Patients’ reasons for non-use of digital patient-reported outcome concepts: A scoping review

Amalie Søgaard Nielsen
University of Copenhagen, Denmark; Deakin University, Australia

Kristian Kidholm
Kristian Kidholm Odense University Hospital, University of Southern Denmark, Denmark

Lars Kayser
University of Copenhagen, Denmark

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 United 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

Corresponding author:
Amalie Søgaard Nielsen, Department of Public Health, University of Copenhagen, Øster Farimagsgade 5, DK-1014 Copenhagen K, Denmark.
Email: asni@sund.ku.dk

Creative Commons Non Commercial CC BY-NC: This article is distributed under the terms of the Creative Commons Attribution-NonCommercial 4.0 License (https://creativecommons.org/licenses/by-nc/4.0/) which permits non-commercial use, reproduction and distribution of the work without further permission provided the original work is attributed as specified on the SAGE and Open Access pages (https://us.sagepub.com/en-us/nam/open-access-at-sage).
Introduction

Digital patient-reported outcomes in routine care

Patient-reported outcome (PRO) data are being increasingly used in routine care of long-term conditions. 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). Numerous PRO concepts were originally developed for research or general evaluation purposes. Currently, PROs are gradually applied in clinical practice and serve as screening tools anticipated to detect disease complications or as clinical monitoring tools to assess the impact of treatment. PROs are expected to facilitate patient involvement, support patients in self-managing long-term conditions and increase health literacy. 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. 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. This digitalization creates additional risks to patient engagement and of increasing inequality in the healthcare system.

Reviews exist of factors affecting enrolment in and engagement with digital health interventions. Similarly, reviews of facilitators and barriers to implementation of PROs have been conducted. 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 and PRISMA-ScR reporting. 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.

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...
to January 2019. We defined routine use as incorporating individual patients’ PRO data into clinical practice as a part of their treatment or care. 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 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.
**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. 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.
| 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., 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) | N/A      | N/A       | N/A                                      | 6%                              | 26.5% (end of study)             | High school or less (6%)         |
| Anne-Marieke Wiggers et al., Netherlands (abstract) | Questionnaire                                                           | Cardiac rehabilitation (n = 94)      | Online questionnaire                                                          | (Not reported)                 | N/A      | N/A       | Health problems                         | 48% never used                  | 72.3 %                          | Median age (56)                   |
| Ashley et al., UK   | Feedback questionnaire                                                   | Breast, colorectal, and prostate cancer (n = 1152) | Online PRO system (ePOCS) at three points in time                           | Online questionnaire           | N/A      | N/A       | Age, IT reasons (e.g. no computer)       | 44.8%                           | 42.4 %                          | Mean age (61.3)                   |
| Bakker and Rickard, Australia | Feedback questionnaire                                                   | Depression and anxiety, MoodPrism users (n = 1349) | Mood questionnaire                                                          | MoodPrism                      | N/A      | 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., UK     | Recruitment data from mixed-methods RCT                                  | Diabetes (n = 1360, recruited n = 81) | Mobile telehealth                                                             | Diabetes-related parameters    | N/A      | N/A       | Too busy                                | 94% (73% of 300 patients due to patient-related constraints or refusal) | N/A                             |                                |
| Basch et al., 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                          | 21%                             | 15% of recruited participants at visit 5 | Median age (57)                   |
| Bauer et al., 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 anxious                            | 44%                             | 65% (no sustained use at 8 weeks) | High school or less education (26.8%) |
| Benze et al., 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 | N/A       | Too busy                                | Concerns about passive data collection | N/A                             | 15%                               |

