REVIEW ARTICLE

The usefulness and acceptability of a personal health record to children and young people living with a complex health condition: A realist review of the literature

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Funding information
Marie Curie Cancer Care, Grant/Award Number: MCCC-RP-16-A21003

Abstract

Background: There are a growing number of children and young people (CYP) with chronic health needs or complex disabilities. Increasingly, CYP with life-limiting or life-threatening conditions are surviving into adulthood. Communication between CYP, their family, and health professionals can be challenging. The use of a personal health record (PHR) is one potential strategy for improving communication by promoting CYP's health advocacy skills. However, PHR implementation has proved difficult due to technical, organisational, and professional barriers. The aim of this realist review is to identify the factors, which help or hinder the use of PHRs with CYP living with a complex health condition.

Methods: Systematic realist review. Literature was sourced from six databases: Medline, Embase, CINAHL, PsychInfo, The Cochrane Library, and Science Direct (from 1946 to August Week 3 2018). The web was searched to identify grey literature. Articles were sourced from reference lists of included studies. Data were extracted using a standardised data extraction form. Two reviewers completed data extraction and synthesis. Methodological rigor was assessed using the relevant Critical Appraisal Skills Programme tool.

Results: Nine articles were included. Contextual factors, which helped implementation, included the CYP having a high perception of need for a PHR and a high level of desire for self-management. Service providers and CYP need knowledge about the purpose and benefits of the PHR, and organisations need a dedicated person to facilitate PHR use. Mechanisms triggered by the PHR included improved understanding and knowledge of health care condition(s) for CYP, an increased feeling of control over condition(s), and more active engagement in their health care. Outcomes for CYP included improved self-advocacy and communication.

Conclusion: Clearer definitions of which young people would benefit from using a PHR must be established to inform which organisations and service providers would be best suited to PHR implementation.

1 | INTRODUCTION

There are a growing number of children and young people (CYP) with complex health needs and/or disabilities (Crowley, Wolfe, Lock, & McKee, 2011), and CYP with life-limiting or life-threatening conditions are now surviving into adulthood (Fraser et al., 2012). There is consensus that CYP have the right to be fully involved in decisions about their care (Coyne, Hallström, & Söderbäck, 2016; Department of Health, 2012; Viner, 2008), including decisions to limit treatment (Larcher, Craig, Bhogal, Wilkinson, & Brierley, 2015). In addition, their views on what matters to them must be given due weight in accordance with Article 12 of the United Nations Convention on the Rights of the Child (1989). Despite this, the quality of communication within multidisciplinary services is highly variable (Williams et al., 2011). CYP and their families report significant difficulties in discussing their preferences for care, with fragmentation of services forcing them to repeat their story to different professionals, due to their medical data being dispersed over multiple records (Abbott, 2014; Hunt et al., 2013). This can make the provision of optimal care for CYP more difficult. Improving the health advocacy of CYP and/or their parents is one method for overcoming such communication difficulties, by empowering CYP to take the lead in the process of decision making, speak about their preferences for care, and ask questions about the management of their health condition (Harrison & Davies, 2009).

The use of a personal health record (PHR) is a potential strategy for improving CYP's health advocacy skills and access to care (Nguyen, Bartlett, Rodriguez, & Tellier, 2016). PHRs are designed to promote self-management by empowering patients to take more control over their health condition; improve communication amongst patients, their families, and health professionals; and facilitate the coordination of care. PHRs range from stand-alone products, with information entered by the patient and/or the clinician, to those linked to official electronic health records (EHRs; Cruickshank, Packman, & Paxman, 2012). They contain key information regarding the individual's communication, medical, and support needs and are completed by the patient or by those who support them, such as a parent or carer. Paper versions are referred to as patient-held records, patient passports, hospital passports, or hand-held health records and electronic versions are referred to as EHRs or patient portals. The PHR can be used in a range of situations, such as during an admission to the emergency department, during consultations with health care professionals, and may also be used as an evolving source of information to support the CYP, and their support network be actively involved in self-management.

The proposed benefits of PHRs include the patient having improved access to credible information about their condition, being able to keep track of a chronic illness in conjunction with a health care provider, and the promotion of earlier intervention for potential issues (Tang, Ash, Bates, Overhage, & Sands, 2005). However, there is mixed evidence on the effectiveness of PHRs (Archer, Fevrier-Thomas, Lokker, McKibbon, & Straus, 2011; Cornbleet, Campbell, Murray, Stevenson,, & Bond, 2002; National Information Board, 2014) with, for example, anecdotal evidence to suggest that a PHR can help improve communication (Bell, 2012). Major projects based on electronic PHRs (ePHR) have also been unsuccessful due to technical and professional barriers, and a lack of self-care information tailored to the needs of the PHR holder (Greenhalgh, Hinder, Stramer, Bratan, & Russell, 2011). PHRs are a complex intervention, with implementation and effectiveness affected by user characteristics, organisational issues, and interpersonal or professional barriers (Archer et al., 2011; Sartain, Stressing, & Prieto, 2015).

To date, few studies have evaluated the usefulness of a PHR for CYP or examined the factors, which help or hinder implementation of the PHR into practice. Therefore, the aim of this review was to identify factors that may help or hinder the implementation of PHRs with CYP managing a health condition. We chose a realist review approach as this is designed to explain the success or failure of complex interventions, such as PHRs (Wong, Greenhalgh, Westhorp, Buckingham, & Pawson, 2013).

1.1 | Realist review

A realist literature review is a theory-driven systematic review of the literature, which aims to make explicit the underlying assumptions about how an intervention is supposed to work (Pawson, Greenhalgh, Harvey, & Walshe, 2005; Rycroft-Malone et al., 2012). The purpose is to identify the theory behind an intervention and develop an understanding of how an intervention may alter the context (C) into which it is implemented, which subsequently triggers mechanisms (M), which may produce either intended or unintended outcomes (O). Context includes the physical, organisational, and social situation in which the PHR is used (Pawson & Tilley, 1997). Mechanisms are the beliefs, reasoning, motivations, and choices of those involved in the use of the intervention, which result in observed outcomes (Archer, 2003; Higgins, O'Halloran, & Porter, 2015). A critical analysis of the interaction among context, mechanism, and outcome (characterised as CMO configurations) is then completed with a sample of identified studies (Wong et al., 2013).

This review seeks to identify the theories, which underpin the intervention (PHRs), the mechanisms at work, and the associated outcomes such mechanisms produce. The aim was to produce recommendations useful to those involved in the production, implementation, and evaluation of PHRs about what was needed to help promote initial use of a PHR by CYP and/or their parents, the features the PHR should include to sustain use, and in which contexts the PHRs

would most likely trigger mechanisms that produce the desired outcomes.

1.2 | Objectives

The objectives of the review were as follows:

1. Identify the programme theories in relation to PHRs.

2. Identify factors that may help or hinder the implementation of PHRs, with reference to the following:

- The characteristics of the intervention
- The outer and inner contexts for implementation
- The characteristics of the individuals involved
- The implementation process (Damschroder et al., 2009)

- Construct context-mechanism-outcome configurations to help explain how the PHR may work.

