Partnering with patients to support patient-centred personal health record access

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Abstract

Background: With rising pressures on healthcare systems, engaging patients in their health and care is receiving health policy attention. Simultaneously, personal health records (PHR) are creating an opportunity for patients to access their health information, offering the possibility for patients to be active participants in their health and care. This research project aims to investigate how access to PHR information can facilitate patient engagement in their health and care.

Methods: The research project starts with reviewing the literature narratively and systematically to form a basis for its subsequent mixed methods approach. The studies including data analytics, surveys, and interviews were designed to build upon each other.

Results: Patients are motivated and able to engage with their health and care through access to their PHR. However, their ability to use PHR effectively is limited by and dependent on various factors. The usability of a system itself and the type of information displayed can potentially hinder patients' understanding and, hence, effective use of a system. But the way information is presented can also support information understanding. The use of PHR by patients can lead to perceived improvements in the quality of and satisfaction with care. However, not everyone uses PHR and benefits from them equally with digital health literacy being an important determinant of both use and perceived benefit. Many PHR users are able and willing to identify and respond to errors in their records, but further research is needed to inform mechanisms by which patients could partner with healthcare professionals to improve the accuracy of their PHR.

Conclusions: Patient engagement in their health and care via PHR access is certainly worthwhile as it comes with improvements in care quality and satisfaction with care. However, steps need to be taken to maximise these benefits and ensure no one is excluded from them.

Lay summary

The research project investigated how patients can use personal health records (PHR) to be active partners in their healthcare. The research approach was shaped by patient and public involvement to focus on issues relevant to patients. From the unclear language around the term *'patient engagement*' in the research literature its three main components were identified as motivation, ability, and opportunity. A review of existing research evidence on how access to PHR impacts patient engagement showed a tendency towards facilitating patient engagement. However, the use and preferred functionalities of a PHR are the basis for any potential impact a PHR might have.

The Care Information Exchange (CIE) was the specific PHR implementation investigated in this research project. All patients treated in North-West London have the opportunity to register with the CIE to be able to access their PHR. However, the overall registrations to and use of the CIE were not very high. Still, there was a clear preference for the functionalities of viewing test results and appointment schedules.

Surveyed patients were mostly able to understand the information in their PHR and some even identified errors within the record even though barriers to an effective use of the CIE existed. These barriers were related to the information and the system themselves as medical knowledge was needed to understand and act upon information, but the system also needed to be usable for the patients in the first place.

Patients perceived the use of the CIE to have a positive impact on their satisfaction with care and the overall quality of the care they received. Hence, indicating that future

investment into understanding and enhancing patient engagement in healthcare through PHR access will be worthwhile.

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Figure 33. Poster presentation: **Freise, L.**, Lawrence-Jones, A., Neves, A. L., Flott, K., Darzi, A., & Mayer, E. K. Patient and public involvement in a PhD project: Co-production of research on partnering with patients in their healthcare. Graduate School PhD Summer Showcase 2019, 12th July 2019, London. 385

Figure 34. Poster presentation: **Freise, L.**, Neves, A. L., Flott, K., Darzi, A., & Mayer, E. K. Patient-controlled electronic health records: Patient registrations and access to the Care Information Exchange. Divisional Research Afternoon 2018, 13th December 2018, London. 386

Figure 35. Poster presentation: **Freise, L.**, Neves, A. L., Flott, K., Darzi, A., & Mayer, E. K. Patient-controlled electronic health record: Patients' ability to understand health information and identify potential errors. 6th Annual NIHR Imperial PSTRC Symposium, 29th November 2018, London. 387

Figure 36. Poster presentation: **Freise, L.**, Neves, A. L., Flott, K., Darzi, A., & Mayer, E. K. Patient-controlled electronic health record: patients' ability, preferences & expectations – preliminary results of an interview study. PSTRC PhD Network Forum 2019, 5th February 2019, Leeds. 388

