Adult patients' experiences of using electronic personal health records for self-management of chronic non-communicable disease: a qualitative systematic review

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Declaration

I certify that this work contains no material which has been accepted for the award of any other degree or diploma in my name in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission in my name for any other degree or diploma in any university or other tertiary institution without the prior approval of The University of Adelaide and, where applicable, any partner institution responsible for the joint award of this degree. The author acknowledges that copyright of published works contained within this thesis resides with the copyright holder(s) of those works. I give permission for the digital version of my thesis to be made available on the web, via the University's digital research repository, the Library Search and also through web search engines, unless permission has been granted by the University to restrict access for a period of time.

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Conflicts of interest

The author declares no conflict of interest.

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Abstract

Objective: The objective of the systematic review was to identify and synthesise the best available evidence on adult patients' experiences of using electronic personal health records (e-PHRs) for chronic non-communicable disease self-management.

Introduction: Self-management is a key component of chronic non-communicable disease management. One of the strategies to support self-management in patients with chronic non-communicable disease is the use of e-PHRs. Electronic personal health records offer patients the opportunity to actively engage with their own health management, promote continuity of care and collaboration through disease tracking, and provide patients and providers with an ongoing connection. For e-PHRs to be adopted and their benefits for chronic non-communicable disease management maximised, they should align with patients' values and preferences.

Methods: The systematic review was conducted in accordance with the Joanna Briggs Institute (JBI) methodology for systematic reviews of qualitative evidence, with meta-aggregation as the method of synthesis. The review included qualitative studies that explored the experiences of adult patients (aged 18 years and over) with a chronic non-communicable disease who had used e-PHRs for the self-management of their condition. Published studies were retrieved following searches conducted in CINAHL, PubMed, PsycINFO, Embase and Scopus. Grey literature was also considered. Critical appraisal and data extraction were conducted using the appropriate JBI tools. Studies were included, regardless of their methodological quality. Extracted data were aggregated and analysed to produce a set of synthesised findings that were used to develop evidence-informed recommendations for the use of e-PHRs in chronic non-communicable disease self-management.

Results: Fifteen studies that considered adult patients' (n= 412) experiences of using e-PHRs for chronic non-communicable disease self-management were included in the review. A total of 113 findings were extracted and aggregated into 17 categories from which four synthesised findings were developed: 1) Electronic personal health records can strengthen patient-practitioner relationships and support person-centred care when both patients and practitioners engage in productive and transparent communication built on mutual trust; 2) The versatility of e-PHR functions can support self-management of various chronic diseases; 3) Adoption of e-PHRs is dependent on individual patient characteristics, and may be compromised if patients' expectations remain unmet, there were unintended consequences that hinder use, and patients believe e-PHRs are unnecessary for their care needs; and 4) Tailoring e-PHRs to the design preferences, training and education needs of patients with chronic disease through developer-user collaboration may facilitate optimal use of e-PHR.

Conclusions: Electronic personal health records are an emerging technology that have the potential to empower patients and facilitate shared decision-making with their health practitioners. The findings of this review suggest that to facilitate adoption of e-PHRs, patients should be proactive in raising and discussing their concerns with healthcare practitioner (HCPs). Additionally, HCPs should learn appropriate ways of communicating with their patients in order to build trust, maintain transparency, and offer reassurance for effective patient and provider encounters. Awareness of the various functions of e-PHRs that are the most useful for the management of a specific chronic disease will assist patients and their providers in making informed decisions regarding which functions best fit their needs and requirements. Adoption of e-PHR may be optimised when the patient's individual characteristics or concerns around their specific chronic disease needs are understood. The findings of this review also suggest that patients require tailored training and education programs which are focused on the technical and non-technical aspects of e-PHR use in chronic disease management. Creating avenues where health information technology developers can engage with patients and obtain their input in relation to the design or modification of e-PHRs can yield useful information that can increase e-PHR adoption. Further studies exploring the experiences of e-PHR use for other prevalent chronic conditions such as obesity, asthma and kidney disease may provide valuable contributions for the enhanced use of e-PHR for self-management. Future studies should also aim to adhere to well established and robust qualitative methodologies, which is a significant issue identified in the current review. Furthermore, to assist future qualitative evidence synthesis and strengthen findings for subsequent systematic reviews, future research should focus on advancing efforts to create a standardised e-PHR taxonomy.

ConQual Summary of Findings

Synthesised finding	Type of research	Dependability	Credibility	ConQual score	Comments
Electronic personal health records (e-PHRs) can strengthen patient-practitioner relationships and support person-centred care when both patients and practitioners engage in productive and transparent communication built on mutual trust.	Qualitative	Downgrade 2 levels	Downgrade 1 level	Low	Dependability: Most primary studies (7 of 11) scored 0 or 1 out of 5 for dependability with the remaining studies scoring 2 or 3 out of 5. Dependability concerns were that studies had no statement locating the researcher culturally / theoretically (11/11) and no acknowledgement of the influence on the research (10/11). Credibility downgraded due to a mixture of unequivocal (U) and credible (C) findings. U = 23, C = 1
The versatility of e-PHR functions can support self-management of various chronic diseases.	Qualitative	Downgrade 2 levels	Downgrade 1 level	Low	Dependability: Most primary studies (10 of 13) scored 0 or 1 out of 5 for dependability with the remaining studies scoring 2, 3 and 4 out of 5. Dependability concerns were that studies had no statement locating the researcher culturally / theoretically (12/13) and no acknowledgement of the influence on the research (10/13). Credibility downgraded due to a mixture of unequivocal (U) and credible (C) findings. U = 37, C = 3
Adoption of e-PHRs is dependent on individual patient characteristics, and may be compromised if patients' expectations remain unmet, there were unintended consequences that hinder use, and patients believe e-PHRs are unnecessary for their care needs.	Qualitative	Downgrade 2 levels	No downgrade	Low	Dependability: Most primary studies (7 of 8) scored 0 or 1 out of 5 for dependability, the remaining study scored 3 out of 5. Dependability concerns were that all studies (8/8) had no statement locating the researcher culturally / theoretically and no acknowledgement of the influence on the research. Credibility - no downgrade. U = 22
Tailoring e-PHRs to the design preferences, training and education needs of patients with chronic disease through developer-user collaboration may facilitate optimal use of e-PHR.	Qualitative	Downgrade 2 levels	Downgrade 1 level	Low	Dependability: Most primary studies (5 of 7) scored 0 or 1 out of 5 for dependability with the remaining studies scoring 2 and 3 out of 5. Dependability concerns were that studies had no statement locating the researcher culturally / theoretically (6/7) and no acknowledgement of the influence on the research (5/7). Credibility downgraded due to a mixture of unequivocal (U) and credible (C) findings. U = 24, C = 3

U = unequivocal – findings accompanied by an illustration that is beyond reasonable doubt and; therefore, not open to challenge.
C = Credible – findings accompanied by an illustration lacking clear association with it and therefore open to challenge.[1]

Abbreviations

AHP	Allied health professional
e-PHRs	Electronic personal health records
eHealth	Electronic health
EMR	Electronic medical record
EHR	Electronic health record
HCP	Health care professional
HIS	Health information system
PCP	Primary care professional
PICo	Population, the Phenomena of Interest and Context
WHO	World Health Organization

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This thesis presents a systematic review conducted in accordance with the Joanna Briggs Institute (JBI) methodology for systematic reviews of qualitative evidence, with meta aggregation as the method of synthesis. The review sought to identify and synthesise the best available qualitative evidence on the use of electronic personal health records (e-PHRs) for self-management of chronic non-communicable disease amongst adult patients. The objective of the review was to explore patient experiences of the use of e-PHRs as an electronic application that allows them access to their clinical data.

Thesis structure

This thesis is organised into five chapters. The following is a brief outline of the purpose of each chapter.

Chapter 1: Introduction

In the first chapter, the author's personal interest on the topic is described. The chapter also defines e-PHRs and explains their purpose and role in chronic non-communicable disease self-management. The scope and state of current e-PHR research is provided, along with a rationale for undertaking a qualitative systematic review on this topic and the objective of the review.

Chapter 2: Methods

In chapter 2, the research design, outlining the JBI methodological principles upon which the systematic review of international qualitative studies is based, is addressed. In this chapter, the methodological process undertaken to conduct the systematic review is described. The inclusion criteria, comprising type of participants, phenomena of interest, context and types of studies, are also outlined. The search strategy and study selection processes are detailed alongside the assessment of methodological quality, as well as the process utilised for data extraction, meta aggregation as the method of data synthesis, and assessment of confidence in findings.

Chapter 3: Results

The search results and the methodological quality and characteristics of included studies are presented in chapter 3. The synthesised findings, categories and associated findings, together with verbatim illustrations, that supported each finding, are also presented in this chapter.

Chapter 4: Discussion

A general overview of the systematic review findings, followed by a discussion of the principal findings in the light of the existing knowledge about e-PHRs and chronic disease management, are presented in chapter 4. The strengths of the review and the limitations of the included studies and systematic review process are discussed.

Chapter 5: Conclusions

In the final chapter of the thesis, the conclusions of the systematic review and recommendations for practice and future research are presented.

Personal interest in the topic

This research was motivated by my interest in healthcare informatics and eHealth. Healthcare informatics is the appropriate and innovative application of concepts and technologies of the digital age to improve health and health care. eHealth encompasses products, systems and services, including digital tools for health authorities and professionals, as well as personalised health systems for patients and individuals. The scope of e-Health ranges from bench-top to bedside, and through population health activities, which present complex information management challenges to support individualised patient care.[2]

The World Health Organization (WHO) Global Strategy on Digital Health (2020 to 2024)[3] recognises the innovative role of digital technologies such as electronic health records (EHRs), telehealth and mobile devices in strengthening the healthcare system. The WHO also acknowledges that, amidst the heightened interest in these digital health innovations, many have been implemented without careful investigation of the evidence base in relation to their benefits and harms. As a result, many are short lived.

To improve health and reduce health inequalities, the WHO recommends undertaking rigorous evaluation of digital technologies to ensure they are people-centred, evidence-based, effective, efficient, sustainable, inclusive, equitable and contextualised.[3] Furthermore, given the significant economic and financial investments required to implement these systems, it is also important to appropriately evaluate their effects in order to ensure that such investments do not inappropriately divert resources from alternative, non-digital approaches.

My experiences as an allied health professional, providing patient-centred care using innovative digital technologies, prompted me to consider how patients might view the use of these innovative digital tools for managing their own health-related care. An initial scoping of digital health literature located a quantitative systematic review protocol that sought to investigate the effects of patients' access to EHRs.[4] This protocol provided the catalyst for the investigation of this phenomenon from a qualitative perspective, as a complement to the existing body of quantitative research on this topic, which could offer useful insights for developing the evidence base for the use of this type of digital health technology.

Within the digital health literature, the terms EHR, electronic medical record (EMR) and electronic personal health record (e-PHR) are often used interchangeably as all three types of health records can contain similar information. Similarly, patient portal, a term used to describe an extension of an EHR that offers healthcare providers online access to information within a record can also be used to describe these types of records. The key distinction between these types of records is how, and by whom, they are accessed.[5]

Electronic personal health records were selected as the phenomenon of interest, owing to their rapid evolution as an innovative, global digital technology, with the potential to enhance the delivery of patient-centred health care.

Background

Chronic non-communicable disease is the leading cause of death worldwide, with over 40 million people dying each year from chronic disease and its associated complications.[6] Deaths secondary to chronic diseases such as stroke, chronic respiratory disease, heart disease, cancer and diabetes, characterised by their long duration and generally slow progression, are projected to increase from 38 million in 2012 to 52 million by 2030.[7] Due to the personal, social and economic impact, chronic disease management remains one of the biggest challenges currently facing the global healthcare community. Clinical practice has focused on the importance of patient-practitioner interaction, shared decision-making and active patient participation through self-management as responses to the increasing burden of chronic disease.[8,9] Self-management of a chronic disease is defined as 'the person with the chronic disease engaging in activities that protect and promote health, monitoring and managing the symptoms and signs of illness, managing the impact of illness on functioning, emotions and interpersonal relationships and adhering to treatment regimes.'[10(p.1)] This approach has led to improvements in clinical outcomes and health service efficiency, and a reduction in healthcare costs.[11]

One of the strategies to support self-management in patients with chronic disease is the use of electronic personal health records (e-PHRs).[12] Electronic personal health records offer patients access to their medical records, recommend self-management tools, and provide an innovative medium for communicating with healthcare providers.[13] Whilst all patients can potentially benefit from the use of e-PHRs,[14-16] those patients with chronic disease may achieve greater benefits due to the increased need to record and access their health-related information on a regular basis and the requirement to actively self-manage their disease in conjunction with their health providers and caregivers.[17-20] Electronic personal health records are defined as an 'electronic application through which individuals can access, manage, and share their health information, and that of others for whom they are authorised, in a private, secure, and confidential environment.[21(p.13)] Electronic personal health records operate through web-based platforms[22] or portals[15] that are accessible with devices such as personal computers, mobile phones, laptops, tablets, personal digital assistants (PDAs) and other wireless devices.[23] Electronic personal health records vary greatly in type and use.[23] Basic applications allow patients access to shared health summaries, generate personal health notes, and maintain laboratory results, diagnostic imaging reports and hospital discharge information.[22] More advanced applications enable integration of patient records with health providers' information systems and allow patients, in conjunction with their providers, the ability to monitor, track and respond to changes in their health status.[24] Electronic personal health records, linked to a health facility's electronic medical records, enable disease tracking that fosters collaboration and promotes continuity of care via an ongoing connection between patients and providers. This, in turn, can promote the delivery of early interventions when problems arise, which can potentially avoid hospitalisation.[25] Innovative software capabilities may include the ability to set up auto generated email reminders, link to the provider's online health information and databases, book and manage clinical appointments, and monitor and store health indicators such as blood pressure or weight.[26]

Although e-PHRs have variable designs and features,[23,27] they share a similar goal of improving patients' engagement in their care.[20] Specific e-PHR literature and research findings suggest that e-PHRs have the potential to empower patients in their shared decision-making, allowing access to health information and communication tools, which in turn aids in self-care, improves clinical outcomes and reduces care costs.[14,28] Other benefits include secure messaging, medication adherence reminders, symptom checking reminders, and more recently collecting and storing data from personal sensors and mobile applications, such as accelerometers, wireless scales, wrist bands and smartwatches.[23] Electronic personal health records provide a central point for health information integration that can reduce geographical barriers to patient care, particularly in fragmented healthcare systems and thus improve continuity of care and efficiency.[26]

Price et al.[20] systematically reviewed 23 quantitative studies and found that chronic disease such as diabetes, hypertension, asthma, acquired immunodeficiency syndrome, fertility management, glaucoma and hyperlipidaemia can benefit from the use of e-PHRs. Benefits were seen in terms of care quality, access and productivity. Specifically, the reviewers found e-PHRs valuable in promoting behaviour change through self-monitoring of disease indicators (e.g. blood pressure for hypertension, glucose for diabetes). In another study, Baudendistel et al.[29] found the e-PHR a useful tool for patients with colorectal cancer, primarily through improved information exchange with health providers. That study also highlighted how e-PHRs can be meaningfully used to meet specific disease needs when users are engaged in the technical development and evaluation process.

While there is evidence to demonstrate favourable outcomes from e-PHR use, there are also a few studies that show its limited or lack of effectiveness for certain chronic diseases. For example, Toscos et al.[30] showed that e-PHRs had minimal impact for intermediate health outcomes (e.g. blood pressure, haemoglobin A1c [HbA1c]) and no significant impact for patient engagement among patients with coronary artery disease. Similarly, Wagner et al.[31] examined the impact of e-PHRs on blood pressure monitoring in hypertensive patients and also assessed outcomes related to patient empowerment, perception of quality of care and use of medical services. Based on an intention-to-treat analysis, the researchers found that e-PHRs did not impact blood pressure values, patient knowledge, skill and confidence in health self-management, and perceived quality of life or medical services utilisation. In another study involving patients with breast cancer, Wiljer et al.[32] demonstrated that e-PHR use had no impact on anxiety levels and perceptions of self-efficacy.

The variability in effects observed with e-PHRs use may be related to the challenges and constraints associated with the adoption of e-PHRs.[33] Lower than expected adoption rates continue to be attributed to issues of privacy and security, inequities related to information and communications technology access, type of e-PHR, and integration into care processes.[23,34,35] People- and organisational-related factors such as age, health literacy, socioeconomic status and policy limitations pose additional challenges.[36-38] Gagnon et al.[39] identified knowledge (e.g. lack of awareness), system design (e.g. usability), user capacities and attitudes (e.g. patient health literacy, education and interest), environmental factors (e.g. government commitment), and legal and ethical issues (e.g. information control and custody) as factors that could influence e-PHR adoption. Recent studies have called for further research to understand how e-PHRs can be meaningfully used and how it can better support patient populations with specific conditions or diseases.[18,40,41] Several authors recommend reorientating research to focus on understanding patients' experiences and perceptions of e-PHRs as a necessary prerequisite to facilitate its optimal and sustainable use.[42-44]

Within today's health and social care systems, e-PHRs are viewed both as a tool for promoting self-management in patients with chronic disease and a strategy to make health care more patient-centred.[36] The benefits of e-PHRs show promise for supporting self-management, especially in facilitating communications among healthcare settings and information access, yet understanding of the patient role in the design, introduction and use of e-PHRs and related health and life outcomes is underdeveloped. To adopt e-PHRs and maximise any benefits for chronic disease management, current evidence indicates that e-PHRs must be in alignment with patients' values and preferences.[23,29,37,45]

An initial limited search of PubMed and CINAHL identified several primary qualitative studies exploring the experiences of patients using e-PHRs for management of chronic disease. These studies affirmed positive attitudes and improved satisfaction related to use of e-PHRs for diabetes,[46] hypertension,[47] and mental health self-management.[48] Furthermore, where e-PHRs were linked with secure messaging, medication prescription refills and ability to share access between the patient and healthcare provider, patient satisfaction was enhanced.[24] Fuji et al.[49] explored patients' experiences in managing their diabetes, reporting positive and negative findings in relation to privacy and security, and ability to use the technology. In another qualitative study, Woollen et al.[50] found that cardiac inpatients using e-PHRs experienced decreased anxiety, improved understanding of health conditions and demonstrated overall satisfaction with their health care. As the phenomenon of using e-PHRs in the context of chronic disease is relatively new,[51] synthesis of qualitative research findings and aggregation of themes across studies may inform the appropriateness and acceptability of e-PHRs for self-management of chronic non-communicable disease.