2 | METHODS

2.1 | Data sources

2.1.1 | Inclusion and exclusion criteria

Articles were included if they addressed the evaluation of PHRs for use with CYP aged 0 to 24 years old, with any health condition. CYP could be attending children's health care services or have transitioned to adult health care services, and the PHR could be utilised by either the CYP themselves or their parent/carer. Originally, the review intended to focus on the evaluation of PHRs for CYP with a life-limiting or life-threatening conditions but as only one study was identified, the criteria were extended to include any health condition. Studies that only described the development of a PHR and documents not in English were excluded (no access to translation services). Articles related to PHRs for recording information on infant/vaccination records or to PHRs with adults aged 24 years and over were also excluded. We placed no restriction on organisational or geographic location of the studies as PHRs are typically made available in countries with relatively well-developed health care systems, which are likely to feature overlapping organisational and cultural issues.

2.1.2 | Resources searched

Six databases (from 1946 to August Week 3 2018) were searched using the relevant search terms or MESH/Thesaurus/Keyword headings for each database: Medline, Embase, CINAHL, PsychInfo, The Cochrane Library, and Science Direct. Medline search terms (which were adapted for other databases) are provided in Table 1. The World Wide Web to include Google Scholar was also searched using the search terms "PHRs" and "implementation" to identify grey literature. Forward citation tracking of articles was carried out to provide

Key Messages

- Personal health records (PHRs) have the potential to produce beneficial outcomes for children and young people (CYP).

- Beneficial outcomes include improvements in their health advocacy, improved understanding of their condition, better control over management of their condition, and improved relationships and communication with health care providers.

- However, organisational support must be in place to ensure longer-term sustainability of PHR implementation.

- PHRs also need to meet the needs of the user to ensure implementation success and clear definitions of which children and young people would benefit from using a PHR must be established.

- Further research is needed to evaluate the use of PHR's by CYP themselves, in particular those with life-limiting or life-threatening conditions.

the richest contribution to programme theories, and their references lists were also searched. The selection of search terms was based on similar review articles and an initial scoping review of the literature.

2.1.3 | Identifying primary sources

The initial search of the databases resulted in 785 articles (Figure 1). Four articles were identified through the search of the grey literature and reference lists. Titles and abstracts were reviewed by two reviewers to assess if the content focused on an evaluation of a PHR. After the removal of duplicates, 420 articles were screened and 384 excluded. Two reviewers screened the 36 full-text texts and assessed them for eligibility. In total, 27 articles were excluded; 12 articles did not carry out an evaluation of the PHR, nine included the wrong patient population, and six were conference abstracts. Nine articles were included for data extraction and synthesis.

2.1.4 | Data extraction and appraisal

A standardised data extraction form developed for a previous realist review was used to extract data (O'Halloran, Scott, Reid, & Porter, 2014). This form included sections related to realist assessment (see Table 2). Realist reviews include a broad spectrum of studies, but the quality of studies is used to moderate findings. The methodological quality of empirical studies was assessed using the appropriate appraisal tools from the Critical Appraisal Skills Programme (see Table 2).

TABLE 1 Medline search strategy

1. Young adult.mp.
2. Pediatric.mp. or exp PEDIATRICS/
3. Paediatric.mp.
4. (Children and young people).mp. [mp = title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading]
5. Teen*.mp.
6. Adolescen*.mp.
7. Juvenile.mp.
8. Youth.mp.
9. Child*.mp.
10. Young person*.mp.
11.1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10
12. Personal health record.mp.
13. (Held adj2 record).mp. [mp = title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading]
14. (Personal adj3 record).mp. [mp = title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading]
15. Personal record.mp.
16. Medical records, personal.mp.
17. Health records, personal.mp.
18.12 or 13 or 14 or 15 or 16 or 17
19.11 and 18
20. Limit 19 to (human and english language and yr = "1946–2018")

FIGURE 1 Flow diagram illustrating the search process

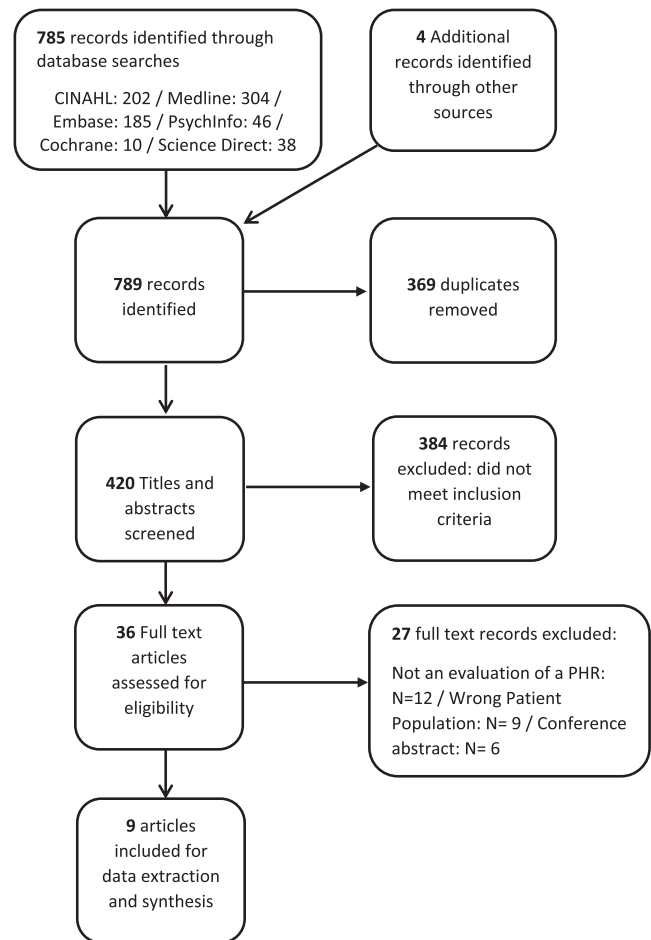## 2.1.5 | Identifying CMO configurations

Programme theories were identified through a close reading of texts by three reviewers. Explicit theories were noted and, where absent, implicit theories deduced from the elements of the interventions. Data synthesis was an iterative process and involved the three reviewers independently assessing each article, identifying common components from the data extraction forms, and reflecting on programme theories before coming together to discuss findings and achieve a consensus regarding the utility of each.

3 | RESULTS

Nine articles were included. A summary of the study objectives, population, intervention, design, results, and information on how the intervention is intended to work along with a description of the contextual factors thought to influence implementation are presented in Table 2.

3.1 | Study design and methodological quality

The included articles had a range of study designs including a randomised controlled trial (McPherson, Ware, Carrington, & Lennox, 2017), mixed methods (Byczkowski, Munafo, & Britto, 2014; Fiks, Mayne, Karavite, DeBartolo, & Grundmeier, 2014; Forchuk et al., 2016; King et al., 2017; Noyes et al., 2013), and qualitative (Bush, Stahmer, & Connelly, 2016; Piras & Zanutto, 2014; Schneider, Hill, & Blandford, 2016). Three articles were rated as having strong methodological rigour, and six were rated as having moderate rigour.

3.2 | Populations

One article focused on adolescents with an intellectual disability who were registered with a special educational school or unit (McPherson et al., 2017), one on young people with depressive symptoms (Forchuk et al., 2016), and one on CYP with complex health and palliative needs and their parents (Noyes et al., 2013). Four articles reported on parents of children with a long-term condition including cystic fibrosis, diabetes mellitus, juvenile idiopathic arthritis, and asthma (Byczkowski et al., 2014; Fiks et al., 2014; Piras & Zanutto, 2014; Schneider et al., 2016), one on caregivers of children admitted to a rehabilitation unit (King et al., 2017), one on parents of a child with autistic spectrum diagnosis (Bush et al., 2016).

