The significance of digitalised Personal Health Records in United Kingdom: a scoping review

(Introduction to research -BMHP 5005)

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ABSTRACT

The enactment of digitised Personal Health Records (PHRs) by citizens in the United Kingdom is seen as a bold step to improve the excellence and performance of health services, as well as a crucial component in creating a more equitable, active and sustainable health system. It is becoming clear that the focus is shifting from the public's growing need for information accessed to a health system that may not be able to provide it. The aim of this scoping review is to appraise update academic papers on patients' health records, their features and functions, and their impacts on health service delivery, to determine the advantages and disadvantages of implementing this technology. A search of relevant journals dated between 2016 and 2022 was performed in the PubMed Central, BioMed Central and ProQuest Central databases, using key elements related to electronic health records, patient portals, and patient access. Articles' selection, after PRISMA 2020 guideline, identified twenty one papers categorised by their focus on system characteristics, current strengths and weaknesses of the PHRs in United Kingdom. Depending on the information presented and the environment in which it is used, adopting modern software can be a difficult task. In one example, this research has shown that it is possible to improve adherence to treatment in patients with chronic diseases by using an online platform and has pointed out the main gains and barriers to adoption of web-based medical sites. The challenging task of choosing the ideal digital mechanism for public consumers could be eased by considering these situational issues. To develop and launch PHRs, a collection of key components with a track record of effectiveness must be identified. Patients' PHRs are currently only a partial reality, but their practical use is already considered "advanced technology". It is essential to adapt the portal specifications to the requirements and capabilities of users to make this technology more accessible and integrated.

Section 1: INTRODUCTION AND RATIONALE

While other countries' health systems, especially those in Estonia and Sweden, have made noteworthy strides in embracing the fast fulfilment of electronic health records (EHRs) (Rumball-Smith, Ross and Bates, 2019), the UK's growth has been relatively slow, as evidenced by research from 2016, which found that only a small percentage of patients actually access their medical records (Louch et al., 2022; Symons et al., 2019) as partial and generalised file, without notes, comments or observations from secondary care specialists, due to cumbersome transfer from paper based support (Hagglund et al., 2022). A definition purposed by Pagliari, Detmer and Singleton (2007) state that a dynamic, basic data set of electronic health information and e-health technologies makes up an electronic personal health record (ePHR), which is a permanent instrument for keeping pertinent health data and encouraging health maintenance. The person as legal representative owns, manages, and shares the personal health records (PHRs), which need to be protected to guarantee the safety and integrity of the health information they hold. According to NHS Digital (2022), they can be classified by their classic structures as follows: 1) ‘EHR -tethered PHRs’ generally assigned to patient portals; 2) ‘untethered PHRs’- a standalone system managed by individuals who directly control or delegate information in the record from a medical source, and their active involvement defines the utility of the virtual records; and 3) ‘untethered integrated’ enables persons to both administer and oversee their own custom applications and grant permission for entry to health care providers.

The "NHS Long Term Plan" (2019) envisions some extended aspirations such that health providers will be operating fully digitalized health services through "paperless records" within a strong IT infrastructure protected by trustworthy cyber security across the country by 2023 or 2024 (Louch et al., 2022). These aspirations are in line with the Department of Health England's "Five Year Forward View" (2014) commitment to providing patients with free and unrestricted access to their health records from 2018 (Kulakiewicz and Powell, 2022) and additionally NHS Digital's goals are set to hasten public access to their data via the NHS app, enabling users to examine latest additions to the medical record and request archived files (Louch et al., 2022). By giving patients the access to fast, detailed, and understandable

medical data and streamlining dialogue patients - healthcare personnel, PHR technology options aim to empower patients, save health and care costs, and improve continuation of treatment (Hagglund et al., 2022). ePHR systems have been the subject of numerous studies, which have demonstrated how well they support and enhance patient access to information about self-managing health and wellness concerns (Mold et al., 2018). Greater advantages than those of a standalone PHRs are offered by this integration through tethering or networking with the EHRs of the healthcare provider or other data sources for varied health services like counselling and assisting patients with health self-care and education (Harahap et al., 2021).