A preliminary search of CINAHL, PubMed, *JBI Evidence Synthesis*, PROSPERO and the Cochrane Library found two systematic reviews which explored patient experiences of using personal health records. Sartain et al.[52] reviewed 10 qualitative studies that investigated the perspectives of patients on the effectiveness or benefits of personal health records. The review identified three main themes: practical benefits of personal health records (e.g. owning a record to aid memory), psychological benefits (e.g. feeling empowered to ask questions, feeling in control of one's own health), and drawbacks (e.g. imposing unwanted responsibility and ineffectiveness). The focus of that review was the paper format of patient-held records and therefore differs from the primary focus of this review. Sartain et al.[52] acknowledged that with the emergence of e-PHRs, different patient factors may affect uptake, including the security and accessibility of electronically held personal information. In addition, the study context was broad, considering antenatal care, learning disability, mental health and other chronic diseases. In a more recent systematic review, Sakaguchi-Tang et al.[53] explored the perspectives and experiences of e-PHRs use from initial access to adoption amongst older adults. Electronic personal health records were found to help older adults better manage their health information and improve their communication with healthcare providers. Key facilitators of use were receiving technical assistance and recommendations from family and healthcare providers. Barriers to use were concerns regarding privacy and security and technological ability. That review specifically focused on older adults' experiences and did not consider e-PHRs for chronic disease self-management. Furthermore, the authors included both quantitative and qualitative studies, and did not undertake meta-aggregation of qualitative findings that would have been useful for generating action statements for policy and practice.

Objectives

The current systematic review sought to address the gap in knowledge pertaining to understanding patients' experiences of using e-PHRs for self-management of chronic non-communicable disease. The findings may assist with informing evidence-based practices for use of e-PHRs in chronic disease self-management. Therefore, the objective of the review was to systematically identify and synthesise all relevant qualitative findings on adult patients' experiences of using e-PHRs for chronic non-communicable disease self-management.

Chapter 2: Methods

In this chapter of the thesis, the research design and methodology used in the systematic review are described. The qualitative systematic review methods are then outlined, including review eligibility criteria, search strategy, study selection process, how studies were critically appraised, data extraction, data synthesis methods and assessment of confidence of findings.

Research design

The research design chosen was a systematic review of qualitative evidence, performed according to the JBI approach to qualitative synthesis.[54] This methodology uses meta-aggregation as the approach to the synthesis of qualitative evidence. In meta-aggregation, the reviewer does not seek to re-interpret the findings but aggregate the findings into a combined whole, whilst preserving the practicality and usability of the primary authors' findings.[54] A strong feature of the meta-aggregative approach is that it seeks to generate generalisable statements in the form of recommendations to guide practitioners and policy makers.[54] This systematic review was therefore conducted in accordance with the JBI methodology for systematic reviews of qualitative evidence.[54] This review was conducted in accordance with the *a priori* protocol,[55] and registered in PROSPERO, registration number CRD42019133301.

Inclusion criteria

Types of participants

This review considered qualitative studies that included adult patients (aged 18 years and over) reported to have a chronic non-communicable disease and who had used an e-PHR for self-management of that condition. Chronic disease is defined as a disease or condition that is ongoing, in contrast to acute conditions which resolve completely within a relatively short time period.[7] Non-communicable diseases are conditions that are not passed from one person to another.[7] This review considered common chronic non-communicable diseases such as stroke, chronic obstructive pulmonary disease, cardiovascular disease, cancer, diabetes mellitus, asthma, epilepsy, Parkinson's disease, Alzheimer's disease, arthritis and renal failure. In accordance with current guidelines for chronic non-communicable disease classification,[7,56] this review also considered obesity (body mass index [BMI] greater than or equal to 30 kg/m^2) as a chronic non-communicable disease, and not being overweight but not obese (BMI less than or equal to 30 kg/m^2). Where there was any doubt as to whether a condition was a chronic non-communicable disease, a discussion was held between the reviewers (J.E. and L.L) until a consensus was reached.

Phenomenon of interest

This review considered studies that explored adult patients' experiences of using e-PHRs to manage their chronic non-communicable diseases. Following the definition applied by Sakaguchi-Tang et al., "experience" was defined as a person's perceptions of their interactions with e-PHRs.[53] Experiences could include, but were not limited to: barriers and facilitators to use, benefits of use and adoption, and acceptance of and satisfaction with e-PHRs or features of those systems (e.g. using secure messaging or having access to electronic medical records).

As the terms electronic personal health records (e-PHRs), personal health record (PHR), electronic medical record (EMR), electronic health record (EHR) and patient portal are used interchangeably within the literature,[17,23] the basic criterion for inclusion in the review was that the electronic application allowed patients access to their clinical data. The term "e-PHR" was adopted for use within the systematic review. The terms chronic non-communicable disease, chronic disease or chronic condition have been used interchangeably throughout this review.

Context

Studies conducted in any country were considered, as were those undertaken in any setting such as community, primary or tertiary healthcare settings.

Type of studies

This review considered studies that focused on qualitative data such as phenomenology, grounded theory, ethnography, action research and qualitative descriptive studies. Only studies published in the English language were considered for inclusion in the review. The adoption of e-PHRs by health institutions commenced in the early 2000s with the rapid emergence of technology use during that time. Therefore, studies published from 2000 were considered for inclusion in the review.

Search strategy

The search strategy aimed to locate both published and unpublished studies. A three-step search strategy was utilised in this review. First, an initial limited search of PubMed and CINAHL was undertaken followed by analysis of the text words contained in the title and abstract and the index terms used to describe the articles. The search strategy, including all identified keywords and index terms, was adapted for each included information source and a second search was undertaken in November 2019. The full search strategies are provided in Appendix I. Finally, the reference lists of all studies selected for critical appraisal were screened for additional studies.

Information sources

The databases searched included PubMed (NLM), CINAHL (EBSCOhost), Embase (Elsevier), PsycINFO (Ovid) and Scopus (Elsevier). Sources of unpublished studies and grey literature searched included ProQuest Dissertations and Theses Global, Google Scholar, WorldWideScience.org and MedNar.

Study selection

Following the search, all identified citations were collated and uploaded into EndNote X8.2 (Clarivate Analytics, PA, USA) and duplicates removed. The primary reviewer (J.E.) screened the titles and abstracts against the inclusion criteria using Covidence (Veritas Health Innovation, Melbourne, Australia); where there was uncertainty, the secondary reviewer (L.L.) was consulted. Potentially relevant studies were retrieved in full and their citation details imported into the Joanna Briggs Institute System for the Unified Management, Assessment and Review of Information (JBI SUMARI), (Joanna Briggs Institute, Adelaide, Australia). Full text studies that did not meet the inclusion criteria were excluded and reasons for their exclusion are provided in Appendix II.

Assessment of methodological quality

Articles selected for retrieval were assessed independently by the reviewers (J.E. and L.L.) for methodological validity prior to inclusion in the review. The standardised critical appraisal checklist (see Appendix III) from JBI SUMARI[54] was used to appraise the methodological quality of the articles. The critical appraisal process involved analysing each individual paper and allocating a response of ‘yes’, ‘no’ or ‘unclear’ to each of the 10 questions in the JBI critical appraisal tool. Qualifying criteria were developed for each of the appraisal questions to ensure consistency between reviewers (J.E. and L.L.). For criteria 1 to 5, the reviewers agreed that if the study design was evident, for example, grounded theory, phenomenology and so on, then the criteria was rated ‘yes’. Where a qualitative descriptive design was evident and no further study design information was provided, the reviewers (J.E. and L.L) were to discuss the rating, until a consensus was reached. In relation to qualitative data analysis (i.e. criterion 4), where no methodology was described, this was deemed to be ‘unclear’. For criterion 7, if there was no mention of the researcher/s’ background, the reviewers (J.E. and L.L.) agreed to rate it as ‘unclear’. For criterion 9, if no ethics approval was evident, but a ‘consent form’ was signed then the reviewers (J.E. and L.L.) agreed to rate it as ‘yes’. All studies, regardless of the results of their methodological quality, underwent data extraction and synthesis. Any disagreements that arose between the reviewers (J.E. and L.L.) were resolved through discussion and so a third reviewer was not required.

Data extraction

Data were extracted by the primary reviewer (J.E.) from included studies using the standardised data extraction tool (see Appendix IV) from JBI SUMARI.[54] The data extracted included specific details about the phenomenon of interest, populations, study methods and findings of significance to the review objective**.** Findings were identified by repeatedly reading the results sections of each study. In this review, a finding was considered to be a verbatim extract of the author’s analytic interpretation, accompanied by a direct quotation representing the participant’s voice (i.e. illustration). Data were initially extracted at the theme level. Repeated reading of the papers, however, revealed that in some studies sub-themes provided better contextual data than the themes. Where this was apparent, data were extracted consistently at the sub-theme level. This approach was necessary to capture a comprehensive understanding of all aspects of the patients’ experiences. All findings were assigned one of three levels of credibility according to the following criteria:

- Unequivocal (U): assigned if the findings were accompanied by an illustration that was beyond reasonable doubt and therefore not open to challenge. These findings were supported by illustrations in the form of direct quotes from participants that supported the finding.
- Credible (C): assigned to findings that were plausible and could be logically inferred from the data. These findings were supported by a direct quote from the participant.
- Not supported (N): assigned where the findings were not supported by any identifiable illustration.[54]

Data synthesis

Data synthesis was conducted using the meta-aggregative approach. The findings were read multiple times by the primary reviewer (J.E.) who developed a set of categories that were then discussed and agreed on with the secondary reviewer (L.L.). Qualitative research findings were pooled using JBI SUMARI.[54] This involved assembling and aggregating the extracted findings from individual studies, based on similarity in meaning, to generate a set of statements (i.e. categories) that represented that aggregation. These categories were then subjected to meta-synthesis to produce a single comprehensive set of synthesised findings that could be used as a basis for evidence-based practice. This was accomplished through discussion with the secondary reviewer (L.L.) to ensure rigour in the interpretation of findings.

Assessment of confidence in findings

The final synthesised findings were graded according to the ConQual[1] approach for establishing confidence in the output of qualitative research synthesis and presented in a Summary of Findings. The Summary of Findings includes the major elements of the review and details how the ConQual score is developed. Each synthesised finding from the review is presented, along with the type of research informing it, the scores for dependability and credibility, and the overall ConQual score.

In chapter 3, the search results, methodological quality and characteristics of included studies are presented. The extracted findings, supported by a verbatim illustration underpinning that finding, are provided, including the aggregation of these findings into categories and the aggregation of these categories into synthesised findings.

Search results

A thorough literature search was conducted initially from July to December 2018 and updated in November 2019. The Preferred Reporting Items for Systematic Reviews and Meta- analyses (PRISMA) flow diagram[57] details the process of study identification, screening and examination of studies in the review. In Figure 1, 5472 possible articles were identified from a detailed search process across a number of selected databases, with an additional 13 articles identified from other sources. Articles were imported from databases into Endnote bibliographic software, and 542 duplicate titles were then removed. Using Covidence software (Veritas Health Innovation, Melbourne, Australia), 4943 titles and abstracts were reviewed against the inclusion criteria, of which 4849 were not relevant to the topic, leaving 94 articles for full text examination. Seventy-nine studies were further excluded as they did not meet the inclusion criteria (see Appendix II for the list of the excluded studies and reasons for their exclusion). A total of 15 studies were included in the systematic review (see Appendix V detailing the included studies and extraction data).

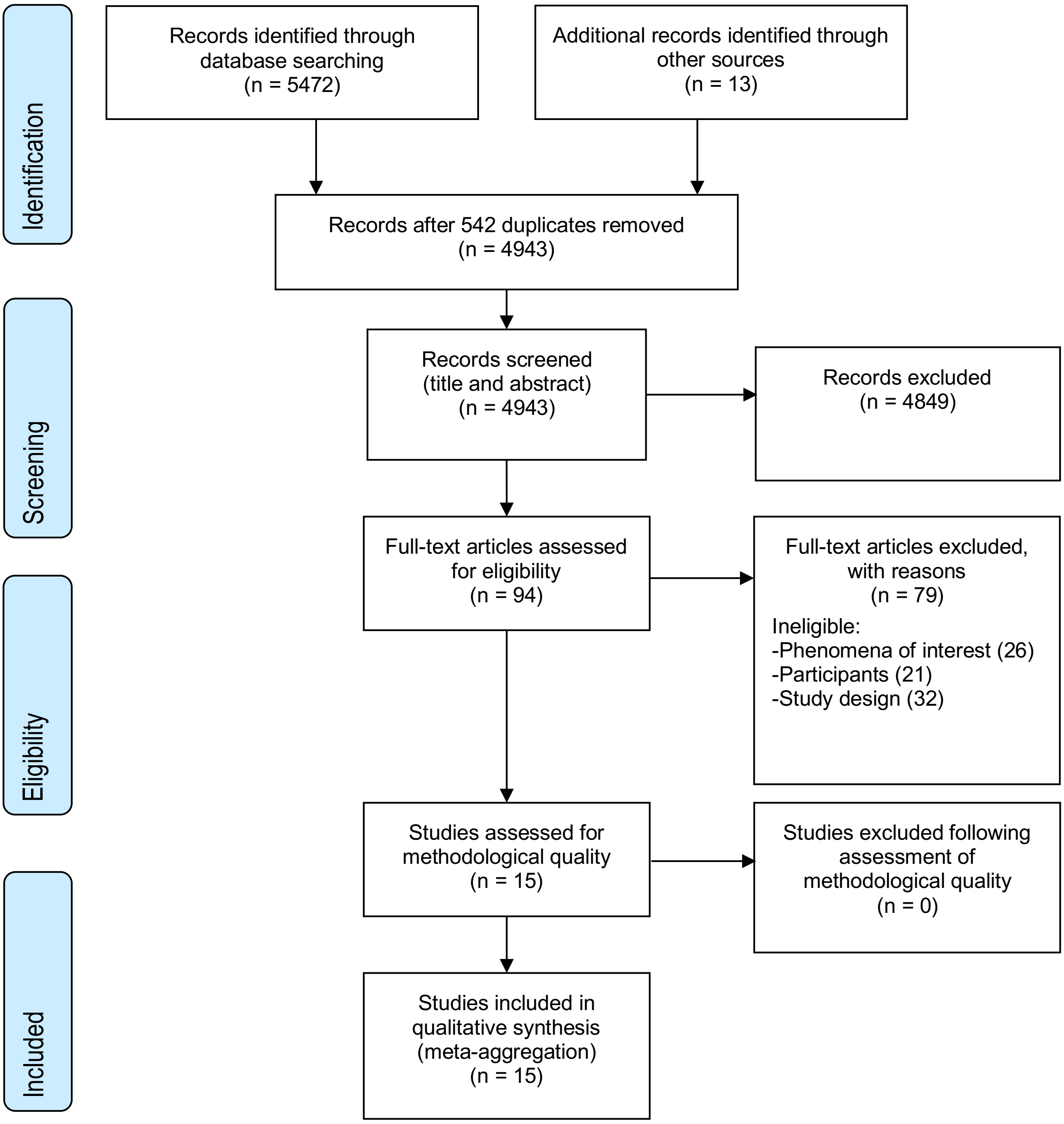

Figure 1: PRISMA flow diagram of search results, study selection and inclusion process[57]

Methodological quality

Only four of the 15 included studies demonstrated congruence between their stated philosophical perspective and the research methodology used (Q1).[51,58-60] Similarly, only these studies showed congruity between their research methodology and the research question/objectives (Q2), methods for data collection (Q3), analysis of data (Q4), and interpretation of results (Q5). Only one study had a statement locating the researcher culturally/theoretically (Q6).[61] Three studies addressed the influence of the researcher on the research (and vice-versa) (Q7).[59,61,62] Thirteen studies demonstrated representation of the participants, and their voices (Q8) [46,49,51,58-67], and reported ethical research or approval by an appropriate body (Q9).[46,49,51,58-66,68] Fourteen studies found the conclusions drawn flowing from the analysis and interpretation of data (Q10).[46,49,51,58-68] Two studies included findings without illustrations and therefore participant voices were not adequately represented (Q8).[49,51] These findings were excluded from the meta-synthesis (Appendix VI). Due to the overall poor reporting of methodological information within the included studies, the reviewers (J.E. and L.L.) were unable to judge the quality of the included studies. The results of the critical appraisal for the 15 included studies are presented in Table 1.

Table 1: Critical appraisal results of eligible studies using the JBI critical appraisal tool

Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Kayastha N *et al.* 2018[68]	U	U	U	U	U	N	U	U	Y	Y
Rexhepi H *et al.* 2018[64]	U	U	U	U	U	N	U	Y	Y	Y
Powell *et al.* 2018[58]	Y	Y	Y	Y	Y	N	U	Y	Y	Y
Rief *et al.* 2017[63]	U	U	U	U	U	N	U	Y	Y	Y
Sieck CJ *et al.* 2017[65]	U	U	U	U	U	N	U	Y	Y	Y
Daley CN *et al.* 2017[62]	U	U	U	U	U	N	Y	Y	Y	Y
Cromer R *et al.* 2017[66]	U	U	U	U	U	N	U	Y	Y	Y
Forchuk C *et al.* 2015[61]	U	U	U	U	U	Y	Y	Y	Y	Y
Gee PM *et al.* 2015[51]	Y	Y	Y	Y	Y	N	U	Y	Y	Y
Rose D *et al.* 2014[60]	Y	Y	Y	Y	Y	N	U	Y	Y	Y
Fuji KT *et al.* 2014[49]	U	U	U	U	U	N	U	Y	Y	Y
Urowitz S *et al.* 2012[46]	U	U	U	U	U	N	U	Y	Y	Y
Hess R *et al.* 2007[69]	U	U	U	U	U	N	U	U	U	U
Winkelman W *et al.* 2005[59]	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Ralston JD *et al.* 2004[67]	U	U	U	U	U	N	U	Y	U	Y

Y = Yes; N = No; U = Unclear [54]

Characteristics of included studies

The qualitative studies included within this review were published from 2004 to 2018. Eleven studies were conducted in the USA[49,51,58,60,62,63,65-69], three in Canada[46,59,61] and one in Sweden.[64] The settings for the studies included: general medical, oncology and endocrinology clinics[49,51,60,62], medical centres and hospitals.[58,63,65,66,69] Four studies were conducted in community or health services centres.[46,59,61,67] One study was conducted at a cancer institute.[68] One study was set in the participant homes.[64]

Seven studies reported using qualitative descriptive methods.[46,51,58,61,64,67,68] Two studies reported using qualitative exploratory methods.[62,65] One study used a phenomenological approach[60] and one used a grounded theory approach.[59] Four studies reported using qualitative methodology with no further information provided.[49,63,66,69] Data were collected by in-depth, semi structured, individual or focus group interviews. Qualitative analysis methods included thematic, constant comparative and iterative approaches. One study[61] used Leininger's phases of qualitative analysis to analyse focus group data, and another study utilised the qualitative 'editing' approach developed by Crabtree and Miller.[63] One study[60] did not specify the data analysis method used. Four studies[51,63,67,69] used Wagner's Chronic Care Model[70] as the guiding theoretical framework underpinning the interpretation of the primary study's findings. One study[59] referred to the Technology Acceptance Model influencing the development of the theoretical framework, based on the grounded theory approach for development of the Patient-Perceived Usefulness theory. The remaining studies did not use frameworks to interpret participant voices.