TABLE 2 Summary of included studies

Author(s), country, and objectives	Population, setting, and intervention	Design and methodological rigour	Key results
Bush, Stahmer, and Connelly, (2016) USA To obtain the perspectives of parents whose children have autistic spectrum disorder (ASD) on the utility of the electronic health record (EHR) as an instrument in their children's treatment.	Parents who had a child less than 19 years old, with a previous diagnosis of ASD recorded in their medical file and had been a patent at a tertiary academic children's hospital. Tertiary academic children's hospital in southern California. Intervention: MyChart is the EHR's linked patient portal providing secure messaging, appointment scheduling, result reporting, and health information.	Qualitative: telephone interviews. Rigour: Moderate: small sample of nine mothers, however, data saturation was proposed to have been reached by nine participants. Not clear who conducted the interviews.	Six respondents had familiarity with the EHR, and three were not familiar with it. For parents who used EHR: Changes in care included a more streamlined approach with fewer difficulties when making appointments, easier and faster access to records, increased sharing of medical information across providers within the children's hospital with more clinicians aware of the type, complexity and frequency of treatment sought, without the parent having to verbally introduce their child's medical record. Parents who did not use EHR explained it was difficult to register and required a two-step, in person process to gain access (often lost their password) and found it was not easy to view it on a smart phone. The number and variety of medical appointments also were a challenge for the scheduling system within the EHR. Not being able to share treatment approaches and outcomes with the multitude of providers that are part of their children's care team was a significant limitation. Majority of parents had no concerns about confidentiality.
Byczkowski, Munafo, and Britto, (2014) USA To measure and understand among parents of children with chronic conditions, their perceptions of usability and value, and their concerns about using a web-based portal to access their child's health records.	Five hundred thirty parents of children with one of three chronic conditions: cystic fibrosis, diabetes mellitus, and juvenile idiopathic arthritis. Disease specific outpatient clinics within a tertiary children's hospital. Intervention: Web-based portal through which parents can access information about their child's health including laboratory results, medication information, and visit history. Content is disease specific, so parents can easily find the information most relevant to	Mixed methods: Telephone survey with portal users and semistructured interviews with parents who had enrolled in but used it less than three times in the year. Rigour: Moderate: adequate response rate and large sample size, but report of validation of survey questionnaire lacks detail.	Majority of parents used the portal once a month (53%): 56% felt reassured that they did not always have to rely on others for medical information about their child's condition. In general, parents found it was easy to use, and the information included in it was useful, accurate, and timely. More than one of three (39%) used the portal to send emails to health care providers. Majority of parents did not have concerns about confidentiality; 2% reported they had seen information they wish they had not

TABLE 2 (Continued)

Author(s), country, and objectives	Population, setting, and intervention	Design and methodological rigour	Key results
	their child. Other capabilities include secure messaging to health care providers, the ability to upload documents to share with health care providers (e.g., school-related forms), and reminders for laboratories and clinic visits. Designed using family input and refined with formal usability methods.		seen, 12% reported they had seen information which frightened them, 11% seen information they would have preferred to get directly from the health care provider. Seventy percent parents felt the portal helped to improve their understanding of and ability to manage their child's condition; 43% agreed the portal improved their relationship with child's health care provider and how they make health care decisions for their child (43%). A higher number of outpatient visits was associated with parents agreeing the portal improved how they make health care decisions for their child.
Fiks et al. (2014) USA To evaluate the determinants of implementation success for a portal in paediatric primary care to facilitate communication between families and clinicians regarding treatment concerns and goals, asthma symptoms, medication use, and side effects.	Parents of children aged 6–12 years old with asthma. Primary care. Intervention: MyAsthma provides educational material, enables sharing of families' treatment concerns, goals, asthma symptoms, medication adherence, and side effects with the primary care clinical team; tracks asthma control over time for families through the portal and clinicians through the PHR and provides decision support to both families and clinicians regarding asthma control and side effects. The portal was developed through a user-centred process and is embedded within an existing patient portal. Families interact with the portal through a web interface, and decision support is provided on screen to families and via fax to practices based on asthma control survey results.	Mixed methods implementation study Rigour: Strong: Although there is sufficient information on statistical analysis, there is more limited information on qualitative analysis. Results well described.	Out of 9,133 eligible patients, 237 (2.59%) completed the portal asthma control survey at least once (adoption); 156 (65.8%) of portal adopters, (1.71% eligible parents) completed the portal survey more than once (sustained use). Portal users were more likely to have children aged 6–9 years, to be white, to be privately insured, to have mild persistent or moderate or severe persistent asthma, to be on asthma controller medication, and to be receiving a greater number of asthma medications at baseline on average than those who did not use the portal. Those with persistent asthma were twice as likely to use the portal versus those with intermittent asthma. Sustained portal users more likely than one time users to have children who were Hispanic, have private insurance, and be from the Northeast, and have higher education levels. Characteristics positively associated with portal adoption included: receipt of a

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TABLE 2 (Continued)

Author(s), country, and objectives	Population, setting, and intervention	Design and methodological rigour	Key results
			controller medication at baseline, private insurance, and greater asthma severity. Those with uncontrolled asthma planned positive changes in their management of the condition after portal use. Follow-up surveys showed 22% reported a medication change, 41% reported contacting their child's doctor, and 16% reported making changes to their child's environment.
Forchuk et al. (2016) Canada To assess the usability and acceptability of an electronic patient held record (ePHR) among patients and care providers.	Young people aged 16 to 21 years old with depressive symptoms. Mental health care providers. Intervention: Lawson Smart Record (LSR) is a web-based application that provides individuals with an ePHR in which people can store, maintain, and manage their personal health information. It can contain a medication list, family history, immunization record, allergies, care provider contact information, care plans, and crisis plans. Care providers can also enter information into their patient's LSR. It also provides interactive tools to help them manage their mental health, such as mood assessments, a mood monitor, and symptom tracking. Patients and health care providers attend separate training sessions during, which they are provided with a manual and taught how to use the LSR.	Mixed methods design: questionnaire and focus groups. Rigour: Moderate—not clear who administered the questionnaires or where they were completed. No detail on where focus groups were conducted. Lack of detail on analysis.	Of eight care providers who responded, four used the LSR often (a few times a week) and the remaining used the LSR frequently (daily) to rarely (less than once a month). Patients managing more severe mental illness and those receiving more intensive treatment programs had more frequent use of the LSR. Patients most commonly used the LSR for tracking moods and behaviours as compared with the other functions. LSR use increased self-awareness and autonomy because of the mood tracking function. Therapeutic boundaries changed because of the ability for clients and care providers to initiate and respond to communication via the LSR at any time. Patients reported that LSR facilitated communication with care providers outside of regularly scheduled appointments and improved communication during appointments. Mood monitoring and diary capabilities fitted well with treatment requirements of Dialectical behaviour therapy (DBT) and cognitive behavioural therapy (CBT). Completion of the diary on a mobile device was more appealing to young people.
King et al. (2017) Canada To examine the use, utility, and impact on engagement in care and caregiver-provider communication of a client/family portal	Caregivers of children admitted to a rehabilitation hospital. Five service providers. Intervention: Consumer health portal (connect2care) that provides electronic	Prospective mixed methods study: quantitative survey and focus groups Rigour: Moderate: location of interviews/focus groups not provided. Not clear who conducted the interviews. Short period	Caregivers: portal useful to provide and easy and timely access to their child's medical history, reports, and appointments. Appreciated having detailed information and knowing the technical language as they felt they could

(Continues)

TABLE 2 (Continued)

