

Review article

Exploring potential drivers of patient engagement with their health data through digital platforms: A scoping review

Robin van Kessel^{a,b,c,1,*}, Sruthi Ranganathan^{d,1}, Michael Anderson^{a,e}, Brian McMillan^e, Elias Mossialos^{a,f}

^a LSE Health, Department of Health Policy, London School of Economics and Political Science, London, United Kingdom

^b Department of International Health, Care and Public Health Research Institute (CAPHRI), Faculty of Health, Medicine and Life Sciences, Maastricht University, Maastricht, Netherlands

^c Digital Public Health Task Force, Association of School of Public Health in the European Region (ASPHER), Brussels, Belgium

^d Department of Medicine, University of Cambridge, United Kingdom

^e Centre for Primary Care and Health Services Research, University of Manchester, Manchester, United Kingdom

^f Institute of Global Health Innovation, Imperial College London, London, United Kingdom

ABSTRACT

Background: Patient engagement when providing patient access to health data results from an interaction between the available tools and individual capabilities. The recent digital advancements of the healthcare field have altered the manifestation and importance of patient engagement. However, a comprehensive assessment of what factors contribute to patient engagement remain absent. In this review article, we synthesised the most frequently discussed factors that can foster patient engagement with their health data.

Methods: A scoping review was conducted in MEDLINE, Embase, and Google Scholar. Relevant data were synthesized within 7 layers using a thematic analysis: (1) social and demographic factors, (2) patient ability factors, (3) patient motivation factors, (4) factors related to healthcare professionals' attitudes and skills, (5) health system factors, (6) technological factors, and (7) policy factors.

Results: We identified 5801 academic and 200 Gy literature records, and included 292 (4.83%) in this review. Overall, 44 factors that can affect patient engagement with their health data were extracted. We extracted 6 social and demographic factors, 6 patient ability factors, 12 patient motivation factors, 7 factors related to healthcare professionals' attitudes and skills, 4 health system factors, 6 technological factors, and 3 policy factors.

Conclusions: Improving patient engagement with their health data enables the development of patient-centered healthcare, though it can also exacerbate existing inequities. While expanding patient access to health data is an important step towards fostering shared decision-making in healthcare and subsequently empowering patients, it is important to ensure that these developments reach all sectors of the community.

1. Introduction

Patient engagement when providing patient access to health data results from an interaction between the tools available to patients (e.g., digital interfaces to access their health data), and their digital and health competency [1–3]. The recent digital advancements of the healthcare field have altered the manifestation and importance of patient engagement [4]. Tools for patients to engage with their health data are also increasingly built into digital systems, resulting in a direct correlation between access to these systems and a patient's ability to engage [5]. A clear example of this can be found in the upcoming Regulation for the European Health Data Space, which seeks to empower people and

patients by facilitating the possibility to engage with their health data. Under the European Health Data Space, this engagement can be exercised through an access service for electronic health data, which requires some level of digital capacity among patients and could magnify inequities [6].

Countries across the world have been experimenting with expanding patient access to their health data [7]. Nevertheless, it is well documented that improving patient engagement is not always the primary reason for expanding patient access to their health data, as increasing quality and safety of healthcare delivery or healthcare outcomes form frequently sought-after goals by improving the transparency of records [7]. For instance, the evidence base on the clinical effects of making

* Corresponding author.

E-mail addresses: r.van-kessel@lse.ac.uk (R. van Kessel), sr932@cam.ac.uk (S. Ranganathan), m.anderson5@lse.ac.uk (M. Anderson), brian.mcmillan@manchester.ac.uk (B. McMillan), e.a.mossialos@lse.ac.uk (E. Mossialos).

¹ These authors contributed equally to the manuscript.

<https://doi.org/10.1016/j.ijmedinf.2024.105513>

Received 24 November 2023; Received in revised form 11 April 2024; Accepted 2 June 2024

Available online 5 June 2024

1386-5056/© 2024 The Author(s). Published by Elsevier B.V. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

health data more accessible to patients by expanding access to electronic health records (EHRs) has grown steadily [7,8], with expanded patient access to health data being associated with improved diabetic control and patient safety in a meta-analysis containing 17,387 participants [9]. However, most evidence has focused on the use of EHRs in clinical environments rather than the broader impact of expanding patient access to health data on patients engagement [9,10]. It also has to be noted that providing patient access to their health data does not guarantee improvements in patient engagement. For example, a 2019 survey of EHRs patient access initiatives in the 27 European Union Member States found that less than 10 % of patients viewed their own medical records and test results routinely [11].

Understanding what factors can impact patient engagement is essential to facilitate the successful expansion of people and patient access to health data when aiming to improve patient engagement with their health data [7,12]. While previous reviews have considered factors that influence use of EHRs specifically [13,14], these were performed prior to the COVID-19 pandemic. Not only has substantial digitalisation of health systems since taken place, but our review also takes a broader perspective and consider factors that influence utilization of health data provided through any digital platform. In this review article, we synthesise the most frequently discussed factors that can foster patient engagement with their health data, covering both patient access to and active utilisation of their health data during healthcare trajectories.

2. Methods

We performed a scoping review with qualitative synthesis in accordance with the scoping review framework [15,16]. This method allows for the rapid mapping of the key concepts underpinning a broad research area, which is particularly valuable for complex issues that have not been reviewed comprehensively to date [15–17]. In this specific context, our scoping review sought to identify articles that capture patient engagement mechanisms associated with the expansion of patient access to their health data until thematic saturation was reached, instead of providing an exhaustive list of published literature [18]. Consequently, a representative sample of the literature was sufficient in this context [18]. We followed JBI Manual for Evidence Synthesis for Scoping Reviews and reported the article according to the Preferred Reporting Items for Systematic reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) guidelines (see eTable 1 in the appendix) [19,20]. As is common with most scoping reviews, no review protocol was published.

2.1. Eligibility criteria

To be eligible for inclusion, the scope of the document had to discuss the concepts of patient engagement and how this may be associated with expanding patient access to health data. We interpreted patient engagement with their health data as patients actively utilising their health data when conveyed through digital platforms, such as EHRs or mobile applications. Supporting measures to improve patient engagement through expanding patient access to health data was also considered for inclusion (e.g., provision of programmes to improve digital literacy). Articles discussing the effects of expanding patient access on health outcomes or health system performance were excluded, as these data have previously been extensively discussed in the literature [8,9,21,22], and were outside the scope of the review which focused specifically on patient engagement with their health data. We also excluded articles that specifically discussed the relationship between patient-reported measures and patient engagement, as this association has also been well-established in prior research [23,24]. We did not put any restrictions on language as this would allow us to identify contextual factors in non-English settings, nor did we restrict publication type. As such, editorials, commentaries, opinion pieces were considered alongside empirical evidence, as these record types may contain qualitative

descriptions of patient engagement mechanisms that may not yet be included in empirical research. Only publications from 2019 onwards were eligible, as this period marks a substantial acceleration of health-care digitisation as a result of the COVID-19 pandemic and the health-care landscape prior to this point may no longer be comparable to the healthcare landscape after this cut-off [4,25–28]. Given the nature of a scoping review, the inclusion criteria were kept broad to ensure all possible mechanisms though patient engagement can be fostered in the context of expanding patient access to health data were covered.

2.2. Search strategy and data collection

Scientific articles were systematically identified through two scientific databases (MEDLINE and Embase); both of which were accessed through the Ovid portal. These databases were chosen to cover health-specific and health-affiliated academic fields. The scientific search was supplemented with a non-systematic search for grey literature using Google Scholar (first 200 hits) [29]. The full query for the scientific databases is shown in eTable 2 in the appendix. Information specialists at the LSE Library and University of Cambridge Library validated the search strategy.

The search strategy was executed on 13 April 2023. The complete screening process (title/abstract and full-text screening) was performed by one reviewer (SR). A second reviewer screened 20 % of the records to improve robustness (RVK). Any discrepancies were resolved by an independent third reviewer (MA). Deduplication was done using Endnote version 22 and screening using Covidence. Reference lists of included articles were also screened for relevant articles.

2.3. Data synthesis

The qualitative synthesis was operationalised by means of a thematic analysis, which was used to extract factors that can affect patient engagement in the process of expanding patient access to health data [30]. Two authors (RVK and SR) reviewed 10 articles together to calibrate and validate the data extraction process. Subsequently, salient factors were extracted by one author (SR). These data were clustered according to the Ability-Motivation-Opportunity (AMO) model by two authors (SR and RVK) [31]: (1) ability, which refers to the knowledge and skills the patient/provider has to have in order to be empowered; (2) motivation, captures the extrinsic and intrinsic motivation of the participant; and (3) opportunity, refers to the availability of and accessibility to solutions, as well as the involvement of patients in the decision-making process. The clustering was subsequently verified by other authors to boost the robustness of the clustering (MA and EM). These clusters were subsequently summarised into seven domains by one author (RVK): (1) social and demographic factors, (2) patient ability factors, (3) patient motivation factors, (4) healthcare providers' attitudes and skills, (5) health system factors, (6) technological factors, and (7) policy factors. The thematic analysis was performed in ATLAS.ti version 23 using an approach validated by previous research [32].

3. Results

Our search strategy resulted in the identification of 5801 records from academic database searches between 2019 and 2023 (5249 after deduplication) and 200 from supplementary searches, totalling 5449 unique records. Ultimately, we included 292 (4.83 %) records in this review. A PRISMA flowchart detailing the data collection process is shown in Fig. 1. Our final sample consisted of 44 viewpoints, editorials, and commentaries [7,34–75], 46 qualitative studies [76–121], 48 literature reviews [9,13,14,22,122–165], 39 reports [2,166–203], 61 cross-sectional studies [14,204–263], 31 mixed-methods studies [264–294], 6 randomized controlled trials [295–300], 5 retrospective studies [301–305], 4 exploratory studies [306–309], 2 policy briefs [310,311], 2 longitudinal studies [312,313], 2 models [314,315], and 1

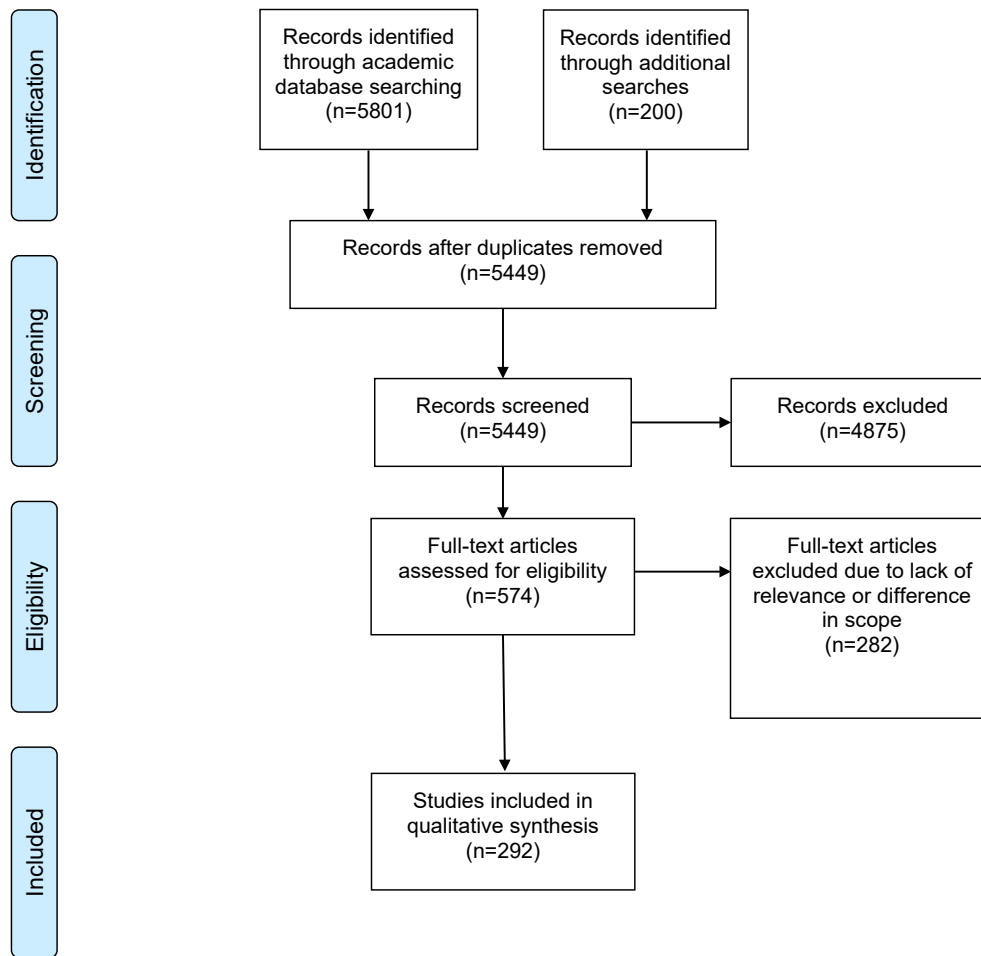


Fig. 1. A PRISMA flowchart outlining the data collection process.

news source [316]. Fig. 2 summarises the seven domains that can positively or negatively affect patient engagement while expanding patient access to their health data. The individual factors in each of the seven domains are discussed in more detail in Table 1 and sections 3.1 to 3.7 below.

3.1. Domain 1: Social and demographic factors

Patients in economically-distressed communities [303] or rural areas [128], older patients [128,159,163,172,191,255], adolescents [163], individuals with mental health conditions [191] or severe diseases or disabilities [159,163], ethnic minorities [66,121], individuals with limited or no broadband access and individuals with lack of access to necessary technology (digital devices, sufficient bandwidth) [40,122,128,144,191,234,241,270,272], are reported to be less likely to use their health data. It is noteworthy that while most studies report patient-intrinsic factors as predictors of use of health data, and report a potential increase in disparities, one study states that access to health data can be most beneficial for those who are usually not well-supported by the current healthcare system [40].

3.2. Domain 2: Patient ability factors

Patients with a lack of awareness of ways and tools used to access their health data access [241], or lower education or general literacy levels are found to be less likely to use their health data [40,122,159,172,191,241,255,287]. Limitation in health literacy is also shown to adversely affect the ability of patients to use EHRs

[97,128,160,253]. This is due to difficulties in understanding medical jargon (such as dyspnoea, Global Initiative for Chronic Obstructive Lung Disease [GOLD] stage), abbreviations (such as Forced expiratory volume [FEV1], COPD Assessment Test [CAT] score), test results, note structure, billing-related terms, imaging results [97]. However, some studies also present the contradictory view that patients' health literacy skills are grossly underestimated, raising ethical concerns [60]. Similarly, limitations in digital skills are shown to limit patient engagement with their health data [40,122,159,163,191,234,242]. With limited literacy and digital health literacy being associated with a reduced engagement with health data, reduced digital health literacy is also shown to be associated with a decreased use of health data [122,172,254]. In addition to these skills, language proficiency is shown to influence a patient's use of their health data, where limited English proficiency can hinder use of the EHR [128,163].