As a guideline for this investigation, the following question was addressed: How significant are digitised Personal Health Records for United Kingdom citizens and its healthcare system?; and the purpose of this scooping review is to present an overview of the current advantages and disadvantages of the PHR system as well as to identify any knowledge gaps by evaluating the PHR system's features and functions and critically analysing how their functionality translates into acceptance by healthcare consumers and their impact on healthcare delivery.

Section 2: METHODOLOGY & METHODS

Following a preliminary search on Google and Google Scholar for recent data, papers, or journals linked to the health and social care thematic, a plan for future development of the topic was useful in outlining the goal and objectives of this research project (see Appendix 1). Through the University of Wales Trinity Saint David's library search, relevant publications were searched out in the PubMed Central, ProQuest Central, and BioMed Central databases. The keywords or search terms were the following: (electronic health records) AND (patient portal) AND (patient access) AND (functionalities) AND (United Kingdom AND England); the full search terms for each database are provided in Appendix 2. Main inclusion criteria for articles were: 1) full text – open access, 2) peer review, 3) written in English, and 4) published between 2016 and 2022. There were not considered papers in the forms of meeting abstracts or proceedings. There were exclude journals referring to patient generated health or mHealth, referring to patient reported outcome measures and research purposes, not included updated surveys, not referring exclusive to

PHRs and not referring to studies for United Kingdom or England. Screening identified 162 papers, of which three excluded duplicates and only twenty one chosen for meeting the criteria after PRISMA 2020 guidelines (see Appendix 3).

Section 3: MAIN BODY OF THE LITERATURE REVIEW AND FINDINGS

Twenty one of the papers (see Appendix 4.) that mainly composed the investigation disseminated findings, assessed the data, or acknowledged relevant, comprehensive works as presenting on:

1. System characteristics

1.1. Architecture

According to Alturkistani et al. (2020) and Harahap et al. (2021), the primary PHRs that are connected to the EHR include data on a person's medical history, including knowledge on allergens, vaccinations, prescriptions, and scheduled consultations. Rarely, however, do portals also provide genetic profiles and personalised or preventative health advice. The additional feature of these records, identified by Harahap et al. (2021) allows users to administratively organise the facts in the records such as updating personal contact details, passwords, basic information, as well as informative data about health providers, like setting area, contacts, and images. Moreover, for engaging people in their own wellness programs the current healthcare platforms offer modernised services that encourage communication through messaging networking , support health education through online informative links, and enhance health management and monitoring through either personal recording or portable Bluetooth-connected devices that measure body temperature, blood pressure, heart rate, and glucose levels. As per Jacquemard, Doherty and Fitzsimons (2021), the EHR includes data from numerical, picture, electromagnetic signals, and other data kinds, for example flowcharts that are taken and maintained in the system; and together with patient’s standardised data are all necessary for a reliable clinical regimen. In terms of graphical content, Warren et al. (2019) recommend an appealing and user-friendly design that can overcome that abstract barrier of unfamiliarity and fill practical knowledge gaps for patients who, by understanding and evaluating healthcare events, will feel more

secure and confident in their own involvement in care transitions. Fraccaro et al. (2018), being on the same page, stress that interface designs that visually provide information configurations that are disorderly or not signalled as critical may have an adverse effect on patient safety by making it more difficult to perceive the risks of being in danger.

For a more actual perspective, Symons et al. (2019) envision the regional PHR hub operating in a "broker" system similar to the NHS app, corresponding with various primary care data system applications, minimising data transfer difficulties among EHRs and PHR providers, and moving patients towards a unified and flexible medical informational authority. Security and updating of personal data would be made easier by up keeping the primary patient ‘master index’ for the health record that is universally validated. Additionally, by implementing open source software within the PHR hub, the responsibility of clinical data governance would be shared among providers-patients who would be empowered to manage their own records.