Author(s), country, and objectives	Population, setting, and intervention	Design and methodological rigour	Key results
providing access to electronic health records (EHRs) and secure, two-way e-messaging with care providers.	access to medical records, online appointment cancelling and booking features, access to clinical documentation, and secure e-messaging to connect with their care providers. Functions include the ability to view the client's schedule, visit history, view and print clinical notes, and update demographic details. Training on the EHR provided to over 100 health care providers.	between the two measurement points (6–8 weeks); a longer period of time may be needed to demonstrate impact of the portal.	communicate on an equal playing field with providers. Evidence that the portal facilitated caregivers' perceptions of engagement in care was not strong. Service providers indicated they saw little evidence of increased engagement. Service providers: saw utility of portal for appointment setting and secure messaging. Technical shortcomings were identified including a lack of notification about emails, no ability to post vacation messages or upload attachments. Changes in format occurred when reports from clinical systems were uploaded to connect2care. Uncertainties in portal use were reported including a lack of knowledge, comfort, and confidence in using the portal. There was a low level of perceived use by families, and it was questioned whether it was worth investing time in the portal. Main difference between caregivers and service providers: caregivers focused on future potential of the portal and wanted to see organisation wide adoption.
McPherson, Ware, Carrington, and Lennox (2017) Australia To determine whether a school-based education/health intervention package, compared with usual care, increased the self-advocacy of adolescents with intellectual disability regarding their health.	Adolescents aged 10–18 years with an intellectual disability, and registered at a Special Education School (SES) or Special Education Unit (SEU). Special education school/Special Education Unit. Intervention: School-based health intervention package consisted of "Ask Health Diary" and the Comprehensive Health Assessment Program health check (systematic recording of a health history prior to health check consultation and a subsequent agreed action plan). "Ask health Diary": contains four sections to record personal details, track problematic areas such as menstruation, bowl and	Parallel-group cluster randomised controlled trial: 247 control participants and 345 intervention participants completed baseline survey. Health advocacy skills measured by carer questionnaire prior to commencement of intervention and at least 12 months after. Rigour: Moderate: concealed randomisation and blind assessment of outcome measures. No sample size calculation; no report that the questionnaire was piloted/validated; multiple comparisons with no attempt to correct.	Larger increases in health advocacy were found in adolescents in the intervention group (increased adolescent confidence in going to the doctor and speaking for themselves without carer assistance). Carers reported the young person was more likely to go into the doctor without them, more likely to explain their health problems to the doctor without their help and more likely to ask questions if they did not understand the doctor. Carers in the intervention group felt they had increased knowledge and improved ability to support the young person. Carers of SEU students reported significantly higher gains for their adolescent having a health check

(Continues)

TABLE 2 (Continued)

Author(s), country, and objectives	Population, setting, and intervention	Design and methodological rigour	Key results
	bladder, and other relevant issues, to provide information to doctors about unrecognised conditions and practical tips and to record details on diagnoses, operations, medications, consultations, etc.		than SES carers, including greater awareness of previously undiagnosed conditions. Increased self-determination behaviours for students with more severe disabilities in comparison with more able SEU students; carers reported they were more likely to go into the doctor's office on their own and ask questions if they did not understand.
Noyes et al. (2013) United Kingdom To develop and evaluate the "My Choices" booklets for use by parents and children to facilitate thinking and engagement with future care planning	Children and young people with complex health and palliative needs, parents, and multi-agency palliative care professionals. Children's complex health and palliative care NHS and social services, and not-for-profit organisations in North Wales. Intervention: Booklets were intended to help children and young people in age-appropriate ways, and help parents to think about their care now and in the future, consider care choices and preferred locations of care, facilitate discussion within families and with health care professionals, and to keep a record that can be added to over time.	Mixed methods implementation: interviews and pre and post study questionnaires. Rigour: Strong. Mixed methods approach justified and clearly described. Not clear who conducted interviews. Small sample. Six months may not be long enough for an evaluation period.	Parents and children fell into three groups: (i) those that liked the booklets and felt they could use them to record information, (ii) those that were positive about the purpose of the booklets as a framework for thinking about care options, (iii) those that did not feel able to think about the future or future care planning or where cynical as to whether the NHS would be responsive to their plans and ideas about to manage their child's care. Sceptical young people and parents experienced low levels of partnership and participation due to the culture of state provided services, which did now empower families to decide for themselves (lack of child centredness). They also lacked clarity about the purpose of the booklets and confused them with assessments and application forms. Parents who were more receptive mostly used the booklets as a way of raising their own awareness about care planning, and some had already used the booklets to think about planning for their child's transition to adult services. Only one of 20 health care professionals reported that parents or children/young people shared their completed "My Choices" booklets with them. Some health care professionals found future care planning and raising sensitive issues with children challenging and were concerned about getting it right.
Piras and Zanutto (2014) Italy	Patients aged between 4 and 20 years old with some years' experience of managing diabetes	Qualitative study: pre-post analysis.	Delegation of the use of DIAB-PHR to children (previously, the parents would have

(Continues)

TABLE 2 (Continued)

Author(s), country, and objectives	Population, setting, and intervention	Design and methodological rigour	Key results
To determine whether paper-based logbooks for patients could be replaced with an electronic instrument and to test forms of remote monitoring by doctors.	and with an onset of diabetes before the age of 6 years. Paediatrics department. Intervention: DIAB-PHR consists of a logbook application for patients' smartphones (the PHR) and a dashboard for data visualisation for doctors, which is also accessible to family members. It is designed to replace a paper-based logbook. Patients can keep track of all the information related to their diabetes (measurements, therapy, symptoms, and annotations) and share it with their hospital doctors.	Rigour: Moderate: Interviews in first phase conducted by persons who usually cared for diabetes patient—possible bias.	completed the logbooks): Parents felt children had greater understanding of technologies and need to become more autonomous. Patient satisfaction was due to having a perception of greater control over their diabetes and being able to see trends over time. The PHR provided the necessary information to estimate glycated haemoglobin trend (main indicator used by doctors during consultation to evaluate control of disease) and provides information for self-evaluation ahead of contact with doctors.

Data entry became part of everyday activity instead of one set time of day (as with paper logbook) and was no longer a cooperative activity between parent and child—the child took control over the entry of the data. There was also a reduction in the role of the parent in analysing the data. The tool that gave parents access to the information without having to use their children's application was entirely ignored. The telemonitoring option was an unwanted channel of communication. |
| Schneider, Hill, and Blandford (2016) United Kingdom

To better understand patients' lived experiences with a patient-controlled electronic health record (PCEHR) and how the use of such a technology may lead to patient empowerment. | Families of a child managing a serious chronic condition. Two departments within a Specialist Children's Hospital, United Kingdom: one specialising in intestinal failure (Department A) and one in inflammatory bowel disease (Department B). Intervention: Patient controlled Electronic Health Record (PCEHR): "Patients Knows Best." It allows patients and clinicians to upload, enter, view, and edit various health data (e.g., symptoms, medications, diagnoses, and test results and measurements). Also | Qualitive field study. Rigour: Strong: aims clear and design appropriate. Not clear who conducted the interviews. No consideration of how location of interviews may have influenced responses. | Differences between the PCEHR needs of patient families were based on their motivation to take responsibility and control of their health management. Three groups established: the controller, the collaborators, and the avoiders. One patient family used the portal more than others (the controller): This family reported more negative experiences with health care providers. Perceived relatedness of family was low, and they had low perceived completeness (worry about doing it right). |

3.3 | Objectives of included studies

The objectives of the studies included (a) investigation of whether the PHR increased self-advocacy or patient empowerment (McPherson et al., 2017; Schneider et al., 2016), (b) exploration of the perceptions of the usability and/or acceptability of using a PHR (Bush et al., 2016; Byczkowski et al., 2014; Forchuk et al., 2016), (c) to determine if a paper-based logbook could be replaced with an electronic alternative (Piras & Zanutto, 2014), (d) to examine the use, utility, and impact on engagement in care and caregiver–provider communication of a client/family portal providing access to EHRs (King et al., 2017), (e) to evaluate the determinants of implementation success of a PHR (Fiks et al., 2014), and (f) to develop and evaluate paper booklets for use by parents and children to facilitate thinking and engagement with future care planning (Noyes et al., 2013).