3.3. Domain 3: Patient motivation

Patients are more likely to start using their health data if they perceive health data as useful [128,130,209,228,234,252,255,272], or the system to access health data easy to use [209,234]. Similarly, the perception of control over their health data benefits health data utilisation [255]. Health data use in general is also associated with patient demographics and attitudes [228,234,255], with people that access health data more likely to be white, female, middle-aged and middle class [319]. Younger people and those with a more advanced educational background were more willing to engage with their health data [209]. In addition, there is also heterogeneity in the types of health data

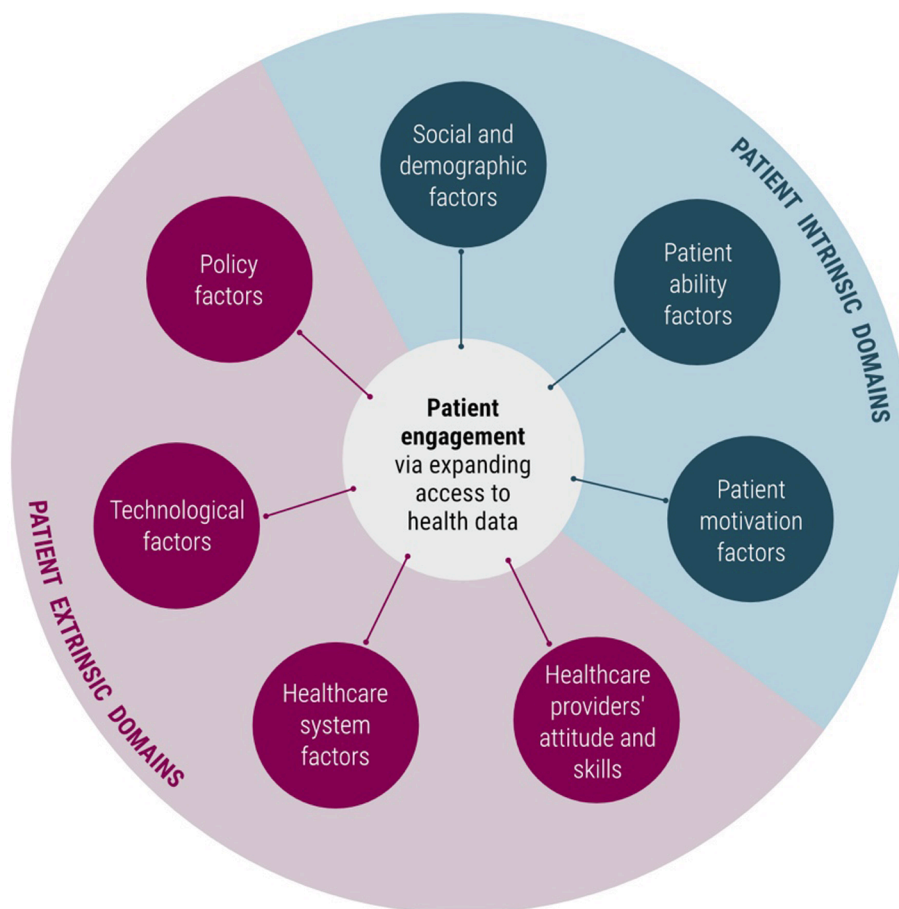


Fig. 2. Summary of the seven domains that contribute patient engagement while expanding patient access to health data.

that patients of different socioeconomic backgrounds want to access. Individuals with a lower annual income are shown to be more receptive to receiving serious test results through EHRs compared to those with a greater annual income [213]. However, for less serious test results, this trend is reversed [213]. In specific medical contexts, such as cancer care, there is a recognized phenomenon of heightened patient anxiety associated with the prospect of undergoing additional scans [36]. The innate motivation to take control of one's health has been associated with increased utilisation of health data by patients [40,290]. This motivation has been documented through various examples, such as patients finding it easier to monitor their medication adherence [40], patients being able to prepare for consultations with their health professionals [290], and access information early to direct their future actions [290]. Lastly, disruptive events such as the COVID-19 pandemic have increased patient motivation to engage with their EHR, potentially due to a decrease in in-person consultations offered to minimize contact and risk of transmission [191,253].

We also mapped a number of factors that can cause patients to avoid using health data. Patients can show a resistance to new technologies [144,241,242], express a hesitation to use health data as a result of privacy or security concerns [123,128,130,209,252,255] or as a result of the perceptions and opinions of healthcare professionals [105,130,144,156,241,255]. Furthermore, anxiety over interpreting results from tests or doctors' notes [290], as well as concerns over data control and stewardship [209] can inhibit the use of health data by patients. Patients that are not interested or do not consider health data useful will avoid using it [93,122,242].

3.4. Domain 4: Healthcare providers' attitude and skills

Healthcare providers' attitudes toward patients accessing health data constitute a patient-extrinsic factor influencing motivation, with widespread hesitation in supporting patient access to health data being reported. Numerous concerns underpin this reluctance, including the anticipated escalation of workload, as evidenced in several studies [93,105,120,120,160,193,241]. Providers also express apprehensions about an increased risk of burnout, potentially linked to the demands imposed by heightened engagement with health data [36]. For instance, the integration of EHR into care processes introduces changes in workflow dynamics, posing challenges that healthcare providers reportedly find unsettling [241]. Hesitation by healthcare professionals is further associated with a decrease in the quality of the notes included in EHRs [40,160], even though some studies show that the notes decreased in complexity and increased in readability after granting patients access to their EHR [263]. Finally, concerns over heightened liability, uncertainties regarding reimbursement matters, concerns about patient privacy and confidentiality, and the perceived impact on the traditional patient–physician dynamic collectively contribute to the negative provider perspectives on expanding health data access [93,156,160,241].

3.5. Domain 5: Healthcare system factors

The successful patient utilization of health data is intricately linked to the healthcare system's capacity to collect, store, access, and effectively manage patient health data [123]. Furthermore, the integration of EHRs into workflows and the standardization of terminology across platforms emerge as pivotal elements in ensuring the seamless incorporation of this technology, as indicated by research findings [234,252].

Table 1

An overview of the individual factors comprising each of the seven domains that can be positively or negatively associated with patient engagement with their health data.

Domain	Factor	Reference
Social and demographic factors	Income level	[303]
	Urbanicity	[128]
	Age	[128,159,163,172,191,255]
	Health status	[159,163,191]
	Race/ethnicity	[66,121]
Patient ability factors	Access to technology	[40,122,128,144,191,234,241,270,272]
	Awareness of EHR access provision	[241]
	Education or literacy	[40,122,159,172,191,241,255,287]
	Health literacy	[60,97,128,160,253]
	Digital literacy	[40,122,159,163,191,234,242]
	Digital health literacy	[122,172,254]
Patient motivation factors	Language proficiency	[128,163]
	Patients' drive to take ownership of their own health	[40,290]
	Perceived usefulness	[122,128,130,209,228,234,252,255,272]
	Perceived ease of use	[209,234]
	Patient attitude specifically towards EHRs	[255]
	Perceived control over health data	[255]
	Changes in patient anxiety	[36]
	Intention to use	[234]
	Perceptions towards new technology	[144,241,242]
	Perceptions towards privacy and security	[123,128,130,209,252,255]
	Perceptions towards health professionals	[105,130,144,156,241,255]
	Anxiety over interpreting results	[290]
	Perceptions towards data stewardship	[209]
Healthcare providers' attitude and skills	Level of interest	[93,242]
	Changes in workload	[93,105,120,120,160,193,241]
	Likelihood of burnout	[36]
	Changes in workflow due to integration of EHR into care processes	[241]
	Perceptions around liability and reimbursement	[241]
Health system factors	Professional perceptions around patient privacy and confidentiality	[160,241]
	Changes in the patient–physician dynamic	[93,156]
	Collect, store, access and effectively manage patient data	[123]
	Integrate EHRs into workflows and standardize terminology used across platforms	[234,252]
	Support patients and professionals to use EHR, such as provision of a training manual, workshops, or having an in-person onboarding	[67,113,241,253,272]
Technological factors	Provide timely access to good quality health information	[253,290]
	User design	[88,122,128,144,144,172,312]
	Mobile device compatibility	[99,221,252,255,317]
	Privacy and security	[123,234]
	Error prevention methods	[272]
	Integrated support and guidance aimed at patient education	[145,270]
Policy factors	Ability to cater to different user groups	[128]
	Regulation of patient access to information	[40,40,66,93,123,132,182,188,213,241,304,316,317]
	Protection of patient privacy and security	[66,123,219,252,312]
	Widening and incentivising uptake of EHRs in general and among specific groups	[163,172,209,253]

The ability of the healthcare system to support both patients and professionals in navigating EHRs is paramount and can be achieved through mechanisms such as the provision of comprehensive training materials, workshops, or in-person onboarding sessions [67,113,241,253,272]. Additionally, the timely provision of access to information stands out as a critical determinant of the effectiveness of health data utilization [253,290]. Overall healthcare organization and delivery can influence patient use of health data. For example, when there is a great delay to receive test results directly, patients are more receptive to receiving them online using their EHRs [213]. However, this is more true for less serious test results such as strep throat tests, and may be less applicable to serious diagnostic tests such as cancer test results [213].

Limitations in the scope and quality of information can also affect patients' perception and use of health data. These include: the absence of images from imaging tests to clarify written text [290], lack of or incomplete information for patients with mental health conditions [156,219], lack of information on dietary supplements [270]. Misalignment between various stakeholders (e.g., health professionals, patients, developers of health data access services) during the implementation of health data access services also negatively affects the use of health data among patients, thereby affecting patient engagement

[105].

3.6. Domain 6: Technological factors

A lack of system-sent reminders [88], as well as difficulty in usability and navigation affect patient engagement with health data [122,128,144,172,312]. Other factors that negatively impact user experience and attitudes towards health data access services include poor user design [145], privacy and security issues and concerns [123,234], insufficient or inadequate error prevention methods, technical problems and unclear instructions [272], a lack of images and audiovisual tools to support patient learning on how to access and use their health data [145,270], and poor catering of the health data access services functionalities for different user groups [128].

Several studies provided support for the utilization of mobile application-based EHRs [99,252,255,317], indicating that individuals with these apps on their devices are more likely to actively engage with their EHRs compared to those who lack access to these applications [221]. However, despite the potential benefits of these application platforms, they also exhibit certain limitations. For instance, one study revealed that mobile application-based health data access systems may

primarily serve a limited user demographic, with usage being predominantly observed among a specific group of individuals (i.e., white, male, and privately insured in the USA) [252]. Mobile application-based health data access systems are shown to have a lack of standards and guidelines to adhere to, and lack the ability to operate across healthcare systems within a country [99]. Moreover, some patient portals and applications are shown to be not user-friendly [270], have many bugs and software updates [241], with insufficient features (such as security features, functions to book appointments online) [241], with insufficient support and training to navigate [93,241].

Improvement of technology is necessary to address privacy and security concerns, which has been established as a key factor in influencing patient motivation to use health data [123,234]. Proposals to address this include the combination of techniques that can improve privacy protection while improving data access from healthcare institutions [167]. Other solutions include Consent2share (C2S) which is a consent tool to support data sharing options that match patients' preferences and existing data privacy legislature [279].

To reduce medical errors on the records and improve its quality, tools such as Revised Safer Dx Instrument have been developed, and patients have been reported to use it to identify medical errors [188]. However, it is possible that individuals of different backgrounds are likely to engage with such tools differently. Patients who are not of Hispanic or Latino ethnicity were reported to be more likely to identify and report errors in their healthcare records. Patient trust in healthcare professionals was also shown to be associated with the effective use of this tool in flagging inaccuracies [188]. In addition to developing tools to highlight errors, the technical integration of patient-reported outcome measures within health data have been explored to improve the quality and comprehensiveness of health data and subsequently contribute to increasing patient engagement [201].

3.7. Domain 7: Policy factors

A range of national policies have aimed to promote increased patient access to health data. Since patient access to health data is still limited in many countries because of, for instance, financial, regulatory, or operational issues, policies to improve patient access to health data access services (directly or indirectly by addressing barriers to implementation) have been established and enforced in some countries. This includes the 21st Century Cures Act in the US [40,40,66,132,182,188,213,304], Health Insurance Portability and Accountability Act in the US [123,317], eHealth strategy in Saudi Arabia (including the National Transformation Programme that aims to increase patient engagement with technology) [241], and patient access provision to EHRs in Sweden and England [182,316]. It is also noteworthy that policies to limit patient access to health data have been developed, such as the Norwegian Patients' Rights Act where patients are denied access to certain health data if access is deemed to risk endangering their life or another individuals' life [93].

In addition to policies that directly stipulate increased patient access to health data, opt-out rather than opt-in policies have been used by governments to improve patient adoption of health data access services [209]. While Estonia, England, and Australia have adopted opt-out systems, France has adopted an opt-in system where patients are required to give explicit consent to be included in the EHR system. Having opt-out systems can therefore increase the amount of health data available, as reported in Australia, where 90 % of individuals are covered by the health data infrastructure [209].

Since privacy and security concerns form a key barrier for patient use of health data, policies to ensure protection of patient privacy and security with increased access to health data have been established. These include the OECD guidelines to protect patient privacy [123], United Nations General Assembly declaration on the importance of privacy [123], General Personal Data Protection Law in Brazil [123], HITECH in the US [123,312], ONC in the US to provide a certification programme

[66,123,219,252], and NIST guidelines in the US on administration safeguards, physical safeguards, technical safeguards, organizational standards and other procedures [123].

Solutions to improve levels of health data access service uptake (in particular in the form of EHRs) include the Electronic Health Records Incentive Programs in the US (i.e., a programme that provides financial incentives to eligible professionals and hospitals as they adopt or implement certified EHR technologies) [172]. To improve the ability of patients with limited digital literacy or decisional capacity to use the health data access service, provision of proxy access for caregiver engagement on patient portals has been discussed [163,253], though this requires tight control for privacy and ethics.

4. Discussion

In this review article, we aimed to synthesise the most frequently discussed factors published in the last 5 years that foster patient engagement with their health data through expanding patient access to digital platforms that provide this information. Overall, 44 factors were extracted: 6 social and demographic factors, 6 patient ability factors, 12 patient motivation factors, 7 factors related to healthcare professionals' attitudes and skills, 4 health system factors, 6 technological factors, and 3 policy factors. Our findings highlight relevant factors for the implementation of expanded patient access to health data in improving patient engagement.

It is important to note that the factors mapped in this review align closely resemble factors related to the uptake of other fields of digital health, such as telehealth and digital therapeutics [32,33,320]. These similarities point to an underlying need to reassess the current state of health infrastructures in light of the digital transformations of healthcare delivery [25,321], as well as the subsequent emergence of the digital determinants of health [322,323]. In particular, the expansion of digital infrastructure to reach all strands of the population and the development of digital and health literacy appear to be vital foundational necessities for any digital transformation in health to be successful, equitable, and sustainable [4,27,28,318]. It is important to note that the development of digital and health literacy, as well as general literacy, is an investment that has to happen in the general population so these skills are present by the time people become patients [4], highlighting the need for these competencies to be fostered in educational settings for children and adults as well as continued social investments to expand access to the digital world [323,324].

The findings of this review complement previous studies that investigated the benefits of expanding patient access to health data. Previous research emphasised how concerns about functionality, lack of awareness, and limited availability to learn more about health data access services can influence uptake and utilisation [325]. It also stressed the importance of developing trustworthy and clinically relevant health data use measures [326–328]. Aligned with our findings, prior research emphasised how including more patient-reported items (i.e., patient-reported outcome measures, patient-reported experience measures, as well as data uploaded by patients themselves including side effects of medications or new symptoms not previously reported in consultation with health professionals) would enhance health, patient-centred care, resulting in improved health-related quality of life and the potential to increase life expectancy [329].

The findings of this review become particularly relevant in contexts where mass-rollout of health data access services are envisioned with the explicit goal of improving people and patient engagement, such as in the context of the upcoming European Health Data Space [6,327,330]. In this context, the findings of this review can complement the framework embedded in the European Health Data Space and impact its national implementation in individual member states of the European Union by providing a range of factors through which improved people and patient engagement can be pursued across multiple levels of governance (e.g., policy, design of technology, and capacity building).

This is especially relevant in the context of the criticism that the European Health Data Space can run the risk of excluding already vulnerable population groups, thus magnifying existing inequalities [6]. However, it can also provide important nuance to recent calls to adopt sophisticated cybersecurity measures for the European Health Data Space [327,331], as these security measures should not come at the expense of the user experience.