(Continued)
| Name, country | Methods | Population | Intervention | Type of PROs | Duration | Reminders | Reasons for nonparticipation or drop out | N/A | Drop out during study | Demographics |
|--------------|---------|------------|--------------|--------------|----------|-----------|------------------------------------------|------|----------------------|-------------|
| Berry et al., USA | RCT | Cancer (n = 374) | Web-based self-report system (ESRA-C) | Symptoms and quality of life (StQOL) | N/A | Push tips | Software error | N/A | 37.7% (never used) | 37.7% (never used) |
| Bildbeck et al., 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 | N/A | Mean age (44) |
| Blocker et al., 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 | N/A | 53% (of included pt) | Mean age (70) |
| Brochmann et al., 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 | N/A | 10% of recruited, online participants | Mean age (62) |
| Chen et al., Taiwan | Pre- and post-measures of blood glucose and behaviour | Diabetes (n = 184, intervention group n = 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 | N/A | 10% never logged in | Mean age (51.3) |
| Cowan et al., 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., 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 | N/A | Mean age of Intervention group (70.2) |

(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., 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., Denmark | Interviews by telephone | Cancer (n = 55) | Online portal for patients to self-report adverse effects | Adverse effects | N/A | N/A | Too ill | N/A | 27% | Median age (61) Average e-health literacy (3.9 on 5-pt scale) |
| Echarri et al., 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., 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 | 45% | 32% | 66% older than 69 years |
| Engelhard et al., 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., Denmark | N/A | 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., 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., France | RCT | Rheumatoid arthritis (n = 320) | Self-assessment website (Sanoia) | Perceived Efficacy in Patient-Physician Interactions (PEPPR-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)
| 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., 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., Switzerland (Poster) | Three-arm study Rheumatic disease (n = 329) | App with questionnaires weekly | Symptoms reporting | 1–16 months | N/A | N/A | N/A | N/A | 50% after 1 month |
| Jamilloux et al., 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 | 14% | 18% | Mean age (42) |
| Jiang et al., 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, Too big a burden | N/A | 42.7% (low use at 12 months) | Mean age (57) |
| Kim et al., 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., 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) |
| Keewoets et al., 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., 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)
| 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.**<sup>50</sup> 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.<sup>51</sup> 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.<sup>52</sup> The Netherlands | Pretest-posttest survey + semi-structured telephone interviews | Breast cancer (n = 101) | E-health self-management application based on PROMs (OncoKompass) 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.<sup>53</sup> 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.<sup>54</sup> USA | RCT | Multiple sclerosis (n = 220) | Web-based electronic messaging system with graphical feedback (MICCO) to self-monitor quarterly and before consultations | Wellbeing | 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.<sup>55</sup> 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)
| 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., 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., Denmark | Prospective pilot study | Crohn’s disease (n = 27) | Webpage (constant-care) for weekly assessment | Disease activity | 52 weeks | N/A | Pregnancy (ex. criteria) | N/A | 37% (at follow-up at 52 weeks) 78% (completed less than 26 weeks) | Median age (38) |
| Pekola et al., 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., UK | Evaluation of use of website | Chronic kidney disease (n = 84) | Online (webpage) PRO for daily use | Well-being, pain, sleep, breathing, energy, appetite | 30 days | None | Death | 5% | 20% | Average age (59.6) |
| Raschaert et al., Belgium | Evaluation of use of tool | Oral cancer (n = 11) | Smartphone with interactive electronic self-report tool (RemeCoach) during radiotherapy | Side effects (CTCAE) | 4 weeks | None | Auditory and visual reminder | N/A | 0 | 55% | Median age (57) |
| Robotham et al., UK | Feasibility study, survey and interviews | Severe mental illness (n = 58) | Electronic questionnaire (myhealthblocker) | Mental Wellbeing (WEMWBS) | 12 months | N/A | Lack of support technical and clinically | 70% | 45% | |
| Seng et al., USA | Naturalistic longitudinal cohort study | Headache (n = 1561) | Mobile application for headach 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., 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., 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 | 8% (one participant) | 27% | Average age (58) |
| 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., 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, Forget, Disruptive in daily life | 53% | 15% | Average age (52.6) |
| Torbjørnsen et al., Norway | Three-arm RCT (RENEWING HEALTH) (HeiQ and SLT AQ measures) | Type II diabetes (n = 101) | Diary app for smartphone | 1 year | Skills to manage symptoms, skills to make use of equipment, Reduced need for monitoring with controlled disease | N/A | 26% lost to follow-up at 1 year | Median age (59) |
| van der Meer et al., The Netherlands | RCT | Asthma (n = 200) | Internet-based weekly monitoring (n = 101) | Effect (Asthma Control Questionnaire) | 1 year | N/A | Scepticism about the questionnaire itself, Reservation about digital device, Poor health, Speech problems, Language barriers, Technical barriers, Treatment discontinuation, Death | N/A | 9% | Mean age (36.3) |
| Wintner et al., 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., UK (Oral Abstract) | Evaluation | Cancer (n = 184, 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.
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 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     |