3.4 | PHR descriptions

Each article reported on the evaluation of a unique PHR; two reported on the evaluation of a paper PHR (McPherson et al., 2017; Noyes et al., 2013), and seven articles on an ePHR. The majority of the ePHRs were developed in house by the hospital department in which they were being used (Byczkowski et al., 2014; Fiks et al., 2014; Forchuk et al., 2016; King et al., 2017;).

Features of ePHRs included the ability to access information about current health status including lab results, information about medication and visit history (Byczkowski et al., 2014; King et al., 2017), the ability to communicate with health care providers using a secure messaging feature (Bush et al., 2016; Byczkowski et al., 2014; King et al., 2017; Schneider et al., 2016), interactive tools such as symptom trackers and/or the option to share this data with people involved in their care (Fiks et al., 2014; Forchuk et al., 2016; Piras & Zanutto, 2014), the opportunity to book appointments (Bush et al., 2016; King et al., 2017), and a reminder system for clinic visits (Byczkowski et al., 2014). One ePHR was integrated with the patient's health records, enabling the user to have direct access to their health information and disease specific information (Byczkowski et al., 2014).

A school-based health intervention used a paper PHR, which included a section to record personal details, diary pages for tracking problematic medical issues, a section to provide practitioners with information about unrecognised conditions and practical hints and tips, and a medical records section (McPherson et al., 2017). The PHR evaluated by Noyes et al. (2013) was a booklet, which was intended to help parents and CYP to think about the care they received now and in the future.

3.5 | Outcomes

Outcomes for the CYP and/or their parents associated with PHR use included increases in health advocacy for young people (McPherson et al., 2017), increased knowledge about the condition (Byczkowski et al., 2014; King et al., 2017; McPherson et al., 2017), improved control over management of their condition (Piras & Zanutto, 2014), and

TABLE 2 (Continued)

Author(s), country, and objectives	Population, setting, and intervention	Design and methodological rigour	Key results
	include electronic messaging, video conference, and file management.		Collaborators were proactive and perceived high levels of competence, autonomy, and relatedness. Collaborators adopted an approach-oriented coping style. Collaborated well with clinical team.
			Cooperators: displayed competence and relatedness but not want to use PCEHR as much as collaborators. Cooperators tried to think about the condition as little as possible. Used more avoidant coping strategies.
			Avoiders: Did not engage with PCEHR and had a tendency towards denial. Lack of relatedness and perceived competence seemed to inhibit development of intrinsic motivation to use PCEHR.

Author(s), country, and objectives	How the intervention was thought to work	Contextual factors thought to influence implementation
Bush, Stahmer, and Connelly, (2016) USA To obtain the perspectives of parents whose children have autistic spectrum disorder (ASD) on the utility of the electronic health record (EHR) as an instrument in their children's treatment.	Providing access to individual health care information as well as being able to communicate with health care providers has the potential to improve the overall care experience through increased health care understanding and knowledge. Using the portal would increase parent's understanding of their child's condition and help improve communication between parent and health care provider	Three of nine participants were registered to use MyChart, which is lower than reported than other studies—other portals had been designed in-house specifically for paediatric patients rather than using an off-the-shelf application for an EHR designed primarily for record use. For some services offered by the portal, such as scheduling appointments, people found it quicker to do over the telephone: The patient portal was regarded as making the interaction more complicated rather than simpler. One user reported using the EHR frequently and for several different types of tasks—they had received extensive EHR training and had a good understanding of how the portal connected to various segments of medical care. Because of logistics, insurance restrictions, and personal choice, nine of 10 children were receiving treatment outside of the hospital system—thus, the information currently captured in the hospital and integrated delivery system EHR resulted in only partial capture of the true type and volume of medical utilisation associated with pediatric patients with ASD.
Byczkowski, Munafo, and Britto, (2014) USA To measure and understand among parents of children with chronic conditions, their perceptions of usability and value, and their concerns about using a web-based portal to access their child's health records.	Access to credible information that can be used by patients to manage disease and improve health; providing collaborative disease tracking capabilities between physicians and patients; making it easier for patients to ask questions, set up appointments, and manage prescriptions and referrals, and lowering communication barriers by providing an ongoing connection between patients and health care providers.	Less use of web messaging then reported in other studies of adults in primary care; this may be because this population of parents may have more opportunities for interactions with health care providers. Low level of concern about confidentiality; parents may be more experienced in receiving and processing information, which is not always positive.
Fiks et al. (2014) USA To evaluate the determinants of implementation success for a portal in paediatric primary care to facilitate communication between families and clinicians regarding treatment concerns and goals, asthma symptoms, medication use, and side effects.	MyAsthma portal was developed to facilitate shared decision making and improve asthma outcomes.	Portal implementation was facilitated at practices that designated a specific person to coordinate the portal surveys and hindered when workflows were not well defined. Lack of follow-up by practices discouraged portal use, whereas responsiveness of practices to messages encouraged people to use the portal. Being short staffed, lacking in terms of care coordinators, and uncertainty about the ideal workflow for managing portal surveys hindered implementation. There was a perceived need for training among clinicians at some sites, which reduced enthusiasm. Parents of children with well-controlled asthma found MyAsthma less useful if they did enrol. For parents of children with uncontrolled asthma, parent use of the portal

(Continues)

Continued)