Some limitations of this review need to be considered. First, the findings of this review should be interpreted as scoping, meaning it provides a high-level overview of the literature and may not capture more specific factors that can affect patient engagement through the expansion of patient access to health data. Second, the quality of the included sources was not assessed, which should be considered when interpreting the results. Third, we acknowledge the presence of evidence selection bias, as only two academic databases and Google Scholar were used. That said, an exhaustive search was not required to reach the aim of this review. In fact, we reached thematic saturation during the extraction of the current sample of articles. Finally, we acknowledge that this review makes broad conclusions about patient engagement holistically and may not be applicable to individual settings.

This review also points to areas for future research. The co-creation of health data access environments with patients was stated as an important facilitator to increase the likelihood of successful expansion of patient access, yet little research in the preferences and needs of different patient groups in the context of health data access services has been performed. The failure to integrate patient-reported measures into patient-facing health data access systems can be seen as a missed opportunity to promote the wider adoption of these measures in clinical practice. Our study can also provide a starting point for the development of more concrete patient empowerment metrics relevant to the multiple domains discerned in this study, which currently remains a rather aspirational concept that lacks consistent metrics and effective measurement tools at an individual level [332]. This would help shed light on the important factors that drive whether patients use their health information to inform decisions regarding their own care, and important prerequisite for patient empowerment resulting from access to health data. The potential beneficial role that healthcare provider attitudes can play in the use of health data among patients, as well as their role in affecting patient engagement with their health data should be further explored as well. The emergence of mobile application-based health data access services warrants further research to identify how their unique features enable increased patient engagement with their health data, especially in empowering underserved and vulnerable communities [333,334]. This is especially pertinent in the context of the upcoming EHDS, seeing as health data access services can include but are not limited to electronic health records systems under this regulation. Finally, current policy initiatives are mostly centered around expanding patient access to health data. Future work should investigate how policy initiatives can be developed to build the necessary capacity in the general population to actively utilize health data.

Ultimately, expanding patient access to health data has the potential to positively impact the way healthcare is organized and delivered. Increasing patient engagement further enables the development of patient-centered healthcare as, if patients actively utilize their health data, then they are better able to make informed decisions within the context of their healthcare trajectories. However, expanding patient access to health data also has the potential to exacerbate existing inequities as those likely to benefit from increased access to their health data tend to be those at risk of not being able to use, understand, or capitalize on these benefits [6]. In fact, in several US surveys, patients who are older, less educated, from racial/ethnic minority groups, or whose first language differs from their provider are less likely to use health data access platforms. However, when patients from these demographic groups gain access, they report greater benefits than do their majority population counterparts, including increased trust and teamwork [67], highlighting the importance to factor in social determinants

of health in pursuing equitable rollout of patient-accessible health data access systems. While expanding patient access to health data is an important step towards improving patient engagement and subsequently fostering shared decision-making in healthcare, it is important to ensure that these developments reach and benefit all parts of the community.

5. Summary table

- While the evidence on the benefits of making health data more accessible to patients is growing steadily, a comprehensive assessment of what factors affect patient engagement remains absent.
- We extracted 44 influential factors scattered across social and demographic factors, patient ability factors, patient motivation factors, factors related to healthcare professionals' attitudes and skills, health system factors, technological functionality factors, and policy factors.
- In the context of the upcoming European Health Data Space, the findings of this review can complement it by providing a broader array of factors through which patient engagement can be pursued through policy, design of technology, and capacity building.
- Improving people's engagement with their health data further enables patient-centered healthcare as persons-turned-patients can better make informed decisions within their healthcare trajectories.

Ethical approval

This study has no inherent ethical implications or considerations.

Funding

EM reports financial support from the European Observatory on Health Systems and Policies.

CRedit authorship contribution statement

Robin van Kessel: Writing – review & editing, Writing – original draft, Visualization, Validation, Software, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Sruthi Ranganathan:** Writing – review & editing, Writing – original draft, Visualization, Validation, Software, Methodology, Investigation, Formal analysis, Conceptualization. **Michael Anderson:** Writing – review & editing, Writing – original draft, Visualization, Validation, Software, Methodology, Investigation, Formal analysis, Conceptualization. **Brian McMillan:** Writing – review & editing, Validation. **Elias Mossialos:** Writing – review & editing, Writing – original draft, Validation, Supervision, Methodology, Formal analysis, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

We would like to thank Sarah Moncrieff for her comments and feedback on the manuscript, as well as her efforts in designing the illustration. We would also like to thank Dr Nienke M. Schutte for the fruitful discussions around patient engagement in the context of the European Health Data Space.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ijmedinf.2024.105513>.

org/10.1016/j.ijmedinf.2024.105513.

References

- [1] D. Wakefield, J. Bayly, L.E. Selman, A.M. Firth, L.J. Higginson, F.E. Murtagh, Patient empowerment, what does it mean for adults in the advanced stages of a life-limiting illness: A systematic review using critical interpretive synthesis, *Palliat Med.* 32 (8) (2018 Sep) 1288–1304.
- [2] M. Hägglund, B. McMillan, R. Whittaker, C. Blease, Patient empowerment through online access to health records, *BMJ* 29 (378) (2022 Sep) e071531.
- [3] World Health Organization, Health Promotion Glossary [Internet], World Health Organization, Geneva, 1998. Available from: https://iris.who.int/bitstream/handle/10665/64546/WHO_HPR_HEP_98.1.pdf?sequence=1.
- [4] I. Kickbusch, D. Piselli, A. Agrawal, R. Balicer, O. Banner, M. Adelhardt, et al., The Lancet and Financial Times Commission on governing health futures 2030: growing up in a digital world, *Lancet* 398 (10312) (2021 Nov 6) 1727–1776.
- [5] European Patients' Forum, Toolkit for Patient Organisations on Patient Empowerment [Internet], European Patients' Forum, Brussels, 2017. Available from: <https://www.eu-patient.eu/globalassets/library/publications/patient-empowerment-toolkit.pdf>.
- [6] R. van Kessel, B.L.H. Wong, R. Forman, J. Gabrani, E. Mossialos, The European Health Data Space fails to bridge digital divides, *BMJ* 8 (378) (2022 Jul) e071913.
- [7] T. Richards, A. Coulter, B. McMillan, M. Hagglund, Patient access to full general practice health records, *BMJ* 19 (379) (2022 Dec) o3019.
- [8] A. Tapuria, T. Porat, D. Kalra, G. Dsouza, S. Xiaohui, V. Curcin, Impact of patient access to their electronic health record: systematic review, *Inform Health Soc Care.* 46 (2) (2021 Jun 2) 194–206.
- [9] A.L. Neves, L. Freise, L. Laranjo, A.W. Carter, A. Darzi, E. Mayer, Impact of providing patients access to electronic health records on quality and safety of care: a systematic review and meta-analysis, *BMJ Qual Saf.* 29 (12) (2020 Dec 1) 1019–1032.
- [10] E. Ammenwerth, S. Neyer, A. Hörbst, G. Mueller, U. Siebert, P. Schnell-Inderst, Adult patient access to electronic health records, Feb 26 [cited 2023 Aug 6]; 2021 (2). Available from: Cochrane Consumers and Communication Group, Editor. Cochrane Database Syst Rev [Internet]. (2021) <http://doi.wiley.com/10.1002/14651858.CD012707.pub2>.
- [11] BDI Research, Directorate-General for Communications Networks, Content and Technology (European Commission), Open Evidence, RAND Europe, Valverde-Albacete J, Folkvord F, et al. Benchmarking deployment of eHealth among general practitioners (2018): final report [Internet]. Publications Office of the European Union; 2018 [cited 2024 Apr 1]. Available from: <https://data.europa.eu/doi/10.2759/511610>.
- [12] T. Richards, H. Scowcroft, E. Doble, A. Price, K. Abbasi, Healthcare decision making should be democratised, *BMJ* 19 (373) (2021 May) n1225.
- [13] Z. Niazkhani, E. Toni, M. Cheshmekaboodi, A. Georgiou, H. Pirnejad, Barriers to patient, provider, and caregiver adoption and use of electronic personal health records in chronic care: a systematic review, *BMC Med Inform Decis Mak.* 20 (1) (2020 Jul 8) 153.
- [14] A.A. Abd-Alrazaq, B.M. Bewick, T. Farragher, P. Gardner, Factors that affect the use of electronic personal health records among patients: A systematic review, *Int J Med Inf.* 126 (2019 Jun) 164–175.
- [15] H. Arksey, L. O'Malley, Scoping studies: towards a methodological framework, *Int J Soc Res Methodol.* 8 (1) (2005 Feb 1) 19–32.
- [16] D. Levac, H. Colquhoun, K.K. O'Brien, Scoping studies: advancing the methodology, *Implement Sci.* 5 (1) (2010 Sep 20) 69.
- [17] A. Sutton, M. Clowes, L. Preston, A. Booth, Meeting the review family: exploring review types and associated information retrieval requirements, *Health Inf Libr J.* 36 (3) (2019) 202–222.
- [18] A. Booth, Searching for qualitative research for inclusion in systematic reviews: a structured methodological review, *Syst Rev.* 5 (1) (2016 May 4) 74.
- [19] A.C. Tricco, E. Lillie, W. Zarin, K.K. O'Brien, H. Colquhoun, D. Levac, et al., PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation, *Ann Intern Med.* 169 (7) (2018 Oct 2) 467–473.
- [20] Peters MDJ, Godfrey C, McInerney P, Munn Z, Tricco AC, Khalil H. Chapter 11: Scoping reviews. In: JBI Manual for Evidence Synthesis [Internet]. JBI; 2020 [cited 2023 Mar 9]. Available from: <https://jbi-global-wiki.refined.site/space/MANUAL/4687342/Chapter+11%3A+Scoping+reviews>.
- [21] Å. Knecht, M. Flink, O. Frykholm, M. Kirsebom, M. Ekstedt, The Information Flow in a Healthcare Organisation with Integrated Units, *Int J Integr Care.* 19 (3) (2019 Sep 26) 20.
- [22] E. Li, J. Clarke, H. Ashrafian, A. Darzi, A.L. Neves, The Impact of Electronic Health Record Interoperability on Safety and Quality of Care in High-Income Countries: Systematic Review, *J Med Internet Res.* 24 (9) (2022 Sep 15) e38144.
- [23] J. Eriksen, A. Bygholm, P. Bertelsen, The association between patient-reported outcomes (PROs) and patient participation in chronic care: A scoping review, *Patient Educ Couns.* 105 (7) (2022 Jul) 1852–1864.
- [24] J. Greenhalgh, K. Gooding, E. Gibbons, S. Dalkin, J. Wright, J. Valderas, et al., How do patient reported outcome measures (PROMs) support clinician-patient communication and patient care? A realist synthesis, *J Patient-Rep Outcomes.* 2 (1) (2018 Sep 15) 42.
- [25] Fahy N, Williams GA, Habicht T, Köhler K, Jormanainen V, Satokangas M, et al. Use of digital health tools in Europe: Before, during and after COVID-19 [Internet]. Copenhagen (Denmark): European Observatory on Health Systems and Policies; 2021 [cited 2022 Nov 24]. (European Observatory Policy Briefs). Available from: <http://www.ncbi.nlm.nih.gov/books/NBK576970/>.
- [26] T. Insel, Digital mental health care: five lessons from Act 1 and a preview of Acts 2–5, *Npj Digit Med.* 6 (1) (2023 Jan 26) 1–3.
- [27] R. van Kessel, I. Kyriopoulos, B.L.H. Wong, E. Mossialos, The Effect of the COVID-19 Pandemic on Digital Health-Seeking Behavior: Big Data Interrupted Time-Series Analysis of Google Trends, *J Med Internet Res.* 25 (1) (2023 Jan 16) e42401.
- [28] R. van Kessel, I. Kyriopoulos, A. Mastylak, E. Mossialos, Changes in digital healthcare search behavior during the early months of the COVID-19 pandemic: A study of six English-speaking countries, *PLOS Digit Health.* 2 (5) (2023 May 1) e0000241.
- [29] N.R. Haddaway, A.M. Collins, D. Coughlin, S. Kirk, The Role of Google Scholar in Evidence Reviews and Its Applicability to Grey Literature Searching, *PLoS One* 10 (9) (2015 Sep 17) e0138237.
- [30] V. Braun, V. Clarke, Using thematic analysis in psychology, *Qual Res Psychol.* 3 (2) (2006 Jan 1) 77–101.
- [31] Bos-Nehles A, Townsend K, Cafferkey K, Trullen J. Examining the Ability, Motivation and Opportunity (AMO) framework in HRM research: Conceptualization, measurement and interactions. *Int J Manag Rev* [Internet]. [cited 2023 Sep 22]; n/a(n/a). Available from: <https://onlinelibrary.wiley.com/doi/abs/10.1111/ijmr.12332>.
- [32] R. van Kessel, A. Roman-Urrestarazu, M. Anderson, I. Kyriopoulos, S. Field, G. Monti, et al., Mapping Factors That Affect the Uptake of Digital Therapeutics Within Health Systems: Scoping Review, *J Med Internet Res.* 25 (1) (2023 Jul 25) e48000.
- [33] R. van Kessel, D. Srivastava, I. Kyriopoulos, G. Monti, D. Novillo-Ortiz, R. Milman, W.W. Zhang-Czabanowski, G. Nasi, A.D. Stern, G. Wharton, E. Mossialos, Digital Health Reimbursement Strategies of 8 European Countries and Israel: Scoping Review and Policy Mapping, *JMIR mHealth and uHealth* 11 (1) (2023) e49003, <https://doi.org/10.2196/49003>.
- [34] C. Blease, L. Salmi, H. Rexhepi, M. Hägglund, C.M. DesRoches, Patients, clinicians and open notes: information blocking as a case of epistemic injustice, *J Med Ethics.* 48 (10) (2022 Oct) 785–793.
- [35] C.R. Blease, T. Delbanco, J. Torous, M. Ponten, C.M. DesRoches, M. Hagglund, et al., Sharing clinical notes, and placebo and nocebo effects: Can documentation affect patient health? *J Health Psychol.* 27 (1) (2022 Jan) 135–146.
- [36] M.S. Mano, G. Morgan, Telehealth, Social Media, Patient Empowerment, and Physician Burnout: Seeking Middle Ground, *Am Soc Clin Oncol Educ Book Am Soc Clin Oncol Annu Meet.* 42 (2022 Apr) 1–10.
- [37] Prokosch HU, Schüttler C, Schraudt M, Öfelein M, Maier C. Digital Patient Communication: Improving the Hospital-Patient Relationship.
- [38] J. Henderson, Patient privacy in the COVID-19 era: Data access, transparency, rights, regulation and the case for retaining the status quo, *Health Inf Manag J.* 50 (1–2) (2021 Jan) 6–8.
- [39] M. Chen, M. Decary, Embedding Health Literacy Tools in Patient EHR Portals to Facilitate Productive Patient Engagement, *Stud Health Technol Inform.* 257 (2019) 59–63.
- [40] C. Blease, J. Walker, C.M. DesRoches, T. Delbanco, U.S. New, Law Mandates Access to Clinical Notes: Implications for Patients and Clinicians, *Ann Intern Med.* 174 (1) (2021 Jan) 101–102.
- [41] T. Ganta, J.M. Appel, N. Genes, Patient portal access for caregivers of adult and geriatric patients: reframing the ethics of digital patient communication, *J Med Ethics.* 49 (3) (2023 Mar) 156–159.
- [42] D. Celuchova Bosanska, M. Huptych, L. Lhotská, Decentralized EHRs in the Semantic Web for Better Health Data Management, *Stud Health Technol Inform.* 3 (299) (2022 Nov) 157–162.
- [43] D. Tardif, Understanding privacy risks when accessing electronic medical records, *Can J Anesth Can Anesth.* 67 (2) (2020 Feb 1) 163–168.
- [44] S. Arzhan, C. Argyropoulos, M.E. Roumelioti, Electronic Health Record Portals and Patient-Centered Outcomes in CKD, *Kidney Med.* 3 (2) (2021 Mar 6) 167–170.
- [45] Bowles J, Webber T, Blackledge E, Vermeulen A. A Blockchain-Based Healthcare Platform for Secure Personalised Data Sharing. In: Mantas J, Stoicu-Tivadar L, Chronaki C, Hasman A, Weber P, Gallos P, et al., editors. *Studies in Health Technology and Informatics* [Internet]. IOS Press; 2021 [cited 2023 Aug 4]. Available from: <https://ebooks.iospress.nl/doi/10.3233/SHTI210150>.
- [46] T. Moerenhout, G.S. Fischer, I. Devisch, The elephant in the room: a postphenomenological view on the electronic health record and its impact on the clinical encounter, *Med Health Care Philos.* 23 (2) (2020 Jun) 227–236.
- [47] L. Salmi, S.A. Mansouri, L.P. Taylor, New federal rule requires open notes: what do clinicians and patients need to know? Insights and suggestions from a neuro-oncologist, a neurosurgeon, and a person living with a brain tumor, *Neuro-Oncol Pract.* 8 (3) (2021 May 26) 233–235.
- [48] D. Miller, Transparency in Patient Access to Dermatopathologic Reports, *JAMA Dermatol.* 156 (3) (2020 Mar 1) 252.
- [49] C.R. Blease, S.F. O'Neill, J. Torous, C.M. DesRoches, M. Hagglund, Patient Access to Mental Health Notes: Motivating Evidence-Informed Ethical Guidelines, *J Nerv Ment Dis.* 209 (4) (2021 Apr) 265–269.
- [50] Kelly MM, Dean SM. Improving transparency in hospitals: perspectives on implementing an inpatient portal. *Future Healthc J.* 2022 Sep 13;fhj.2021-0127.
- [51] M.F. Ebeling, Patient disempowerment through the commercial access to digital health records, *Health Interdiscip J Soc Study Health Illn Med.* 23 (4) (2019 Jul) 385–400.
- [52] C.T. Hess, Optimize Your Patient Portal and Streamline Your Workflows, *Adv Skin Wound Care.* 33 (7) (2020 Jul) 390–391.