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

(Continued)
questionnaire for people with severe mental illness found that lack of clinical support was regarded as a reason for dropout.\textsuperscript{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.\textsuperscript{30} A Canadian study of questionnaires for complex chronic diseases found that some patients dropped out

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

**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 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. 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

---

**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 | 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                |
symptoms are reduced. 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 study55 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 room24 and a cohort of knee surgery patients42 – 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 issue 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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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. Issues related to trust in digital devices and data security are becoming more widely known, and privacy concerns are very important to some patients. 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. 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. 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.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

ORCID iD

Amalie Søgaard Nielsen https://orcid.org/0000-0002-2884-3902

References

1. Ishaque S, Karnon J, Chen G, et al. A systematic review of randomised controlled trials evaluating the use of patient-reported outcome measures (PROMs). Qual Life Res 2019; 28: 567–592, http://link.springer.com/10.1007/s11136-018-2016-z (accessed 26 October 2018).

2. Kingsley C and Patel S. Patient-reported outcome measures and patient-reported experience measures. BJA Educ 2017; 17(4): 137–144.

3. Dawson J, Doll H, Fitzpatrick R, et al. The routine use of patient reported outcome measures in healthcare settings. BMJ 2010; 340: c186, http://www.bmj.com/content/340/bmj.c186.abstract

4. Garratt A, Schmidt L, Mackintosh A, et al. Quality of life measurement: bibliographic study of patient assessed health outcome measures. BMJ 2002; 324(7351): 1417.

5. Porter I, Gonçalves-Bradley D, Ricci-Cabello I, et al. Framework and guidance for implementing patient-reported outcomes in clinical practice: evidence, challenges and opportunities. J Comp Eff Res 2016; 5(5): 507–519.
6. Greenhalgh J. The applications of PROs in clinical practice: what are they, do they work, and why? *Qual Life Res* 2009; 18(1): 115–123.

7. Valderas J, Kotzeva A, Espallargues M, et al. The impact of measuring patient-reported outcomes in clinical practice: a systematic review of the literature. *Qual Life Res* 2008; 17(2): 179–193.

8. Greenhalgh J, Dalkin S, Gooding K, et al. Functionality and feedback: a realist synthesis of the collation, interpretation and utilisation of patient reported outcome measures data to improve patient care. *Health Serv Deliv Res* 2017; 5(2): e005601.

9. Schamber EM, Takemoto SK, Chenok KE, et al. Barriers to completion of patient reported outcome measures. *J Arthroplasty* 2013; 28(9): 1449–1453.

10. Howell D, Molloy S, Wilkinson K, et al. Patient-reported outcomes in routine cancer clinical practice: a scoping review of use, impact on health outcomes, and implementation factors. *Ann Oncol* 2015; 26(9): 1846–1858.

11. Chen J, Ou L and Hollis SJ. A systematic review of the impact of routine collection of patient reported outcome measures on patients, providers and health organisations in an oncologic setting. *BMC Health Serv Res* 2013; 13(1): 211.