Four studies explored barriers and facilitators to use of e-PHRs.[49,61,65,69] Nine studies explored patient perspectives, attitudes and experiences towards the use of e-PHRs for self-management.[46,51,58,62-64,66-68] One study[60] explored satisfaction with e-PHRs, and one study[59] was an exploratory study focused on how patients valued e-PHRs for management of chronic disease.

Of the 15 included studies, 13 focused on the experiences of patients whereas two studies explored both patient and provider experiences.[58,65] A total of 412 patients were represented in the 15 studies, and a total of 20 healthcare providers participated in the study. Three studies reported the experiences and perspectives of patients with cardiovascular and cardiopulmonary disease using e-PHRs, specifically, secure messaging and remote monitoring functions to self-manage their illnesses.[62,63,65] Five studies considered the use of e-PHRs for self-management of diabetes.[46,49,60,67,69] The use of e-PHRs to explore the perceptions and perspectives of patients with mental health disorders was reported in two studies.[61,66] Cancer patients' attitudes and experiences with e-PHRs were explored in two studies.[64,68] One study reported on self-management of inflammatory bowel disease,[59] and two studies reported on experiences of how and why they used e-PHRs for self-management support and productive patient-provider interactions amongst patients with chronic disease.[51,58]

The specific e-PHR functions reported in the studies supporting these chronic non-communicable diseases are presented in Table 2. Only six studies[46,49,60,62,63,65] reported e-PHRs that supported non-communicable chronic disease for all seven functions. Appendix V details the characteristics of the included studies.

Table 2: Electronic personal health record functions that support chronic non-communicable diseases

Citation	Chronic disease	Access	Communicate	Share	Manage	Educate	Remind	Request
Kayastha *et al.* 2018[68]	Cancer	▨				▨		
Rexhepi *et al.* 2018[64]	Cancer	▨	▨	▨	▨			
Powell *et al.* 2018[58]	Diabetes, CVD	▨						
Rief *et al.* 2017[63]	CVD	▨	▨	▨	▨	▨	▨	▨
Sieck *et al.* 2017[65]	CVD	▨	▨	▨	▨	▨	▨	▨
Daley *et al.* 2017[62]	CVD	▨	▨	▨	▨	▨	▨	▨
Cromer *et al.* 2017[66]	Mental Health	▨						
Forchuk *et al.* 2015[61]	Mental Health	▨			▨		▨	
Gee *et al.* 2015[51]	Chronic Disease	▨	▨	▨	▨	▨	▨	
Rose *et al.* 2014[60]	Diabetes	▨	▨	▨	▨	▨	▨	▨
Fuji *et al.* 2015[49]	Diabetes	▨	▨	▨	▨	▨	▨	▨
Urowitz *et al.* 2012[46]	Diabetes	▨	▨	▨	▨	▨	▨	▨
Hess *et al.* 2007[69]	Diabetes	▨	▨	▨	▨	▨	▨	
Winkelman *et al.* 2005[59]	IBD	▨						
Ralston *et al.* 2004[67]	Diabetes	▨	▨	▨	▨	▨	▨	

CVD: Cardiovascular disease; IBD: Inflammatory bowel disease

Access: access to health-related data (e.g., visit notes, test results, medical history); Remind: personalised health care reminders; Request: transactional services (e.g., scheduling appointments, prescription request); Communicate: mutual communication (e.g., secure messaging); Share: patient self-documentation and sharing (e.g., patient uploads of blood pressure measurements); Manage: disease management (e.g., individualised recommendations from guidelines); Educate: general health-related education (e.g., disease information leaflets). Table 2: Adapted from Ammenwerth et al (2019).[71]

Findings of the review

Fifteen primary studies were included in this review. From these studies, a total of 118 qualitative findings and their illustrations were extracted. Of the 118 extracted findings, 106 were unequivocal (U), seven were credible (C) and five were unsupported. The qualitative findings extracted from these 15 studies with corresponding illustrations are shown in Tables 3 to 6. The five unsupported findings lacked illustrations and were excluded from the meta-synthesis. The excluded study findings without illustrations are listed in Appendix VI. The remaining 113 extracted findings were organised into 17 categories, and then grouped to generate four synthesised findings:

1. Electronic personal health records can strengthen patient-practitioner relationships and support person-centred care when both patients and practitioners engage in productive and transparent communication built on mutual trust.

2. The versatility of e-PHR functions can support self-management of various chronic diseases.

3. Adoption of e-PHRs is dependent on individual patient characteristics, and may be compromised if patients' expectations remain unmet, there were unintended consequences that hinder use, and patients believe e-PHRs are unnecessary for their care needs.

4. Tailoring e-PHRs to the design preferences, training and education needs of patients with chronic disease through developer-user collaboration may facilitate optimal use of e-PHRs.

Synthesised finding 1

Electronic personal health records can strengthen patient-practitioner relationships and support person-centred care when both patients and practitioners engage in productive and transparent communication built on mutual trust

Patients valued trust, transparency and reassurance as key drivers of the meaningful use of e-PHRs that facilitated shared decision-making and strengthened patient-practitioner encounters. This synthesised finding was generated from the aggregation of five categories, underpinned by 24 extracted findings (Table 4). The categories are as follows:

- Electronic personal health records promote productive communications with primary care physicians.
- Patients value electronic encounters with allied health professionals.
- Transparent electronic communications strengthen patient-physician relationships.
- Trust is a critical element for useful electronic communication.
- Electronic personal health records provide reassurance to patients.

Category: 1.1 Electronic personal health records promote productive communications with primary care physicians

Patients valued direct and productive communication with primary care physicians (PCPs) through the secure messaging function of e-PHRs. The electronic record acted as a reminder for patients, which improved their dialog with PCPs, making communication more efficient. This positively promoted their engagement in shared decision-making and enhanced their relationship with their PCPs. This category was supported by three findings.

1. Personal health record (PHR) messaging with the provider most important feature (U)
   "That's key. That's the guts. That's the core of it is - all the other stuff is just handy, but the - being able to communicate with your doctor is what it's all about." 51 (p.234)
2. Electronic record of communication (U)
   "It's just I can go in and access the message. I have a written copy, too, of what was said which, again to me getting older, is enormously important for me to have something I can go back to and go, 'Now, what did he say about that'." 65 (p.5)
3. Physician-patient relationship (C)
   Patients do not believe that the record has affected their physician-patient relationship. Another patient stresses that the preparations have enhanced the shared decision-making with her doctor. 64 (p.6)

Category 1.2: Patients value electronic encounters with allied health professionals

Allied health professionals (AHPs) such as dietitians, nurse practitioners and diabetes nurse educators monitored the health status of most patients. Patients felt they received more responsive care from these practitioners than from their PCPs. In contrast to PCPs, the AHPs used these electronic encounters with patients as opportunities for health education and monitoring trends which patients found valuable. This category was supported by four findings.

1. Desire to communicate with more team members (U)
   "I sent her a message during the day, and I usually get a response that day." 51 (p.235)
2. Communication issues (U)
   "At each visit it was… 'How are you, what's any problems, any questions? OK, let's go over this,' and she'd turn to the computer and say 'OK, let me keep this all accurate,' and once that was done, turn back to me and talk to me, so I never felt like I was being ignored or not taken care of." 60 (p.677)
3. Role of allied health provider (U)
   "They went over them. (The dietitian) went over (them) when I saw (her) and (the nurse) went through them. [The doctor] never really did go through them...he left it to, like the dietitian and the nurse to go through with me..." "Well, the doctors are so busy these days and you really hate to bother them, and the nurse was always available." 46 (p.6)
4. Patient preferences for electronic health records (U)
   "At first, I just thought it was just some silly numbers, but through her showing me on the computer and different things, now I see my A1c is five or as close as possible to five, that I'm doing well…So it helped a lot. It did." 46 (p.678)

Category 1.3: Transparent electronic communications strengthen patient-physician relationships

Patients were better able to cope with illness when they knew PCPs were committed to the use of e-PHRs. Patients placed high importance on PCPs who used respectful language in these communications. Patients felt their relationships were either strengthened or strained, depending on the level of transparency and respect conveyed through the content of the e-PHR. This category was supported by five findings.

1. Provider modelling (U)

Patient responses included "most definitely" and "I would use that if he (provider) asked me to." 58(p.7)

2. Partnering with providers

   "As a patient dealing with health care, I feel . . . a need to be a part of that (the process), so I like that . . . it provides me with, you know, a check point. . .so I can be in partnership with, with my doctors. So I'm not relying on them to tell me when this is (occurring). I keep on track with them." 63 (p.313)

3. Respect: strengthening patient-clinician relationships (U)

   "It's nice to know when I read the notes that the doctor noticed I was staying on task, because I was really trying to." 66 (p.522)

4. Personalised support (U)

   "You want to be able to feel comfortable that you know that there is someone else at the other end." 59 (p.311)

5. Transparency: strengthening patient-clinician relationships (U)

   "It made that relationship stronger, the trust was there, because they were open to talking to me about (the diagnosis] . . . instead of stuffing it under the carpet." 66 (p.521)

Category 1.4: Trust is a critical element for useful electronic communication

Mutual trust is the cornerstone of good health care, particularly for mental health patients. Patients needed and wanted to be trusted and conversely to trust healthcare professionals through e-PHR technology. When patients believed that nothing was being hidden from them, they had more trust in their clinicians. Seeing a written record of what was discussed made patients feel heard and cared for, such that patients were confident that their clinicians were engaged in providing optimal care. Trusted relationships affirmed the patient's aptitude to exercise self-care intentions. This category was supported by three findings.

1. Increases trust (U)

   "They're not just telling you something, they're also writing it in your chart, it's there. They're not hiding anything. Yeah, it's a trust thing." 68 (p.e255)

2. The therapeutic relationship and trust (U)

   "Open Notes is a move in the right direction. Like anything when you first start it, it has fits and starts, and people are reluctant and people don't like change, and psychiatrists like to keep their secrets, you know, and not hurt somebody's feelings or whatever. It kind of misses the point. The point is to develop this relationship." 66 (p.521)

3. Mutual trust between physicians and patients (U)

> *"I'd rather (not] wait a couple of days for my doctor to call me. If it has gone up, that means I have to take one iron pill a day. If it has gone down, I have to take two. A couple of days of feeling better, to me, is worth it. A good day for me is very important."* 59 (p.312)

Category 1.5: Electronic personal health records provide reassurance to patients

Patients felt less stressed and anxious when they had immediate and easy access to their medical information, such as test results and medical records. Cancer patients, for example, felt less fear when they could access detailed information about their medical condition. They also felt that, through the e-PHR, their provider was benevolently watching over them. Patients felt the virtual presence of their healthcare professional monitoring and that being looked after was important to their health care management. Patients felt e-PHRs had the equivalent security of internet banking and posed no harm or threat to their care. This category was supported by nine findings.

1. Relieves anxiety (U)
   "I have a better understanding of what our conversations are about...It makes visits here I guess peaceful. Less anxious, less stress, more trusting...because communication is the best way to let the patients know what's going on." 68 (p.e255)
2. Ameliorates uncertainty (U)
   "It just gives you a peace of mind that you know what to expect because this is uncharted territory." 68 (p.255)
3. Patient support (U)
   "I felt more comfortable because I knew that somebody was getting my results and they were looking at them and if there was a problem they could email through the portal and just tell me if there's, you know, you should be doing this or that the other thing." 46 (p.6)
4. Suspect inaccuracies (U)
   "I was upset about my cancer situation, but not for entering and reading my medical record." 64 (p.6)
5. Feeling secure (U)
   "I feel much safer now than I did before...If I had to pick one thing out of how this (programme) has affected my life and my everyday living, (it's) the fact that I'm not chronically worrying about everything. If I didn't have any access to knowing what's going on with my health, I think I'd probably go back on ulcer medicine . . . If I suddenly didn't have all this, I would probably be just a raving hypochondriac." (Patient 4) 67 (p.3)
6. Not concerned about privacy of health information (U)

"Now if we were talking about my banking or personal information, that would be a different story. There is really nothing to see in my medical chart." So does it matter if the whole world can see that I had a 7.8 HbA1c—you know, I could care less? What are they going to do with it?" 'What am I going to talk about in lung disease that I'm going to be afraid to have somebody else see?" 51 (p.235)

7. Security and privacy (U)

   "I assume that the security is very high. If not, then it should not be available to patients. It must be 110% secure so that no one but me, and those who are authorised can access and read the information." 64 (p.8)

8. Safety and security concerns (U)

   "Well, for me, when I first started here and the doctors talked to me and asked me things, then we would talk about the medications and he would write stuff down, and then when I came back for the next visit, they couldn't find their notes, and they would ask me, well, if I remembered what I discussed, or you know, what the doctor told me and I wasn't trying to remember because I thought the doctor should remember and they were always losing things and you had to do stuff or ask stuff over again, that kind of turned me off. Like, I really, I wanted another doctor. Cause I figured, like, this doctor didn't know what he was doing, losing the paper and all that." 60. (p.678)

9. Enhanced efficiency and accuracy (U)

   "One thing that I would like to do obviously is avoid all this paperwork when it comes to the doctor's office, having to type it in and read. I mean there is incorrect information and simply because people use their hands to write. When you write things down, it's inevitable that 6 turns into an A, or a 5 turns into a 6 and a 7 or an 8, so there's incorrect information in there. Ideally, it would be ideal if it could be done electronically." 58 (p.5)

Table 3: Synthesised finding 1: Electronic personal health records can strengthen patient-practitioner relationships and support person-centred care when both patients and practitioners engage in productive and transparent communication built on mutual trust

Findings	Category	Synthesised findings
Personal health record messaging with the provider most important feature (u) Electronic record of communication (u) Physician–patient relationship (c)	Electronic personal health records promote productive communications with Primary Care Physicians	Electronic personal health records can strengthen patient-practitioner relationships and support person-centred care when both patients and practitioners engage in productive and transparent communication built on mutual trust.
Desire to communicate with more team members (u) Communication issues (u) Role of allied health provider (u) Patient preferences for e-PHRs (u)	Patients value electronic encounters with Allied Health Professionals	
Provider modelling (u) Partnering with providers (u) Respect: strengthening patient clinician relationships (u) Personalised support (u) Transparency: strengthening patient -clinician relationships (u)	Transparent electronic communications strengthen patient-physician relationships	
Increases trust (u) The therapeutic relationship and trust (u) Mutual trust between physicians and patients (u)	Trust is a critical element for useful electronic communication	
Relieves anxiety (u) Ameliorates uncertainty (u) Patient support (u) Suspect inaccuracies (u) Feeling secure(u) Not concerned about privacy of health information (u) Security and privacy (u) Safety and security concerns (u) Enhanced efficiency and accuracy (u)	Electronic personal health records provide reassurance to patients	

U = Unequivocal – findings accompanied by an illustration that is beyond reasonable doubt and; therefore, not open to challenge.

C = Credible – findings accompanied by an illustration lacking clear association with it and therefore open to challenge.[1]

Synthesised finding 2

The versatility of electronic personal health record functions can support self-management of various chronic diseases

Patients valued the versatile functions of e-PHRs that supported their chronic disease self-management activities. Specifically, the versatility afforded by interactive and advanced e-PHR functions, such as secure messaging, personalised alerts, prescription refill requests and reminders, allowed them greater engagement with their healthcare providers and promoted individual behaviour change. Perceived benefits included a sense of empowerment, positive behaviour change, increased understanding of one's illness, ability to plan for future clinical encounters and better management of one's condition through instant connectivity with health records. This synthesised finding comprises six categories, which were generated from 40 findings. The categories are as follows:

- Electronic personal health records make patients feel in control.
- Electronic personal health records promote behaviour change.
- Electronic personal health records facilitate increased understanding of one's chronic disease.
- Electronic personal health records integrated into daily life optimise chronic non-communicable disease self-management.
- Electronic personal health records facilitate future clinical encounters.
- The instant connectivity of e-PHRs supports longitudinal management of chronic non-communicable diseases.

Category 2.1: Electronic personal health records make patients feel in control

Electronic personal health records gave patients a feeling of greater personal control over their illness. The ability of patients to control and decide on e-PHR content, track their health data and share information with whom they choose, facilitated self-management practices crucial for well-being. Having control over their communications and interactions shifted the focus to them as drivers of disease management, enabling a new type of partnership to be formed. This category was supported by five findings.

1. Facilitates control (U)

"For the overall ability to access your own record, really does give you a sense of control to be able to look in there, to be able to get answers to your questions at 3:00 in the morning, which is my time of day when I'm wide awake and thinking about those things." 68 (p.e255)

2. Illness ownership (U)

   "I would have the symptoms and the descriptions and then a chronology. Other medical problems. my own treatments. Self-help treatments did you do. That would sort of complement the doctors." 59 (p.310)

3. Control of the messaging (U)

   "I can put it down in my own words, using my own language and be confident that my doctor is getting what I am saying precisely, instead of what I've dictated to a receptionist." 51 (p.234)

4. Increased understanding of medical issues and increased sense of control (C)

   Patients from group A emphasised that they wanted to read their health information because they wanted to learn more about their health condition. Patients also emphasised that they used the EMR in order to know whether they had understood the information from the physician correctly. Other patients emphasised that EMRs helped them feel more in control of their care.64 (p.4)

5. Patient-driven communication (U)

   "I live in a senior building, and we're asking a lotta questions, medical questions, so I go online, go right on here and type it in . . . Within maybe a half an hour, maybe the next day, I get an answer. Straight from the doctor. . .I really like it cause. . .some things you don't have to go, like they said non-emergency question. And so even though it goes in your folder or whatever, but I, I really enjoy doin' it because it informs me that my doctor is on top of things." 63 (p.313)

Category 2.2: Electronic personal health records promote behaviour change

Electronic personal health records raised patients' awareness of their condition through tracking and monitoring of their health markers to facilitate health behaviour change. This category was supported by 13 findings.