- [53] J.H. Shore, Managing Virtual Hybrid Psychiatrist-Patient Relationships in a Digital World, *JAMA Psychiat*. 77 (5) (2020 May 1) 541.
- [54] B.J. Miller, J.M. Slota, J.M. Ehrenfeld, Redefining the Physician's Role in Cost-Conscious Care: The Potential Role of the Electronic Health Record, *JAMA* 322 (8) (2019 Aug 27) 721.
- [55] C.M. DesRoches, J. Walker, T. Delbanco, Care Partners and Patient Portals—Faulty Access, Threats to Privacy, and Ample Opportunity, *JAMA Intern Med*. 180 (6) (2020 Jun 1) 850.
- [56] L.D. Leonard, E. Cumbler, R. Schulick, S.E. Tevis, From paternalistic to patient-centered: Strategies to support patients with the immediate release of medical records, *Am J Surg*. 222 (5) (2021 Nov) 909–910.
- [57] I.G. Cohen, M.M. Mello, Big Data, Big Tech, and Protecting Patient Privacy, *JAMA* 322 (12) (2019 Sep 24) 1141.
- [58] D.F. Sittig, H. Singh, Policies to Promote Shared Responsibility for Safer Electronic Health Records, *JAMA* 326 (15) (2021 Oct 19) 1477.
- [59] R. Rubin, How Sharing Clinical Notes Affects the Patient-Physician Relationship, *JAMA* 325 (16) (2021 Apr 27) 1596.
- [60] J. Bernstein, Not the Last Word: Seeing Ourselves as Doctors See Us, *Clin Orthop Relat Res*. 480 (9) (2022 Sep) 1653.
- [61] R.M. Wachter, S.G. Murray, J. Adler-Milstein, Restricting the Number of Open Patient Records in the Electronic Health Record: Is the Record Half Open or Half Closed? *JAMA* 321 (18) (2019 May 14) 1771.
- [62] S.T. Savitz, L.A. Savitz, N.S. Fleming, N.D. Shah, A.S. Go, How much can we trust electronic health record data? *Healthcare*. 8 (3) (2020 Sep) 100444.
- [63] A. Kouroubali, D.G. Katehakis, The new European interoperability framework as a facilitator of digital transformation for citizen empowerment, *J Biomed Inform*. 94 (2019 Jun) 103166.
- [64] D. deBronkart, Open Access as a Revolution: Knowledge Alters Power, *J Med Internet Res*. 21 (12) (2019 Dec 11) e16368.
- [65] C. Blease, L. Salmi, M. Hägglund, D. Wachenheim, C. DesRoches, COVID-19 and Open Notes: A New Method to Enhance Patient Safety and Trust, *JMIR Ment Health*. 8 (6) (2021 Jun 21) e29314.
- [66] S. Arvais-Anhalt, M. Lau, C.U. Lehmann, A.J. Holmgren, R.J. Medford, C. M. Ramirez, et al., The 21st Century Cures Act and Multiuser Electronic Health Record Access: Potential Pitfalls of Information Release, *J Med Internet Res*. 24 (2) (2022 Feb 17) e34085.
- [67] C. Blease, B. McMillan, L. Salmi, G. Davidge, T. Delbanco, Adapting to transparent medical records: international experience with “open notes”, *BMJ* 21 (379) (2022 Nov) e069861.
- [68] D. Greenfield, U. Iqbal, Y.C. Li (Jack), High quality, safe healthcare = technology + people + systems thinking, *BMJ Health Care Inform*, Online 29 (1) (2022 Sep) e100673.
- [69] R.J. Baron, Using Artificial Intelligence to Make Use of Electronic Health Records Less Painful—Fighting Fire With Fire, *JAMA Netw Open*. 4 (7) (2021 Jul 23) e2118298.
- [70] D.E. Casey, Patient-Reported Outcome Measures—Challenges and Opportunities for China, *JAMA Netw Open*. 5 (5) (2022 May 11) e2211652.
- [71] J.L. Carlson, R. Goldstein, T. Buhr, N. Buhr, Teenager, Parent, and Clinician Perspectives on the Electronic Health Record, *Pediatrics* 145 (3) (2020 Mar 1) e20190193.
- [72] H. Salisbury, Helen Salisbury: Confusion over patient access to notes, *BMJ* 1 (379) (2022 Nov) o2607.
- [73] E. Doble, H. Scowcroft, Access to personal health records—why is progress so slow? *BMJ* 4 (2021 Nov) n2687.
- [74] J. Silberner, The US opened up access to health records—how do patients use them? *BMJ* 8 (2021 Dec) n2789.
- [75] C. DesRoches, J. Walker, T. Delbanco, US experience with transparent medical records should reassure doctors, *BMJ* 9 (379) (2022 Dec) o2969.
- [76] G.L. Dimaguila, F. Batchelor, M. Merolli, K. Gray, “We are very individual”: anticipated effects on stroke survivors of using their person-generated health data, *BMJ Health Care Inform*. 27 (3) (2020 Sep) e100149.
- [77] E. Post, K. Fautro, Z.O. Kadro, J. Hill, C. Nguyen, G.N. Asher, et al., Patient Perspectives on the Development of a Novel Mobile Health (mHealth) Application for Dietary Supplement Tracking and Reconciliation—A Qualitative Focus Group Study, *Glob Adv Health Med*. 11 (2022) 21649561221075268.
- [78] H.L. Wolfe, T.L. Boyer, K.L. Rodriguez, G.J. Klima, J.C. Shipherd, M.R. Kauth, et al., Exploring Research Engagement and Priorities of Transgender and Gender Diverse Veterans, *Mil Med*. 188 (5–6) (2023 May 16) e1224.
- [79] C. Hudson, M. Darking, J. Cox, Understanding the Value of Patientview for Enabling Self-Care Practice in Chronic Kidney Disease, *J Ren Care*. 46 (1) (2020 Mar) 13–24.
- [80] J.H. Holmes, J. Beinlich, M.R. Boland, K.H. Bowles, Y. Chen, T.S. Cook, et al., Why Is the Electronic Health Record So Challenging for Research and Clinical Care? *Methods Inf Med*. 60 (01/02) (2021 May) 032–048.
- [81] L.M. Beskow, K.M. Brelsford, C.M. Hammack, Patient perspectives on use of electronic health records for research recruitment, *BMC Med Res Methodol*. 19 (1) (2019 Feb 26) 42.
- [82] J.L. Hefner, S.R. MacEwan, A. Biltz, C.J. Sieck, Patient portal messaging for care coordination: a qualitative study of perspectives of experienced users with chronic conditions, *BMC Fam Pract*. 20 (1) (2019 May 3) 57.
- [83] A.S. McAlearney, N. Fareed, A. Gaughan, S.R. MacEwan, J. Volney, C.J. Sieck, Empowering Patients during Hospitalization: Perspectives on Inpatient Portal Use, *Appl Clin Inform*. 10 (1) (2019 Jan) 103–112.
- [84] S.S.J. Lee, M.K. Cho, S.A. Kraft, N. Varsava, K. Gillespie, K.E. Ormond, et al., “I don't want to be Henrietta Lacks”: diverse patient perspectives on donating biospecimens for precision medicine research, *Genet Med off J Am Coll Med Genet*. 21 (1) (2019 Jan) 107–113.
- [85] A. Weis, S. Pohlmann, R. Poss-Doering, B. Strauss, C. Ullrich, H. Hofmann, et al., Caregivers' role in using a personal electronic health record: a qualitative study of cancer patients and caregivers in Germany, *BMC Med Inform Decis Mak*. 20 (1) (2020 Jul 13) 158.
- [86] C.M. Hammack-Aviran, K.M. Brelsford, K.C. McKenna, R.D. Graham, Z. M. Lampron, L.M. Beskow, Research Use of Electronic Health Records: Patients' Views on Alternative Approaches to Permission, *AJOB Empir Bioeth*. 11 (3) (2020) 172–186.
- [87] M.M. Kelly, A.S. Thurber, R.J. Collier, A. Khan, S.M. Dean, W. Smith, et al., Parent Perceptions of Real-time Access to Their Hospitalized Child's Medical Records Using an Inpatient Portal: A Qualitative Study, *Hosp Pediatr*. 9 (4) (2019 Apr 1) 273–280.
- [88] E. Toni, H. Pirnejad, K. Makhdoomi, A. Mivefroshan, Z. Niazhani, Patient empowerment through a user-centered design of an electronic personal health record: a qualitative study of user requirements in chronic kidney disease, *BMC Med Inform Decis Mak*. 21 (1) (2021 Nov 24) 329.
- [89] E.S. Nahm, H. Son, J.M. Yoon, Older adults' use of patient portals: Experiences, challenges, and suggestions shared through discussion board forums, *Geriatr Nur (lond)*. 41 (4) (2020 Jul) 387–393.
- [90] G. Strudwick, R.G. Booth, D. McLean, K. Leung, S. Rossetti, M. McCann, et al., Identifying indicators of meaningful patient portal use by psychiatric populations, *Inform Health Soc Care*. 45 (4) (2020 Oct 1) 396–409.
- [91] K. Eriksson-Backa, N. Hirvonen, H. Enwald, I. Huvila, Enablers for and barriers to using My Kanta – A focus group study of older adults' perceptions of the National Electronic Health Record in Finland, *Inform Health Soc Care*. 46 (4) (2021 Dec 2) 399–411.
- [92] S.V. Burton, A.L. Valenta, J. Starren, J. Abraham, T. Nelson, K. Kochendorfer, et al., Examining perspectives on the adoption and use of computer-based patient-reported outcomes among clinicians and health professionals: a Q methodology study, *J Am Med Inform Assoc*. 29 (3) (2022 Jan 29) 443–452.
- [93] P. Zanaboni, E. Kristiansen, O. Lintvedt, R. Wynn, M.A. Johansen, T. Sørensen, et al., Impact on patient-provider relationship and documentation practices when mental health patients access their electronic health records online: a qualitative study among health professionals in an outpatient setting, *BMC Psychiatry* 22 (1) (2022 Jul 28) 508.
- [94] Haldar S, Khelifi M, Mishra SR, Apodaca C, Beneteau E, Pollack AH, et al. Designing Inpatient Portals to Support Patient Agency and Dynamic Hospital Experiences.
- [95] S. Hochwarter, G. Fehler, C. Muentze, Y. Eisenmann, M. Heinze, C. Hibsche, et al., Design of a Patient-Accessible Electronic Health Record System in Mental Health, in: B. Séroussi, P. Weber, F. Dhombres, C. Grouin, J.D. Liebe, S. Pelayo (Eds.), *Studies in Health Technology and Informatics [internet]*, IOS Press, 2022 [cited 2023 Aug 4]. Available from: .
- [96] A.S. Bajracharya, B.H. Crotty, H.B. Kowloff, C. Safran, W.V. Slack, Patient experience with family history tool: analysis of patients' experience sharing their family health history through patient-computer dialogue in a patient portal, *J Am Med Inform Assoc*. 26 (7) (2019 Jul 1) 603–609.
- [97] K.A. Fisher, K. Kennedy, S. Bloomstone, M.I. Fukunaga, S.K. Bell, K.M. Mazor, Can sharing clinic notes improve communication and promote self-management? A qualitative study of patients with COPD, *Patient Educ Couns*. 105 (3) (2022 Mar) 726–733.
- [98] Demiris G, Lin SY, Turner AM. The Role of Personal Health Information Management in Promoting Patient Safety in the Home: A Qualitative Analysis.
- [99] D.F. Lobach, A. Boxwala, N. Kashyap, K. Heaney-Huls, A.B. Chiao, T. Rafter, et al., Integrating a Patient Engagement App into an Electronic Health Record-Enabled Workflow Using Interoperability Standards, *Appl Clin Inform*. 13 (5) (2022 Oct) 1163–1171.
- [100] J.M. Alpert, B.B. Morris, M.D. Thomson, K. Matin, R.F. Brown, Identifying How Patient Portals Impact Communication in Oncology, *Health Commun*. 34 (12) (2019 Oct 15) 1395–1403.
- [101] Z. Fritz, F.E. Griffiths, A.M. Slowther, Custodians of Information: Patient and Physician Views on Sharing Medical Records in the Acute Care Setting, *Health Commun*. 36 (14) (2021 Dec 6) 1879–1888.
- [102] D.B. Wesley, L. Schubel, C.J. Hsiao, S. Burn, J. Howe, K. Kellogg, et al., A socio-technical systems approach to the use of health IT for patient reported outcomes: Patient and healthcare provider perspectives, *J Biomed Inform*. 100 (2019) 100048.
- [103] L. Wagner, M. Frisch, L. Turner-Brown, S. Andrews, A. Edwards, R. Moultrie, et al., Preferences for the research use of electronic health records among young adults with fragile X syndrome or autism spectrum disorder, *Disabil Health J*. 13 (4) (2020 Oct) 100927.
- [104] B. Alshoumr, P. Yu, D. Hailey, F. Bindaeyl, S. Alnanazi, S. Alshammery, Understanding cancer patients' use and perceptions of inpatient portal: A case study at a tertiary hospital in Saudi Arabia, *Int J Med Inf*. 148 (2021 Apr) 104398.
- [105] A.V. Sergeeva, Why developers matter: The case of patient portals, *Health Informatics J*. 29 (1) (2023 Jan) 146045822311527.
- [106] R.R. Thielmann, C. Hoving, E. Schutgens-Kok, J.W. Cals, R. Crutzen, Patient online access to general practice medical records: A qualitative study on patients' needs and expectations, *Health Inf Manag J*. 19 (2023 Jan) 183335832211446.
- [107] S.R. Greysen, Y. Magan, J. Rosenthal, R. Jacobia, A.D. Auerbach, J.D. Harrison, Patient Recommendations to Improve the Implementation of and Engagement With Portals in Acute Care: Hospital-Based Qualitative Study, *J Med Internet Res*. 22 (1) (2020 Jan 14) e13337.

