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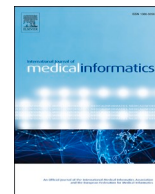
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Review article

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.

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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

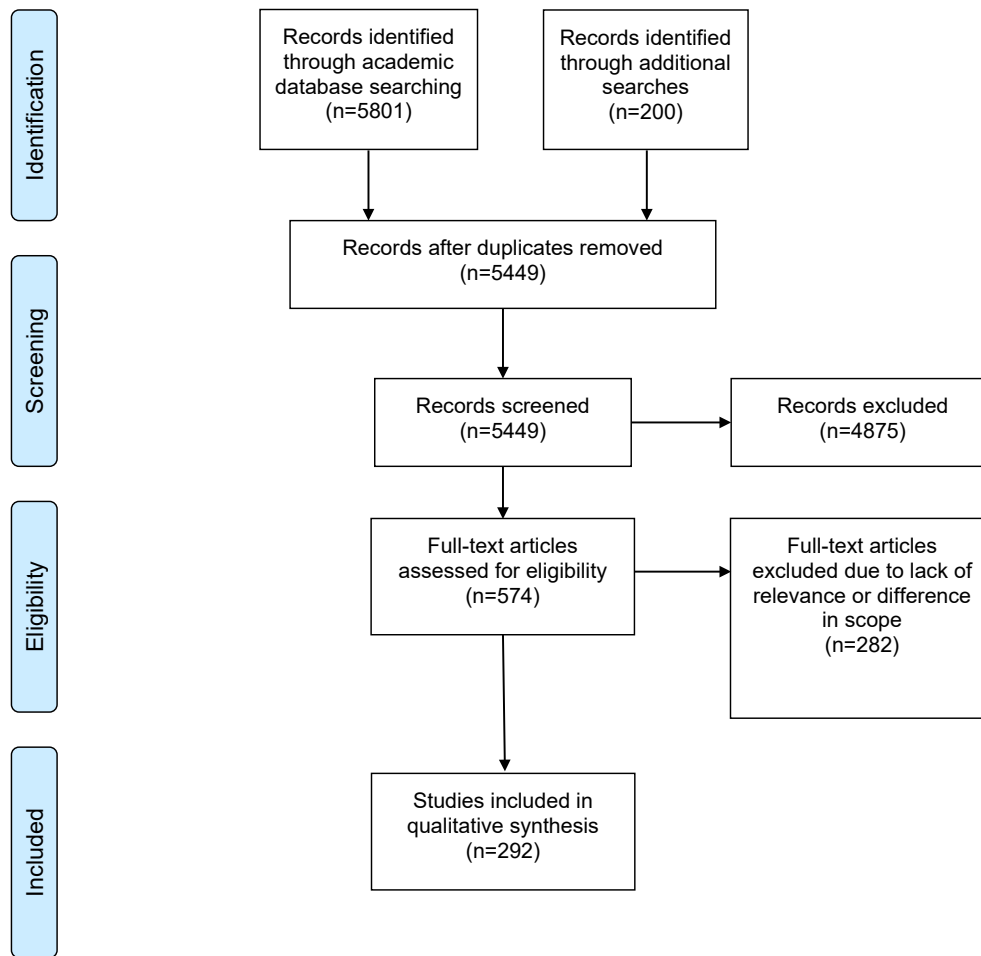


Fig. 1. A PRISMA flowchart outlining the data collection process.

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

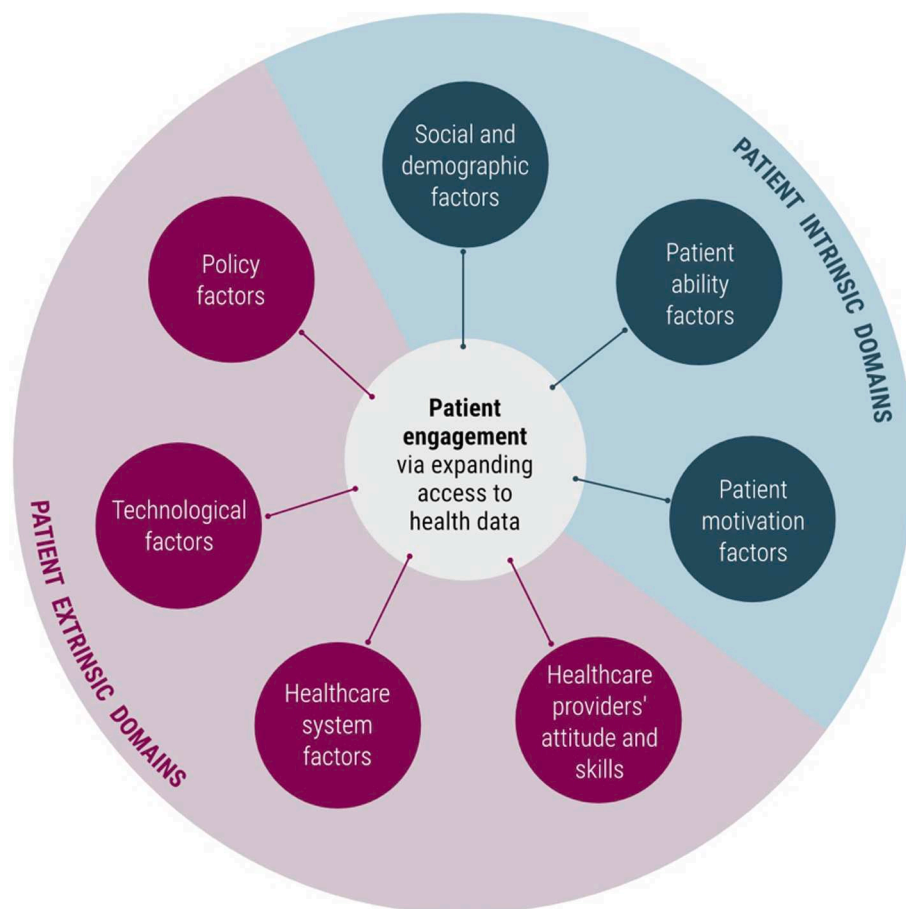


Fig. 2. Summary of the seven domains that contribute patient engagement while expanding patient access to health data.

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]
Health system factors	Likelihood of burnout	[36]
	Changes in workflow due to integration of EHR into care processes	[241]
	Perceptions around liability and reimbursement	[241]
	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]
Technological factors	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]
	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]
Policy factors	Integrated support and guidance aimed at patient education	[145,270]
	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.

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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.

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Appendix A. Supplementary data

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

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