1. Increasing awareness and proactivity in tracking (U)

   "I think, overall, HealthTrak makes you—or I think the whole object of HealthTrak, to me—is to make yourself more proactive in taking care of your health. You know, because if you don't wanna use it, well then it's really not HealthTrak's fault. You know what I mean? You've got the option now to do preventative health . . . To know that this needs to be done, and um, if you say, well you know what, I'm skippin' these reminders, I don't need to go to the doctors for another 6 months, you know, that is your choice then. But I think the HealthTrak is trying to encourage you to be proactive in keeping your health at its optimum level." 63 (p.314)

2. Self-efficacy and behaviour change (U)

   "I also found it kind of, you know, embarrassing because I would look on it and say, okay, I haven't put a blood record in in 52 days and I haven't really checked my blood, I guess I'd better do that, you know. Like, it gave me the kick in the butt, on the butt to...oh, gee, I better start putting logs again and that." 46 (p.4)

3. Behavioural changes (U)

   "It allowed me to adjust my insulin because if it (blood glucose levels) was too low then I wouldn't take as much." 49 (p.298)

4. Increased tracking of symptoms and moods (U)

   "I've enjoyed the instant connection to people." 61 (p.7)

5. Tracking of laboratory and diagnostic results (U)

   "Nowadays I have at my fingertips the actual tests, test results that I can read... I can read trends; I can read the actual levels." 51 (p.233)

6. Accessing test results is crucial for well-being (U)

   "Accessing test results, it is a tremendous difference, and it really means a lot to me. To get the information at once so you do not have to wait. It's so difficult to wait, whether it is bad or good news, it's very good to know." 64 (p.5)

7. Awareness of preventive care and screening (U)

   "I think I'm due for my physical, can we set up a physical or I think I'm due for a vaccination or another test." 51 (p.233)

8. Increased awareness (U)

   "I like that I can track my glucose level and I can see what I've been doing and if food is what was causing me to have highs or lows." 49 (p.298)

9. Positive effects on mood (U)

   "It's very nice to go back and look at what you've written before and also sort of monitor your mood that way." 61 (p.7)

10. Patient awareness (U)

    "It helped me understand that, so it made me watch my sugar more often when I was in pain. I would check my sugar to find out if it was high or low and try to tie in the highness of the sugar with the pain I was in or you know, stuff like that and with the eyesight as well it took a lot of, like, what I was really worried about was the eyesight when I found I was diabetic and it helped me with that quite a bit..." 46 (p.4)

11. Patient reactions (C)

    "Some of the things that I can do something about…I do…prior to my next visit. And I think it helps me out that way, especially helping me out with cholesterol. Because I reduced mine, you know, way down from where it was." 69 (p.513)

12. Patient-driven communication (U)

    "Let's say I have an appointment with my doctor, I will look back to. what I have written. then I see my doctor, (and the) doctor says "how are you" at least I have something to report". 59 (p.310)

13. Suggesting course of treatment (U)

    "Then I'll think potassium, you know, I need potassium. So then I'll instead of having to call the office, I just use my (PHR) to message (provider name) and say I need do you think I need potassium since I'm taking the Lasix?" 51 (p. 233)

Category 2.3: Electronic personal health records facilitate increased understanding of one's chronic disease

Electronic personal health records enhanced patients' ability to understand their own chronic disease crucial for well-being. Access to relevant information through e-PHR assisted patients and their carers to review medical records, track progress of treatments and therapies, and understand their complex medical conditions at their own pace in a quiet and secure environment. This was particularly important for cancer patients often overwhelmed with distressing or large volumes of complicated medical information. This category was supported by three findings.

1. Increased comprehension (U)

   "Having chemo brain you tend to forget things...So it's nice to be able to go back and see it in writing." 68 (p.e255)

2. Learning more about their medical issues (U)

   "I want to be able to understand my illness a little better in silence." 64 (p.7)

3. Access to information (U)

   "I found it easy to use and with using the health portal, using that section I found it much easier and faster because it gave me the topics that were relevant to what I was looking for and not a list of suggestions, that might be relevant as well, it just gave me what was relevant to what I was looking for..." 46 (p.4)

Category 2.4: Electronic personal health records integrated into daily life optimise chronic non-communicable disease self-management

Patients viewed e-PHRs as versatile and customisable when connected with smartphone devices, making them more easily integrated into daily life, thus optimising chronic non-communicable disease self-management. Patients' daily use of the tool was facilitated by common functions such as secure messaging, tracking and appointment reminders. Advanced functions such as remote monitoring, and access to e-PHRs coupled with additional functions such as internet, music and social media made access more meaningful, appealing and part of daily life. This category was supported by seven findings.

1. Technology-related benefits (U)
   "One of the biggest things, I like, the technology, I'm interested in that." 58(p.5)
2. Applications associated with the smartphone (e.g. music, internet browsing, social media), made it an appealing tool to integrate into daily life (U)
   "Definitely I've been happier just because I can like actually listen to my music...and watch it...before I could only listen to it, now I can watch it." 61 (p.7)
3. Tracking and appointment reminders were valuable functions (U)
   "...keeps me on track...to actually stay on my meds." 61 (p.7)
4. Increased connection with family/friends and care providers (U)
   "I like that I can track my glucose level and I can see what I've been doing and if food is what was causing me to have highs or lows." 61 (p.298)
5. Positive feelings towards the mental health engagement network technologies increased over time (U)
   "I find it really helpful and it is really good to have it in my hand because then I don't have to go and log on the computer and wait for it to boot up." 61 (p.7)
6. Meaningful applications for the implantable cardiac device data summary (U)
   "For me personally I wanna see if it started recording, I had an increased heart rate... I want the date, the time, and what the heart rate was, how long it was sustained at that rate, when it came back down... I want the nitty gritty details... just because it blows me away that I don't feel anything. I mean when those times happened, I just, I didn't feel nothing so it just kind of freaks me out." 62 (p.1112)
7. Facilitators and barriers to personal health record use (U)
   "I thought I would be... more active... I just set this aside and didn't do anything, you know, I sort of forgot about it... to tell you the truth. So I thought maybe I'd be getting some calls or... getting some emails or something." 62 (p.1111)

Category 2.5: Electronic personal health records facilitate future clinical encounters

Patients, particularly those whose memory were affected by chronic disease, like cancer, found e-PHRs invaluable as a memory aid, giving them freedom to write questions down, reflect and set goals or targets, which in turn made them feel safe, more engaged and satisfied with their healthcare encounter. This category was supported by four findings.

1. Plan for upcoming appointments (U)

   "If I can see the results before I talk to my doctor, I pretty much know what the visit's going to be all about." 51 (p.233)

2. Better preparation for future visits (U)

   "When you are visiting the doctor, you get quite blocked. You can't remember. Here I have the opportunity based on what I read in my medical record to write down the questions I want to ask my doctor otherwise I might not think of them during the meeting." 64 (p.6)

3. Aiding memory (U)

   "I think you get a much better mental preparation when you have the opportunity to return to your medical record instead of just relying everything on these occasional doctor visits that are so short and so confusing sometimes. I'm curious about my case and I think it is good to have something to go back to. When you talk to a doctor, you will not always remember everything, therefore it can be good to be able to go back to the medical records." 64 (p.7)

4. Reasons for using the personal health record (U)

   "I'm very interested if something's going wrong... and I would like to know about it. I love the idea of getting that (health data)... and then you can make an adjustment, whether it's you exercise more, you exercise less, you lose weight, you know." 62 (p.1111)

Category 2.6: The instant connectivity of e-PHRs supports longitudinal management of chronic non-communicable diseases

Patients appreciated the instant connectivity offered by e-PHRs, recognising the potential for unhindered accessibility that could enhance self-management tasks. Multi-functional e-PHRs allowed unlimited opportunities to connect and communicate, based on their own needs and according to their own and providers' individual schedules. The portability and accessibility of e-PHRs for patients and their family members gave them enhanced physical safety and independence. Being able to receive support quickly for mental health issues was particularly important. The ability to access test results the minute they were available was highly valued by patients, which they viewed as being critical to their well-being. This was apparent for cancer patients experiencing perceived risk of recurrence. This category was supported by eight findings.

1. Access to information (U)

   "I don't think she has (logged in). She counts on me to do it." Another participant gave a similar account: "I like to keep up with my information, and of course, my husband. I do for both of us." 58 (p 5)

2. 24/7 access to health records (U)

“So, in that sense, it frees you from the tyranny of the clock.” 51 (p.233)

3. Improved access to information when and where it is needed. (C)

   All patients from group A emphasised that having access to medical records helps them receive information in a timely manner.64 (p.7)

4. Feeling that non-acute concerns are uniquely valued (U)

   “I know how busy they (providers) are and to get through to my doctor is sometimes really difficult. You call and they say, ‘Well, we can take a message and we’ll get it to them,” and then I say, “Well, could I talk to the nurse? So this (living with diabetes programme) has just totally relieved that and I’ve felt good, because I don’t want to just be calling the provider all the time about these details. I think with anybody that has a continuing sort of a terminal problem; the computer can really be a great help.’ ” 67 (p.2)

5. Asynchronous communication (U)

   “If I had a question for them, I would call in and deal with what seems to be a number of (people). First you talk to the receptionist, and then you get to the nurse, and then you try to do the medication option. And call back when you get lost in the line of communication there some way.” 65 (p.4)

6. Enhanced feelings of safety, security, independence and confidence (U)

   “I’ve added emergency contacts.” 61 (p.7)

7. Complete and accessible record (U)

   “Personal data vault” and a “general overall record of my health.” “If something happens and I needed medical records, now they can get it.” 49 (p.298)

8. Enhanced ability to contact and be contacted (by care providers and family/friends) was important (U)

   “...good way for me to...keep in contact with (my)social worker so we could send...messages...in between appointments.” 49 (p.7)

Table 4: Synthesised finding 2: The versatility of electronic personal health record functions can support self-management of various chronic diseases

Findings	Category	Synthesised findings
Patient-driven communication(U) Facilitates control (U) Illness ownership (U) Control of the messaging (U) Increased understanding of medical issues and increased sense of control (C)	Electronic personal health records make patients feel in control.	The versatility of electronic personal health record functions can support self-management of various chronic diseases.
Increasing awareness and proactivity in tracking(U) Self-efficacy and behaviour change (U) Behavioural changes (U) Increased tracking of symptoms and moods (U) Tracking of laboratory and diagnostic results (U) Accessing test results is crucial for well-being (U) Awareness of preventive care and screening (U) Increased awareness. (U) Positive effects on mood (U) Patient awareness (U) Patient reactions (C) Patient-driven communication (U) Suggesting course of treatment (U)	Electronic personal health records promote behaviour change.	
Increases comprehension (U) Learning more about their medical issues. (U) Access to information (U)	Electronic personal health records facilitate increased understanding of one's chronic disease.	
Technology-related benefits (U) Applications associated with the smartphone (e.g., music, internet browsing, social media), made it an appealing tool to integrate into daily life (U) Tracking and appointment reminders were valuable functions (U) Increased connection with family/friends and care providers (U) Positive feelings towards the mental health engagement network technologies increased over time (U) Meaningful applications for the implantable cardiac device data summary (U) Facilitators and barriers to personal health record use (U)	Electronic personal health records integrated into daily life optimise chronic non-communicable disease self-management.	
Plan for upcoming appointments (U) Better preparation for future visits. (U) Aiding memory (U) Reasons for using the personal health record (U)	Electronic personal health records facilitate future clinical encounters	

Asynchronous Communication (U) Access to Information (U) 24/7 Access to health records (U) Improved access to information when and where it is needed (C) Feeling that non-acute concerns are uniquely valued (U) Complete and accessible record. (U) Enhanced ability to contact and be contacted (by care providers and family/friends) was important (U) Enhanced feelings of safety, security, independence, and confidence (U)	The instant connectivity of e-PHRs supports longitudinal management of chronic non-communicable diseases.	

U = Unequivocal – findings accompanied by an illustration that is beyond reasonable doubt and; therefore, not open to challenge.

C = Credible – findings accompanied by an illustration lacking clear association with it and therefore open to challenge.[1]

Synthesised finding 3

Adoption of e-PHRs is dependent on individual patient characteristics, and may be compromised if patients' expectations remain unmet, there were unintended consequences that hinder use, and patients believe e-PHRs are unnecessary for their care needs

Individual patient characteristics, in conjunction with chronic disease-related healthcare needs impacted patients' expectations of use of e-PHRs. For some patients, their expectations of e-PHRs for self-management were not met, or resulted in unintended consequences, rendering e-PHRs peripheral to their needs. This synthesised finding comprises four categories generated from 22 findings. The categories are as follows:

- Unmet expectations of electronic personal health records cause frustration and anxiety.
- Unintended consequences impact the patient's optimal use of e-PHRs.
- Electronic personal health records are viewed as peripheral to self-management needs
- Certain individual patient characteristics limit the use of e-PHRs.

Category 3.1: Unmet expectations of electronic personal health records cause frustration and anxiety

Patients experienced frustration with unmet expectations. Cancer patients, for example, found reading their cancer care notes taxing. This was unexpected, as these patients had not experienced this until they were diagnosed with cancer. Cancer patients experienced this anxiety as a result of access to medical records making the disease more evident for them. Patients also expected e-PHR systems to be sufficiently integrated to allow for additional interactions with a range of other healthcare professionals, but this was often not facilitated. This category was supported by seven findings.

1. Disappointment from unmet expectations (U)

   "Somebody should have been looking at them (the blood glucose levels), and if they were looking at them, I would have thought that they might have at least let me know that they were looking at them and that they understood what was going on. Maybe they looked at the record, I don't know, but they never let me know that they had done anything about it. I mean it was like sending it off into a void, into a black hole, and never hearing anything back." [67] (p.3)

2. Respect: straining patient clinician relationship (U)

   "Did (the clinician) actually listen to me? . . . It seems like a very different person written (about) in the notes at times." [66] (p.522)

3. Increased anxiety (U)

   "It usually brings up more questions, more concerns, more fears, which is why they all tell me to stay off of it. So under normal circumstances I think MyChart is great but in this whole cancer thing MyChart has not been a good thing." 68 (p.255)

4. Transparency: straining patient clinician relationships (U)

   "I'm...giving up a lot of time...I would like you to take it seriously too, not just spit something out on paper and not proofread it." 66 (p.522)

5. Concern that message may not be only between patient and provider (U)

   "And it can be a bit deceiving she may have to share that e-mail with either other doctors or with the nursing staff." 51 (p.234)

6. Poor coordination of care and integration of systems. (U)

   "If you're seeing a dietitian in the normal course of your treatment, shouldn't you be able to message them, even though they don't have an MD after their name?" 51 p.234

7. Unavailable features. (U)

   "There's a lot of potential there for instance, if there was some way that something could be set up so, that if I have osteopenia. What if something was offered to me, a link on you know on that to explain it to me and tell me what I could do about it...that would be helpful." 58

Category 3.2: Unintended consequences impact the patient's optimal use of e-PHRs

Patients felt frustrated when inaccuracies or errors in their clinical data could not be altered. Some patients experienced challenges engaging with providers disinclined to use e-PHRs. There were also patients who felt concerned that the extra time health providers spent in contacting them out of usual business hours would not be compensated. Other unintended consequences described by participants were related to the cost of internet access and computer hardware problems. This category was supported by six findings.

1. See incorrect data and information in the patient record (U)

   "I went to information about my medications; I did not even know why I was on some of them. The med info said, 'link not available at this time'; it was frustrating. I still don't know what the medication is for." 51 (p.234)

2. Uncompensated provider time (U)

   "So yeah, there have been times when I might have gone up for an appointment and I got enough answers through MyChart that I did not. So yeah, in one sense that's good for me that it prevented a trip, you know. For the business of medicine, I don't know." 65 (p.6)

3. Uncertainty of who will see and receive the records (U)

"Yes the fact that the PHR message is seen by others would keep me from putting anything really sensitive in a PHR message." 51 (p.234)

4. Provider engagement challenging (U)

   "No...I found it easy to use and I guess I would have liked to have seen it more central in my discussions and my appointments with the doctor but that's not a major issue. Like, I know he checked it once when I was there to see what my records and that were when I was with him and...but that's just because I was there with them and I believe that even then it came up that it was checked by (the nurse) on the behalf of (the Dr.) not him checking it and I thought that was a little weird. I thought it should be the fact that the doctor actually checked it." 46 (p.6)

5. Privacy and security concerns. (U)

   "I'm a private person and dislike my entire life being recorded on some electronic device." Another participant wondered if the PHR "is adequately secure enough, because it's in the cloud and I'm always a little worried. 'Are the insurance companies watching or how secure is it? Those are part of my concerns.' " 49(p.299)

6. Imposing on providers' time (U)

   "I try to make sure that I only use it for important things. Or things that I know they want to know about. Well, like when I contact the doctor about getting labs before I come in, that is a useful thing. But, I am not going to contact one of my specialists in the middle, or 6 months away from an appointment just to say, hey I have this little itch or something." 65 (p.5)

Category 3.3: Electronic personal health records are viewed as peripheral to self-management needs

Electronic personal health records were not viewed as a necessary tool for self-management of chronic non-communicable disease. Patients were comfortable using existing mechanisms for tracking health information such as memory, printouts, handwritten notes and excel spreadsheets. This category was supported by six findings.

1. Frequency and timing of use (U)

   "(The portal) doesn't come into consideration to remember to check or look at unless there's an appointment or something active going on. I did it more (logged on) when I was having scans and a lot of lab work a few years ago. Most of the time my lab results are good, and I'm in good health. I don't know why I'd be accessing it." 58 (p. 4)

2. Appropriateness (U)

   "I've got other things that are pressing on my mind that I've taken, you know, precedence and overridden everything else that's going on and until those matters get taken care of I've put a lot

of stuff that I shouldn't, especially the diabetes and that on the back burner until the other stuff gets taken care of...No, I don't think so, really. Just 'cause...I mean...see, I've been a diabetic and high blood pressure that has been under control...for a very long time. Well, I know myself probably better than the doctor does, you know what I mean?" 46 (p.5)

3. Out of sight, out of mind (U)
   "I never got into the habit of doing it. It was out of sight, out of mind." 49 (p.298)
4. Lack of patient–provider engagement with the personal health record (U)
   "doctor already has all my information." 49 (p.299)
5. Double tracking (U)
   "Being able to average and get my blood sugars in Excel is what I am used to." Just give me a piece of paper and I can write it down." 51 (p.299)
6. Preference for personal interaction (U)
   "I always enjoy talking to them when they call. We have a good conversation and a good thing about them is that they can ask things that usually you don't have time to ask your doctor about". 58 (p.6)

Category 3.4: Certain individual patient characteristics limit the use of e-PHRs

Patients' illnesses, family and work responsibilities, temporary displacement from their residence and the need to travel impacted on their use of e-PHRs. Patients' ability to remember usernames and passwords also led to non-use. For some patients, a positive health status deemed e-PHR use redundant to their needs; however, if they had been more ill, e-PHRs would have been more useful. This category was supported by three findings.