- [108] G. Erlingsdóttir, L. Petersson, K. Jonnergård, A Theoretical Twist on the Transparency of Open Notes: Qualitative Analysis of Health Care Professionals' Free-Text Answers, *J Med Internet Res.* 21 (9) (2019 Sep 25) e14347.
- [109] A. Casillas, A.G. Cemballi, A. Abhat, M. Lemberg, J.D. Portz, S. Sadasivaiah, et al., An Untapped Potential in Primary Care: Semi-Structured Interviews with Clinicians on How Patient Portals Will Work for Caregivers in the Safety Net, *J Med Internet Res.* 22 (7) (2020 Jul 20) e18466.
- [110] P. Scalia, F. Ahmad, D. Schubbe, R. Forcino, M.A. Durand, P.J. Barr, et al., Integrating Option Grid Patient Decision Aids in the Epic Electronic Health Record: Case Study at 5 Health Systems, *J Med Internet Res.* 23 (5) (2021 May 3) e22766.
- [111] O.H. Ordaz, R.L. Croff, L.D. Robinson, S.A. Shea, N.P. Bowles, Optimization of Primary Care Among Black Americans Using Patient Portals: Qualitative Study, *J Med Internet Res.* 23 (6) (2021 Jun 3) e27820.
- [112] M. Raj, K. Ryan, P.S. Amara, P. Nong, K. Calhoun, M.G. Trinidad, et al., Policy Preferences Regarding Health Data Sharing Among Patients With Cancer: Public Deliberations, *JMIR Cancer.* 31 (9) (2023 Jan) e39631.
- [113] B. McMillan, G. Davidge, L. Brown, M. Lyons, H. Atherton, R. Goulding, et al., A qualitative exploration of patients' experiences, needs and expectations regarding online access to their primary care record, *BMJ Open* 11 (3) (2021 Mar) e044221.
- [114] M. Khazen, M. Mirica, N. Carlile, A. Groisser, G.D. Schiff, Developing a Framework and Electronic Tool for Communicating Diagnostic Uncertainty in Primary Care: A Qualitative Study, *JAMA Netw Open.* 6 (3) (2023 Mar 9) e232218.
- [115] O. Chivilgina, B.S. Elger, M.M. Benichou, F. Jotterand, 'What's the best way to document information concerning psychiatric patients? I just don't know'-A qualitative study about recording psychiatric patients notes in the era of electronic health records, *PLoS One* 17 (3) (2022) e0264255.
- [116] S. Kristensen, J. Holmskov, L. Baandrup, P. Videbeck, M. Bonde, J. Mainz, Evaluating the implementation and use of patient-reported outcome measures in a mental health hospital in Denmark: a qualitative study, *Int J Qual Health Care.* 31;34(Supplement_1):ii49–58 (2022 Mar).
- [117] K. Mercer, L. Guirguis, C. Burns, J. Chin, M.J. Dogba, L. Dolovich, et al., Exploring the role of teams and technology in patients' medication decision making, *J Am Pharm Assoc.* 59 (2) (2019 Mar) S35.
- [118] L. Beaton, I. Williams, L. Sanci, Exploring adolescent and clinician perspectives on Australia, *Aust J Prim Health* (2021 Mar 15).
- [119] T.H. Nøst, A. Faxvaag, A. Steinsbekk, Participants' views and experiences from setting up a shared patient portal for primary and specialist health services- a qualitative study, *BMC Health Serv Res.* 21 (1) (2021 Feb 24) 171.
- [120] G. Davidge, L. Brown, M. Lyons, C. Blease, D. French, T. van Staa, et al., Primary care staff's views and experience of patients' online access to their electronic health record: a qualitative exploration, *Br J Gen Pract.* 73 (731) (2023 Jun 1) e418.
- [121] C. Blease, J. Torous, Z. Dong, G. Davidge, C. DesRoches, A. Kharko, et al., Patient Online Record Access in English Primary Care: Qualitative Survey Study of General Practitioners' Views, *J Med Internet Res.* 25 (1) (2023 Feb 22) e43496.
- [122] I. Radparvar, M.K. Ross, Barriers and facilitators of electronic patient portal uptake for asthma management, *J Asthma off J Assoc Care Asthma.* 60 (4) (2023 Apr) 635–646.
- [123] Tertulino R, Antunes N, Morais H. Privacy in electronic health records: a systematic mapping study. *J Public Health* [Internet]. 2023 Jan 23 [cited 2023 Aug 4]; Available from: <https://link.springer.com/10.1007/s10389-022-01795-z>.
- [124] A.M. Hazara, K. Durrans, S. Bhandari, The role of patient portals in enhancing self-care in patients with renal conditions, *Clin Kidney J.* 13 (1) (2020 Feb 1) 1–7.
- [125] N. Shen, T. Bernier, L. Sequeira, J. Strauss, M.P. Silver, A. Carter-Langford, et al., Understanding the patient privacy perspective on health information exchange: A systematic review, *Int J Med Inf.* 125 (2019 May) 1–12.
- [126] S. Paydar, H. Emami, F. Asadi, H. Moghaddasi, A. Hosseini, Functions and Outcomes of Personal Health Records for Patients with Chronic Diseases: A Systematic Review, *Perspect Health Inf Manag.* 18 (Spring) (2021 Mar 15) 11.
- [127] M.A. Ryan, E.F. Boss, Patient Engagement in Otolaryngology, *Otolaryngol Clin North Am.* 52 (1) (2019 Feb) 23–33.
- [128] K. Cresswell, M. Rigby, A. Georgiou, Z.S.Y. Wong, P. Kukhareva, S. Medlock, et al., The Role of Formative Evaluation in Promoting Digitally-based Health Equity and Reducing Bias for Resilient Health Systems: The Case of Patient Portals, *Yearb Med Inform.* 31 (1) (2022 Aug) 33–39.
- [129] Z. Hollo, D.E. Martin, An equitable approach to enhancing the privacy of consumer information on *My Health Record* in Australia, *Health Inf Manag J.* 52 (1) (2023 Jan) 37–40.
- [130] T. Zhang, N. Shen, R. Booth, J. LaChance, B. Jackson, G. Strudwick, Supporting the use of patient portals in mental health settings: a scoping review, *Inform Health Soc Care.* 47 (1) (2022 Jan 2) 62–79.
- [131] Rai BK. PcBEHR: patient-controlled blockchain enabled electronic health records for healthcare 4.0. *Health Serv Outcomes Res Methodol* [Internet]. 2022 Jun 7 [cited 2023 Aug 4]; Available from: <https://link.springer.com/10.1007/s10742-022-00279-7>.
- [132] J.M. Fogler, K. Ratliff-Schaub, L. McGuinn, P. Crutchfield, J. Schwartz, N. Soares, OpenNotes: Anticipatory Guidance and Ethical Considerations for Pediatric Psychologists in Interprofessional Settings, *J Pediatr Psychol.* 47 (2) (2022 Mar 1) 189–194.
- [133] A. Tapuria, T. Porat, D. Kalra, G. Dsouza, S. Xiaohui, V. Curcin, Impact of patient access to their electronic health record: systematic review, *Inform Health Soc Care.* 46 (2) (2021 Jun 2) 192–204.
- [134] H.J.T. Van Mens, R.D. Duijn, R. Nienhuis, N.F. De Keizer, R. Cornet, Determinants and outcomes of patient access to medical records: Systematic review of systematic reviews, *Int J Med Inf.* 129 (2019 Sep) 226–233.
- [135] P.S. Kallmerten, L.R. Chia, K. Jakub, M.T. Turk, Patient Portal Use by Adults With Heart Failure: An Integrative Review, *CIN Comput Inform Nurs.* 39 (8) (2021 Aug) 418–431.
- [136] C.M. DesRoches, Healthcare in the new age of transparency, *Semin Dial.* 33 (6) (2020 Nov) 533–538.
- [137] A.L. Joseph, H. Monkman, A.W. Kushniruk, E.M. Borycky, Are Personal Health Records (PHRs) Facilitating Patient Safety? A Scoping Review, *Stud Health Technol Inform.* 25 (294) (2022 May) 535–539.
- [138] Wildenbos GA, Jaspers M, Peute L. The equity paradox: older patients' participation in patient portal development. *Int J Qual Health Care* [Internet]. 2018 Dec 20 [cited 2023 Aug 4]; Available from: <https://academic.oup.com/intqhc/advance-article/doi/10.1093/intqhc/mzy245/5253759>.
- [139] Reynolds TL, Ali N, Zheng K. What Do Patients and Caregivers Want? A Systematic Review of User Suggestions to Improve Patient Portals.
- [140] Ammenwerth E, Hoerbst A, Lannig S, Mueller G, Siebert U, Schnell-Inderst P. Effects of Adult Patient Portals on Patient Empowerment and Health-Related Outcomes: A Systematic Review.
- [141] Alshoumr B, Yu P, Cui T, Song T. Using Inpatient Portals to Engage Family Caregivers in Acute Care Setting : A Literature Review.
- [142] T.Y. Tuan Soh, N.M.M. Nik Mohd Rosdy, M.Y.P. Mohd Yusof, S.H. Azhar Hilmy, B.A. Md Sabri, Adoption of a Digital Patient Health Passport as Part of a Primary Healthcare Service Delivery, *Systematic Review.* *J Pers Med.* 1;12(11):1814 (2022 Nov).
- [143] R. Taitingfong, C.S. Bloss, C. Triplett, J. Cakici, N. Garrison, S. Cole, et al., A systematic literature review of Native American and Pacific Islanders' perspectives on health data privacy in the United States, *J Am Med Inform Assoc.* 27 (12) (2020 Dec 9) 1987–1998.
- [144] D.E. Yehualashet, B.T. Seboka, G.A. Tesfa, A.D. Demeke, E.S. Amede, Barriers to the Adoption of Electronic Medical Record System in Ethiopia: A Systematic Review, *J Multidiscip Healthc.* 17 (14) (2021 Sep) 2597–2603.
- [145] F. Rangraz Jeddi, E. Nabovati, S. Saeedi, S. Rezaei, S. Amirzodi, Design and evaluation of a web-based personal health record for patients under dialysis, *Inform Med Unlocked.* 32 (2022) 101034.
- [146] O. Fennelly, C. Cunningham, L. Grogan, G. Cronin, C. O'Shea, M. Roche, et al., Successfully implementing a national electronic health record: a rapid umbrella review, *Int J Med Inf.* 144 (2020 Dec) 104281.
- [147] S. Nijor, G. Rallis, N. Lad, E. Gokcen, Patient Safety Issues From Information Overload in Electronic Medical Records, *J Patient Saf.* 18 (6) (2022 Sep) e999–e.
- [148] R. Dendere, C. Slade, A. Burton-Jones, C. Sullivan, A. Staib, M. Janda, Patient Portals Facilitating Engagement With Inpatient Electronic Medical Records: A Systematic Review, *J Med Internet Res.* 21 (4) (2019 Apr 11) e12779.
- [149] M. Raspa, R. Moultrie, L. Wagner, A. Edwards, S. Andrews, M.K. Frisch, et al., Ethical, Legal, and Social Issues Related to the Inclusion of Individuals With Intellectual Disabilities in Electronic Health Record Research: Scoping Review, *J Med Internet Res.* 22 (5) (2020 May 21) e16734.
- [150] J. Benjamins, A. Haveman-Nies, M. Gunnink, A. Goudkuil, E. de Vet, How the Use of a Patient-Accessible Health Record Contributes to Patient-Centered Care: Scoping Review, *J Med Internet Res.* 23 (1) (2021 Jan 11) e17655.
- [151] P. Durneva, K. Cousins, M. Chen, The Current State of Research, Challenges, and Future Research Directions of Blockchain Technology in Patient Care: Systematic Review, *J Med Internet Res.* 22 (7) (2020 Jul 20) e18619.
- [152] D. Golinelli, E. Boetto, G. Carullo, A.G. Nuzzolese, M.P. Landini, M.P. Fantini, Adoption of Digital Technologies in Health Care During the COVID-19 Pandemic: Systematic Review of Early Scientific Literature, *J Med Internet Res.* 22 (11) (2020 Nov 6) e22280.
- [153] E. Carini, L. Villani, A.M. Pezzullo, A. Barbara, W. Ricciardi, et al., The Impact of Digital Patient Portals on Health Outcomes, System Efficiency, and Patient Attitudes: Updated Systematic Literature Review, *J Med Internet Res.* 23 (9) (2021 Sep 8) e26189.
- [154] M. Lang, S. Lemieux, J. Hébert, G. Sauvageau, M.H. Zawati, Legal and Ethical Considerations for the Design and Use of Web Portals for Researchers, Clinicians, and Patients: Scoping Literature Review, *J Med Internet Res.* 23 (11) (2021 Nov 11) e26450.
- [155] M.P. Ingle, C. Valdovinos, K.L. Ford, S. Zhou, S. Bull, S. Gornail, et al., Patient Portals to Support Palliative and End-of-Life Care: Scoping Review, *J Med Internet Res.* 23 (9) (2021 Sep 16) e28797.
- [156] T.C. Kariotis, M. Pricor, S. Chang, K. Gray, Impact of Electronic Health Records on Information Practices in Mental Health Contexts: Scoping Review, *J Med Internet Res.* 24 (5) (2022 May 4) e30405.
- [157] J. Schwarz, A. Bärkås, C. Blease, L. Collins, M. Hägglund, S. Markham, et al., Sharing Clinical Notes and Electronic Health Records With People Affected by Mental Health Conditions: Scoping Review, *JMIR Ment Health.* 8 (12) (2021 Dec 14) e34170.
- [158] G. Kang, Y.G. Kim, Secure Collaborative Platform for Health Care Research in an Open Environment: Perspective on Accountability in Access Control, *J Med Internet Res.* 24 (10) (2022 Oct 14) e37978.
- [159] H.M.H. Fjellå, A.M.L. Husebo, M. Storm, eHealth in Care Coordination for Older Adults Living at Home: Scoping Review, *J Med Internet Res.* 24 (10) (2022 Oct 18) e39584.
- [160] J. Hagström, C. Blease, B. Haage, I. Scandurra, S. Hansson, M. Hägglund, Views, Use, and Experiences of Web-Based Access to Pediatric Electronic Health Records for Children, Adolescents, and Parents: Scoping Review, *J Med Internet Res.* 24 (11) (2022 Nov 22) e40328.