12. ViBIS. Program PRO. Anvendelse af PRO–data i kvalitetsudviklingen af det danske sundhedsvæsen – anbefalinger og vidensgrundlag, 2016, https://www.danskepatienter.dk/files/media/Publikationer%20-%20Egne/B_ViBIS/A_Rapporter%20og%20unders%C3%B8gelser/program_pro-rapport.pdf

13. O’Connor S, Hanlon P, O’Donnell CA, et al. Understanding factors affecting patient and public engagement and recruitment to digital health interventions: a systematic review of qualitative studies. *BMC Med Inform Decis Mak* 2016; 16(1): 120.

14. Antunes B, Harding R, Higginson I, et al. Implementing patient-reported outcome measures in palliative care clinical practice: a systematic review of facilitators and barriers. *Palliat Med* 2014; 28(2): 158–175.

15. Arksley H and O’Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol* 2005; 8(1): 19–32.

16. Tricco AC, Lillie E, Zarin W, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): checklist and explanation. *Ann Intern Med* 2018; 169(7): 467.

17. Duncan E and Murray J. The barriers and facilitators to routine outcome measurement by allied health professionals in practice: a systematic review. *BMC Health Serv Res* 2012; 12: 96.

18. Greenhalgh J, Gooding K, Gibbons E, et al. How do patient reported outcome measures (PROMs) support clinician-patient communication and patient care? A realist synthesis. *J Patient Rep Outcomes* 2018; 2: 42, https://jpro.springeropen.com/articles/10.1186/s41687-018-0061-6 (accessed 26 October 2018).

19. Andikyan V, Rezk Y, Einstein MH, et al. A prospective study of the feasibility and acceptability of a Web-based, electronic patient-reported outcome system in assessing patient recovery after major gynecologic cancer surgery. *Gynecol Oncol* 2012; 127(2): 273–277.

20. Anne-Marieke Wiggers JMR, Vosbergen S, Kraaijenhagen R, et al. Uptake of an online questionnaire system for cardiac rehabilitation patients: preliminary results. *Eur J Prev Cardiol* 2014; 21: S73.

21. Ashley L, Jones H, Velikova G, et al. Collecting patient reported outcome measures (PROMs) and linking with clinical cancer registry data: preliminary results from feasibility testing of a novel, UK-scalable electronic system (ePOCS). *Psychooncology* 2013; 22: 5.

22. Bakker D and Rickard N. Engagement in mobile phone app for self-monitoring of emotional wellbeing predicts changes in mental health: MoodP prism. *J Affect Disord* 2018; 227: 432–442.

23. Baron J, Hirani S and Newman S. Challenges in patient recruitment, implementation, and fidelity in a mobile Telehealth Study. *Telemed J E Health* 2016; 22(5): 400–409.

24. Basch E, Dueck AC, Rogak LJ, et al. Feasibility assessment of patient reporting of symptomatic adverse events in multicenter cancer clinical trials. *JAMA Oncol* 2017; 3(8): 1043–1050.

25. Bauer AM, Iles-Shih M, Ghomi RH, et al. Acceptability of mHealth augmentation of collaborative care: a mixed methods pilot study. *Gen Hosp Psychiatry* 2018; 51: 22–29.

26. Benze G, Nauck F, Alt-Epping B, et al. PROutine: a feasibility study assessing surveillance of electronic patient reported outcomes and adherence via smartphone app in advanced cancer. *Ann Palliat Med* 2019; 8: 104–111.
27. Berry DL, Blonquist TM, Patel RA, et al. Exposure to a patient-centered, Web-based intervention for managing cancer symptom and quality of life issues: impact on symptom distress. *J Med Internet Res* 2015; 17(6): e136.

28. Bilderbeck AC, Atkinson LZ, McMahon HC, et al. Psychoeducation and online mood tracking for patients with bipolar disorder: a randomised controlled trial. *J Affect Disord* 2016; 15205: 245–251.