1. Difficulty with portal access (U)
   "I tried to get on it once and I couldn't get all the way in for some reason on my computer and I don't know what happened there. I was busy so I didn't have time to come back and check again." 58 (p.6)
2. I would have used it if I were sicker (U)
   "My A1c has been steady. So I didn't feel like I really needed to use it as often. That wasn't particularly useful for me." 49 (p.298)
3. Economic, infrastructure and computer literacy barriers (U)
   "Got rid of my computer service (Internet access) because I couldn't afford it." "I'm not a computer person so for me to get on to it, it took a while." 49 (p.298)

Table 5: Synthesised finding 3: Adoption of e-PHRs is dependent on individual patient characteristics, and may be compromised if patients’ expectations remain unmet, there were unintended consequences that hinder use, and patients believe e-PHRs are unnecessary for their care needs

Findings	Category	Synthesised findings
Disappointment from unmet expectations (U) Respect: straining patient clinician relationship (U) Increases anxiety (U) Transparency: straining patient clinician relationships (U) Concern message may not be between only the provider (U) Poor coordination of care and integration of systems (U) Unavailable Features (U)	Unmet expectations of electronic personal health records cause frustration and anxiety.	Adoption of e-PHRs is dependent on individual patient characteristics, and may be compromised if patients’ expectations remain unmet, there were unintended consequences that hinder use, and patients believe e-PHRs are unnecessary for their care needs
See incorrect data and information in the patient record (U) Uncompensated Provider Time (U) Uncertainty of who will see and receive the records (U) Provider engagement challenging (U) Privacy and security concerns (U) Imposing on Providers’ Time (U)	Unintended consequences impact patient’s optimal use of e-PHRs.	
Frequency and Timing of Use (U) Appropriateness (U) Out of sight, out of mind. (U) Lack of patient–provider engagement with the PHR (U) Double tracking (U) Preference for Personal Interaction (U)	Electronic personal health records are viewed as peripheral to self-management needs.	
Difficulty with Portal Access(U) I would have used it if I were sicker. (U) Economic, infrastructure, and computer literacy barriers (U)	Certain individual patient characteristics limit the use of e-PHRs.	

U = Unequivocal – findings accompanied by an illustration that is beyond reasonable doubt and; therefore, not open to challenge.

C = Credible – findings accompanied by an illustration lacking clear association with it and therefore open to challenge.[1]

Synthesised finding 4

Tailoring e-PHRs to the design preferences, training and education needs of patients with chronic disease through developer-user collaboration may facilitate optimal use of e-PHR

Patients identified improvements for the design of e-PHRs that were better aligned with and considered the nuances associated with their specific diseases. Patients wanted easily accessible training, tailored to their individual technology skills level and needs. They wanted disease specific and contextual education options available to them to support long term use of e-PHRs. Patients expected the seamless integration of e-PHRs across the continuum of their care to facilitate patient-practitioner encounters, explanation and support from a range of healthcare providers to encourage e-PHR use, and to receive ongoing reassurance that the digital environment offered optimal security and privacy. Collaboration between developer-user might optimise use of e-PHRs. This synthesised finding comprises two categories generated from 27 findings. The categories are as follows:

- Electronic personal health record design enhancements may optimise use.
- Training and education in the use of e-PHRs may optimise use.

Category 4.1: Electronic personal health record design enhancements may optimise use

Design, usability aspects and discoverability (i.e. ability to intuitively navigate the e-PHR) made e-PHR use challenging for patients, hindering self-management activities. For some patients, a lack of experience and knowledge with technology, including setting up internet access and data plans, limited their use of e-PHR. Navigation tools, large volumes of information and poor layout contributed to the tool lacking intuitiveness, which distracted patients from its use as a self-management tool. This category was supported by 13 findings.

1. Need to correct wrong information in the chart (U)
   "When I went through my health record, it said I had four drinks a night. Actually, I have about four drinks a year; I tried to change it to that, and it kept defaulting back to four drinks a night." [51] (p.234)
2. Want access to more results and progress results (C)
   "It's my body; it's my right to worry. And I want to read, I want to read everything. I want to see everything." [51] (p.234)
3. Need to improve personal health record design (U)

"These seem to be designed by computer people who set them up the way they think they ought to be set up, but the experience of the user isn't a guiding light." 51 (p.234)

4. Navigation of the personal health record is a concern (U)

   "The current PHR system is not set up right, too hard to look for historic data; I cannot easily select a test result; it can be difficult to find things." 51 (p.235)

5. Insufficiencies of the implantable cardiac device data summary (U)

   "I think this would be great if I could get this information (in the widget) ... But that big long page I wouldn't be interested... A few things but not... I wouldn't click on all of those." 62 (p.1111)

6. Lack of knowledge about technology and data plans prevented use (U)

   "I just don't understand plans, so I just don't get it. Like the minutes and the data, I don't get that." 61 (p.7)

7. An onerous login process and the requirement to remember a password for the Lawson Smart Record was challenging (U)

   "... it was...frustrating to have to...log in at every single point... and... wait for the loading process..." 61 (p.7)

8. Prompts and reminders did not always occur as programmed (U)

   "I find it sometimes hard to keep track of all the password (sic) I have now." 61 (p.7)

9. Small font and button size on the smartphone were difficult to see/use (U)

   "I put it in for a reminder and it emails at the beginning of the day. Well that doesn't help remind...to take my bedtime meds." 61 (p.7)

10. Smartphone battery life was insufficient (U)

    "...the battery only lasted a couple hours" 61 (p.7)

11. The appearance and functionality of the Lawson Smart Record should be improved (U)

    "I would make it (look) less clinical." 61 (p.7)

12. Alerts should be sent directly to the smartphone when messages or changes are made to the Lawson Smart Record (U)

    "Could be nicer if gives forwarding messages to my email then I (would) get to see it directly." 61(p.7)

13. Usability and discoverability (U)

    "I didn't enjoy using it. And it was a real pain and it took a lot of time and would rather have had something like, you gave me a blood monitor and I just downloaded it...I can't take a half a day to sit in front of the computer to put the information in." 46 (p.5)

Category 4.2: Training and education in the use of e-PHRs may optimise use

Patients felt training and technical support should be provided in the form of ‘on the spot’ sessions, webinars and video tutorials for e-PHRs. For some patients who received training, they reported difficulties in remembering the content of training. They also mentioned that training and provision of information should be developed according to the individual’s level of experience with basic, intermediate or advanced technologies, and tailored to their computer literacy skills and the pace at which they could adopt the technology. It should also take into account the compatibility of the system with their web browsers. Patients thought glossary or ‘cheat sheets’ would be useful. Patients wanted training on how to construct messages directed to health professionals, and ‘rules of engagement’ in non-acute situations. This category was supported by 14 findings.

1. Learning to use the portal (U)
   “The majority of patients reported learning to use the portal on their own. They used phrases such as ‘trial and error’, ‘hook or crook’ or ‘played around with it’ to describe learning to navigate the website.” 58(p.4)
2. Medical jargon in the PHR frustrating (U)
   “Don’t give me that jargon, put it in plain English.” 51 (p.234)
3. No participants had personal health record training (U)
   “None whatsoever. No. Not even an orientation or hi, this is the PHR.” 51 p.235
4. Health numeracy is a problem for some (U)
   “Actually that’s one of the reasons I made an appointment with my doctor because I was looking at my lab results I didn’t even know what the scale meant.” 51 (p.235)
5. Most were self-taught (U)
   “They really do need to provide a class if they’re going to expect people to use (PHRs).” 51 (p.235)
6. Training in personal health record use may encourage more usage (C)
   “No training whatsoever, that is part of the reason why I don’t use it that much.” 51 (p.235)
7. Need to learn how to construct messages to providers (U)
   “My doctor tells me I am too wordy with my e-mail. He says I send too much e-mail. He asked me to limit my e-mail.” 51 (p.235)
8. Additional training should be provided on the use of the Lawson Smart Record (U)
   “There’s so much on the SMART record that I don’t even know what to do with it.” 61 (p.7)
9. Access to information (U)
   “(We) were never instructed when we went for our little introduction to doing this, instructed where our numbers should be, what we should do with our numbers, what the heck they were doing...” 46 (p.7)
10. Technical aspect (U)

“I did enter my data and in this case I had several months of...I had been collecting data for a num...and I wanted to enter all that data but I had to go back and retroactively enter it and I found that very cumbersome and awkward to do. As soon as I would get a piece of data entered the computer would keep bouncing back to the current date and I had to scroll all the way back again to the next day and enter that data. So, it was very time consuming and awkward.” 46 (p.7)

11. Lack of clarity about when to send a secure message (U)

    “If everything is stable, I could probably go three months without using it. It’s more when something is stirred up, which is, as I get older, that happens more frequently. And, you know, it’s just a transitional time of life when, ‘I don’t even know if that’s normal or not. Should I come in for that or am I wasting your time?’ ” 65 (p.6)

12. Perceptions and understanding about remote monitoring (U)

    “I guess I don’t really understand totally how it works... if you call it and ask for a report or does it do it automatically or... Does it call in on its own at a certain predetermined time or something?... How often do they do it?” 62 (p.1111)

13. Transition problems (C)

    “Participants were frustrated with providers’ slow speed in typing, and worried about the accuracy of providers in data entry. Patients expressed a fear that information would be entered incorrectly if they distracted providers.” 60 (p.679)

14. Suggestions for enhanced utilisation (U)

    “It just needs to be easy, easier to navigate through.” 58(p.7)

Table 6: Synthesised finding 4: Tailoring e-PHRs to the design preferences, training and education needs of patients with chronic disease through developer-user collaboration may facilitate optimal use of e-PHR

Findings	Category	Synthesised findings
Suggestions for Enhanced Utilization (U) Medical jargon in the PHR frustrating (U) No participants had PHR training (U) Health numeracy is a problem for some (U) Most were self-taught (U) Training in PHR use may encourage more usage (C) Need to learn how to construct messages to providers (U) Additional training should be provided on the use of the Lawson Smart Record (U) Access to information for improvements (U) Technical aspect (U) Lack of Clarity About When to Send a Secure Message (U) Perceptions and Understanding about Remote Monitoring (U) Transition problems. (C)	Electronic personal health record design enhancements may optimise use.	Tailoring e-PHRs to the design preferences, training and education needs of patients with chronic disease through developer-user collaboration may facilitate optimal use of e-PHR.
Learning to Use the Portal (U) Need to correct wrong information in the chart (U) Want access to more results and progress results (C) Need to improve PHR design (U) Navigation of the PHR is a concern (U) Insufficiencies of the ICD Data Summary (U) Lack of knowledge about technology and data plans prevented use (U) An onerous login process and the requirement to remember a password for the LSR was challenging (U) Prompts and reminders did not always occur as programme (U) Small font and button size on the smartphone were difficult to see/ use (U) Smartphone battery life was insufficient (U) The appearance and functionality of the LSR should be improved (U) Alerts should be sent directly to the smartphone when messages or changes are made to the LSR (U) Usability and discoverability (U)	Training and education in the use of e-PHRs may optimise use.	

U = Unequivocal – findings accompanied by an illustration that is beyond reasonable doubt and; therefore, not open to challenge.

C = Credible – findings accompanied by an illustration lacking clear association with it and therefore open to challenge.[1]

Chapter 4: Discussion

In this chapter, a general overview of the systematic review findings, followed by a detailed discussion of these findings in the light of the existing knowledge about e-PHRs for chronic non-communicable disease self-management, are presented. The strengths of the review, and the limitations of included studies and those related to the systematic review process are also discussed.

General discussion

This review explored adult patients' experiences of e-PHR use for self-management of chronic non-communicable disease. Fifteen studies were included following a thorough search process and assessment of methodological quality. Included studies were conducted in three countries across North America and Europe. The findings of this review indicated that adult patients' experiences of use e-PHRs were predominantly positive and aligned with their values and preferences. The first synthesised finding demonstrated patients' preferences for productive and transparent communication, built on mutual trust that offered reassurance. When these values were evident, patients accepted and felt satisfied that e-PHRs were appropriate for self-management of their chronic disease. Moreover, the perceived benefits of e-PHR use included strengthened patient-practitioner relationships and a sense of empowerment that facilitated positive behaviour change through increased understanding of their chronic disease. The second synthesised finding found a wide range of functionalities offered by e-PHRs, including the ability to communicate, access and share clinical data, be informed and request health-related information, which made e-PHRs versatile for the patient's self-management activities. The third synthesised finding suggested that for some patients, their individual characteristics, and those related to their chronic disease, impacted their expectations of e-PHR use, as did the unintended consequences of e-PHRs (e.g. perception that providers were not compensated for their time) and their unmet needs. Lastly, the fourth synthesised finding presented design enhancements identified by patients as being desirable, and highlighted the training and education support they believed was paramount to optimising sustainable use of e-PHRs.

The findings of this review align with previous e-PHR literature reporting e-PHR systems improve patient empowerment, can increase patients' adherence to self-care and impact clinical outcomes.[18,40,71] A systematic review exploring older adults' experiences[53] found privacy and security, and access to and ability to use technology and the internet as the two main barriers to e-PHR use, whilst technical assistance and provider advice were facilitators. Similarly, a systematic review[43] exploring barriers and facilitators to e-PHR use identified the following patient-perceived facilitators: provider encouragement, access/control over health information and enhanced communication, themes similar to those found in this review. However, in terms of barriers, only ‘lack of awareness/training’ aligned closely with the findings of the current review. Privacy and security concerns that were also identified did not appear to be as strongly evident in this review. This finding aligned with other studies examining privacy and security, suggesting that this is becoming less of a concern for patients accessing health-related information using these types of technologies.[72,73]

This review also presented new findings, extending the knowledge base for e-PHR use, by highlighting the experiences of patients’ use of interactive e-PHR functions, such as ‘remind’ functions e.g. secure messaging and symptom checking reminders; and ‘request’ functions, that facilitated transactional services e.g. prescription requests, through smart devices. A recent quantitative systematic review[71] found only one study where the ‘remind’ functionality was included in e-PHR functions. Furthermore, none of the e-PHR systems examined in that review offered the ‘request’ functionality. The authors attributed this to the date of the conduct of those studies where only basic e-PHRs systems were examined, as most were published before 2012. In contrast, most of the included studies in this review were published between 2017 and 2018, which might reflect the examination of the very recent and rapid advancements in e-PHR systems.

Furthermore, this review encompassed the experiences of patients who had cancer, mental health conditions and gastrointestinal disease, specifically, inflammatory bowel disease, not identified in previous e-PHR systematic reviews on this topic.[20] Previous research related to benefits of e-PHR use has predominantly focused on chronic diseases such cardiovascular disease[30,50] and diabetes.[74-76] This review highlighted the potential for the scope of e-PHR use for self-management activities to extend beyond these types of chronic diseases.

Discussion of key findings

The first of the four synthesised findings indicated that 'e-PHRs can strengthen patient-practitioner relationships and support person-centered care when both patients and practitioners engage in productive and transparent communication built on mutual trust'.

Trust, transparency, respect and reassurance were values identified by patients as being key to facilitating direct and productive communications. When patients felt these values were present in their communications with their HCPs, these communications were viewed as personalised, which positively impacted their health care. Patients felt that this enhanced their encounters, leading to better relationships with their HCPs. In addition, patients valued the ability to connect through a single shared e-PHR that enabled collaboration with all the members of their healthcare team. Robotham et al.[77] found that patients with severe mental health conditions appreciated being able to connect with their trusted healthcare and social support networks.

To support and sustain the patient-practitioner relationship, the 'rules of engagement' should be clear to both parties to facilitate trusted communications.[78] Health record transparency is a significant and important criterion for promoting trust. Bell et al.[79] noted that building trust between patients and practitioners was especially important for vulnerable patient populations, such as those with mental health conditions. Health record transparency was also viewed as crucial to facilitating positive patient experiences and appeared to empower patients and enhance their contributions to care.[48] This is important as access to electronic health records 'anytime and anywhere' means that HCPs and patients must work collaboratively.[80]

Transparency and trust were also determined by the appropriate use of language, when tailored to the needs of the intended recipient. Attention to wording in this context was therefore important, as this can help patients feel more comfortable when interacting with new technology. This aligns closely with the view that incorporating empathic language in healthcare encounters was an essential aspect of effective, meaningful communication that can increase patient satisfaction.[95] Patients are also inclined to trust HCPs when HCPs can explain e-PHR use and how it can help improve their health care. This finding is consistent with e-PHR research[43,81,82] that showed improved rates of use when providers recommended or explained how an e-PHR might benefit an individual patient. Laugsen et al.[41] found that the most important factors in increasing e-PHRs adoption involved ensuring prospective users were fully informed of the short and long term benefits of using e-PHRs, that they were made to feel confident that they could use e-PHRs, that they could see the fit between e-PHR technology and self-management, and that they believed the cost of using e-PHRs were offset by the potential benefits. Overall, patients with chronic non-communicable diseases need reassurance from healthcare providers to understand how sharing information in an e-PHR will improve their care.[58] The lack of reassurance offered by providers is highlighted in reviews exploring patient-provider experience of use of e-PHRs as undermining both parties' intention to use and or adopt this technology.[43,83]

This synthesised finding showed that patients and practitioners engaging in communication within this digital environment bestowed an opportunity for a more 'innovative partnership' or relationship with healthcare providers.[43] Patients did not view these types of encounters as a substitute for usual face-to-face care but rather an enhancement to their usual care. Irizarry et al.[37] reported personalisation and collaborative communication between patients and providers patients as the top two features of patient portals desired by patients.

The second synthesised finding suggested that 'the versatility of e-PHR functions can support self-management of various chronic diseases.'