List of acronyms and terms

ALJ	Anna Lawrence-Jones
ALN	Ana Luisa Neves
BCW	Behaviour Change Wheel
BDAU	Big Data & Analytical Unit
CHERRIES	Checklist for Reporting Results of Internet E-Surveys
CI	Confidence interval
CIE	Care Information Exchange
COREQ	Consolidated criteria for reporting qualitative research
cRCT	Cluster randomised controlled trial
EHR	Electronic health record
EMR	Electronic medical record
GRIPP	Guidance for Reporting Involvement of Patients and Public
HCEI	Health Care Empowerment Inventory
HCP	Healthcare professional
HMIC	Healthcare Management Information Consortium
HIAT	Health Inequalities Assessment Tool
ICT	Information and communications technology
IOM	Institute of Medicine
JK	Jacqueline Kemp
LD	Lindsay Dewa
LF	Lisa Freise
LR	Lily Roberts
MeSH	Medical Subject Headings
MHRM	Mental Health Recovery Measure
MMAT	Mixed Methods Appraisal Tool

NHS	National Health Service
NIHR	National Institute for Health Research
OR	Odds ratio
PAM	Patient activation measure
PAM-C	Carer version of patient activation measure
PHE model	Patient health engagement model
PHR	Personal health record
PKB	Patients Know Best
PPG	Project Partner Group
PPI	Patient and public involvement
PPIE	Patient and public involvement and engagement
PRISMA	Preferred Reporting Items for Systematic Reviews
PSTRC	Patient Safety Translational Research Centre
RCT	Randomised controlled trial
RL	Rachael Lear
RPG	Research Partners Group
SDT	Self-Determination Theory
SE	Secure Environment
UK	United Kingdom

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Thank you all from the bottom of my heart for accompanying me on this path.

Statement of originality

I hereby confirm that the content of this dissertation is my own work and sources, contributions, and assistance from others are acknowledged appropriately to the best of my knowledge and belief in the individual chapters and/or related publications.

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Publications and presentations

Underneath follows a list of publications and presentations organised by the related thesis chapters. For reference, posters are included in *Appendix B: Poster presentations.* In addition, co-authored publications not directly underlying any thesis chapter are listed according to their topic areas in *Other related publications* below.

Chapter 3: Patient and public involvement

- Poster presentation

  Freise, L., Lawrence-Jones, A., Neves, A. L., Flott, K., Darzi, A., & Mayer, E. K. Patient and public involvement in a PhD project: Co-production of research on partnering with patients in their healthcare. Graduate School PhD Summer Showcase 2019, 12th July 2019, London.

Chapter 4: Analysing patient registrations and access to a personal health record: Care Information Exchange case study

- Poster presentation

  Freise, L., Neves, A. L., Flott, K., Darzi, A., & Mayer, E. K. Patient-controlled electronic health records: Patient registrations and access to the Care Information Exchange. Divisional Research Afternoon 2018, 13th December 2018, London.

Chapter 5: A cross-sectional survey on patients' perceived ability to understand PHR information and identify potential errors

- Journal article

  Freise L., Neves A. L., Flott K., Harrison P., Kelly J., Darzi A., & Mayer E. K. Assessment of Patients' Ability to Review Electronic Health Record Information to Identify Potential Errors: Cross-sectional Web-Based Survey. *JMIR Form Res*. 2021;5(2): e19074. https://formative.jmir.org/2021/2/e19074/

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- Oral presentation

  Freise, L., Neves, A. L., Flott, K., Darzi, A., & Mayer, E. K. Patient-controlled electronic health record: Patients' ability to understand health information and identify potential errors. Divisional Research Afternoon 2018, 13th December 2018, London.

- Oral presentation

  Freise, L., Neves, A. L., Flott, K., Darzi, A., & Mayer, E. K. Patient-controlled electronic health record: Patients' ability to understand health information and identify potential errors. PSTRC PhD Network Forum 2019, 5th February 2019, Leeds.

- Poster presentation

  Freise, L., Neves, A. L., Flott, K., Darzi, A., & Mayer, E. K. Patient-controlled electronic health record: Patients' ability to understand health information and identify potential errors. 6th Annual NIHR Imperial PSTRC Symposium, 29th November 2018, London.