Author(s), country, and objectives	How the intervention was thought to work	Contextual factors thought to influence implementation
		was associate with a significant increase in asthma medication changes/refills and visits to primary care. Clinicians in less affluent areas felt that lack of computer access was a barrier.
Forchuk et al. (2016) Canada To assess the usability and acceptability of an electronic patient held record (ePHR) among patients and care providers.	The ePHR allowed the individual to access and edit their personal health information collaboratively with one or more health care provider. The ePHR facilitates engagement of individuals in their health care, and it is expected that adoption of this technology will be associated with improved health outcomes.	Use of electronic technology in this context is not new so use of LSR may be more acceptable. LSR use related to level of engagement patients had in their treatment programs with patients receiving DBT more likely to regularly use the LSR. LSR less useful as symptoms improved. Reduced usage over time may not be indicative of an ineffective tool, but rather may be a sign of symptom improvement. The LSR technology was easily integrated into psychological treatments youth were already receiving. With DBT and CBT patients are often asked to record their moods and thoughts every day using a paper-based diary card or thought records.
King et al. (2017) Canada To examine the use, utility, and impact on engagement in care and caregiver-provider communication of a client/family portal providing access to electronic health records (EHRs) and secure, two-way e-messaging with care providers.	Health care portals have the potential to improve consumers' access to information, engagement in care, and health outcomes. Through electronic access to health records and e-messaging, clients and families may feel a greater personal connection to care and partnership in the care process.	Education and resources are needed to support providers. Organisations need to ensure service providers see the value of the portal. Future suggestion is to share family stories with providers so they can get a better understanding of the positive impact of the portal and feel their investment in terms of their time is worthwhile. Portal adoption is a process that requires a feedback loop to allow organisations to improve portal adoption based on the needs of the people who use it. If caregivers are already engaged in their child's care, the portal may not make a big difference in engagement compared with nonpaediatric portals.
McPherson, Ware, Carrington, and Lennox (2017) Australia To determine whether a school-based education/health intervention package, compared with usual care, increased the self-advocacy of adolescents with intellectual disability regarding their health.	The "Ask Health Diary" and the Comprehensive Health Assessment Program is designed to increase patients' self-advocacy skills and enable them to communicate more effectively with health professionals and in doing so, promote better access to health services. The "Ask Health Diary" provides a sound curriculum framework for teachers, adolescents, and carers to work together to promote self-determination.	Young people attending SESs are more likely to have chronic conditions requiring ongoing care and are more likely to be seen regularly by medical practitioners, and undiagnosed conditions may be less likely. Involvement of carers helped the skills to be used beyond the school environment. Knowledge and communication are major components of self-advocacy and so the health check was thought to play a role in the outcomes.
Noyes et al. (2013) United Kingdom	Booklets were designed to be used in different ways such as (i) at home and in private to facilitate thinking and help clarify thoughts and feelings and preferred care options, (ii)	There was incomplete local children's palliative care service provision, e.g., families reported limitations in access to care and accessibility to information. The existing culture

(Continues)

(Continued)

Author(s), country, and objectives	How the intervention was thought to work	Contextual factors thought to influence implementation
To develop and evaluate the "My Choices" booklets for use by parents and children to facilitate thinking and engagement with future care planning	during clinical encounters with health care professionals, (iii) as a basis for sharing thoughts and information to inform care planning. There were no preconceived ideas about whether the booklets would be filled in or not or merely used as a basis for thinking and initiating conversations.	and ethos of service delivery would need to change for implementation of the intervention to be optimal. Health care professionals had been hindered in their efforts to facilitate forward planning due to the lack of resources, such as the My Choices booklets, and they needed additional support to increase their communication skills in children's palliative care contexts. Planning ahead by parents was often only for short periods of time, and some parents were worried about planning too far ahead as their child's condition could change. Staff and parents would benefit from additional training and support to actively engage with a future planning resource such as the My choices suite of booklets.
Piras and Zanutto (2014) Italy To determine whether paper-based logbooks for patients could be replaced with an electronic instrument and to test forms of remote monitoring by doctors.	PHR makes it possible for the patient to manage and share information with people involved in their care. Patients can track all information relative to their diabetes (measurements, therapy, and symptoms) in between their three monthly appointments and then share this with their doctor.	Parent transferred responsibility of PHR to child if they had limited technological knowledge (change from paper-based logbook which tended to be completed by parent). Level of desire for autonomy in patients managing their own health, without reliance on clinicians. The electronic PHR led to the end of close supervision by parents. The paper logbook was often kept in a shared space.
Schneider, Hill, and Blandford (2016) United Kingdom To better understand patients' lived experiences with a patient-controlled electronic health record (PCEHR) and how the use of such a technology may lead to patient empowerment.	The PCEHR is intended improve the patient experience and foster patient empowerment. The feeling of control that patients have through use of web-based management tools will help them to better cope with and manage their illness.	Willingness to use the PCEHR depends on patient (parent) coping style and perceived competence, autonomy, and relatedness. These coping styles need to be considered when designing PCEHR. Extensive use of the PCEHR did not necessarily indicate that patient felt empowered. Motivation to take control is only empowering if it is intrinsic—i.e., if basic needs for competence, autonomy, and relatedness are fulfilled. Adding to or editing, a PCEHR can cause concern for a patient as they may think any mistake may have negative consequences on their treatment. Data security mechanisms need to be made clear to users so they are more comfortable with using it. Adequate training is needed. Use of a PHR and all associated features needs to be voluntary. Participants were families of a child with a complex chronic condition under the care of multiple providers so they may had strong motivations to engage with a PCEHR.

improved relationships and communication with health care providers (Byczkowski et al., 2014; Forchuk et al., 2016). Unexpected outcomes included one family who used an ePHR intensively worrying about whether they were using it correctly, and parents feeling they had lost control over their child's data as the tele-monitoring feature of the ePHR gave doctors the opportunity to intervene in their everyday routine (Piras & Zanutto, 2014; Schneider et al., 2016).

Outcomes for the service as a result of PHR use included a change in therapeutic boundaries through the young person's ability to initiate contact (Forchuk et al., 2016). Enhanced engagement in treatment was also observed if PHR features matched current treatment requirements, for example, symptom trackers, which facilitated a more positive therapeutic relationship by allowing professionals to engage with young people in new ways (Forchuk et al., 2016). Increased sharing of medical information across providers in the children's hospital system with the clinician being more aware of the nature, complexity, and frequency of treatments sought without the parent having to verbally discuss this with the provider was also reported (Bush et al., 2016). In addition, PHR use was felt to improve communication between families and the primary care physicians (Fiks et al., 2014) and promote a positive message to users by inviting them to more engaged in their health care (King et al., 2017).

3.6 | Programme theories in relation to how PHRs can be used successfully

Self-determination theory was referenced by two studies as a way of understanding the motivation to use a PHR (McPherson et al., 2017; Schneider et al., 2016). Self-determination theory has been defined as "volitional actions that enable one to act as the primary causal agent in one's life and to maintain or improve one's quality of life" (Wehmeyer, 2005, p. 6). The use of a PHR may increase CYP's self-advocacy skills and promote patient empowerment, enabling them to communicate better and more collaboratively with health care professionals, which in turn may result in improved access to services and enable them to engage more successfully with management of the condition (Bush et al., 2016; Byczkowski et al., 2014; King et al., 2017; McPherson et al., 2017). Forchuk et al. (2016) proposed that as the ePHR facilitates engagement of CYP in their health care, adoption of this technology would in turn be associated with improved health outcomes.

3.7 | Factors that may help or hinder implementation of the PHR

3.7.1 | Characteristics of the intervention

Features that enable collaboration in disease/symptom tracking between CYP and health care provider (Forchuk et al., 2016) and access to credible information to manage the condition aim to lower communication barriers by providing an ongoing connection between CYP and health care provider (Byczkowski et al., 2014; King et al., 2017). This enables CYP to gain increased knowledge about their condition, which in turn helps improve their communication with the health care professional and makes it easier for them to ask questions (Bush et al., 2016; McPherson et al., 2017). Electronic access to health records promotes a feeling of control for CYP and more active engagement in their health care, which helps them better cope with and manage illness and promotes partnership in care (Fiks et al., 2014; King et al., 2017; Schneider et al., 2016). The ability for care providers to enter information into the PHR also facilitates communication outside of regularly scheduled appointments (Forchuk et al., 2016). Paper versions of PHRs were thought to help the CYP feel more comfortable in thinking and talking about more sensitive issues (Noyes et al., 2013), be a source of empowerment, and help the CYP become more confident in initiating conversations with health care providers (Fiks et al., 2014; Noyes et al., 2013).