Patients identified a range of e-PHR functionalities and features that supported self-management. Advanced and interactive e-PHR functions such as the ability to communicate through secure messaging, immediate access to test results, ease of monitoring and tracking health indicators, and reminders and requests were key to their self-care. These features contributed to improved feelings of control and understanding of their chronic disease, which in turn, enabled behaviour change important for facilitating self-management. Specifically, these functions allowed patients to integrate self-care tasks into their daily lives, plan for encounters, and connect according to their own schedules. Immediate access to test results was highly valued, which is consistent with other studies that found patients benefited from early release of test results.[71] For example, oncology patients highlighted their preference to check their laboratory results or scan reports before being contacted by their provider.[84]

The secure messaging function provided a safe environment which enabled patients to share and communicate with their HCPs. For patients, this e-PHR function made the e-PHR more versatile, i.e. it was more than just a repository of health information. In a controlled before-and-after study with a six-month follow-up, the effect of an electronic patient portal with secure messaging increased patient activation. Furthermore, the study identified that using a patient portal with secure messaging might be more cost-effective than usual care among chronically ill patients. The authors concluded that offering the possibility of substituting healthcare visits with less costly contacts using self-management tools did not seem to compromise the health status or treatment of chronic care patients. Secure messaging is one way of activating patients and improving adoption where passive platforms have not succeeded.[85]

Other advanced or interactive functions of e-PHRs, for example, personalised alerts for preventative health care were viewed favourably by patients. This is consistent with studies that found health maintenance reminders such as mammography screening and influenza vaccinations delivered by e-PHRs were beneficial, leading to improved patient adherence to preventative healthcare programs.[86] Furthermore, the ability for patients to proactively, track and monitor their own chronic disease-specific biomarkers, such as blood sugar levels and blood pressure, enabled an understanding of their illness. The flexibility offered by 'anywhere/anytime' e-PHR access and the improved knowledge of their chronic disease offered by the education function of e-PHRs meant patients could respond immediately, maximising control of their disease. Grossman et al.[87] and others[72] found similar themes related to e-PHR use, i.e. empowerment and proactivity in self-care. Those studies affirm that access to health record information can endow patients with improved self-awareness and that for some patients, it can lessen the anxiety, disempowerment and suffering patients' experience due to uncertainty about their condition. A study,[84] that examined cancer survivors' experiences of access to their health information, found cancer patients were most positive about e-PHR features that could provide them with more personally relevant information, including access to a survivorship care plan, access to their medical records and appointments.

An additional benefit identified amongst patients was the ability to plan for future clinical encounters. Electronic personal health records can help patients recall vital health information which is important for planning questions and setting their own agendas for future visits. This is consistent with studies that found patients who had been provided with agendas for future visits experienced better health outcomes.[28 88] Patients with chronic disease often visit multiple healthcare providers, and e-PHRs could overcome the need to repeat their medical history to every HCP. They also offered opportunities for multiple providers to add up-to-date and accurate information to the e-PHRs. These interactive or personalised functions, if utilised effectively, may be an avenue for addressing some of the barriers identified in other studies[14,17,33,89] that have led to low e-PHR adoptions rates.

The third synthesised finding described how ‘adoption of e-PHRs is dependent on individual patient characteristics, and may be compromised if patients’ expectations remain unmet, there were unintended consequences that hinder use, and patients believe e-PHRs are unnecessary for their care needs.’

This synthesised finding illustrated that for some patients, their individual characteristics, including those related to their chronic disease, influenced their perspective and expectations of e-PHR use. This finding also provided valuable insights regarding the impact of unmet expectations and unintended consequences on patient’s perceived usefulness and satisfaction with e-PHRs, leading to their suboptimal adoption for chronic non-communicable disease self-management.

Ammenwerth et al.[15] in a systematic review of randomised control trials examining the effects of patient access to electronic health records found that some patients experienced increased feelings of confusion and anxiety, particularly when reading clinical information that was unclear to them. Similarly, Tieu et al. 2016 found that individual patient characteristics and the degree of chronic disease could impact e-PHR use. Severely ill patients, such as those with advanced cancer, might experience increased anxiety or fear due to a heightened sense of worry related to accessing information or test results highlighting the progression of their disease. The literature suggest access to e-PHRs may not be suitable for use by some patients at an advanced or terminal stage of their disease or condition, or during palliative care.[90] Furthermore, for some patients, providing access to health records may not be possible due to individual characteristics related to health numeracy and literacy[91], societal and economic inequities, and technological limitations such as internet access.[92]

Although patients desire access to their own health care information, challenges exist in determining the most beneficial information to include, as well as the quality, quantity and specificity of that information, to avoid overwhelming patients which can lead to frustration and anxiety. Unintended consequences have been reported in previous literature,[93] such as data errors, documentation inaccuracies and medication errors, that can cause patient distress or harms. Interestingly, this systematic review showed that patients worried that HCPs might not be renumerated for the extra time spent in attending to the administrative tasks associated with e-PHRs such as sending secure messages. Patients struggled with balancing their desire to respect HCPs’ time with their need for an answer to their health-related questions. This was complicated further, as patients felt they did not know when to approach HCPs as some patients did not understand how to distinguish between acute and non-acute concerns, and therefore when it was appropriate to send HCPs messages. This highlighted that HCPs should reassure patients on an individual basis about the expectations of their communication. Personal health information management is an additional burden that chronic non-communicable disease management places upon patients, unrecognised by the medical establishment.[47]

This synthesised finding also illustrated that for some patients there would be unexpected or unwanted consequences because of the additional responsibility conferred by gaining control of their health information through e-PHR access. Some patients preferred not to disclose relevant health information due to concerns that this information might be used against them, for example, by future employers, health insurers and biased HCPs. This is the case for mental health patients who may choose to only reveal certain parts of their records for fear of reprisal, or under circumstances that lead to exposure of personal health information, such as security breaches.[77] Other patients may have different priorities or privacy concerns that override their interest in sharing their health information. Patients concerned about the security of their personal health information, including third party access, may choose to not disclose relevant health information.[77]

‘Tailoring e-PHRs to the design preferences, training and education needs of patients with chronic disease through developer-user collaboration may facilitate optimal use of e-PHR’ was the fourth synthesised finding.

Patients identified several design factors and features of e-PHR that might optimise e-PHR use. Ease of access to e-PHRs was viewed as one element critical to patient satisfaction. The simple task of securely logging-in could challenge some users. Findings indicated that many participants experienced unsuccessful logins, requiring complex password requirements for logins which could discourage sustainable use of e-PHRs. In one included study[62], patients found navigating the e-PHRs to retrieve test results or wading through large volumes of data, for example, cardiac rhythm data, frustrating. Another design aspect that impacted their use of e-PHRs was the overtly clinical look of e-PHRs, which some patients found off-putting. Patients preferred e-PHRs that integrated with electronic personal devices that they used regularly. For example, findings indicated mental health patients preferred access through smartphones that also allowed them to connect with their social networks. Storni et al.[94] suggest of a more holistic view of self-management of chronic disease in everyday life is needed, with more attention being paid to the perspective of affected individuals, as this has potential implications for the way e-PHR systems are conceived and designed to support self-management of chronic disease.

This synthesised finding also identified training and education as paramount for patients to enhance sustainable use of e-PHRs. Patients wanted training and support in various forms that could cater for their individual characteristics and self-care needs. This related to not only software aspects of e-PHRs but the type and complexity of disease specific information they had to digest through the e-PHRs, for example, reading test results or interpreting complex health data. According to Toscos et al.,[30] a study focused on an e-PHR for delivering patients’ cardiac monitoring data found the e-PHR deficient as it did not consider the need for those patients to understand and interpret the cardiac data for which it was designed. The patients felt that they were receiving too much information that was too complicated for them to understand, which led to frustration and disinterest. Furthermore, some patients needed assistance with understanding complex medical jargon. For mental health patients understanding clinical observations and case notes impacted their perceptions of the care they received from mental health clinicians.[77]

This synthesised finding indicated that patients also wanted e-PHR training and education on e-PHR-specific topics, for example, secure messaging, personalised alerts, medication management functions and constructing a message to their HCP. Similar to the above, patients desired this training to be tailored to their specific individual characteristics. As e-PHRs allow patient-provider interactions anywhere and anytime, patients raised concerns related to their knowledge and ability to document or construct well-articulated messages, including the circumstances under which it was appropriate to contact their HCPs. Patients felt they did not always understand 'the rules of engagement'.[65(p.9)] This is consistent with e-PHR literature that found the ability to use the interactive functions of e-PHRs, for example, to send messages to the HCPs requires appropriate training that is more than just the technical aspects but encompasses the 'etiquette' for online communication.[83] Current e-PHR literature indicates that little guidance is available for patients to guide use surrounding these features.[95] Guidance is required on when messaging is appropriate, what topics can be addressed by secure messaging, the type of information to include, how to understand the information sent by providers and usage during emergency situations. Belyeu et al.[96] found the need to educate and coach patients in the use of web-based platforms, citing that opportunities exist to train patients with limited computer literacy by connecting them with tech-savvy peers. For patients challenged using complex health systems, peer navigators are effective advocates and have demonstrated benefits for patients with diabetes and multiple chronic disease.[96] Family, friends and caregivers have also been reported as integral in supporting patients in their use of e-PHRs.[38]

Strengths of the review

A recently published umbrella review[97] found that systematic reviews on e-PHRs (including quantitative reviews and qualitative reviews) were suboptimal, given their 'modest quality'[97(p.232)] which were primarily related to poor compliance with universally agreed standards for systematic review methodology. Specifically, the review found that systematic reviews in this area lacked published *a priori* protocols, had poor transparency in reporting their methodology, and inadequate assessment of risk of bias in the quantitative reviews. The current review addressed those issues by adhering to a well-established and robust methodology for systematic reviews of qualitative studies. The current review also had an *a priori* protocol which explicitly reported on the methods used for the systematic review. Including both published and unpublished sources in the review contributed further to the strength of this review. In addition, by focusing on qualitative studies on patient experiences, an in-depth perspective and exploration was achieved. Furthermore, the JBI meta-aggregative approach is "an important and impactful approach to qualitative research synthesis because it moves beyond theory to produce statements in the form of 'lines of action' which then lead to recommendations for policy and practice."[98(p.445)]

Limitations of included studies

This review has a few limitations which should be considered when interpreting the findings. The poor reporting of the methods and qualitative methodologies used in the primary studies prevented the reviewers (J.E. and L.L.) from adequately assessing their methodological quality. Only three included primary studies [51,59,60] were found to be strong in their methodological reporting. Furthermore, the primary authors' cultural and theoretical orientation, important for understanding the impact their beliefs and values might have on the research, was not evident in most studies. Similarly, researcher reflexivity, important for acknowledging author bias in qualitative research,[54] was not addressed. Additionally, the identification of, or potential to have missed, relevant studies due to the lack of a universal definition or taxonomy for describing e-PHR technology[71] was a potential limitation of this review.

Limitations of the review process

This review limited its focus to the experiences of patients with chronic non-communicable disease who were already using e-PHRs for self-management and may therefore be considered 'enthusiastic' adopters. The generalisability of findings to other user types was limited. In addition, although the search strategy was developed to include participants with a broad range of chronic non-communicable diseases, some might have been missed. The list of conditions was limited to those studied and included in the search, despite efforts to include a comprehensive list of chronic disease. Furthermore, screening of the articles and data extraction was undertaken by only one of the reviewers (J.E.), with validation by the other reviewer (L.L.) if required, which could have led to relevant studies being missed and potential for researcher bias. Excluding studies published in languages other than English might have also limited the retrieval of other relevant studies. Although an international perspective was taken, the review was limited to included studies conducted in developed countries within the northern hemisphere. The review did not include the experiences of adult patients in developing countries, potentially limiting the transferability of the review findings to those populations. Finally, this review focused only on adult patients' experiences and did not consider the perspectives of their caregivers, who might also access e-PHRs on their behalf. The results of this review may therefore have limited transferability to this population. Despite these limitations, a qualitative synthesis such as this offers the needed insights into the experiences of patients, shedding light on what patients want and expect from e-PHRs.

In this chapter of the thesis, the conclusions of the systematic review are presented. The implications of the qualitative review are addressed through the identification of recommendations for practice and future research.

This review is unique because it is the first to systematically synthesise the best available evidence from primary qualitative studies examining adult patients' experiences of e-PHR use for self-management of chronic non-communicable diseases. This qualitative systematic review makes several contributions to e-PHR research, including valuable insights into patients' experiences, attitudes and perceptions of using e-PHRs for chronic non communicable disease self-management.

Exploring patients' experiences of use of e-PHRs, in the context of self-management of their chronic non-communicable disease, reveals new benefits and highlights some of the complexities associated with electronic access to health information. Overall, the findings of this review indicate that e-PHRs can address the gap that exists for patients, between being merely informed and becoming actively engaged in self-management of their health care. Patients value trust and transparency for productive communications with HCPs. Similarly, reassurance is identified as being vital in supporting and strengthening patient's practitioner relationships to optimise person-centred care. Advanced functions of e-PHRs, such as secure messaging, reminders and personalised alerts stand out as empowering patients to take an active role in their healthcare. It is important for patients to be aware of and understand the benefits of using e-PHRs for self-management to minimise their uncertainties related to their chronic disease. When patients are well informed and their needs identified, they are more likely to actively participate in their care, engage in shared decision-making with their healthcare providers, leading to improved e-PHR adoption and sustainable use. The versatility offered by e-PHRs enables patients to take ownership of their illness, an essential component of chronic non-communicable disease self-management. Furthermore, the versatile functions offered by e-PHRs align well with and support the longitudinal nature of chronic non-communicable disease self-management. Whilst many patients with chronic non-communicable disease may benefit, there will be some who will not use e-PHRs that can be attributed to their own individual characteristics, unmet expectations and unintended consequences of e-PHRs. Therefore, identifying these unmet needs, unintended consequences or patients' individual characteristics, for example, those experiencing increased worry, anxiety or distress, may help in understanding those factors, enabling them to be addressed. Finally, patients want and expect e-PHR features and functions to be easy to use, provide intuitive and effective navigation options, look more user-friendly and less clinical, offer enhanced interoperability, interface with the smart devices of their choosing, and offer integrated education for interpreting test results and other clinical data, with ongoing access to flexible training, education and technical support. Developer-user collaboration is therefore integral to the improvement of the design of e-PHRs. Consequently, it is important to gain input from all stakeholders in the design and modification of these systems to ensure optimal patient-centred health care. It is important to understand these experiences as they are useful to guide development of future e-PHRs to ensure they are better aligned with the self-care needs of patients with chronic non-communicable diseases, necessary in optimising patient-centred health care.

Overall, to be meaningful, patients prefer e-PHRs that are structured in a way that they can understand, are more than a summary of their health data, and allow interaction across the continuum of their healthcare journey. As patients gain greater experience with the use of e-PHRs for chronic non-communicable disease self-management, new considerations will emerge to inform the future 'rules of engagement'. Successful and sustained integration of e-PHRs into chronic non-communicable disease self-management, however, requires future research efforts to continue the focus on the value of patients' perspectives, in order to enable the development of best practices that reflect the nuances of a wide range of chronic non-communicable diseases. The development of evidence-based practices aimed at improving the sustainable use of e-PHRs for self-management of chronic non-communicable disease must employ rigorous and well-established methodologies and methods to ensure confidence in the quality of research that informs future policy recommendations for patient-centred care.

Recommendations for practice

Grades of recommendations are used to classify recommendations for practice, based on the strength of evidence, with the intent to inform decision-making. Grade A recommendations are rated as strong recommendations, whereas Grade B recommendations are 'weak' or 'conditional' recommendations.[99] The strength of the recommendations for this review were impacted by the low grade assigned to the four synthesised findings as shown in the ConQual Summary of Findings. The low grade was based on the critical appraisal criteria that were either unclear or not achieved in the studies assessed.

- HCPs should learn appropriate ways of communicating with their patients through this new medium as this could help foster and build trust, create and maintain transparency for effective patient and provider encounters and communications (Grade B).

- To improve patients' experience and engagement with using e-PHRs, patients should be encouraged to be proactive in raising and discussing their concerns with HCPs so they can be addressed as they arise. This approach should be considered as essential for HCPs in order to increase their understanding of how best to guide patients and provide the needed reassurance (Grade B).

- Healthcare providers and patients should be aware of the various functions of e-PHRs. By identifying the functions that are most useful for the management of specific chronic diseases, they can make more informed decisions regarding what functions would best fit their needs and requirements. HCPs should understand these functions so that they know how best, and what features of e-PHRs they need, to highlight to patients (Grade B).

- HCPs should explore with their patients any barriers to their use of e-PHRs so that they can be addressed, particularly with respect to individual characteristics or concerns around their specific needs related to their chronic disease. HCPs should discuss confidentiality and security, and endeavour to provide ongoing reassurance, as and when required (Grade B).

- Patients should be provided with avenues that allow them to participate and be supported in tailored training and education programs designed for use of e-PHRs in chronic disease management (Grade B).

- Training program development should focus on technical and non-technical aspects of e-PHR use such as options for internet and data plan access, interoperability, availability of functions that can allow patients the ability to turn on or off features that they do not want or require, connection to smart devices, navigation, documentation and message construction support in a variety of forms that cater for patients of various literacy and numeracy levels (Grade B).

- Health information technology developers should aim to seek input from patients with chronic non-communicable diseases when they design or modify e-PHRs (Grade B).

Recommendations for research

Future qualitative studies should improve adherence to well-established and robust methodologies for reporting the qualitative methods and methodologies used in primary studies investigating this topic area. Additionally, by broadening the focus of future primary research to include participants with chronic conditions not represented in this review, such as obesity, asthma, kidney disease, fibromyalgia, musculoskeletal diseases, stroke, neurodegenerative and gastrointestinal diseases, the generalisability of findings for chronic non-communicable disease can be strengthened. With e-PHRs implemented worldwide[100], opportunities exist to further explore the use of e-PHRs outside of the countries included in this review. Furthermore, to assist evidence synthesis across a range of methodologies and methods, and strengthen findings for subsequent systematic reviews, future research should focus on advancing efforts to create a standardised e-PHR taxonomy.