29. Blocker O, Bullock A, Morgan-Jones R, et al. Using text messaging in long-term arthroplasty follow-up: a pilot study. *JMIR Res Protoc* 2017; 6(5): e88.

30. Brochmann N, Zwisler AD, Kjerholt M, et al. A new internet-based tool for reporting and analysing patient-reported outcomes and the feasibility of repeated data collection from patients with myeloproliferative neoplasms. *Qual Life Res* 2016; 25(4): 835–846.

31. Chen L, Chuang L-M, Chang C-H, et al. Evaluating self-management behaviors of diabetic patients in a telehealthcare program: longitudinal study over 18 months. *J Med Internet Res* 2013; 15(12): e266.

32. Cowan RA, Suidan RS, Andikyan V, et al. Electronic patient-reported outcomes from home in patients recovering from major gynecologic cancer surgery: a prospective study measuring symptoms and health-related quality of life. *Gynecol Oncol* 2016; 143(2): 362–366.

33. Cummings E, Robinson A, Pratt HC, et al. Pathways Home: comparing voluntary IT and non-IT users participating in a mentored self-management project. *Stud Health Technol Inform* 2010; 160(Pt 1): 23–27.

34. Drion I, Pameijer LR, van Dijk PR, et al. The effects of a mobile phone application on quality of life in patients with type 1 diabetes mellitus: a randomized controlled trial. *J Diabetes Sci Technol* 2015; 9(5): 1086–1091.

35. Due J, Christensen HG and Vestlev PM. Treatment adverse effect registration. A PC based electronic patient – hospital communication portal that allows registration of adverse effects of chemotherapy and returns advice and recommendations for action. *Cancer Res* 2015; 75: P2-10-02, http://cancerres.aacr-journals.org/content/75/9_Supplement/P2-10-02?sid=d6b4efa4-d277-4496-b085-0e9ca8688fb0

36. Echarri A, Vera I, Guardiola J, et al. Crohn’s disease and self-monitoring through a mobile app: the medicrohn study. *J Crohns Colitis* 2018; 12(1): S273.

37. Elves A, Dunk S, Perry S, et al. A patient centred, self-management app providing digital support and follow up care for citizens with prostate cancer. *J Clin Urol* 2018; 11: 26.

38. Engelhard MM, Patek SD, Sheridan K, et al. Remotely engaged: lessons from remote monitoring in multiple sclerosis. *Int J Med Inform* 2017; 100: 26–31.

39. Faurholt-Jepsen M, Frost M, Vinberg M, et al. Smartphone data as objective measures of bipolar disorder symptoms. *Psychiatry Res* 2014; 217(1–2): 124–127.

40. Girgis A, Durcinoska I, Levesque JV, et al. eHealth system for collecting and utilizing patient reported outcome measures for personalized treatment and care (PROMPT-Care) among cancer patients: mixed methods approach to evaluate feasibility and acceptability. *J Med Internet Res* 2017; 19(10): e330.

41. Gossec L, Cantagrel A, Soubriere M, et al. An e-health interactive self-assessment website (Sanoia) in rheumatoid arthritis. A 12-month randomized controlled trial in 320 patients. *Jt Bone Spine* 2018; 85: 709–714, 10.1016/j.jbspin.2017.11.015

42. Howard JS, Toonstra JL, Meade AR, et al. Feasibility of conducting a web-based survey of patient-reported outcomes and rehabilitation progress. *Digit Health* 2016; 2: 1–10.

43. Jaeger VK, Schiffer P, Zufferey P, et al. Patient’s self-monitoring of disease activity of rheumatic diseases via webapp-study design, patient’s perspective and recruitment in the first 11 months of the Swiss multicentre, longitudinal compass ii study. *Ann Rheum Dis* 2017; 76(Suppl. 2): 1445.

44. Jamilloux Y, Sarabi M, Kerever S, et al. Adherence to online monitoring of patient-reported outcomes by patients with chronic inflammatory diseases: a feasibility study. *Lupus* 2015; 24(13): 1429–1436.