1.2. Privacy and security

The privacy principles supported by Jacquemard, Doherty, and Fitzsimons (2021) and Harahap et al. (2021) acknowledge the patient's right to agree to the disclosure, divide, and usage of his delicate personal data by healthcare staff, but it is undeniably a joint stakeholders’ obligation. Patients' medical documents are private and protected from any unauthorised or unintentional exposure under the protection of the health system's legislative requirements and rules of professional staff behaviour. But even under the Caldicott principles of ensuring confidentiality during the handling and employ of health information (National Data Guardian, 2020), data sharing at the local level remains greatly affected and restricted by both the physician’s and patient's positions of approval of the decision (Symons et al., 2019). To ensure the confidentiality and preservation of online documents, Abd-Alrazaq et al. (2019) suggest security protocols include strong routers, challenging passwords, periodic renewals, and security screening. Jacquemard, Doherty, and Fitzsimons (2020) advocate for role-based entry controls that restrict login rights and safeguard records of mental illness, substance misuse, and sexual health are also advised. On the other hand, McMillan et al. (2021) explain that users prefer the upgraded authentication method of biometric access since it increases confidence

and cyber security. Bloom et al. (2021) agree that by imposing clinical security protocols, a strong emergency department IT system may considerably improve therapeutic, administrative, and economic performance. It can also actively prevent medical malpractices. According to Louch et al. (2022) strong technological security of a record cannot ensure that the individual who accesses it is the legitimate owner. Some medical records, according to therapeutic specialists, may be got in through control and compulsion by unauthorised individuals, to the damage of mentally ill, mistreated, or minors who may be susceptible in such circumstances. McMillan et al. (2021), speaking in patients' account, contend that elderly persons in particular are wary of trusting web access out of concern for scammers. In terms of safety and confidentiality, patients must be capable of trusting that their data is transmitted and preserved safely to adhere to them openly (D'Costa, Kuhn and Fritz, 2020). Jacquemard, Doherty, and Fitzsimons (2021) advance the idea of fusing artificial intelligence with medical records that will offer the potential to automate some facets of data collection, dissemination, and patient diagnostic communication. However, such automation may have unintended ethical consequences related to privacy, transparency, and impeding timely detection of recorded errors, in addition to necessitating artificial intelligence training to perform the specific activity by storing large files incorporating the individual's medical data of many service users.

2. *Current strengths of the PHRs*

Alturkistani et al. (2020) affirm the advantages of utilising a portal's particular functions are typically used to show how using them contributes to better results. Patients are able to regularly and directly review annotations from consultations and clinical results thanks to the freedom from time and access constraints that comes with access to medical record keeping. This helps patients maintain and monitor their treatment pathway and also improves their emotional state. Some studies (D'Costa, Kuhn and Fritz, 2020; Mold et al., 2018) notified that by allowing patients to examine their health history and identify inaccurate information, this technology improved the information quality. One out of every five patients in Lear et al. (2022b) survey's showed active involvement in the process of correcting errors and discrepancies in medical records. Lear et al.'s (2022a) patients' desire and capacity to update general inaccuracies in their EHRs benefits the decrease in adverse drug

events, delayed in care and prognosis, and enhances the commitment to the correctness of their own health data. Clinical mistakes that might have a negative impact on future care and prognosis can be avoided by monitoring information errors made by users and identifying inconsistent, partial, or omitted medical details. Same concept adopted by Jacquemard, Doherty and Fitzsimons (2021) points that accuracy of patient record completion and data entry is vital in avoiding a negative impact on a patient's health, and moral and ethical professional qualities are paramount in storing and recording good quality information. In the same view, Harahap et al. (2021) sustain that health professionals' duty is to carefully monitor input data entry to ensure that it does not compromise the verity of medical records used for clinical judgements and therapeutic procedures. Considering the views of the health care staff, Louch et al. (2022) highlight that even accepting the users' chance to draw attention to mistakes in their records, especially to update prescriptions or allergy status, the definition of faulty information can be perceived as divergent and challenging. Additionally, reading specialist notes and information-related reflections during consultations can lead to a relational discord between the patient and the medical professional, which can cause miscommunication, anxiety or confusion (Niazkhani et al., 2020) on the part of the patient whose perception of the illness or diagnosis is sensitive and personal. Jacquemard, Doherty and Fitzsimons (2020) having the same perception add that physicians may start obscuring or minimize the retention of critical medical information in patient records to prevent patients from misinterpreting information. D'Costa, Kuhn and Fritz (2020) highlight that in practice, health files are functional medical documents that serve both as a transition and instruction tool, including continuous thinking, and are the result of clinical discussions. The changeover might become corrupted, compromising the patient's treatment and future physicians' learning, if clinicians fail to express worries in the files explicitly out of fear of upsetting the patient.