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Appendix I: Search strategy

PubMed

ID	Query
1	(“electronic health records”[mh] OR “Medical Records Systems, Computerised”[mh] OR “Patient Portals”[mh] OR electronic health record*[tw] OR electronic personal health record[tw] OR Patient Portal*[tw] OR Computerised Medical Record[tw] OR Computerised Medical Record[tw] OR electronic medical record*[tw] OR patient record systems[tw])
2	(“Patient Satisfaction”[mh] OR Patient satisfaction[tw] OR “Patient Preference”[mh] OR Patient Preference*[tw] OR “Qualitative Research”[mh] OR qualitative research[tw] OR patient experience*[tw] OR patient perception*[tw] OR qualitative study[tw] OR qualitative studies[tw])
3	(“Chronic Disease”[mh] OR chronic disease*[tw] OR chronic disease[tw] OR chronically ill[tw] OR chronic condition[tw] OR “asthma”[mh] OR asthma[tw] OR “kidney failure, chronic”[mh] OR chronic kidney disease[tw] OR chronic obstructive pulmonary disease[tw] OR “pulmonary disease,Chronic obstructive”[mh] OR chronic obstructive lung disease[tw] OR cardiovascular disease*[tw] OR “cardiovascular diseases”[mh] OR fibromyalgia[tw] OR “fibromyalgia”[mh] OR “neoplasms”[mh] OR cancer[tw] OR neoplasm[tw] OR obesity[tw] OR “obesity”[mh] OR musculoskeletal diseases[tw] OR “musculoskeletal diseases”[mh] OR diabetes mellitus[tw] OR “diabetes mellitus”[mh] OR diabetes[tw] OR hypertension[tw] OR “hypertension”[mh] OR chronic mental disorder*[tw] OR mental disorder*[tw] OR “mental disorders”[mh] OR mental condition[tw] OR “Mental Health”[mh] OR stroke[tw] OR stroke patient[tw] OR “Stroke”[mh] OR Alzheimer's Disease[tw] OR “Alzheimer Disease”[mh] OR Alzheimer[tw] OR epilepsy[tw] OR “Epilepsy”[mh] OR Parkinson disease[tw] OR “Parkinson Disease”[mh] OR Parkinson[tw] OR noncommunicable[tw] OR “Multiple Sclerosis”[mh] OR multiple sclerosis[tw] OR “Cystic Fibrosis”[mh] OR cystic fibrosis[tw] OR “Inflammatory Bowel Diseases”[mh] OR inflammatory bowel disease[tw] OR “Irritable Bowel Syndrome”[mh] OR irritable bowel syndrome[tw])
4	1 AND 2 AND 3
5	4 AND 5
6	5 AND 6

CINAHL

ID	Query
1	(MH “Patient Record Systems+” OR MM “Electronic Health Records” OR MH "Medical Records, Personal" OR MH “Access to Information” OR TX “electronic health record*” OR TI “electronic personal health record*” OR AB “electronic personal health record*” OR TX “patient portals” OR TX “computerised medical record” OR TX “computerised medical record” OR TX “electronic medical record” OR TX “patient record systems”)
2	(MH “patient attitudes+” OR MH "Patient Satisfaction Evaluation" OR MM "Patient Centered Care" OR MH "Life Experiences" OR MH "Qualitative Studies+" OR TX “patient satisfaction” OR TX “patient preference” OR TX “patient perception” OR TX “patient attitudes” OR TX “Qualitative Research” OR TX “Patient experience” OR TX “qualitative study” OR TX “qualitative studies”)
3	(MH "Chronic Disease+" OR TX “chronic disease” OR TX “noncommunicable diseases” OR MH respiratory tract diseases+ OR MH “kidney failure,chronic+” OR MH "Cardiovascular Diseases+" OR MH "Musculoskeletal Diseases+" OR TX Fibromyalgia OR MH "Neoplasms+" OR MH "Obesity+" OR MH "Diabetes Mellitus+" OR MH "Hypertension+" OR MH "Mental Disorders+" OR MH "Stroke+" OR MM "Alzheimer's Disease" OR MH "Epilepsy+" OR MM "Parkinson Disease" OR MH "Multiple Sclerosis+" OR MM "Cystic Fibrosis" OR MH "Inflammatory Bowel Diseases+" OR MH "Colonic Diseases+")
4	1 AND 2 AND 3
5	4 AND 5
6	5 AND 6 Limited to exclude MEDLINE records

Embase

ID	Query
1	('medical record'/exp OR 'electronic patient record'/exp OR 'patient portal'/exp OR 'electronic medical record system'/de OR 'electronic medical record'/de OR 'electronic health record*':ti,ab OR 'electronic personal health record':ti,ab OR 'computerised medical record*':ti,ab OR 'computerised medical record*':ti,ab OR 'electronic medical record':ti,ab OR 'patient record systems':ti,ab)
2	('qualitative research'/exp OR phenomenology/de OR 'attitude to computers'/de OR 'personal experience'/de OR experience/de OR perception/de OR 'thematic analysis'/exp OR ethnography/de OR 'patient satisfaction':ti,ab OR 'patient preference':ti,ab OR 'patient experience':ti,ab OR 'qualitative study':ti,ab OR 'qualitative studies':ti,ab)
3	('chronic disease'/exp OR 'chronic disease':ti,ab OR 'non communicable disease'/de OR 'non-communicable disease*:ti,ab' OR asthma/exp OR 'chronic kidney failure'/exp OR 'chronic kidney disease':ti,ab OR 'chronic obstructive pulmonary disease'/de OR 'Chronic obstructive pulmonary disease':ti,ab OR 'chronic obstructive lung disease':ti,ab OR 'cardiovascular disease'/exp OR 'musculoskeletal disease'/exp OR Fibromyalgia/de OR neoplasm/exp OR cancer*:ti,ab OR obesity/exp OR 'diabetes mellitus'/exp OR hypertension/exp OR 'mental disease'/de OR 'mental disorder*":ti,ab OR 'cerebrovascular accident'/exp OR stroke:ti,ab OR 'Alzheimer Disease'/de OR epilepsy/de OR 'Parkinson disease'/de OR 'multiple sclerosis'/de OR 'cystic fibrosis'/de OR 'inflammatory bowel disease'/exp OR 'irritable colon'/de OR 'irritable colon syndrome':ti,ab)
4	1 AND 2 AND 3
5	4 AND 5
6	5 AND 6 Limited to exclude MEDLINE records

PsycINFO

ID	Query
1	exp medical records OR exp electronic communication OR electronic health record*.tw OR electronic personal health record.mp OR electronic personal health record.tw OR patient portal.tw OR computerised medical record.tw OR computerised medical record.tw OR electronic medical records.tw OR patient record systems.tw
2	exp client attitudes OR exp client satisfaction OR exp computer attitudes OR exp qualitative research OR exp phenomenology OR exp grounded theory OR exp life experiences OR patient satisfaction.tw OR patient OR patient perception.tw OR preference.tw OR patient experience.tw OR qualitative study.tw OR qualitative studies.tw
3	Exp chronic disease OR chronic disease.tw OR exp asthma OR exp kidney diseases OR exp chronic obstructive pulmonary disease OR exp cardiovascular disorders OR exp fibromyalgia OR exp neoplasms OR cancer.tw OR exp obesity OR exp musculoskeletal disorders OR exp diabetes OR type 2 diabetes.tw OR hypertension.tw OR exp chronic mental illness OR exp cerebrovascular disorders OR stroke.tw OR exp Alzheimer’s disease OR exp epilepsy OR exp Parkinson’s disease OR exp multiple sclerosis OR exp cystic fibrosis OR exp colon disorders OR inflammatory bowel disease.tw OR exp irritable bowel syndrome
4	1 AND 2 AND 3
5	4 AND 5
6	5 AND 6

Scopus

ID	Query
1	“electronic health records” OR “Medical Records Systems, Computerised” OR “Patient Portals” OR “Medical record” OR “electronic patient record” OR “Electronic medical record” OR “electronic medical system” OR “Health Records, Personal”
2	“Patient experience” OR “Patient Satisfaction” OR “Patient Preference” OR “Qualitative Research”
3	“Chronic Disease” OR “Noncommunicable Diseases” OR “asthma” OR “kidney failure, chronic” OR “pulmonary disease, Chronic obstructive” OR “cardiovascular diseases” OR “cardiac” OR “fibromyalgia” OR “neoplasms” OR “cancer” OR “obesity” OR “musculoskeletal diseases” OR “diabetes mellitus” OR “hypertension” OR “mental disorders” OR “Mental Health” OR “Stroke” OR “Alzheimer Disease” OR “Epilepsy” OR “Parkinson Disease” OR “Multiple Sclerosis” OR “Cystic Fibrosis” OR “Inflammatory Bowel Diseases” OR “Irritable Bowel Syndrome”
4	1 AND 2 AND 3
6	4 and 6
7	6 and 7

The search for unpublished studies in relevant websites

ProQuest Dissertation and Theses

ID	Query
1	Electronic health records and chronic noncommunicable disease and self-management and experience

A hand search for primary studies published in relevant journals was conducted 2000 – 2019.

Appendix II: Studies ineligible following full text review

Reason for exclusion: Ineligible phenomena of interest

Ancker JS, Barron Y, Rockoff ML, Hauser D, Pichardo M, Szerencsy A, et al. Use of an electronic patient portal among disadvantaged populations. J Gen Intern Med 2011; 26(10): 1117-1123.

Ancker JS, Witteman HO, Hafeez B, Provencher T, Van de Graaf M and Wei E. The invisible work of personal health information management among people with multiple chronic disease: qualitative interview study among patients and providers. J Med Internet Res 2015; 17(6): e137.

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Dupont A, Wheeler J, Herndon Ii JE, Coan A, Zafar SY, Hood L, et al. Use of tablet personal computers for sensitive patient-reported information. Journal of Supportive Oncology 2009; 7(3): 91-97.

Federman AD, Sanchez-Munoz A, Jandorf L, Salmon C, Wolf MS and Kannry J. Patient and clinician perspectives on the outpatient after-visit summary: a qualitative study to inform improvements in visit summary design. J Am Med Inform Assoc 2017; 24(e1): e61-e68.

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Komura K, Yamagishi A, Akizuki N, Kawagoe S, Kato M, Morita T, et al. Patient-perceived usefulness and practical obstacles of patient-held records for cancer patients in Japan: OPTIM study. Palliat Med 2013; 27(2): 179-184.

Kuijpers W, Groen WG, Loos R, Oldenburg HS, Wouters MW, Aaronson NK, et al. An interactive portal to empower cancer survivors: a qualitative study on user expectations. Support Care Cancer 2015; 23(9): 2535-2542.

Lee YK, Ng CJ and Low WY. Addressing unmet needs of patients with chronic diseases: Impact of the VISIT website during consultations. J Eval Clin Pract 2017; 23(6): 1281-1288.

MacPhail LH, Neuwirth EB and Bellows J. Coordination of diabetes care in four delivery models using an electronic health record. Med Care 2009; 47(9): 993-999.

Rassin M, Zilcha L, Berger M and Silner D. Personal medical documents management--How patients perceive, keep and manage their medical documents: A qualitative study. International Journal of Nursing Studies 2007; 44(6): 862-868.

Robertson AR, Fernando B, Morrison Z, Kalra D and Sheikh A. Structuring and coding in health care records: a qualitative analysis using diabetes as a case study. J Innov Health Inform 2015; 22(2): 275-283.

Rudin RS, Fanta CH, Predmore Z, Kron K, Edelen MO, Landman AB, et al. Core Components for a Clinically Integrated mHealth App for Asthma Symptom Monitoring. Appl Clin Inform 2017; 8(4): 1031-1043.

Sedlander E, Barboza KC, Jensen A, Skursky N, Bennett K, Sherman S, et al. Veterans' Preferences for Remote Management of Chronic disease. Telemed J E Health 2018; 24(3): 229-235.

Storni C. Diabetes self-care in-the-wild: Design challenges for personal health record systems and self-monitoring technologies. Information Technology & People 2014; 27(4): 397-420.

Strudwick G, Clark C, McBride B, Sakal M and Kalia K. Thank you for asking: Exploring patient perceptions of barcode medication administration identification practices in inpatient mental health settings. Int J Med Inform 2017; 105: 31-37.

Woods SS, Schwartz E, Tuepker A, Press NA, Nazi KM, Turvey CL, et al. Patient experiences with full electronic access to health records and clinical notes through the My HealtheVet Personal Health Record Pilot: qualitative study. J Med Internet Res 2013; 15(3): e65.
Chronic disease not specified: contacted author for more information – not supplied.

Woollen J, Prey J, Wilcox L, Sackeim A, Restaino S, Raza ST, et al. Patient experiences using an inpatient personal health record. Appl Clin Inform 2016; 7(2): 446-460.

Ventres W, Kooienga S, Vuckovic N, Marlin R, Nygren P and Stewart V. Physicians, patients, and the electronic health record: an ethnographic analysis. Ann Fam Med 2006; 4(2): 124-131.

Reason for exclusion: Ineligible participants

Bergevi C, Lendahls L, Crang-Svalenius E and Oscarsson MG. From passive passenger to participating co-pilot - Pregnant women's expectations of being able to access their online journal from antenatal care. Sex Reprod Healthc 2018; 15: 35-39.

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Reason for exclusion: Ineligible study design

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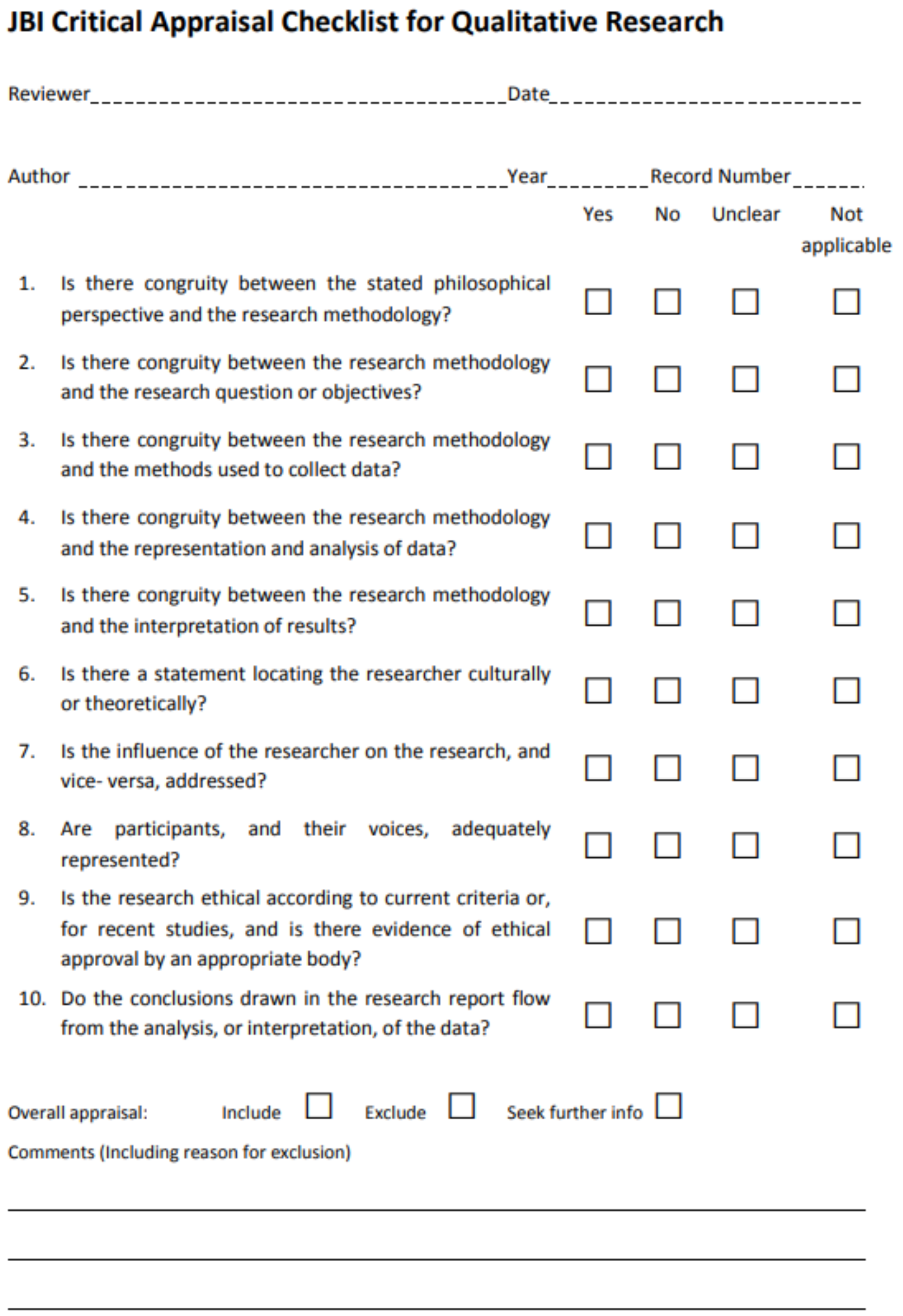
Appendix III: Critical Appraisal Checklist



JBI Critical Appraisal Checklist for Qualitative Research

Reviewer___________________________________Date___________________________

Author ____________________________________Year_________Record Number______

		Yes	No	Unclear	Not applicable
1.	Is there congruity between the stated philosophical perspective and the research methodology?	☐	☐	☐	☐
2.	Is there congruity between the research methodology and the research question or objectives?	☐	☐	☐	☐
3.	Is there congruity between the research methodology and the methods used to collect data?	☐	☐	☐	☐
4.	Is there congruity between the research methodology and the representation and analysis of data?	☐	☐	☐	☐
5.	Is there congruity between the research methodology and the interpretation of results?	☐	☐	☐	☐
6.	Is there a statement locating the researcher culturally or theoretically?	☐	☐	☐	☐
7.	Is the influence of the researcher on the research, and vice- versa, addressed?	☐	☐	☐	☐
8.	Are participants, and their voices, adequately represented?	☐	☐	☐	☐
9.	Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	☐	☐	☐	☐
10.	Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