- [161] E. Li, J. Clarke, A.L. Neves, H. Ashrafian, A. Darzi, Electronic Health Records, Interoperability and Patient Safety in Health Systems of High-income Countries: A Systematic Review Protocol, *BMJ Open* 11 (7) (2021 Jul) e044941.
- [162] C.P. Subbe, G. Tellier, P. Barach, Impact of electronic health records on predefined safety outcomes in patients admitted to hospital: a scoping review, *BMJ Open* 11 (1) (2021 Jan) e047446.
- [163] K.T. Gleason, D. Peereboom, A. Wec, J.L. Wolff, Patient Portals to Support Care Partner Engagement in Adolescent and Adult Populations: A Scoping Review, *JAMA Netw Open*. 5 (12) (2022 Dec 28) e2248696.
- [164] Lyles CR, Nelson EC, Frampton S, Dykes PC, Cembali AG, Sarkar U. Using Electronic Health Record Portals to Improve Patient Engagement: Research Priorities and Best Practices. *Ann Intern Med*. 2020 Jun 2;172(11, Supplement): S123–9.
- [165] E. Negro-Calduch, N. Azzopardi-Muscat, R.S. Krishnamurthy, D. Novillo-Ortiz, Technological progress in electronic health record system optimization: Systematic review of systematic literature reviews, *Int J Med Inf*. 152 (2021 Aug) 104507.
- [166] K. Power, Z. McCrean, M. White, A. Breen, B. Dunleavy, S. O'Donoghue, et al., The development of an epilepsy electronic patient portal: Facilitating both patient empowerment and remote clinician-patient interaction in a post-COVID-19 world, *Epilepsia* 61 (9) (2020 Sep) 1894–1905.
- [167] F.N.D.S. Vanin, L.M. Policarpo, R.D.R. Righi, S.M. Heck, V.F. Da Silva, J. Goldim, et al., A Blockchain-Based End-to-End Data Protection Model for Personal Health Records Sharing: A Fully Homomorphic Encryption Approach, *Sensors* 23 (1) (2022 Dec 20) 14.
- [168] Glöggler M, Ammenwerth E. Using the Taxonomy of Patient Portals to Classify the ELGA Patient Portal. In: Schreier G, Pfeifer B, Baumgartner M, Hayn D, editors. *Studies in Health Technology and Informatics* [Internet]. IOS Press; 2022 [cited 2023 Aug 4]. Available from: <https://ebooks.iospress.nl/doi/10.3233/SHTI220340>.
- [169] T.B. Plante, K.T. Gleason, H.N. Miller, J. Charleston, K. McArthur, C. D. Himmelfarb, et al., Recruitment of trial participants through electronic medical record patient portal messaging: A pilot study, *Clin Trials*. 17 (1) (2020 Feb) 30–38.
- [170] H. Aboumatar, S. Pitts, R. Sharma, A. Das, B.M. Smith, J. Day, et al., Patient engagement strategies for adults with chronic conditions: an evidence map, *Syst Rev*. 11 (1) (2022 Dec) 39.
- [171] D. Morrow, R.F.L. Azevedo, R. Garcia-Retamero, M. Hasegawa-Johnson, T. Huang, W. Schuh, et al., Contextualizing numeric clinical test results for gist comprehension: Implications for EHR patient portals, *J Exp Psychol Appl*. 25 (1) (2019 Mar) 41–61.
- [172] H. Son, E.S. Nahm, S. Zhu, E. Galik, B. Van de Castle, K.L. Seidl, et al., Older Adults' Perception on and Use of Patient Portals: A Comparative Analysis of Two Samples, *Comput Inform Nurs Clin*. 40 (1) (2022 Jan 1) 61–68.
- [173] J.A. García-Berná, S. Ouhbi, J.L. Fernández-Alemán, J.M.C. De Gea, J. Nicolás, Investigating the Impact of Usability on Energy Efficiency of Web-based Personal Health Records, *J Med Syst*. 45 (6) (2021 Jun) 65.
- [174] T. Eyasu, K. Leung, G. Strudwick, Guiding Improvements in User Experience: Results of a Mental Health Patient Portal User Interface Assessment, *Stud Health Technol Inform*. 257 (2019) 110–114.
- [175] H.T. Gold, R.J. Karia, A. Link, R. Leibwohl, J.D. Zuckerman, T.J. Errico, et al., Implementation and early adaptation of patient-reported outcome measures into an electronic health record: A technical report, *Health Informatics J*. 26 (1) (2020 Mar) 129–140.
- [176] M.J. Yeh, R.B. Saltman, Creating online personal medical accounts: Recent experience in two developed countries, *Health Policy Technol*. 8 (2) (2019 Jun 1) 171–178.
- [177] S. Edmonds, Y. Lou, B. Robinson, P. Cram, D.W. Roblin, N.C. Wright, et al., Characteristics of older adults using patient web portals to view their DXA results, *BMC Med Inform Decis Mak*. 19 (1) (2019 Sep 18) 187.
- [178] Kariotis T, Prictor M, Chang S, Gray K. Evaluating the Contextual Integrity of Australia's My Health Record.
- [179] B.D. Reuland, C.T. Redman, J.Z. Kneifati-Hayek, Y. Fernandes, R. Kosber, C. Ortuno-Garcia, et al., Observation and Patients' Perceptions of Incorporating Their Photograph Into the Electronic Health Record, *J Patient Saf*. 18 (5) (2022 Aug) 377–381.
- [180] I. Voigt, M. Benedict, M. Susky, T. Scheplitz, S. Frankowitz, R. Kern, et al., A Digital Patient Portal for Patients With Multiple Sclerosis, *Front Neurol*. 22 (11) (2020 May) 400.
- [181] A. Dhamija, J.A. Moskovitz, J. Bick, T.J. O'Connor, J. Regan, L.A. Perry, et al., Image-Enabling the Patient Portal of an Electronic Health Record, *J Digit Imaging*. 34 (2) (2021 Apr) 483–488.
- [182] A. Bärkås, M. Häggglund, J. Moll, Å. Cajander, H. Rexhepi, I. Hörhammer, et al., Patients' Access to Their Psychiatric Records - A Comparison of Four Countries, *Stud Health Technol Inform*. 25 (294) (2022 May) 510–514.
- [183] C. Blease, C.M. DesRoches, Open notes in patient care: confining deceptive placebos to the past? *J Med Ethics*. 48 (8) (2022 Aug) 572–574.
- [184] S. Seiedfarajollah, R. Safdari, M. Ghazisaedi, L. Keikha, Key security and privacy issues from implementing the National Electronic Health Record in the Islamic Republic of Iran, *East Mediterr Health J*. 25 (09) (2019 Sep 1) 656–659.
- [185] S.J. Javier, L.K. Trozak, S.L. Shimada, D.K. McInnes, M.E. Ohl, T. Avoundjian, et al., Racial and ethnic disparities in use of a personal health record by veterans living with HIV, *J Am Med Inform Assoc*. 26 (8–9) (2019 Aug 1) 696–702.
- [186] Marcilly R, Schiro J, Heyndels L, Guerlinger S, Pigot A, Pelayo S. Competitive Usability Evaluation of Electronic Health Records: Preliminary Results of a Case Study. In: Mantas J, Stoicu-Tivadar L, Chronaki C, Hasman A, Weber P, Gallos P, et al., editors. *Studies in Health Technology and Informatics* [Internet]. IOS Press; 2021 [cited 2023 Aug 4]. Available from: <https://ebooks.iospress.nl/doi/10.3233/SHTI210296>.
- [187] S. Khan, M.W. Lewis-Thames, Y. Han, L. Fuzzell, M.E. Langston, J.X. Moore, A Comparative Analysis of Online Medical Record Utilization and Perception by Cancer Survivorship, *Med Care*. 58 (12) (2020 Dec) 1075–1081.
- [188] T.D. Giardina, D.T. Choi, D.K. Upadhyay, S. Korukonda, T.M. Scott, C. Spitzmueller, et al., Inviting patients to identify diagnostic concerns through structured evaluation of their online visit notes, *J Am Med Inform Assoc*. 29 (6) (2022 Jun 1) 1091–1100.
- [189] M. Al-Zubaidie, Z. Zhang, J. Zhang, PAX: Using Pseudonymization and Anonymization to Protect Patients' Identities and Data in the Healthcare System, *Int J Environ Res Public Health*. 16 (9) (2019 Apr 27) 1490.
- [190] Sahama T, Stranieri A, Butler-Henderson K. Patient-Empowered Electronic Health Records.
- [191] H. Onyeaka, K.V. Ajayi, C. Muoghalu, P.O. Eseaton, C.O. Azuikwe, G. Anugwom, et al., Access to online patient portals among individuals with depression and anxiety, *Psychiatry Res Commun*. 2 (4) (2022 Dec 1) 100073.
- [192] M. Farzandipour, E. Nabovati, A. Farrokhan, H. Akbari, F. Rezaei Hasanvand, R. Sharif, Designing and usability assessing an electronic personal health record for patients with chronic heart failure in a developing country, *Inform Med Unlocked*. 27 (2021) 100804.
- [193] M. Hertzum, G. Ellingsen, Å. Cajander, Implementing Large-Scale Electronic Health Records: Experiences from Implementations of Epic in Denmark and Finland, *Int J Med Inf*. 1 (167) (2022 Sep) 104868.
- [194] M. Fitzsimons, K. Power, Z. McCrean, R. Kiersey, M. White, B. Dunleavy, et al., Democratizing epilepsy care: Utility and usability of an electronic patient portal, *Epilepsy Behav*. 122 (2021 Sep) 108197.
- [195] L. Walsh, B. Hemsley, M. Allan, M.R. Dahm, S. Balandin, A. Georgiou, et al., Assessing the information quality and usability of *My Health Record* within a health literacy framework: What's changed since 2016? *Health Inf Manag J*. 50 (1–2) (2021 Jan) 13–25.
- [196] M. Glöggler, E. Ammenwerth, Development and Validation of a Useful Taxonomy of Patient Portals Based on Characteristics of Patient Engagement, *Methods Inf Med*. 60 (Suppl 1) (2021 Jun) e44–e55.
- [197] K.O. Schnock, J.E. Snyder, T.E. Fuller, M. Duckworth, M. Grant, C. Yoon, et al., Acute Care Patient Portal Intervention: Portal Use and Patient Activation, *J Med Internet Res*. 21 (7) (2019 Jul 18) e133336.
- [198] L. Agrawal, T. Ndabu, P. Mulgund, R. Sharman, Factors Affecting the Extent of Patients' Electronic Medical Record Use: An Empirical Study Focusing on System and Patient Characteristics, *J Med Internet Res*. 23 (10) (2021 Oct 28) e30637.
- [199] J. Sun, L. Ren, S. Wang, X. Yao, A blockchain-based framework for electronic medical records sharing with fine-grained access control, *Debiao h, Editor. PLOS ONE*. (2020). Oct 6;15(10):e239946.
- [200] Chenthara S, Ahmed K, Wang H, Whittaker F, Chen Z. Healthchain: A novel framework on privacy preservation of electronic health records using blockchain technology. Huang X, editor. *PLOS ONE*. 2020 Dec 9;15(12):e0243043.
- [201] D.R. Friedman, V. Patil, C. Li, K.M. Rassmussen, S. Burningham, S. Hamilton-Hill, et al., Integration of Patient-Reported Outcome Measures in the Electronic Health Record: The Veterans Affairs Experience, *JCO Clin Cancer Inform*. 6 (2022 May) e2100086.
- [202] M. Rosenlund, E. Kivekäs, S. Mikkonen, S. Arvonen, J. Reponen, K. Saranto, Health Professionals' Perceptions of Information Quality in the Health Village Portal, *Stud Health Technol Inform*. 4 (262) (2019 Jul) 300–303.
- [203] R.B. Sangal, E. Powers, C. Rothenberg, C. Ndumele, A. Ulrich, A. Hsiao, et al., Disparities in Accessing and Reading Open Notes in the Emergency Department Upon Implementation of the 21st Century CURES Act, *Ann Emerg Med*. 78 (5) (2021 Nov) 593–598.
- [204] S. Jiang, P.L. Liu, C.W.J. Chia, Can Online Patient-Provider Communication Improve Emotional Well-Being? Examining the Roles of Social Presence and Patient Empowerment, *Cyberpsychology Behav Soc Netw*. 26 (5) (2023 May 1) 366–370.
- [205] Vink S, Fareed N, MacEwan SR, Scheck A. An Exploration of the Association between Inpatient Access to Tablets and Patient Satisfaction with Hospital Care. 2019;.
- [206] S. AlSuwaidi, I.A. Moonesar, UAE Resident Users' Perceptions of Healthcare Applications from Dubai Health Authority: Preliminary Insights, *Dubai Med J*. 4 (1) (2021 Mar 15) 10–17.
- [207] S. Belfrage, G. Helgesson, N. Lynøe, Trust and digital privacy in healthcare: a cross-sectional descriptive study of trust and attitudes towards uses of electronic health data among the general public in Sweden, *BMC Med Ethics*. 23 (1) (2022 Mar 4) 19.
- [208] G.N. Honein-AbouHaidar, J. Antoun, K. Badr, S. Hlais, H. Nazaretian, Users' acceptance of electronic patient portals in Lebanon, *BMC Med Inform Decis Mak*. 20 (1) (2020 Dec) 31.
- [209] E. Cherif, M. Mzoughi, Electronic health record adopters: a typology based on patients' privacy concerns and perceived benefits, *Public Health* 207 (2022 Jun) 46–53.
- [210] R. Dobson, R. Whittaker, H. Wihongi, P. Andrew, D. Armstrong, K. Bartholomew, et al., Patient perspectives on the use of health information, *N Z Med J*. 134 (1547) (2021 Dec 17) 48–62.
- [211] S. Bar-Lev, D. Beimel, Numbers, graphs and words – do we really understand the lab test results accessible via the patient portals? *Isr J Health Policy Res*. 9 (1) (2020 Oct 28) 58.