Another functions detected by Mold et al. (2018) and Hagglund et al. (2022) refer to options like constant dialogue with the doctor and medical staff, access and request medication lists, manage consultations, view test results, and reading helpful information about the disease. White et al. (2016) declare that for patients with chronic illnesses who depend on medications for adequate disease control, medication adherence is important. For their long-term care to be efficient, it is essential that they have access to their medical record, which enables them to order

prescriptions, learn about medication changes, and even receive reminders to repeat drug orders. The secure messaging services through the medical platform facilitated a better control of the general disease's care management (Mold et al., 2018); the secure messaging services acted as an effective tool for keeping under control the diabetes' normal parameters, even improve them. Doctor-patient contacts using secure texting and electronic medical reminder letters enabled for quicker refinement of prescription regimens and established improvements in disease variable monitoring. The use of text messaging has led to a rise in ambulatory, urgent care, and primary care visits, which has resulted in increased of 13% yearly service expenditures (Mold et al., 2018).

Studying patients' perspectives, Lear et al (2022b)'s research showed encouraging results in terms of the contentment of individuals who used a web-based platform, reporting that they thought their health was safer, better, and more effective, and that they valued having a voice in medical choices and responsibility over their own health condition. Personal anxieties were minimised by having access to immediate health records and receiving prompt response on laboratory diagnoses, which significantly improved therapeutic intervention (Mold et al., 2018). Even though patients actively advocated for the immediate disclosure of test results, doctors prefer to wait so they may properly analyse the data, provide assistance, and develop a future healthcare plan. This is the right course of action to avoid overwhelming or needlessly worrying patients (D'Costa, Kuhn and Fritz, 2020).

An innovative service aspired by Khadjesari et al. (2022) called OptiMine is attached to the EHR with the goal of changing patients' health behaviours like smoking and drinking by providing signposting assistance and getting in touch with them via text messages, email, and patient portals in addition to its standard function of monitoring early cancer diagnosis, medication management, and vaccine administration. The findings of his investigation revealed a decent adoption rate of 3%, which is still regarded as viable and reasonable at this early stage.

By having access to health-related information, D'Costa, Kuhn and Fritz (2020) consider that people have the decisional power to choose what they are interested in and in whom they can put their faith. A moderate level of trust in the doctor-patient connection is advised for improved care services connected to treatments and investigations required for patients' fast regaining health. Moreover, patients have an additional opportunity to challenge their treatment plans and seek

second views as a result of having access to records, which increases their level of knowledge. Also, McMillan et al. (2021) optimistic discovery was that disable and people from rural areas felt content about their lessen access to healthcare provided by online portals. Khadjesari et al. (2022) favour the idea of a new method of minimal and tailored care applicable to everyone at high risk of addiction via text messaging, which may be used to direct patients to applications that address addictive behaviours.

Availability of information online, according to participants, fosters accountability, boosts quality of healthcare, and enhances interactions with medical professionals (McMillan et al., 2021). The simplicity of digital information exchange via PHR builds a harmonious and trusting interaction between patients and healthcare providers that fosters an equal comprehension of medical knowledge, but at the same time, medical records are standardised and technically complex, lacking the human element of perception and contact, which from some persons detracts the closeness of human-to-human connection (Jacquemard, Doherty, and Fitzsimons, 2020). As an opposite patient's reaction, Hagglund et al. (2022) found that a patient who is hesitant or not very talkative who feels anxious during in-person consultations embraces the idea of online communication.

