report. The same was the case in a Dutch study of an e-health self-management application for breast cancer.[52] An American study of knee surgery patients exposed to digital questionnaires every 2–4 weeks for 24–26 weeks found that patients stopped completing the questionnaire when their

symptoms are reduced.[42] The authors of a Dutch study from 2010 of Internet-based weekly monitoring of asthma symptoms concluded that there was a reduced need for monitoring when the disease was controlled.[67]

In addition, the notion of being 'too busy' or lacking time to actively engage in the intervention appeared in eight studies.[23–25,30,44,48,50,65] In an English mobile telehealth intervention for people with diabetes, people declined participation because they were 'too busy' and did not want additional stress related to their disease.[23] A single study[55] found that none of the 38 responders reported that being 'too busy' was a problem.

In a Danish study, some patients did not participate because they saw no personal benefits of doing so.[30] Two American studies – a multicentre trial of cancer patients using a tablet in the waiting room[24] and a cohort of knee surgery patients[42] – found that some patients were simply not interested. In a Dutch study of online assessment of disease activity for people with RA, some patients simply do not want to perform disease assessments.[48]

A Canadian study of a diary to be used for 4 weeks by patients with complex chronic disease found that data entry became a tedious task, causing some patients to drop out.[64] Likewise, a French study of a self-assessment website for people with RA found that some patients lost interest in self-assessment over a 12-month period and dropped out.[41]

An American study of a mobile headache diary found that people who paid for the application had higher adherence than people who got the app at no cost,[62] which the authors explain as the fee increasing the incentive to use the app.

Technical issues and usability. The included studies frequently found technical problems that comprised technical barriers, such as missing hardware or software and low technical proficiency among patients, and technical errors, such as system failures.

An English study of a text messaging system for patients with hip and knee arthroplasty found that poor eyesight (an issued not related to the long-term condition) was stated as a reason for nonparticipation.[29] Other usability issues occur in a Danish study of an online portal for cancer patients, where it is reported that people dropout because the system was too complicated.[35] A French study of a self-assessment website found that a poorly organized website was a reason for dropout.[41] An American survey of an online questionnaire for people with RA found 'dissatisfaction with online tool' and technical frustrations as reasons for dropout.[50] Another American study on a web-based electronic messaging system for people with multiple sclerosis found difficulties in using the system as a reason underlying dropout.[54]

Data security and trust. In an English mobile telehealth study of diabetes patients, some nonparticipants did not want to be monitored because of concerns about data security.[23] An American study of an app-based questionnaire for collaborative care patients also found that some nonparticipants had issues with passive data collection.[25] A German study of an app-based questionnaire also found uncertainty about the device and technology.[26] A German study of a weekly self-assessment of people with amyotrophic lateral sclerosis found that some patients felt uncomfortable about reporting data,[51] and a French study of a self-assessment website for people with RA found that 'fear of Internet' was a reason for nonparticipation.[41]

Discussion

Despite substantial variations in the studies included in this review, most reported problems with both nonparticipation and dropout. As noted earlier in this report, included studies did generally not examine differences between participants and nonparticipants. A wide range of reasons were

reported by patients as underlying their nonparticipation and dropping out, so it should come as no surprise that people declining participation are diverse. In general, patients who are unwilling to give informed consent to participate in clinical studies are younger and more likely to be women.[71] We included studies of both routine practice and routine-like practice, meaning that some people might have declined participation because of a lack of willingness to participate in research but not necessarily in the intervention itself.

Patients' reasons for declining participation and dropping out during studies are manifold. We captured these reasons using a thematic approach. However, most studies simply listed the reasons with no further explanation, making it difficult to fully understand the underlying logic and thus group them. A different grouping structure could have been relevant. For all included studies, nonparticipation and dropout data were secondary outcomes. As a result, the list of reasons presented here should not be regarded as comprehensive.

However, this review suggests that a group of reasons for nonparticipation and dropout are prevalent in many studies, and some could be accounted for in the design process. The following sections reflect upon the themes recommended to address in the design process of the digital PRO intervention.

Ability to use PROs

Digitally administered PROs are intended to be a tool for people with long-term health conditions as well as a tool for healthcare professionals managing their care. Many people with long-standing conditions experience severe symptom exacerbations that consume their energy, strength and mental capacity, are hospitalized or die. However, most included studies did not define health issues that interfered with participation, limiting our understanding of the level of health problems that lead to nonparticipation or dropping out. Other circumstances could explain why people leave a study when it is simply reported that they 'feel too ill'. Interventions designed for people with long-term conditions should allow participants to continue to use them even when they feel ill. When physical or mental conditions hinder patients' ability to engage, the intervention may be too burdensome in terms of both time and cognitive requirements, compared to the value experienced by patients.[72,73]