- [212] F.M. Al-Anezi, Evaluating the Readiness of Mobile Technology with Respect to e-Health for Medication in Saudi Arabia: An Integrative Perspective, *J Multidiscip Healthc.* 14 (2021) 59–66.
- [213] B. Bruno, S. Steele, J. Carbone, K. Schneider, L. Posk, S.L. Rose, Informed or anxious: patient preferences for release of test results of increasing sensitivity on electronic patient portals, *Health Technol.* 12 (1) (2022) 59–67.
- [214] Y.H. Yan, C.W. Yang, S.C. Fang, Patient-centered e-health supports value cocreation and quality of medical care in Taiwan, *Health Inf Libr J.* 39 (1) (2022 Mar) 68–78.
- [215] C. Sarabu, T. Lee, A. Hogan, N. Pageler, The Value of OpenNotes for Pediatric Patients, Their Families and Impact on the Patient-Physician Relationship, *Appl Clin Inform.* 12 (1) (2021 Jan) 76–81.
- [216] H. Son, E.S. Nahm, S. Zhu, E. Galik, K.L. Seidl, B. Van de Castle, et al., Testing a Model of Patient Portal Use in Adult Patients, *J Nurs Scholarsh off Publ Sigma Theta Tau Int Honor Soc Nurs.* 53 (2) (2021 Mar) 143–153.
- [217] E. Seltzer, J. Goldshear, S.C. Guntuku, D. Grande, D.A. Asch, E.V. Klingler, et al., Patients' willingness to share digital health and non-health data for research: a cross-sectional study, *BMC Med Inform Decis Mak.* 19 (1) (2019 Aug 8) 157.
- [218] L. Van Velsen, I. Flierman, M. Tabak, The formation of patient trust and its transference to online health services: the case of a Dutch online patient portal for rehabilitation care, *BMC Med Inform Decis Mak.* 21 (1) (2021 Dec) 188.
- [219] C.L. Turvey, L.A. Fuhrmeister, D.M. Klein, J. Moeckli, M.B. Howren, E.E. Chasco, Patient and Provider Experience of Electronic Patient Portals and Secure Messaging in Mental Health Treatment, *Telemed J E-Health off J Am Telemed Assoc.* 28 (2) (2022 Feb) 189–198.
- [220] T.M. Klein, M. Augustin, M. Otten, How should electronic health records be designed? A cross-sectional study in patients with psoriasis, *BMC Med Inform Decis Mak.* 19 (1) (2019 Dec) 218.
- [221] H. Wang, A.F. Ho, R.C. Wiener, U. Sambamoorthi, The Association of Mobile Health Applications with Self-Management Behaviors among Adults with Chronic Conditions in the United States, *Int J Environ Res Public Health.* 18 (19) (2021 Sep 30) 10351.
- [222] J.I.S. Wong, B.D. Steitz, S.T. Rosenbloom, Characterizing the impact of health literacy, computer ability, patient demographics, and portal usage on patient satisfaction with a patient portal, *JAMIA Open.* 2 (4) (2019 Dec 1) 456–464.
- [223] M. Abdekhdha, A. Dehnad, H. Khezri, The effect of confidentiality and privacy concerns on adoption of personal health record from patient's perspective, *Health Technol.* 9 (4) (2019 Aug) 463–469.
- [224] Iott BE, Campos-Castillo C, Anthony DL. Trust and Privacy: How Patient Trust in Providers is Related to Privacy Behaviors and Attitudes.
- [225] C.M. Swoboda, M.J. DePuccio, N. Fareed, A.S. McAlearney, D.M. Walker, Patient Portals: Useful for Whom and for What? A Cross-Sectional Analysis of National Survey Data, *Appl Clin Inform.* 12 (3) (2021 May) 573–581.
- [226] Y. Jung, H. Choi, H. Shim, Individual Willingness to Share Personal Health Information with Secondary Information Users in South Korea, *Health Commun.* 35 (6) (2020 May 11) 659–666.
- [227] M. Eberts, D. Capurro, Patient and Physician Perceptions of the Impact of Electronic Health Records on the Patient-Physician Relationship, *Appl Clin Inform.* 10 (04) (2019 Aug) 729–734.
- [228] D.J. Van Der Nat, V.J.B. Huiskes, M. Taks, B.P.H. Pouls, B.J.F. Van Den Bemt, H.A. W. Van Onzenoort, Usability and perceived usefulness of patient-centered medication reconciliation using a personalized health record: a multicenter cross-sectional study, *BMC Health Serv Res.* 22 (1) (2022 Dec) 776.
- [229] C. Henderson, Z.P. Nahmias, A. Fossa, E. Barnes, S. Huang, Analysis of patient preferences on patient-provider interactions through the OpenNotes online portal in dermatology, *Int J Womens Dermatol.* 7 (5) (2021 Dec) 793–798.
- [230] C. Latulipe, S.F. Mazumder, R.K.W. Wilson, J.W. Talton, A.G. Bertoni, S. A. Quandt, et al., Security and Privacy Risks Associated With Adult Patient Portal Accounts in US Hospitals, *JAMA Intern Med.* 180 (6) (2020 Jun 1) 845.
- [231] M.A. Clarke, E.R. Lyden, J. Ma, K.M. King, M. Siahpush, T. Michaud, et al., Sociodemographic Differences and Factors Affecting Patient Portal Utilization, *J Racial Ethn Health Disparities.* 8 (4) (2021 Aug) 879–891.
- [232] Griffin AC, Chung AE. Health Tracking and Information Sharing in the Patient-Centered Era: A Health Information National Trends Survey (HINTS) Study.
- [233] E. Tashkandi, M. BaAbdullah, A. Zeeneldin, A. AlAbdulwahab, O. Elemam, S. Elsamany, et al., Optimizing the Communication with Cancer Patients During the COVID-19 Pandemic: Patient Perspectives, *Patient Prefer Adherence.* 14 (2020 Jul) 1205–1212.
- [234] A. Alsyouf, A. Lutfi, N. Alsubahi, F.N. Alhazmi, K. Al-Mugheed, R.J. Anshasi, et al., The Use of a Technology Acceptance Model (TAM) to Predict Patients' Usage of a Personal Health Record System: The Role of Security, Privacy, and Usability, *Int J Environ Res Public Health.* 20 (2) (2023 Jan 11) 1347.
- [235] H. Rexhepi, J. Moll, I. Huvila, Online electronic healthcare records: Comparing the views of cancer patients and others, *Health Informatics J.* 26 (4) (2020 Dec) 2915–2929.
- [236] C.M. DesRoches, L. Salmi, Z. Dong, C. Blease, How do older patients with chronic conditions view reading open visit notes? *J Am Geriatr Soc.* 69 (12) (2021 Dec) 3497–3506.
- [237] N. Ploner, M.F. Neurath, M. Schoenthaler, A. Zielke, H.U. Prokosch, Concept to gain trust for a German personal health record system using public cloud and FHIR, *J Biomed Inform.* 95 (2019 Jul) 103212.
- [238] E. Cherif, N. Bezaz, M. Mzoughi, Do personal health concerns and trust in healthcare providers mitigate privacy concerns? Effects on patients' intention to share personal health data on electronic health records, *Soc Sci Med.* 283 (2021 Aug) 114146.
- [239] T. Moerenhout, I. Devisch, L. Cooreman, J. Bernaerd, A. De Sutter, V. Provoost, Patients' moral attitudes toward electronic health records: Survey study with vignettes and statements, *Health Informatics J.* 27 (1) (2021 Jan) 146045822098003.
- [240] Rexhepi H, Moll J, Huvila I, Ahlfeldt RM. Do you want to receive bad news through your patient accessible electronic health record? A national survey on receiving bad news in an era of digital health. *Health Informatics J.*
- [241] C.C. Yousef, T.M. Salgado, K. Burnett, I. Aldossary, L.E. McClelland, H. S. Alhamdan, et al., Perceived barriers and enablers of a personal health record from the healthcare provider perspective, *Health Informatics J.* 29 (1) (2023) 14604582231152190.
- [242] O.E. Asagbra, A. Burch, F.L. Chivela, The association between information technology sophistication and patient portal use: A cross sectional study in Eastern North Carolina, *Health Informatics J.* 29 (1) (2023) 14604582231154478.
- [243] S.K. Bell, P. Folcarelli, A. Fossa, M. Gerard, M. Harper, S. Leveille, et al., Tackling Ambulatory Safety Risks Through Patient Engagement: What 10,000 Patients and Families Say About Safety-Related Knowledge, Behaviors, and Attitudes After Reading Visit Notes, *J Patient Saf.* 17 (8) (2021 Dec 1) e791–e799.
- [244] J. Wang, J. Huang, C.S.K. Cheung, W.N. Wong, N.T. Cheung, M.C. Wong, Adoption of an Electronic Patient Record Sharing Pilot Project: Cross-Sectional Survey, *J Med Internet Res.* 22 (4) (2020 Apr 6) e13761.
- [245] K.M.P. Jackman, J. Kane, H. Kharrazi, R.M. Johnson, C. Latkin, Using the Patient Portal Sexual Health Instrument in Surveys and Patient Questionnaires Among Sexual Minority Men in the United States: Cross-sectional Psychometric Validation Study, *J Med Internet Res.* 23 (2) (2021 Feb 10) e18750.
- [246] K. Turner, A. Clary, Y.R. Hong, A. Alishahi Tabrizi, C.M. Shea, Patient Portal Barriers and Group Differences: Cross-Sectional National Survey Study, *J Med Internet Res.* 22 (9) (2020 Sep 17) e18870.
- [247] A.L. Neves, K.R. Smalley, L. Freise, P. Harrison, A. Darzi, E.K. Mayer, Determinants of Use of the Care Information Exchange Portal: Cross-sectional Study, *J Med Internet Res.* 23 (11) (2021 Nov 11) e23481.
- [248] H. Clarke, S. Clark, M. Birkin, H. Iles-Smith, A. Glaser, M.A. Morris, Understanding Barriers to Novel Data Linkages: Topic Modeling of the Results of the LifeInfo Survey, *J Med Internet Res.* 23 (5) (2021 May 17) e24236.
- [249] S. Elkefi, Z. Yu, O. Asan, Online Medical Record Nonuse Among Patients: Data Analysis Study of the 2019 Health Information National Trends Survey, *J Med Internet Res.* 23 (2) (2021 Feb 22) e24767.
- [250] M. Sääskilähti, R. Ahonen, J. Timonen, Pharmacy Customers' Experiences of Use, Usability, and Satisfaction of a Nationwide Patient Portal: Survey Study, *J Med Internet Res.* 23 (7) (2021 Jul 16) e25368.
- [251] V. Gupta, M. Raj, F. Hoodin, L. Yahng, T. Braun, S.W. Choi, Electronic Health Record Portal Use by Family Caregivers of Patients Undergoing Hematopoietic Cell Transplantation: United States National Survey Study, *JMIR Cancer.* 7 (1) (2021 Mar 9) e26509.
- [252] J. Rolnick, R. Ward, G. Tait, N. Patel, Early Adopters of Apple Health Records at a Large Academic Medical Center: Cross-sectional Survey of Users, *J Med Internet Res.* 24 (1) (2022 Jan 25) e29367.
- [253] S. Kujala, I. Hörhammer, A. Väyrynen, M. Holmroos, M. Nättiäho-Rönnholm, M. Häggglund, et al., Patients' Experiences of Web-Based Access to Electronic Health Records in Finland: Cross-sectional Survey, *J Med Internet Res.* 24 (6) (2022 Jun 6) e37438.
- [254] R. Lear, L. Freise, M. Kybert, A. Darzi, A.L. Neves, E.K. Mayer, Perceptions of Quality of Care Among Users of a Web-Based Patient Portal: Cross-sectional Survey Analysis, *J Med Internet Res.* 24 (11) (2022 Nov 17) e39973.
- [255] J. Huang, W.S. Pang, Y.Y. Wong, F.Y. Mak, F.S.W. Chan, C.S.K. Cheung, et al., Factors Associated With the Acceptance of an eHealth App for Electronic Health Record Sharing System: Population-Based Study, *J Med Internet Res.* 24 (12) (2022 Dec 12) e40370.
- [256] J. Kim, H. Kim, E. Bell, T. Bath, P. Paul, A. Pham, et al., Patient Perspectives About Decisions to Share Medical Data and Biospecimens for Research, *JAMA Netw Open.* 2 (8) (2019 Aug 21) e199550.
- [257] D.C. Classen, A.J. Holmgren, Z. Co, L.P.S. Newmark, D. Seger, M. Danforth, et al., National Trends in the Safety Performance of Electronic Health Record Systems From 2009 to 2018, *JAMA Netw Open.* 3 (5) (2020 May 29) e205547.
- [258] M. Khatatbeh, L.F. Gharaibeh, O.F. Khabour, R.K. Abu-Farha, K.H. Alzoubi, Jordanian views regarding sharing of medical data for research: A cross-sectional study during COVID-19 pandemic, *Yon DK, Editor. PLOS ONE.* (2022). Mar 21;17 (3):e0265695.
- [259] T.A.W. Holderried, K. Hecker, L. Reh, M. Kirschner, J. Walter, P. Brossart, et al., The potential of eHealth for cancer patients—does COVID-19 pandemic change the attitude towards use of telemedicine services? Zou D, editor, *PLoS One* 18 (2) (2023 Feb 10) e0280723.
- [260] R.L. Goldstein, A. Anoshiravani, M.V. Svetaz, J.L. Carlson, Providers' Perspectives on Adolescent Confidentiality and the Electronic Health Record: A State of Transition, *J Adolesc Health off Publ Soc Adolesc Med.* 66 (3) (2020 Mar) 296–300.
- [261] A.T. Langford, K. Orellana, N. Buderer, Use of Online Medical Records to Support Medical Decision Making: A Cross-Sectional Study of US Adults, *J Health Commun.* 26 (9) (2021 Sep 2) 618–625.
- [262] Moll J, Rexhepi H. The Effect of Patient Accessible Electronic Health Records on Communication and Involvement in Care - A National Patient Survey in Sweden.
- [263] D. Zoorob, Y. Hasbini, K. Chen, V. Wangia-Anderson, H. Moussa, B. Miller, et al., Ageism in healthcare technology: the older patients' aspirations for improved online accessibility, *JAMIA Open.* (2022). Oct 1;5(3):oao061.