3. *Current weaknesses of the PHRs*

Bloom et al.'s (2021) study revealed a sad result of EHRs' usability in Emergency Departments in United Kingdom scored lower than the 68-point threshold for satisfactory usability; as possible consequence defined by the frequent health personnel turnover and the burden of clerical duties. Even with a legal basis for regulating the collection of databases, the IT system in emergency departments fails to facilitate the medical act that incorporates both clinical and administrative operations (Bloom et al., 2021). From the patient side, Niazkhani et al.'s (2020) review and Chapman et al.'s (2022) study found that only adults with comorbidities, ranging in age from middle to old age, who were mainly interested in medical outcomes, consultation programmes, medical news, and prescription specifications, often used the My Health@QEHB hospital-based platform. Conclusions of his study have shown that barriers to using the online site transcend differences in people's ages, social statuses, linguistic abilities, educational levels, and financial status. White et al. (2016) emphasise that to fully utilise the patient portal, health knowledge

and math abilities may act as obstacles. A similar position expressed by Lear et al. (2022b) and Niazkhani et al. (2020) indicate that users frequently struggled to grasp the value or importance of the material on the website without medical terminology and knowledge, particularly the test results, which were organized and shown in a certain format.

Patients expressed concern that access to online records could compromise patient safeness by inducing actions on their own initiative regarding diagnosis and administration of medication without medical advice, and by intimidating medical staff from expressing worries about problems such as emotional stability or mistreatment for apprehension of offending patients (McMillan et al., 2021). D'Costa, Kuhn and Fritz (2020) emphasise that often more information can make it difficult for patients to make an informed decision about whether or not to seek medical help, replacing it with ambiguity and emotional turmoil. The technological obstacles mentioned by both users and service providers include the password-based login process, issues with the portal's technical functionality, and users' inability to acknowledge the operation or availability of this internet platform (Mold et al., 2018).

Section 4: CONCLUSION AND RECOMMENDATIONS

According to the findings of this scoping review, there is a plethora of studies being done on PHR's functionality for different consumer groups, with a primary focus on advantages and adoption hurdles. The greatest difficulty found by virtually all research continues to be the differences in user profiles, particularly those with lesser eHealth literacy who will continue to be neglected by digitalisation until the obstacles preventing access to PHR data are resolved. However, there is still more to be done in terms of modifying PHRs for patient health self-management and sustainability. There are several relevant studies, demonstrating a generally expanding interest in PHR's usability.

The existing technical infrastructure prevents personal health record systems from being uniformly and universally connected by technology, which would benefit the many healthcare professionals that utilise and manage patient data for the necessary medical services (Symons et al., 2019). Online platforms could be useful in improving the quality of medical treatment for disadvantaged communities if the

requirements of technologically disabled users are met, in light of government legislation advocating for the elimination of inequalities in health services (Lear et al., 2022a).

Emotional education interventions are needed for disclosure of written information in medical records, both to build doctors' confidence in annotation and to make patients aware of the pros and cons of reading them (Hagglund et al., 2022). Users' education alone will never be sufficient (Hagglund et al., 2022) unless practical online tools for accessing health data are more patient-friendly (White et al., 2016), so that they utilise them without hindering the learning of medical professionals. It is crucial for healthcare practitioners to be aware of the risk of escalating inequality for groups with lower levels of health literacy and to develop and test strategies to lessen it when sharing medical data D'Costa, Kuhn and Fritz (2020).

Constructive suggestions are proposed by participants in McMillan et al.'s (2021) study affirm that adding a "medical dictionary" and a translate feature might help to some extent with literacy and language problems. To educate nonusers about the system's user-friendly features, functions, and benefits, Abd-Alrazaq et al. (2019) advise running promotional activities, particularly among older and less educated individuals. Providers need to set up both theoretical and practical assistance for infrastructure awareness. White et al. (2016) articulate that patients tend to be concentrating on pragmatic solutions, which might be a key component of future tailored accessibility. Lear et al. (2022b) stand for sectional approaches with systemic effects, such as user-centric portal platform design that complies with ease of access, coherency, and comprehension criteria, as well as a dedication to web security and protection methods are necessary to guarantee that disadvantaged groups can benefit from portal use. McMillan et al.'s (2021) study patients have voiced a need for a centralized system with many operational and functional possibilities, such as consistent information in clear English, quick linkages to reliable resources, triage features for online consultations, and even pharmaceutical supply alerts.