The technological characteristics of the PHR impacted on PHR use. If the use of electronic technology was not new to the CYP and/or their family, an ePHR was more acceptable (Forchuk et al., 2016). The replacement of a paper logbook with an ePHR for young people with diabetes encouraged delegation of the monitoring of symptoms from parents to children as parents felt they had more limited technological knowledge (Piras & Zanutto, 2014). The PHR has to offer benefits to, or complement, existing methods used by CYP to manage their health condition. If features offered by an ePHR, such as scheduling appointments, were much quicker to do over the phone than via with ePHR, parents would be less likely to engage (Bush et al., 2016). Similarly, CYP with more opportunities for interactions with health care providers saw less need for features such as a web message function (Byczkowski et al., 2014).

3.7.2 | Characteristics of the outer contexts

Fiks et al. (2014) reported that parents who sustained use of an ePHR over time were more likely to have private health insurance. CYP whose families have private health insurance may have a higher income and may be more likely to have access to technology to use the PHR. Indeed, the potential for computer access to be more restricted in less affluent areas was reported as a concern by clinicians. Parents felt that there was a culture of state providing services and not empowering families to decide for themselves what care or treatment they wanted for their child, and so motivation to engage with the PHR was low (Noyes et al., 2013).

3.7.3 | Characteristics of the inner contexts

Training in use of the PHR is needed for the CYP and/or their parents and the service provider to provide both the technical knowledge on how to access and/or use the PHR and an understanding of its purpose and to sustain enthusiasm over time (Fiks et al., 2014; Forchuk et al., 2016; King et al., 2017; Schneider et al., 2016). This training may be accompanied by a training manual (Forchuk et al., 2016). Service providers may be less likely to invest their time in using an ePHR if they perceive that use by CYP and/or their parents is low (King et al., 2017). A designated person within an organisation to coordinate

PHR use and follow-up with CYP will help to facilitate PHR implementation (Fiks et al., 2014). A well-defined workflow is also needed to manage the use of the PHR (Fiks et al., 2014). Data security mechanisms need to be made clear, particularly for an ePHR so CYP and/or their parents are clear on how their confidentiality will be maintained (Schneider et al., 2016).

3.7.4 | Individual characteristics

Use of the PHR was influenced by the perceived need of the CYP and/or their parents to engage. If the CYP had a more chronic condition requiring ongoing care, had an undiagnosed condition, was seen by multiple medical professionals and had a need for improved coordination of their care, was receiving more medications, or had uncontrolled symptoms (Fiks et al., 2014; McPherson et al., 2017; Schneider et al., 2016), they had stronger motivations to use the PHR. Existing engagement with treatment programmes influenced use of an ePHR, either positively, with higher levels of engagement in treatment by CYP associated with more regular use of the ePHR (Forchuk et al., 2016), or negatively, with use of an ePHR not viewed as bringing any additional benefit to parents who were already very engaged with their child's care (King et al., 2017). Furthermore, the level of integration of the PHR with existing treatment programs impacted on use; if CYP or parents were already recording symptoms each day with a paper-based diary, they were more accepting of the concept of using a symptom tracker function with an ePHR and were more likely to engage with it (Forchuk et al., 2016; Piras & Zanutto, 2014).
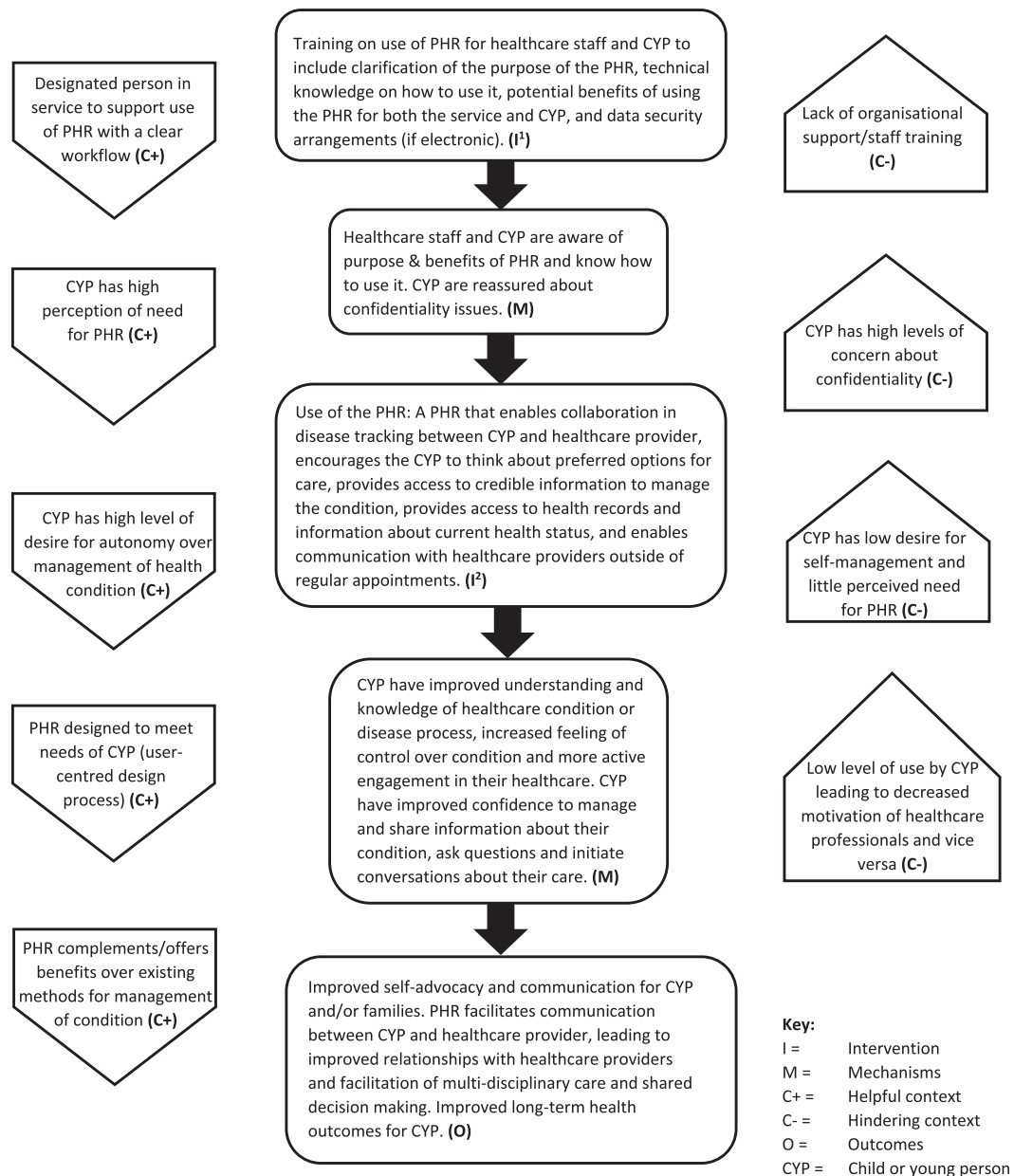

FIGURE 2 Theoretical model of how personal health records are thought to work with children and young people living with a complex health condition

A greater perceived need for more autonomy by CYP over management of their health condition with less reliance on health care professionals influenced greater engagement with, and use of, the PHR (Schneider et al., 2016). The coping styles of parents impacted on engagement with the PHR; users with avoidance coping styles engaged less with the PHR, whereas users with approach-oriented coping styles engaged with and used the PHR more (Schneider et al., 2016). Resistance to PHR use by parents included scepticism of whether professionals would listen or have any resources to improve existing care provision and a lack of clarity about its purpose (Noyes et al., 2013).