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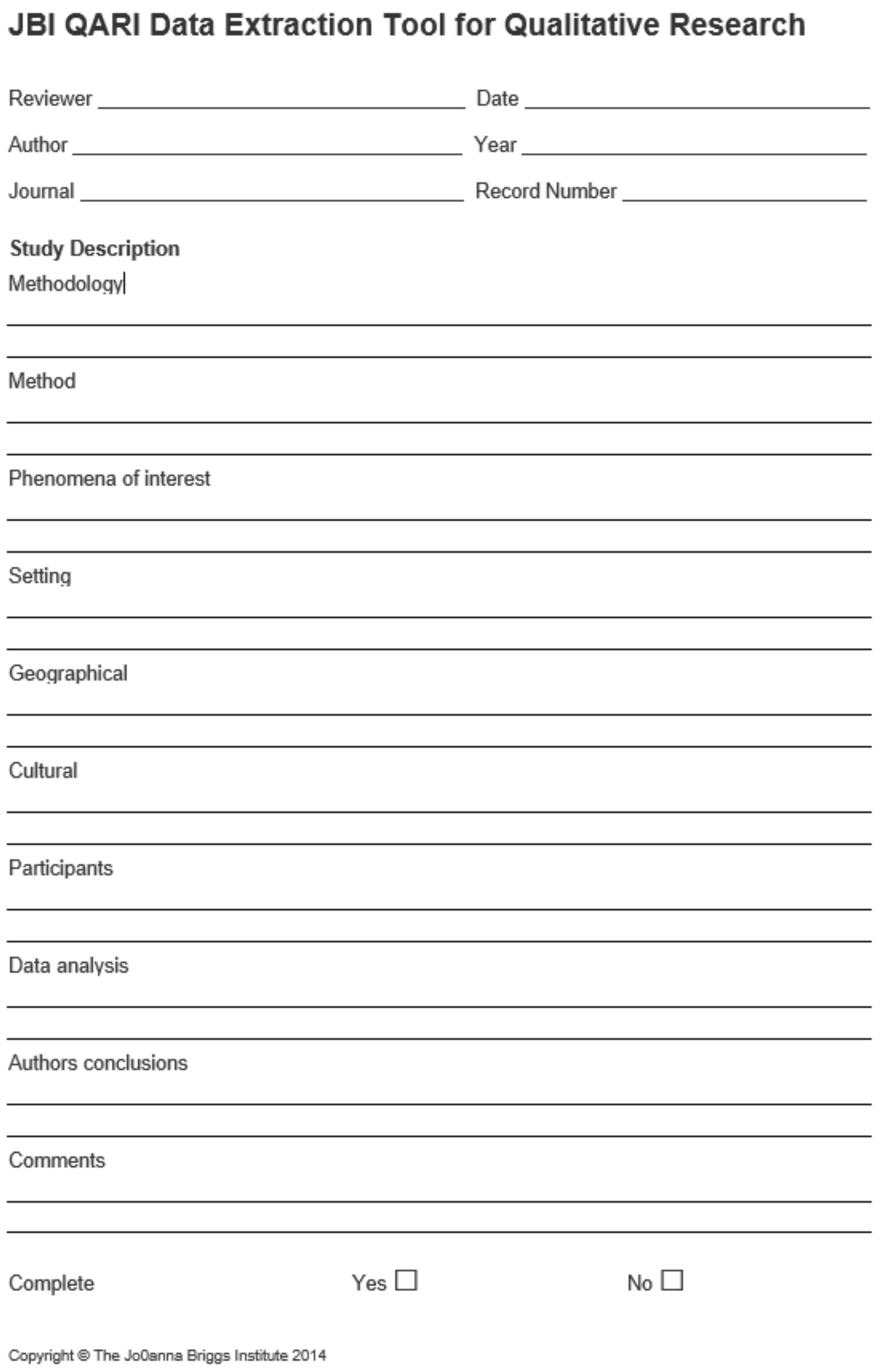
Appendix IV: Data Extraction Tool



JBI QARI Data Extraction Tool for Qualitative Research

Reviewer ____________________ Date ____________________

Author ____________________ Year ____________________

Journal ____________________ Record Number ____________________

Study Description

Methodology

Method

Phenomena of interest

Setting

Geographical

Cultural

Participants

Data analysis

Authors conclusions

Comments

Complete Yes ☐ No ☐

Findings	Illustration form Publication (page number)	Evidence		
		Unequivocal	Credible	Unsupported

Extraction of findings complete Yes ☐ No ☐

Appendix V: Characteristics of included studies

Study citation	Methods for data collection and analysis	Country	Phenomenon of interest	e-PHR technology	Setting	Participants	Description of main results
Rief *et al.* 2017[63]	Qualitative design Data collection: focus group discussions Data analysis: qualitative "editing" approach developed by Crabtree and Miller (1999) Theoretical Frameworks: Patient-provider Communication; Chronic Care Model (CCM); Patient Activation	USA	Experiences of patients interacting with an "active" e-PHR	e-PHR: HealthTrak Provider: University of Pittsburgh medical Centre Connectivity: Web based patient portal. e-PHR functions: problem and medication lists, allergies and immunizations, medical and surgical histories, laboratory test results, health reminders, secure messaging, personalised alerts Use: not specified	Three University of Pittsburgh Medical Centres (UPMC) primary care practices	41 participants Chronic disease: coronary artery disease, congestive heart failure, or either hypertension or hyperlipidaemia Age: average 62 years Gender: 66% female	Patients reported improved communication, and a sense of self-management, improving partnerships with their providers. This study adds further insights for e-PHR use, that benefit designers; address low adoption rates and overcome other patient barriers to the development and use of this technology.
Powell *et al.* 2018[58]	Qualitative descriptive Data collection: semi-structured interviews Data analysis: conventional content analysis) Theoretical Frameworks: not specified	USA	Patients and providers perceived usefulness of a portal.	e-PHR: not specified Provider: not specified Connectivity: not specified e-PHR functions: not specified Use: not specified	Three primary care offices: small-rural practice, medium-urban practice large-rural practice	16 participants (9 patients, 7 healthcare providers) Chronic disease: diabetes, hypertension, heart disease, coronary artery disease Age: 45 years or older Gender: not specified	Four broad themes were identified: 1) how patients were introduced to the portal, 2) perceived benefits of the portal, 3) perceived barriers to using the portal, and 4) perceptions of using the portal for self-management of chronic disease were revealed.
Daley *et al.* 2017[62]	Qualitative exploratory Data collection: in-depth semi-structured interviews Data analysis: thematic analysis Theoretical frameworks: not specified	USA	Experiences using an e-PHR to receive and monitor implantable cardiac device data (ICD).	e-PHR: not specified Provider: not specified, other than secure, technical framework for delivering cardiac device data Connectivity: implantable Cardiac Device Observation framework (IDCO) with remote, access login to PHR e-PHR functions: novel widget display embedded in summary page e-PHR displaying implantable cardioverter defibrillator (ICD) data, heart rhythm. Additional ability to view test results, make follow up appointments add own health data Use: 3 months 2014	Cardiology ambulatory clinic	21 participants Chronic disease: cardiovascular disease. Age: 36 to 90 years. Mean age: 67 years Gender: 76% male	Sharing ICD data from remote monitoring requires adequate context and scaffolding to support patient understanding. Engaging patients with information that is useful and valuable to them through a PHR may require appropriate and individualised tailoring of information.
Cromer *et al.* 2017[66]	Qualitative design Data collection: semi-structured qualitative interviews. Data analysis: constant comparative analysis. Theoretical frameworks: not specified	USA	Veterans Affairs patients' perspectives of access to online clinical notes	e-PHR: my HealtheVet© patient portal Provider: Department of Veterans Affairs Connectivity: secure online portal via "authentication "process e-PHR functions: access to OpenNotes with Blue Button function providing access to lab, clinical and imaging notes Use: regular users from May 2013-2014	Veterans Affairs Medical centre	28 participants Chronic disease: depressive and bipolar disorders; PTSD; schizophrenia. Age: 30 to 69 years; mean age: 47 years Gender: 16 women	Findings suggest that ensuring consistency between what occurs during appointments and what appears in clinical notes, as well as highlighting patient individuality and strengths in notes, may help engender patient trust and avoid negative consequences of OpenNotes in mental health care.
Fuji *et al.* 2015[49]	Qualitative design Data collection: audio-recorded interviews Data analysis: iterative approach Theoretical frameworks: not specified	USA	Patients' experiences using an e-PHR to manage their diabetes-related health information for self-care	e-PHR: Microsoft (Redmond VA) HealthVault © Provider: Redmond Veterans Affairs Department Connectivity: Web based, online standalone e-PHR functions: secure messaging, email, access clinical records, organ donation, customizable, restricted access, ability to share, access health information, receive feedback Use: 3 – 6 months prior to study.	Two internal medicine clinics and an endocrinology clinic Midwest metropolitan city	59 participants Chronic disease: type 2 diabetes Age: 28-80 years; mean age 59 years Gender: 61% female	Despite some potential positive benefits resulting from PHR use, several barriers inhibited sustained and effective use over time. Provider and patient education about the benefits of PHR use and about the potential for filling in information gaps in the provider-based record is key to engage patients and stimulate PHR adoption and use
Gee *et al.* 2015[51]	Qualitative descriptive Data collection: semi-structured interviews Data analysis: grounded theory approach of constant comparative analysis	USA	Chronically ill adults' experiences of how and why they use personal health records for self-management.	e-PHR: not specified Provider: not specified Connectivity: tethered, no other detail specified e-PHR functions: email, test results, health information, screening Use: 2.9 years' experience using e-PHR	Large, internal medicine group practice in a metropolitan Northern California city and a two-provider arthritis	18 participants Chronic disease: average of three chronic disease (not specified). Age: 50-65 years; mean 60yrs Gender:7 females: 11 males	The participants in this study found that the e-PHR is useful for the self-management of their illness and for productive interactions with their provider. Knowledge gained from the e-patient personal health record users suggest that making improvements to the portal system and providing education to consumers and providers will increase the utility among

Study citation	Methods for data collection and analysis	Country	Phenomenon of interest	e-PHR technology	Setting	Participants	Description of main results
	Theoretical frameworks: Chronic Care Model				practice in a suburban community in far Northern California.		the experienced users and encourage new users to embrace adoption and use.
Hess *et al.* 2007[69]	Qualitative design Data collection: focus groups Data analysis: transcripts analysed using Grounded theory Theoretical frameworks: Chronic Care Model	USA	Patient reaction to e-PHR technology in the context of diabetes care.	e-PHR: UPMC Health Trak Provider: University of Pittsburgh medical Centre Connectivity: Web based patient portal, connects patient, physician and EMR e-PHR functions allows access resources view & schedule appointments test results, medication, problem lists health reminders Use: 8.1 months	Three University of Pittsburgh Medical Centers (UPMC) primary care practices	18 participants Chronic disease: diabetes Age: mean age 55 years Gender: 10 males; 8 females	Patients are responsive to e-PHR technology. Participants felt that the system would enhance communication; the reminder system would be helpful; they liked remote access to laboratory tests. Patients were frustrated when tests were not released, and messages not answered. Whilst, patient portals can be integrated into a clinical office, patients may not quickly change communication patterns. Future work should focus on diabetes-related outcomes assessment and intensifying interventions.
Kayastha *et al.* 2018[68]	Qualitative design Data collection: semi-structured qualitative interviews Data analysis: constant comparative approach Theoretical frameworks: not specified	USA	Experiences of patients with cancer using an online portal	e-PHR: Epic's MyChart Provider: Duke Cancer Institute Connectivity: Online portal accessed via computer, tablet, phone e-PHR functions: access online medical notes, test results, clinical health information. Use: regular, used daily	The Duke Cancer Institute	20 participants Chronic disease: metastatic or incurable cancer (colon, breast, lung, prostate, pancreas, bladder, kidney, testicular, ovary, head & neck and unknown primary). Age 39 - 76 years: mean 55.85 years Gender: 11 males; 9 females	Patients described increased comprehension because notes refreshed their memory and clarified their understanding of visits. This helped mitigate the unfamiliarity of cancer, addressing uncertainty and relieving anxiety. Notes facilitated control, empowering patients to ask clinicians more questions. The transparency of notes also increased trust in clinicians. For a subset of patients, however, notes were emotionally difficult to read and raised concerns. Patients identified medical jargon and repetition in notes as areas for improvement.
Rexhepi *et al.* 2018[64]	Qualitative design Data collection: semi-structured interviews Data analysis: thematic analysis Theoretical frameworks: not specified	Sweden	Understanding of cancer patients' attitudes and experiences of online portal.	e-PHR: '1177.se' Provider: Swedish Government, County Council of Uppsala (LUL) Connectivity: National e-Health portal, accessed with e-ID e-PHR functions: EMR access, appointment bookings, medications, test results, diagnoses, health practitioner names, share records., securely with next of kin, communicate via PHR. Use: regular, used daily.	Department of Oncology at the Uppsala University Hospital or patient residences	15 participants from group (A) Chronic disease: Cancer patients undergoing treatment, with varying stages of cancer (recurrence, newly diagnosed, advanced cancer, palliative treatment). Age: 30 – 92 years Gender: not specified	Online access can help patients prepare for doctor visits and to understand their medical issues. In contrast to the fears of many physicians, the study shows that online access to medical records did not generate substantial anxiety, concerns or increased phone calls to the hospital.
Ralston *et al.* 2004[67]	Qualitative design Data collection: semi-structured interviews Data analysis: phenomenological approach Theoretical frameworks: Wagner's Chronic Care Model	USA	Experiences of patients with using an interactive e-PHR.	e-PHR: My Health Record Provider: University of Washington Connectivity: internet, web based 'real-time' EMR e-PHR functions: secure email, clinical reminders, blood glucose readings using My Upload meter, interactive feedback through My Diabetes Diary, Use: several times per week to few times in 6 month of study period	Patients' homes in Washington state	Nine participants Chronic disease: diabetes Age: 43 – 65 years Gender: Six males, three females	Six themes emerged: feeling that non-acute concerns are uniquely valued; enhanced sense of security about health and health care; frustration with unmet expectations; feeling more able to manage; valuing feedback; and difficulty fitting the programme into activities of daily life. Three themes - valuing non-acute concerns, feeling secure, and unmet expectations - have relevance to the design and use of web-based tools for care of patients with diabetes and chronic disease.
Rose *et al.* 2014[60]	Qualitative phenomenological design Data collection: semi-structured interviews Data analysis: method not specified. Theoretical frameworks: not specified	USA	Adult patient's perceptions and knowledge of using e-PHRs and EHRs.	e-PHR: not specified Provider: Diabetes Clinic Connectivity: not specified e-PHR functions: interactive communication with provider through EHR/PHR, test results, medications, tracking functions Use: 2-year period from 2008	Diabetes clinic, Baltimore	21 participants Chronic disease: diabetes Age: 35 – 84 years Gender: Eight males, 13 females	The four themes that emerged from the three focus groups included communication issues, patient preferences for electronic records, safety and security concerns, and transition problems with implementation of EHRs.
Sieck *et al.* 2017[65]	Qualitative exploratory Data collection: semi-structured telephone interviews Data analysis: constant comparative analysis Theoretical frameworks: not specified	USA	Patients' and providers' perspectives on patient portals.	e-PHR: Epic My Chart Provider: Midwestern Academic Medical Centre Connectivity: interactive tethered, patient portal e-PHR functions: secure messaging, view test results, request refills prescriptions, appointment scheduling Use: experienced frequent users, since 2012	Department of Family Medicine, Academic Medical Centre (AMC)	29 participants (29 patients and 13 physicians) Chronic disease: cardiopulmonary disease Aged 36 – 54 years Gender: not specified	Experienced portal users discussed several emergent themes related to a need for greater clarity on when and how to use the secure messaging feature. Patient concerns included worry about imposing on their physician's time, the lack of provider compensation for responding to secure messages, and uncertainty about when to use secure messaging to communicate with their providers. Patient

Study citation	Methods for data collection and analysis	Country	Phenomenon of interest	e-PHR technology	Setting	Participants	Description of main results
							training could include orienting patients to the “rules of engagement” at portal sign-up, either in the office or through an online tutorial.
Urowitz *et al.* 2012[46]	Qualitative design Data collection: interview Data analysis: thematic analysis Theoretical frameworks: not specified	Canada	Experience of patients and providers using an online diabetes management portal.	e-PHR: not specified Provider: Waterloo Wellington Local Health Integration Network Connectivity: online patient portal e-PHR functions: Log health metrics, access and record Blood glucose, blood pressure, body weight data. Provide Interactive diabetes education via health library and PHR access, medication profiles Use: 6 months use.	Waterloo Wellington Local Health Integration Network	17 patients Chronic disease: 16 patients Type 2 Diabetes: 1 patient Type 1 Diabetes Age: not specified Gender: Eight males; nine females	Online chronic disease management portals increase patient access to information and engagement in their health care, but improvements in the portal itself may improve usability and reduce attrition. Furthermore, this study identifies a grey area that exists in the roles that PCPs and AHPs should play in the facilitation of online disease management.
Winkelman *et al.* 2005[59]	Qualitative descriptive design Data collection: in-depth interviews and focus groups Data analysis: constant comparative Theoretical frameworks: Technology Acceptance Model (TAM) / Patient-perceived Usefulness	Canada	Patient access to electronic patient records.	e-PHR: iChart Provider: University health Network Connectivity: standalone, online EMR e-PHR functions: access EMRs, specific features not specified Use: not specified.	University Health Network, tertiary care centre in Toronto, Ontario	12 participants Chronic disease: inflammatory bowel disease - Crohns disease and ulcerative colitis Age: 21 – 60 years Gender: five males; seven females	For patients with chronic IBD, useful technology must be multifaceted, self-care promoting, and integrated into the patient’s already existing health and psychosocial support infrastructure. The four identified themes serve as focal points for the evaluation of information technology designed for patient use, thus providing a patient-centered framework for developers seeking to adapt existing EMR systems to patient access and use for the purposes of improving health care quality and health outcomes. Further studies in other populations are needed to enhance generalizability of the emergent theory.
Forchuk *et al.* 2015[61]	Qualitative design Data collection: individual and focus group semi-structured interviews Data analysis: Leininger’s phases of qualitative data analysis Theoretical frameworks: not specified	Canada	Mental health patients' perceptions of an electronic personal health record.	e-PHR: Lawson SMART record Provider: Microsoft HealthVault, TELUS health space Connectivity: internet access via web-based application on desktop and /or via smart phone iphone4s e-PHR functions: secure messaging, mood monitor, a health journal, personal crisis plan Use: over 12- 18 months use	Remote access via Smartphone. London, Ontario Health Services Centers	95 participants Chronic disease: mood or psychotic disorder Age:18 – 80 years Gender: 56 males; 39 females	Assessing clients’ perspectives regarding the use of smart technologies in mental health care provides an invaluable addition to the current literature. Qualitative findings support the feasibility of implementing a smartphone and electronic personal health record intervention with individuals who are living in the community and experiencing a mental illness and provide considerations for future development and implementation.

Appendix VI: Excluded study findings without illustrations

Study: Gee et al. (2015) [51]	
Finding	Still keep paper-based records (Not supported)
Illustration	Illustration not available
Finding	Wish that results were released by the provider sooner (Not supported)
Illustration	Illustration not available
Study: Fuji et al. (2014)[49]	
Finding	Feeling more able to manage (Not supported)
Illustration	Illustration not available
Finding	Difficulty fitting the programme into activities of daily life (Not supported)
Illustration	Illustration not available
Finding	Valuing feedback (Not supported)
Illustration	Illustration not available