Overall, the existing dearth of knowledge on the best way to use and operate these technologies and how they promote self-managed healthcare also calls for more research.

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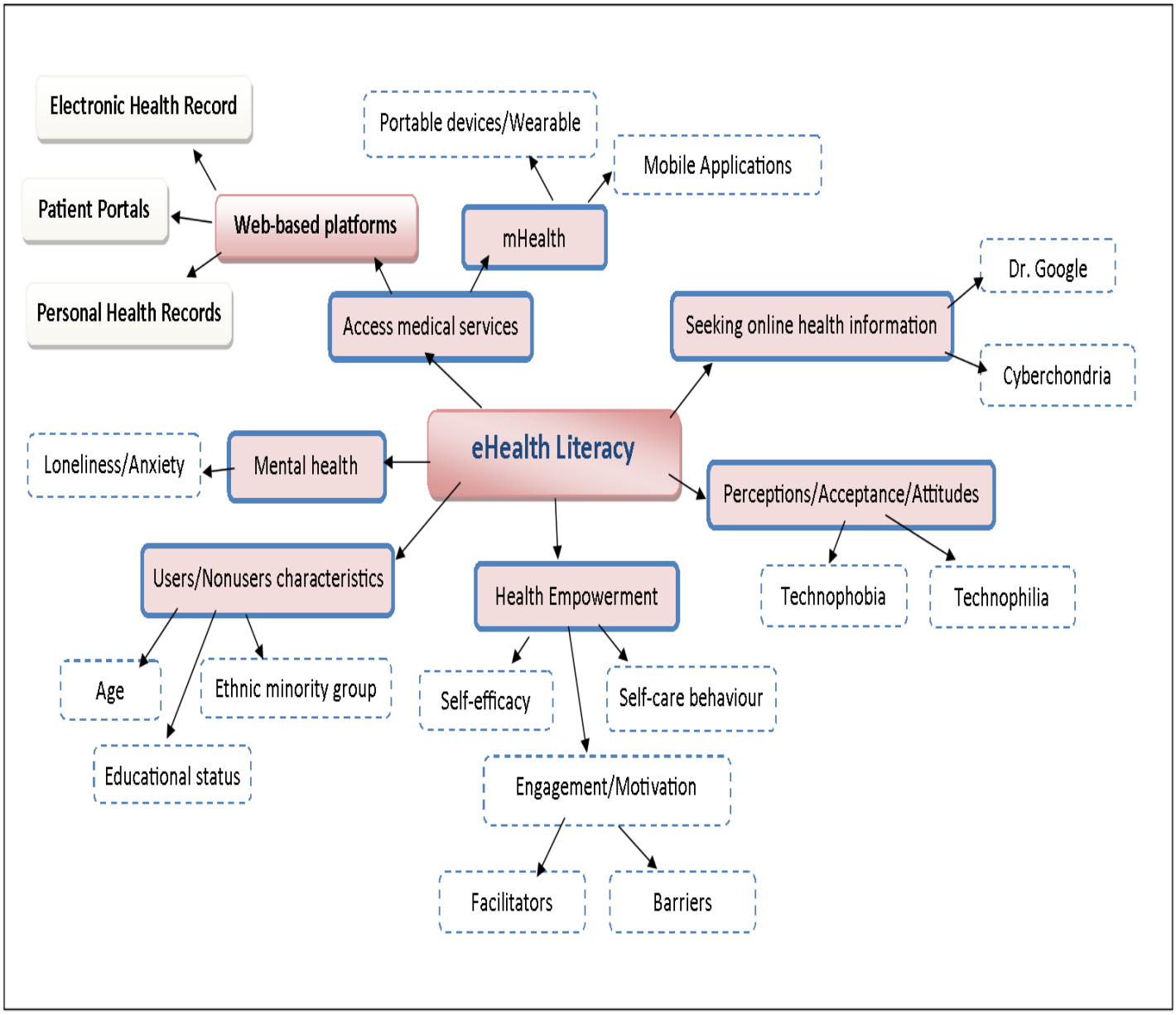
APPENDICES