45. Jiang Y, Sereika SM, Dabbs AD, et al. Acceptance and use of mobile technology for health self-monitoring in lung transplant recipients during the first year post-transplantation. *Appl Clin Inform* 2016; 7(2): 430–445.

46. Kim ES, Kim SK, Jang BI, et al. Disease activity patterns recorded using a mobile monitoring system are associated with clinical outcomes of patients with Crohn’s disease. *Dig Dis Sci* 2018; 63(9): 2220–2230.
47. Kjær ASHK, Rasmussen TA, Hjollund NH, et al. Patient-reported outcomes in daily clinical practise in HIV outpatient care. *Int J Infect Dis* 2018; 69: 108–114.

48. Koevoets R, de Glas NA, le Bourlout C, et al. Autonomous online health assessment questionnaire registry in daily clinical practice. *Rheumatology (Oxford)* 2013; 52(5): 883–887.

49. Lauritsen L, Andersen L, Olsson E, et al. Usability, acceptability, and adherence to an electronic self-monitoring system in patients with major depression discharged from inpatient wards. *J Med Internet Res* 2017; 19(4): e123.

50. Li J, Yazdany J, Trupin L, et al. Capturing a patient-reported measure of physical function through an online electronic health record patient portal in an ambulatory clinic: implementation study. *JMIR Med Inform* 2018; 6(2): e31.

51. Maier A, Holm T, Wicks P, et al. Online assessment of ALS functional rating scale compares well to in-clinic evaluation: a prospective trial. *Amyotroph Lateral Scler* 2012; 13(2): 210–216.

52. Melissant HC, Verdonck-de Leeuw IM, Lissenberg-Witte BI, et al. ‘Oncokompas’, a web-based self-management application to support patient activation and optimal supportive care: a feasibility study among breast cancer survivors. *Acta Oncol* 2018; 57(7): 924–934.

53. Michaud K, Schumacher R, Wahba K, et al. Are Rheumatic disease patient reported outcomes collected passively and directly through smart phones feasible? Early results from a nation-wide pilot study. *Ann Rheum Dis* 2014; 73(Suppl. 2): 455–456, 10.1136/annrheumdis-2014-eular.4581

54. Miller DM, Moore SM, Fox RJ, et al. Web-based self-management for patients with multiple sclerosis: a practical, randomized trial. *Teled Med J E Health* 2011; 17(1): 5–13.

55. Min YH, Lee JW, Shin Y-W, et al. Daily collection of self-reporting sleep disturbance data via a smartphone app in breast cancer patients receiving chemotherapy: a feasibility study. *J Med Internet Res* 2014; 16(5): e135.

56. Montserrat JM, Setta V, Fernando M, et al. Web-based follow-up of CPAP compliance in obstructive sleep apnea syndrome. *Sleep Biol Rhythms* 2011; 9(4): 298.

57. Pedersen N, Elkjaer M, Duricova D, et al. eHealth: individualisation of infliximab treatment and disease course via a self-managed web-based solution in Crohn’s disease. *Aliment Pharmacol Ther* 2012; 36(9): 840–849.

58. Peltola MK, Lehikoinen JS, Sippola LT, et al. A novel digital patient-reported outcome platform for head and neck oncology patients—a pilot study. *Clin Med Insights Ear Nose Throat* 2016; 9: 1–6.

59. Pittman ZCL, John SG and McIntyre CW. Collection of daily patient reported outcomes is feasible and demonstrates differential patient experience in chronic kidney disease. *Hemodial Int* 2017; 21(2): 265–273.

60. Rasschaert M, Helsen S, Rolfo C, et al. Feasibility of an interactive electronic self-report tool for oral cancer therapy in an outpatient setting. *Support Care Cancer* 2016; 24(8): 3567–3571.