Engagement

Some conditions are monitored using digital PROs when people are experiencing no or very few symptoms, and they may view the intervention as less important or relevant. Eight studies found that some patients reported being 'too busy' to participate, suggesting the possibility of perceived discrepancies between personal benefits of and time required for the intervention. Another potential issue related to time bears examination. The included studies differed in length, intensity and dropout rates. For instance, studies of daily reports for 90 days had a dropout rate of 67 per cent, and studies of quarterly reports for 12 months had a dropout rate of only 19 per cent. In general, studies of daily reports had a slightly higher dropout rate than those with less frequent entries. Similarly, the proportion of people who never participated was greater for interventions requiring daily use, compared with weekly use. Although out of scope for this review, further examination of the relationship between intervention intensity, length and dropout rates deserves further investigation. It could also be valuable to investigate the relationship between questionnaire length and dropout rates.

Emotional distress

Another important concern for digital services and, especially, for monitoring health is emotional distress.[73] Repeatedly answering questions about symptoms and general health could contribute to

an increased focus on the disease, causing anxiety and general dissatisfaction with the intervention for some people. Four studies reported on this concern but most did not, and its prevalence is consequently unclear from our findings. It is challenging to accommodate this concern in the design of PROs because their very nature is to present questions that might cause emotional distress for patients. However, this is an important concern that may be relevant for clinicians to discuss with patients before asking them to engage in PROs.

Technical issues and privacy

More than half the studies found that technical software or hardware problems were reasons for nonparticipation or dropout. It is obviously necessary for patients to have access to hardware and software, but access alone is not sufficient because technical problems still occur. This can lead to distrust and participants 'giving up' on the system.[74] As with any technical solution, designers should be well aware of this potential.

Issues related to trust in digital devices and data security are becoming more widely known, and privacy concerns are very important to some patients.[75] Only a few included studies addressed concerns with monitoring or distrust in digital devices or websites, but thorough investigation could reveal that these issues are of greater importance. Designers must also be aware of these concerns and able to provide assurances about privacy and data security.

System usability is also a major concern. For instance, if people with poor eyesight are unable to use a digital solution, changes in the system are required. If people simply do not know how to use the system, they may drop out. The included studies examined native apps for smartphones, text messages, new webpages and new features added to existing software. There may be differences between these approaches, as well as between different layouts and additional functionalities. We did not investigate usability in this study, as it is not possible for us to make a comprehensive usability testing of the included systems. This means that we cannot know whether the digital systems, poor usability and user experience is a major reason for dropping out. Poor usability could also be related to burdensome systems.[72] Usability should be accounted for when designing digital PROs.

Digitally administered PROs

All of the reasons for nonparticipation and dropout identified in this review are consistent with previous research into prerequisites for use and acceptability of e-health solutions.[73,76] Digitally administered PROs are a digital health intervention and a system that requires patients to self-report symptoms and well-being, often on a daily or weekly basis and without the presence of a healthcare worker. Factors affecting the non-use of these systems touch both on barriers to use observed in other digital health solutions and barriers that are more specific to digitally administered PROs. A need is apparent to focus on the potential for emotional distress and the relationship between patients' symptoms and the intensity of symptom reporting required from digital PROs.

Limitation

Conducting a comprehensive search is challenging because digital questionnaires are used as outcome measures in many clinical studies and it is often hard to distinguish these from PROs used as part of or an entire intervention. Similarly, many terms can describe PRO interventions. We tried to capture this variety using a range of very broad search terms, but we could have missed some studies. In addition, many studies of digital PROs combine them with other interventions. Most of

these studies were excluded from this review. Including these data could have led to different results. Furthermore, this review only included studies that reported on nonparticipation and dropout. Excluding studies that did not do so could have created bias affecting our findings in unknown ways.

Issues not addressed in this review are clinicians' attitude towards interventions and patients' ability to engage in interventions. In most studies we included, clinicians invited patients to participate in the intervention; the sample of patients could thus be biased before the recruitment process starts and clinicians themselves may be a significant barrier to the use of digital PROs.[71,77] In addition, this review does not distinguish between dropout and early termination and only addresses the dropout definitions used in the examined studies. A more detailed analysis of when and why patients stop the intervention could lead to a more comprehensive and nuanced understanding.

Conclusion

Numerous factors are at stake when patients with long-term conditions do not use digital PROs as intended. This should be reflected when designing digital PRO interventions in collaboration with patients, for example, in participatory design studies.[78] Relevance to patients' current health situation is of utmost importance, and appropriate actions should be considered when their health situation changes.

Some reasons for nonparticipation stated before the intervention begins could be related to fear or expectations. They may be addressed by providing information to patients and screening for concerns identified in the studies we included. The digital solution is often not a stand-alone solution and interaction with the clinic and surrounding factors can play a great part in a successful intervention.

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