Appendix 1: **Mind Map**—design followed the preliminary research (Wheeldon and Faubert, 2009)



Appendix 2: Searching method using keywords and terms (Tricco et al., 2018)

1. **ProQuest Central**

Search terms: (electronic health records) AND (patient portal) AND (patient access) AND (functions OR functionalities)

Filters: 2016-2022; English; Scholarly journals; full-text; peer reviewed; United Kingdom or England

2. **PubMed Central Open Access**

Search terms: (electronic health records) AND (patient portal AND patient access) AND (functionalities) AND (United Kingdom AND England)

Filters: 2016-2022; English; open access

3. **BioMed Central Open Access Free**

Search terms: (electronic health records) AND (patient portal AND patient access) AND (functionalities)

Filters: 2016-2022

Appendix 3: PRISMA flow diagram used for the scoping review (Tricco et al., 2018)

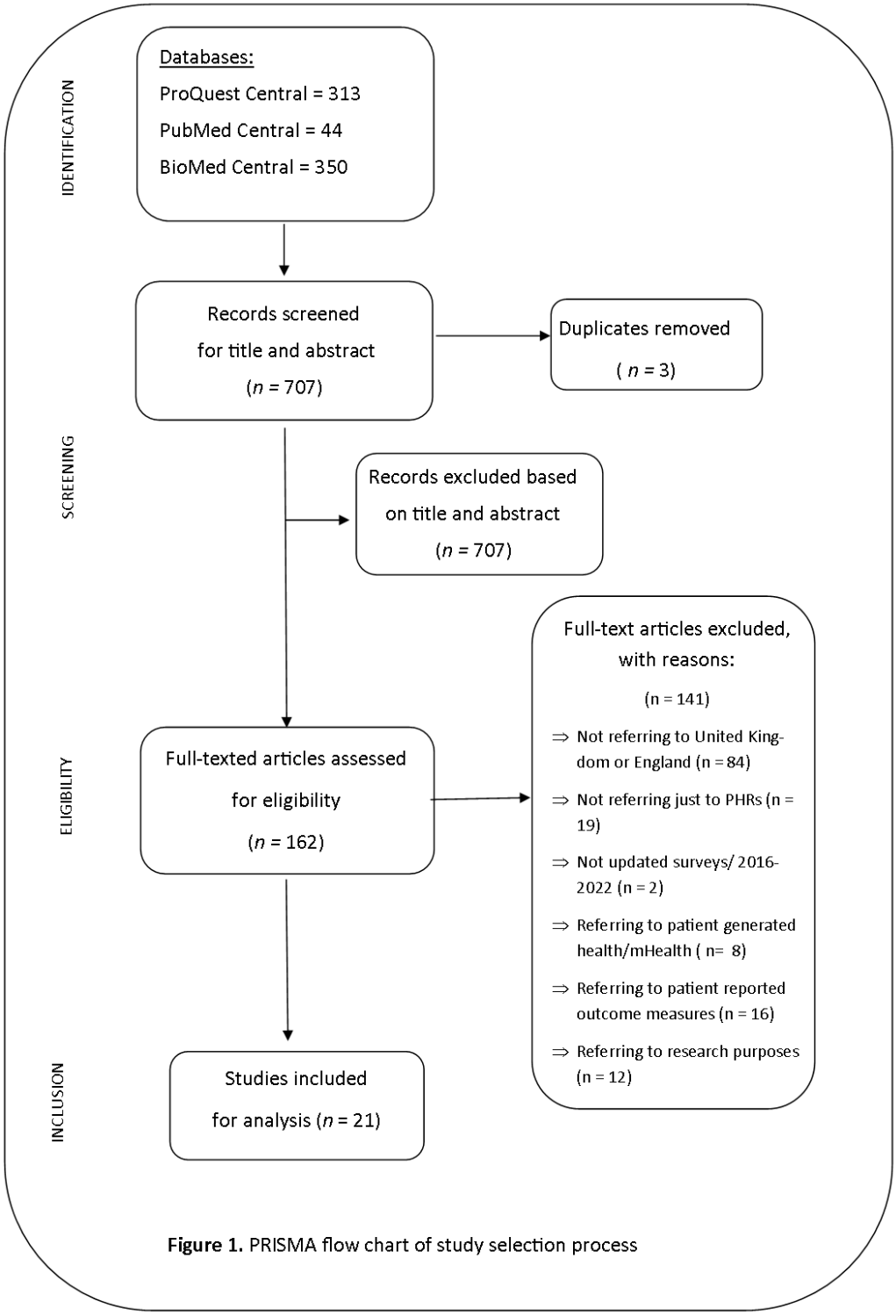


Figure 1. PRISMA flow chart of study selection process

Appendix 4: Table 1. Study design and research focus of included studies (Tricco et al., 2018)

Reference	Study design	Study or intervention aim
Abd-Alrazaq et al., 2019	Cross-Sectional study	To examine the motivational factors of nonusers becoming users
Alturkistani et al., 2020	Systematic review	To compile data on adult patients' usage of patient portals in relation to health and care delivery results
Bloom et al., 2021	Qualitative study - survey	To assess the usability of the primary EHR systems presently in use in UK EDs utilising System Usability Scale
Chapman et al., 2021	Cross-Sectional study	To ascertain the probability of socio-demographic characteristics related to a patient's ability to access a PHR in secondary and tertiary care. To evaluate how people utilise PHRs in a hospital context.
D'Costa, Kuhn and Fritz, 2020	Systematic review	To investigate empirical studies related to the ethical consequences of accessing and sharing medical notes with patients in real time in acute care setting
Fraccaro et al., 2018	Randomised controlled study	To examine if certain visual search patterns were related to right readings of laboratory results. To evaluate and contrast parameters such as mental demand and query efficiency obtained from eye-tracking information.
Hagglund et al., 2022	Descriptive study	To discuss the benefits and risks of patients 'online access to their records and the current challenges in implementing this mechanism
Harahap et al., 2021	Systematic review	To overview studies related to PHRs system functionalities and their technological hassles