3.7.5 | CMO configurations

This section brings together the mechanisms (M) and context (C), which produce the outcomes (O) in relation to implementation of PHRs (see Figure 2).

Implementation of PHRs for CYP managing a health condition involves two intervention stages: First, training and preparation of the CYP, parents, and health care professionals (I^1), and second, the use of a PHR with desirable characteristics (I^2). Training should focus on the purpose of the PHR, how to use it, data security, and potential benefits (I^1). This will help motivate CYP and their parents to use the PHR by ensuring they have the necessary skills and expectations (M). Knowing that CYP and their parents are adequately prepared will reassure health care professionals that their investment of time in the PHR will be useful (M). These mechanisms will promote use of the PHR both by health care professionals and CYP. The PHR itself should be easy to use with features that bring additional benefits over, or complement, existing methods of management of the condition. The PHR should enable collaboration in disease/symptom tracking between the CYP and health care provider, encourage the CYP to think about their care options, provides access to credible information about the CYP's medical condition and their health care record and/or information about their current health status, and provide the ability to communicate with health care providers outside of regular appointments (I^2).

Through use of the PHR, CYP may have improved knowledge and understanding about their condition or disease process and have increased feelings of confidence and control over self-management issues (M). This in turn may lead to improved self-advocacy skills and more active engagement in their health care in the form of asking questions and initiating conversations about their care (O), with a greater likelihood of multidisciplinary shared-decision making and improvement in the long-term health outcomes for CYP (O).

These mechanisms and outcomes will be hindered in the presence of the following contextual factors: a lack of organisational support including training provision for both the CYP and health care providers, unclear data protection arrangements with CYP and/or their parents having concerns about confidentiality, CYP do not perceive themselves to have a high level of need for a PHR to help them manage their condition or have a low desire for autonomy over management of their health condition (C), low use by CYP and/or their parents may reduce engagement of health care professionals in PHR

implementation (C). In contrast, use of the PHR and the positive outcomes associated are helped by having organisational support behind implementation, including a designated person to coordinate PHR use and a clear work-flow process (C). Outcomes will also be helped by implementing a PHR, which has been designed specifically to meet the needs of the CYP (a user-centred design process) and which complements or offers benefits over existing methods for management of their condition (C).

Recommendations for those involved in the production, implementation, and evaluation of PHRs are provided in Table 3.

4 | DISCUSSION

The aim of this review was to identify the factors that may help or hinder the implementation of PHRs with CYP managing a health condition and/or their families. The majority of studies were mixed methods or qualitative with only one randomised control trial. Three articles were judged to be of strong methodological rigour, and six were rated as having moderate rigour. The main outcomes reported from PHR use included increases in health advocacy for CYP (McPherson et al., 2017), increased knowledge for CYP about the condition and disease process (Byczkowski et al., 2014; King et al., 2017; McPherson et al., 2017), improved control over management of their condition (Piras & Zanutto, 2014), and improved relationships and communication with health care providers (Byczkowski et al., 2014; Forchuk et al., 2016). The main theory around what use of a PHR would achieve was therefore supported. However, longer-term health outcomes were not investigated.

The majority of studies did not explicitly examine organisational issues, focusing more on the CYP and/or their parent's perspective of the PHR and outcomes associated with their use of the PHR. However, examining the programme theories in relation to how PHRs could be successfully implemented, and identifying contexts that may help or hinder PHR use, has allowed synthesis of an integrated theory to explain and support PHR implementation. The first stage is for both the CYP and/or their parents and health care professional to receive adequate training to ensure they understand the purpose of the PHR and the potential benefits associated with using it. If it is an ePHR, data security arrangements should be made clear. The second stage is use of the PHR by both the CYP and health care provider. The PHR should have features, which either complement or bring benefits to CYP's existing methods of managing their health condition. A user-centred design process would help achieve this. Organisational support also needs to be in place to promote use of the PHR and sustain motivation by health care providers. This may take the form of having a designated person in place to coordinate PHR use and ensuring there is clear work-flow system in place.

The individual characteristics of the CYP strongly determine PHR use. CYP need to have a high level of perceived need for a PHR and a strong desire to have autonomy over management of their condition. This raises an important issue on whether PHRs should be targeted at CYP who will benefit from them the most, rather than a blanket roll-

TABLE 3 Recommendations for those involved in the production, implementation, and evaluation of personal health records for children and young people

Stakeholder	Recommendation
For training providers	Training for health care staffs and CYP should include a clear description of the purpose of the PHR, the potential benefits of using the PHR for both the organisation and CYP, technical advice on how to use it, a description of the data security arrangements (if PHR is electronic), and provision of a training manual. Health care staffs need to understand that use of the PHR will vary depending on symptom levels and CYP perception of need for a PHR.
For organisations	Facilitate training as outlined above. Implement a PHR that has been designed around the needs of CYP and which complements/offers benefits over existing methods for management of their condition. Clear guidance on which CYP would benefit most from using a PHR should be established.
	Features of the PHR should enable collaboration in symptom tracking between CYP and health care provider, encourage the CYP to think about preferred options for care, provide access to credible information about their condition, provide access to their health records and information about current health status, and enable communication with health care providers outside of regular appointments (if PHR is electronic).
	A designated person in the service implementing the PHR is needed to support PHR use by both health care staff and CYP, and a clear workflow process is needed so staffs are clear where the PHR "fits" within their practice.
For health care staff	Participate in PHR training and take the initiative to include the PHR in interactions with CYP in order to motivate use by the CYP.

Note. PHR: personal health record; CYP: children and young people.

out across a service. If CYP do not engage, this will impact on the motivation of the service providers; if they feel that use of the PHR is low, they may feel their investment in terms of time and resources are not worthwhile. For these reasons, the PHR must include features, which will be of optimal benefit to the user. Indeed, King et al. (2017) suggested that PHR adoption must be a process and include an opportunity for users to provide feedback to enable organisations to improve PHR adoption based on the needs of people who are actively using it. In addition, Forchuk et al. (2016) observed that use of the ePHR reduced as the CYPs' symptoms improved and suggests that this may not be because the tool is ineffective but a sign of symptom improvement. This would be an important addition to training provided to health care professionals to ensure they remain motived to use the PHR.

A limitation of this review is that only one study evaluated the implementation of PHRs for CYP with life-threatening or life-limiting conditions, which made it difficult to determine the usefulness of PHRs for this specific population. Furthermore, in six of nine of the studies, the parents were mainly responsible for use of the PHR on behalf of their child. Nonetheless, the studies reviewed provided important insight into the organisational considerations and the features of a PHR, which may lead to optimal outcomes for CYP managing a health condition. Further research is therefore needed to evaluate the use of PHR's by CYP themselves, in particular those with life-limiting or life-threatening conditions who are becoming more involved in making decisions around their care.

5 | CONCLUSIONS

The findings of this review suggest that PHRs have the potential to bring multiple benefits to CYP living with a complex health condition including increased self-advocacy skills and improved communication with health care providers, which in turn could empower CYP to

become more involved in decision making around the care they receive. The potential benefits of PHRs thus align not only with recent policies and guidance around the care of CYP, which recommend that health care professionals should work in partnership with CYP and their families but also to the fundamental human rights of CYP to express what matters to them and to have their opinions valued. However, organisational support must be in place to ensure longer-term sustainability. Clear definitions of which CYP would benefit from using a PHR must be established. This will enable resources to be directed accordingly and ensure the PHR is designed to meet the needs of the user, which in turn will promote PHR use and produce improved outcomes for CYP.

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