- [264] V.K. Mishra, R.E. Hoyt, S.E. Wolver, A. Yoshihashi, C. Banas, Qualitative and Quantitative Analysis of Patients' Perceptions of the Patient Portal Experience with OpenNotes, *Appl Clin Inform.* 10 (1) (2019 Jan) 10–18.
- [265] S. Tosoni, I. Voruganti, K. Lajkosz, S. Mustafa, A. Phillips, S.J. Kim, et al., Patient consent preferences on sharing personal health information during the COVID-19 pandemic: "the more informed we are, the more likely we are to help", *BMC Med Ethics.* 23 (1) (2022 May 20) 53.
- [266] E. Agapie, L. Kendall, S.R. Mishra, S. Haldar, M. Khelifi, A. Pollack, et al., Using Priorities of Hospitalized Patients and Their Caregivers to Develop Personas, *AMIA Annu Symp Proc.* 4 (2019) (2020 Mar) 200–209.
- [267] M.A. Clarke, R.M. Schuetzler, J.R. Windle, E. Pachunka, A. Fruhling, Usability and cognitive load in the design of a personal health record, *Health Policy Technol.* 9 (2) (2020 Jun 1) 218–224.
- [268] F. Sieverink, S. Kelders, A. Braakman-Jansen, J. Van Gemert-Pijnen, Evaluating the implementation of a personal health record for chronic primary and secondary care: a mixed methods approach, *BMC Med Inform Decis Mak.* 19 (1) (2019 Dec) 241.
- [269] K. Leung, C. Clark, M. Sakal, M. Friesen, G. Strudwick, Patient and Family Member Readiness, Needs, and Perceptions of a Mental Health Patient Portal: A Mixed Methods Study, *Stud Health Technol Inform.* 257 (2019) 266–270.
- [270] S.E. Spratt, D. Ravneberg, B. Derstine, B.B. Granger, Feasibility of Electronic Health Record Integration of a SMART Application to Facilitate Patient-Provider Communication for Medication Management, *Comput Inform Nurs CIN.* 40 (8) (2022 Aug 1) 538–546.
- [271] B.D. Lam, F. Bourgeois, Z.J. Dong, S.K. Bell, Speaking up about patient-perceived serious visit note errors: Patient and family experiences and recommendations, *J Am Med Inform Assoc.* 28 (4) (2021 Mar 18) 685–694.
- [272] M. De Regge, E. Van Caelenberg, N. Van Belle, K. Eeckloo, M. Coppens, Encouraging Digital Patient Portal Use in Ambulatory Surgery: A Mixed Method Research of Patients and Health Care Professionals Experiences and Perceptions, *J PeriAnesthesia Nurs off J Am Soc PeriAnesthesia Nurses.* 37 (5) (2022 Oct) 691–698.
- [273] J.W. Dexheimer, M.V. Greiner, S.J. Beal, D. Johnson, A. Kachelmeyer, L. M. Vaughn, Sharing personal health record data elements in protective custody: youth and stakeholder perspectives, *J Am Med Inform Assoc.* 26 (8–9) (2019 Aug 1) 714–721.
- [274] S.K. Bell, F. Bourgeois, J. Dong, A. Gillespie, L.H. Ngo, T.W. Reader, et al., Patient Identification of Diagnostic Safety Blindspots and Participation in "Good Catches" Through Shared Visit Notes, *Milbank Q.* 100 (4) (2022 Dec) 1121–1165.
- [275] Soni H, Grando A, Aliste MP, Murcko A, Todd M, Mukundan M, et al. Perceptions and Preferences About Granular Data Sharing and Privacy of Behavioral Health Patients.
- [276] L. Nurgalieva, Å. Cajander, J. Moll, R.M. Ahlfeldt, I. Huvila, M. Marchese, 'I do not share it with others. No, it's for me, it's my care': On sharing of patient accessible electronic health records, *Health Informatics J.* 26 (4) (2020 Dec) 2554–2567.
- [277] R. Henkenjohann, Role of Individual Motivations and Privacy Concerns in the Adoption of German Electronic Patient Record Apps—A Mixed-Methods Study, *Int J Environ Res Public Health.* 18 (18) (2021 Sep 10) 9553.
- [278] H. Soni, A. Grando, A. Murcko, S. Diaz, M. Mukundan, N. Idouraine, et al., State of the art and a mixed-method personalized approach to assess patient perceptions on medical record sharing and sensitivity, *J Biomed Inform.* 101 (2020 Jan) 103338.
- [279] G. Karway, J. Ivanova, T. Kaing, M. Todd, D. Chern, A. Murcko, et al., My Data Choices: Pilot evaluation of patient-controlled medical record sharing technology, *Health Informatics J.* 28 (4) (2022 Oct) 146045822211438.
- [280] C. Baum, M. Vogens, M.K. Nielsen, P.F. Højlund-Carlsen, M.G. Hildebrandt, Perspective of Patients with Metastatic Breast Cancer on Electronic Access to Scan Results: Mixed-Methods Study, *J Med Internet Res.* 22 (2) (2020 Feb 10) e15723.
- [281] M.T. Crafoord, M. Fjell, K. Sundberg, M. Nilsson, A. Langius-Eklöf, Engagement in an Interactive App for Symptom Self-Management during Treatment in Patients With Breast or Prostate Cancer: Mixed Methods Study, *J Med Internet Res.* 22 (8) (2020 Aug 10) e17058.
- [282] Z. Zhang, D. Citardi, A. Xing, X. Luo, Y. Lu, Z. He, Patient Challenges and Needs in Comprehending Laboratory Test Results: Mixed Methods Study, *J Med Internet Res.* 22 (12) (2020 Dec 7) e18725.
- [283] R.A. Cochran, S.S. Feldman, N.V. Ivankova, A.G. Hall, W. Opoku-Agyeman, Intention to Use Behavioral Health Data From a Health Information Exchange: Mixed Methods Study, *JMIR Ment Health.* 8 (5) (2021 May 27) e26746.
- [284] S.L. Janssen, N. Venema-Taata, S. Medlock, Anticipated Benefits and Concerns of Sharing Hospital Outpatient Visit Notes With Patients (Open Notes) in Dutch Hospitals: Mixed Methods Study, *J Med Internet Res.* 23 (8) (2021 Aug 11) e27764.
- [285] J. Walker, S. Leveille, G. Kriegl, C.T. Lin, S.K. Liu, T.H. Payne, et al., Patients Contributing to Visit Notes: Mixed Methods Evaluation of OurNotes, *J Med Internet Res.* 23 (11) (2021 Nov 8) e29951.
- [286] J. Baek, B. Simon-Friedt, A. Lopez, J.M. Kolman, J. Nicolas, S.L. Jones, et al., Assessing Patient Needs During Natural Disasters: Mixed Methods Analysis of Portal Messages Sent During Hurricane Harvey, *J Med Internet Res.* 23 (9) (2021 Sep 1) e31264.
- [287] R. Lear, L. Freise, M. Kybert, A. Darzi, A.L. Neves, E.K. Mayer, Patients' Willingness and Ability to Identify and Respond to Errors in Their Personal Health Records: Mixed Methods Analysis of Cross-sectional Survey Data, *J Med Internet Res.* 24 (7) (2022 Jul 8) e37226.
- [288] S.K. Bell, T. Delbanco, J.G. Elmore, P.S. Fitzgerald, A. Fossa, K. Harcourt, et al., Frequency and Types of Patient-Reported Errors in Electronic Health Record Ambulatory Care Notes, *JAMA Netw Open.* 3 (6) (2020 Jun 1) e205867.
- [289] G. Coorey, D. Peiris, T. Usherwood, L. Neubeck, J. Mulley, J. Redfern, Persuasive design features within a consumer-focused eHealth intervention integrated with the electronic health record: A mixed methods study of effectiveness and acceptability, *MacLure k, Editor. PLOS ONE.* (2019). Jun 20;14(6):e0218447.
- [290] Hulter P, Langendoen W, Pluut B, Schoonman GG, Luijten R, Van Wetten F, et al. Patients' choices regarding online access to laboratory, radiology and pathology test results on a hospital patient portal. Rubinelli S, editor. *PLOS ONE.* 2023 Feb 3;18(2):e0280768.
- [291] Griffin AC, Xing Z, Mikles SP, Bailey S, Khairat S, Arguello J, et al. Information needs and perceptions of chatbots for hypertension medication self-management: a mixed methods study. *JAMIA Open.* 2021 Apr 19;4(2):oab021.
- [292] K. Absolom, A. Gibson, G. Velikova, Engaging Patients and Clinicians in Online Reporting of Adverse Effects During Chemotherapy for Cancer: The eRAPID System (Electronic Patient Self-Reporting of Adverse Events: Patient Information and Advice), *Med Care.* 57 (Suppl 1) (2019 May) S59–S65.
- [293] K.T. Fuji, A.A. Abbott, K.A. Galt, A MIXED-METHODS EVALUATION OF STANDALONE PERSONAL HEALTH RECORD USE BY PATIENTS WITH TYPE 2 DIABETES, *Perspect Health Inf Manag.* 18 (4) (2021) 1e.
- [294] M. Soto, C. Sicotte, A. Motulsky, Using Health Information Exchange: Usability and Usefulness Evaluation, *Stud Health Technol Inform.* 21 (264) (2019 Aug) 1036–1040.
- [295] A. Shannahan, A. Shah, K. Wright, D.S. Clements, Physician Monitoring of FitBit Use for Patient Health, *Glob Adv Health Med.* 10 (2021 Jan) 216495612110189.
- [296] H. Son, E.S. Nahm, Older Adults' Experience Using Patient Portals in Communities: Challenges and Opportunities, *CIN Comput Inform Nurs.* 37 (1) (2019 Jan) 4–10.
- [297] L. Grossman, R. Masterson Creber, J. Ancker, B. Ryan, F. Polubriaginof, M. Qian, et al., Technology Access, Technical Assistance, and Disparities in Inpatient Portal Use, *Appl Clin Inform.* 10 (01) (2019 Jan) 040–050.
- [298] C.R. Lyles, L. Tieu, U. Sarkar, S. Kiyoi, S. Sadasivaiah, M. Hoskote, et al., A Randomized Trial to Train Vulnerable Primary Care Patients to Use a Patient Portal, *J Am Board Fam Med.* 32 (2) (2019 Mar) 248–258.
- [299] E.S. Nahm, S. Zhu, M. Bellantoni, L. Keldsen, K. Charters, V. Russomanno, et al., Patient Portal Use Among Older Adults: What Is Really Happening Nationwide? *J Appl Gerontol.* 39 (4) (2020 Apr) 442–450.
- [300] M.J. DePuccio, G. Di Tosto, D.M. Walker, A.S. McAlearney, Patients' Perceptions About Medical Record Privacy and Security: Implications for Withholding of Information During the COVID-19 Pandemic, *J Gen Intern Med.* 35 (10) (2020 Oct) 3122–3125.
- [301] M. Hägglund, C. Blease, I. Scandurra, Mobile Access and Adoption of the Swedish National Patient Portal, *Stud Health Technol Inform.* 23 (275) (2020 Nov) 82–86.
- [302] R. Tsai, E.J. Bell, H. Woo, K. Baldwin, M.A. Pfeffer, How Patients Use a Patient Portal: An Institutional Case Study of Demographics and Usage Patterns, *Appl Clin Inform.* 10 (1) (2019 Jan) 96–102.
- [303] I.A. Khan, J.A. Magnuson, K.A. Ciesielka, E.A. Levicoff, A. Cohen-Rosenblum, C. A. Krueger, et al., Patients From Distressed Communities Who Undergo Surgery for Hip Fragility Fractures Are Less Likely to Have Advanced Care Planning Documents in Their Electronic Medical Record, *Clin Orthop.* 481 (2) (2023 Feb) 312–321.
- [304] H.H. Choi, A.L. Kotsenas, J.V. Chen, C. Bronsky, C.J. Roth, M.D. Kohli, Multi-institutional Experience with Patient Image Access Through Electronic Health Record Patient Portals, *J Digit Imaging.* 35 (2) (2022 Apr) 320–326.
- [305] C.R. Parsons, J.D. Hron, F.C. Bourgeois, Preserving privacy for pediatric patients and families: use of confidential note types in pediatric ambulatory care, *J Am Med Inform Assoc.* 27 (11) (2020 Nov 1) 1705–1710.
- [306] C.P. Subbe, N. Pearson, S. Wischhusen, R. Hibbs, S. Wright, M. Xenou, Scenario-based design for a hospital setting: An exploratory study of opportunities and barriers for personal health records usage, *Future Healthc J.* 7 (2) (2020 Jun) 125–130.
- [307] S. Bonacina, S. Koch, I. Meneses, C. Chronaki, Can the European EHR Exchange Format Support Shared Decision Making and Citizen-Driven Health Science? in: J. Mantas, L. Stoicu-Tivadar, C. Chronaki, A. Hasman, P. Weber, P. Gallos (Eds.), *Studies in Health Technology and Informatics [internet]* IOS Press, 2021 [cited 2023 Aug 4]. Available from:.
- [308] B. Ncube, M. Mars, R.E. Scott, Perceptions and attitudes of patients and healthcare workers towards the use of telemedicine in Botswana: An exploratory study, *PLoS One* 18 (2) (2023) e0281754.
- [309] M. Rahimian, J.L. Warner, L. Salmi, S.T. Rosenbloom, R.B. Davis, R.M. Joyce, Open notes sounds great, but will a provider's documentation change? An exploratory study of the effect of open notes on oncology documentation, *JAMIA Open.* 4(3):oab051 (2021 Jul).
- [310] N.A. Schapiro, L.K. Mihaly, The 21st Century Cures Act and Challenges to Adolescent Confidentiality, *J Pediatr Health Care.* 35 (4) (2021 Jul) 439–442.
- [311] Webber EC, Brick D, Scibilia JP, Dehnel P, COUNCIL ON CLINICAL INFORMATION TECHNOLOGY, COMMITTEE ON MEDICAL LIABILITY AND RISK MANAGEMENT, et al. Electronic Communication of the Health Record and Information With Pediatric Patients and Their Guardians. *Pediatrics.* 2019 Jul 1; 144(1):e20191359.
- [312] S. Upadhyay, W. Opoku-Agyeman, S. Choi, R.A. Cochran, Do Patient Engagement IT Functionalities Influence Patient Safety Outcomes? A Study of US Hospitals, *J Public Health Manag Pract JHPMP.* 28 (5) (2022 Oct 1) 505–512.

- [313] W. Martinez, A.J. Hackstadt, G.B. Hickson, T. Knoerl, S.T. Rosenbloom, K. A. Wallston, et al., The My Diabetes Care Patient Portal Intervention: Usability and Pre-Post Assessment, *Appl Clin Inform.* 12 (03) (2021 May) 539–550.
- [314] E. Andrikopoulou, P. Scott, Personal Health Records an Approach to Answer: What Works for Whom in What Circumstances? in: B. Séroussi, P. Weber, F. Dhombres, C. Grouin, J.D. Liebe, S. Pelayo (Eds.), *Studies in Health Technology and Informatics* [internet] IOS Press, 2022 [cited 2023 Aug 4]. Available from: <https://www.pulsetoday.co.uk/news/technology/practices-told-to-offer-automatic-patient-records-access-by-end-of-october/>.
- [315] O. Enaizan, B. Eneizan, M. Almaaitah, A.T. Al-Radaideh, A.M. Saleh, Effects of privacy and security on the acceptance and usage of EMR: The mediating role of trust on the basis of multiple perspectives, *Inform Med Unlocked.* 21 (2020) 100450.
- [316] R. Jenkins, Practices told to offer automatic patient records access by end of October [Internet], Available from: Pulse Today. (2023 [cited 2023 Oct 17].) <https://www.pulsetoday.co.uk/news/technology/practices-told-to-offer-automatic-patient-records-access-by-end-of-october/>.
- [317] C. Blease, Sharing online clinical notes with patients: implications for nocebo effects and health equity, *J Med Ethics.* 49 (1) (2023 Jan) 14–21.
- [318] R. van Kessel, B.L.H. Wong, T. Clemens, H. Brand, Digital health literacy as a super determinant of health: More than simply the sum of its parts, *Internet Interv.* 1 (27) (2022 Mar) 100500.
- [319] F. Mold, S. de Lusignan, A. Sheikh, A. Majeed, J.C. Wyatt, T. Quinn, et al., Patients' online access to their electronic health records and linked online services: a systematic review in primary care, *Br J Gen Pract.* 65 (632) (2015 Mar 1) e141–e151.
- [320] J. Cantor, R.K. McBain, A. Kofner, R. Hanson, B.D. Stein, H. Yu, Telehealth Adoption by Mental Health and Substance Use Disorder Treatment Facilities in the COVID-19 Pandemic, *Psychiatr Serv.* 73 (4) (2022 Apr 1) 411–417.
- [321] R. van Kessel, R. Hrzic, E. O'Nuallain, E. Weir, B.L.H. Wong, M. Anderson, et al., Digital Health Paradox: International Policy Perspectives to Address Increased Health Inequalities for People Living With Disabilities, *J Med Internet Res.* 24 (2) (2022 Feb 22) e33819.
- [322] I. Kickbusch, L. Holly, Addressing the digital determinants of health: health promotion must lead the charge, *Health Promot Int.* 1;38(3):daad059 (2023 Jun).
- [323] L. Holly, B.L.H. Wong, R. van Kessel, I. Awah, A. Agrawal, N. Ndili, Optimising adolescent wellbeing in a digital age, *BMJ* 20 (380) (2023 Mar) e068279.
- [324] R. van Kessel, B.L.H. Wong, I. Rubinić, E. O'Nuallain, K. Czabanowska, Is Europe prepared to go digital? making the case for developing digital capacity: An exploratory analysis of Eurostat survey data, *PLOS Digit Health.* 1 (2) (2022 Feb 17) e0000013.
- [325] R.M. Rahal, J. Mercer, C. Kuziemy, S. Yaya, Factors affecting the mature use of electronic medical records by primary care physicians: a systematic review, *BMC Med Inform Decis Mak.* 21 (1) (2021 Dec) 67.
- [326] E.R. Melnick, C.A. Sinsky, H.M. Krumholz, Implementing Measurement Science for Electronic Health Record Use, *JAMA* 325 (21) (2021 Jun 1) 2149–2150.
- [327] R. van Kessel, M. Haig, E. Mossialos, Strengthening Cybersecurity for Patient Data Protection in Europe, *J Med Internet Res.* 25 (1) (2023 Aug 24) e48824.
- [328] D. Srivastava, R. van Kessel, M. Delgrange, A. Cherla, H. Sood, E. Mossialos, A Framework for Digital Health Policy: Insights from Virtual Primary Care Systems Across Five Nations, *PLOS Digit Health.* 2 (11) (2023 Nov 8) e0000382.
- [329] Yeung T. Local health department adoption of electronic health records and health information exchanges and its impact on population health. *Int J Med Inf* [Internet]. 2019 [cited 2023 Aug 6];128. Available from: <https://consensus.app/details/when-health-departments-adopt-health-records-improves-yeung/d12f535680c758b7bd086de1cb1ee2d1/>.
- [330] European Commission. European Health Union: A European Health Data Space for people and science [Internet]. 2022 [cited 2022 May 4]. Available from: https://ec.europa.eu/commission/presscorner/detail/en/ip_22_2711.
- [331] R. Raab, A. Küderle, A. Zakreuskaya, A.D. Stern, J. Klucken, G. Kaissis, et al., Federated electronic health records for the European Health Data Space, *Lancet Digit Health.* S2589–7500 (23) (2023 Sep 21) 00156.
- [332] A. Pekonen, S. Eloranta, M. Stolt, P. Virolainen, H. Leino-Kilpi, Measuring patient empowerment – A systematic review, *Patient Educ Couns.* 103 (4) (2020 Apr 1) 777–787.
- [333] Mancini T, Sibilla F, Argiropoulos D, Rossi M, Everri M. The opportunities and risks of mobile phones for refugees' experience: A scoping review. *Triberti S, editor. PLOS ONE.* 2019 Dec 2;14(12):e0225684.
- [334] D. Zenner, A.R. Méndez, S. Schillinger, E. Val, K. Wickramage, Health and illness in migrants and refugees arriving in Europe: analysis of the electronic Personal Health Record system, *J Travel Med.* (2022 Mar 2);taac035.).