Jacquemard, Doherty and Fitzsimons, 2020	Systematic review	To analyse the potential, issues, and stakeholders involved in the design, development, and implementation of EPRs while identifying the most common ethical concepts used in the literature today.
Jacquemard, Doherty and Fitzsimons, 2021	Research project	To develop a supportive framework for identifying and evaluating opportunities and ethical challenges in electronic patient records (EPR) that addresses designers, software developers, healthcare managers and end users
Khadjesari et al., 2022	Mixed Methods study	To expand the impact of behavioural therapy applications by an innovative electronic signposting strategy for patients at risk of addictive habits through an acute care hospital EHR.
Lear et al., 2022a	Mixed Methods analysis	To assess patients' readiness and capability to recognise and react to problems in their PHRs

Lear et al., 2022b	Cross-Sectional study	To explain perceived changes in the standard of care among patients using a patient web portal and identify patient traits that endorse the benefits of portal use.
Louch et al., 2022	Qualitative study	To gather the opinions of primary care professionals regarding patient access to electronic health information, the identification of problems in electronic health records, and comments made via virtual care platforms.
McMillan et al., 2021	Qualitative study	To investigate the needs and preferences of individuals for online access to their EPHRs, as well as their usage patterns, preferred methods of interaction, and potential support requirements.
Mold et al, 2018	Systematic review	To investigate the utilisation and effects of providing patients with type 2 diabetes mellitus in primary care with online access to electronic medical data and services.
Niazkhani et al., 2020	Systematic review	To categorise the many forms of ePHRs adoption/use and obstacles and to assess their significance in the management of chronic diseases in stakeholders .
Rumball-Smith, Ross and Bates, 2019	Descriptive study	To debate the adoption and full employment of the EHR
Symons et al., 2019	Descriptive study	To purpose a regional PHR hub to provide a universal PHR interface and integrate EHR system to easily enable the patient accountability
Warren et al., 2019	Qualitative Mixed Methods study	To create a scientific proof electronic health record (EHR) display by incorporating citizens in the interactive design stage
White et al., 2016	Cross-Sectional survey	To determine the patient's interests for progress and their opinions on the operability needed for customised entry to the secondary care EHR.