61. Robotham D, Mayhew M, Rose D, et al. Electronic personal health records for people with severe mental illness; a feasibility study. *BMC Psychiatry* 2015; 15: 192, https://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2015-36722-001&site=ehost-live

62. Seng EK, Prieto P, Boucher G, et al. Anxiety, incentives, and adherence to self-monitoring on a mobile health platform: a naturalistic longitudinal cohort study in people with headache. *Headache* 2018; 58: 1541–1555.

63. Sevick MA, Stone RA, Zickmund S, et al. Factors associated with probability of personal digital assistant-based dietary self-monitoring in those with type 2 diabetes. *J Behav Med* 2010; 33(4): 315–325.

64. Steele Gray C, Gill A, Khan AI, et al. The electronic patient reported outcome tool: testing usability and feasibility of a mobile app and portal to support care for patients with complex chronic disease and disability in primary care settings. *JMIR mHealth uHealth* 2016; 4(2): e58.

65. Steinert A, Eicher C, Haesner M, et al. Effects of a long-term smartphone-based self-monitoring intervention in patients with lipid metabolism disorders. *Assist Technol off J RESNA* 2018; 32: 109–116.

66. Torbjørnsen A, Småstuen MC, Jenum AK, et al. Acceptability of an mHealth app intervention for persons with type 2 diabetes and its associations with initial self-management: randomized controlled trial. *JMIR mHealth uHealth* 2018; 6(5): e125.
67. van der Meer V, van Stel HF, Bakker MJ, et al. Weekly self-monitoring and treatment adjustment benefit patients with partly controlled and uncontrolled asthma: an analysis of the SMASHING study. *Respir Res* 2010; 11: 74.

68. Wintner LM, Giesinger JM, Zabernigg A, et al. Evaluation of electronic patient-reported outcome assessment with cancer patients in the hospital and at home. *BMC Med Inform Decis Mak* 2015; 15: 110.

69. Wright P, Ashley L, Jones H, et al. Collecting and linking patient reported outcomes to clinical and cancer registration data: preliminary results from a feasibility study using the electronic patient reported outcomes (ePOCS) system. *Asia Pac J Clin Oncol* 2012; 8(Suppl. 3): 142.

70. Braun V and Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; 3(2): 77–101.

71. Bartlett G, Tamblyn R, Kawasumi Y, et al. Non-participation bias in health services research using data from an integrated electronic prescribing project: the role of informed consent. *Acta Bioethica* 2005; 11(2): 145–159.

72. Chuttur M. Overview of the technology acceptance model: origins, developments and future directions. *Sprouts Content* 2009; 9: 290.

73. Sanders C, Rogers A, Bowen R, et al. Exploring barriers to participation and adoption of telehealth and telecare within the whole system demonstrator trial: a qualitative study. *BMC Health Serv Res* 2012; 12(1): 220.

74. Davis FD, Bagozzi RP and Warshaw PR. User acceptance of computer technology: a comparison of two theoretical models. *Manag Sci* 1989; 35(8): 982–1003.

75. Abdelhamid M, Gaia J and Sanders GL. Putting the focus back on the patient: how privacy concerns affect personal health information sharing intentions. *J Med Internet Res* 2017; 19(9): e169.

76. Norgaard O, Furstrand D, Klokker L, et al. The e-health literacy framework: a conceptual framework for characterizing e-health users and their interaction with e-health systems. *Knowl Manag e-Learn* 2015; 7: 522–540.

77. Mercieca-Bebber R, Palmer MJ, Brundage M, et al. Design, implementation and reporting strategies to reduce the instance and impact of missing patient-reported outcome (PRO) data: a systematic review. *BMJ Open* 2016; 6(6): e010938, http://bmjopen.bmj.com/content/6/6/e010938.abstract

78. Clemensen J, Larsen SB, Kyng M, et al. Participatory design in health sciences: using cooperative experimental methods in developing health services and computer technology. *Qual Health Res* 2007; 17(1): 122–130.