Chapter 6: A semi-structured interview study on patient expectations of the Care Information Exchange, its functionalities, and their usefulness

- Poster presentation

  Freise, L., Neves, A. L., Flott, K., Darzi, A., & Mayer, E. K. Patient-controlled electronic health record: patients' ability, preferences & expectations – preliminary results of an interview study. PSTRC PhD Network Forum 2019, 5th February 2019, Leeds.

Chapter 7: A cross-sectional survey outlining patients' motivation and abilities for using a PHR and the patient perceived impact of PHR access on care quality

- Journal article

  Lear, R., **Freise, L.**, Kybert, M., Darzi, A., Luisa Neves, A., & Mayer, E. K. (2022). Perceptions of Quality of Care Among Users of a Web-Based Patient Portal: Cross-sectional Survey Analysis. *Journal of Medical Internet Research*, *24*(11), e39973. https://doi.org/10.2196/39973

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- Journal article

  Neves, A. L., Smalley, K. R., **Freise, L.**, Harrison, P., Darzi, A., & Mayer, E. K. (2021). Determinants of use of the care information exchange portal: Cross-sectional study. *Journal of Medical Internet Research*, *23*(11), e23481. https://doi.org/10.2196/23481

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- Journal article

  Lear, R., **Freise, L.**, Kybert, M., Darzi, A., Neves, A. L., & Mayer, E. (2022). Patients' willingness and ability to identify and respond to errors in their personal health records: a mixed methods analysis of cross-sectional survey data. *Journal of Medical Internet Research*, *24*(7), e37226. https://doi.org/10.2196/37226

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Other related publications

Care Information Exchange

- Report

  Neves, A. L., Roy, R., Wadge, H., Fugard, A., **Freise, L.**, Carter, A. W., & Mayer, E. K. (2017) *A framework for evaluating the economic impact of EHR-based interventions*. Imperial College London, London. Retrieved from www.imperial.ac.uk/media/imperial-college/institute-of-global-health-innovation/FINAL-DRAFT-REPORT-3---OCTOBER-2017-FINAL-.pdf

- Report

  Poovendran, D., Wadge, H., Roy, R., **Freise, L.**, Neves, A., Fugard, A., & Mayer, E. K. (2017). *A qualitative evaluation of the CIE Programme implementation in North West London*. Imperial College London, London. Retrieved from http://www.imperial.ac.uk/media/imperial-college/institute-of-global-health-innovation/FINAL-REPORT-2-OCTOBER-FINAL.pdf

Impact of electronic health record access

- Systematic literature review journal article

  Neves A. L., **Freise L.**, Laranjo L., Carter A. W., Darzi A., & Mayer E. K. Impact of providing patients access to electronic health records on quality and safety of care: A systematic review and meta-analysis. *BMJ Qual Saf*. 2020;29(12):1019–1032. PMID:32532814

- Systematic literature review protocol

  Neves, A. L., Carter, A. W., **Freise, L.**, Laranjo, L., Darzi, A. & Mayer, E. K. (2018) Impact of sharing electronic health records with patients on the quality and safety of care: a systematic review and narrative synthesis protocol. *BMJ Open.* https://doi.org/10.1136/bmjopen-2017-020387

Perspectives on data sharing for secondary use of health records

- Journal article

  Neves, A. L., Poovendran, D., **Freise, L.**, Ghafur, S., Flott, K., Darzi, A., & Mayer, E. K. (2019). Health Care Professionals' Perspectives on the Secondary Use of Health Records to Improve Quality and Safety of Care in England: Qualitative Study. *J Med Internet Res,* 21(9): e14135. https://doi.org/10.2196/14135

Quality improvement and complaint handling

- Journal article

  Van Dael, J., Reader, T. W., Gillespie, A. T., **Freise, L.**, Darzi, A., & Mayer, E. K. (2022). Do national policies for complaint handling in English hospitals support quality improvement? Lessons from a case study. *Journal of The Royal Society of Medicine*. https://doi.org/10.1177/01410768221098247

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Chapter 1: Introduction

This dissertation is written as journal publication like chapters that represent the individual studies constituting the research project. At the same time, general chapters relating to the overall project background, patient and public involvement, and discussion are included to demonstrate how the studies are situated within the context of the project and the larger research area.

An introduction to patient engagement – A narrative review of the literature

Health policy concerning patients' role and responsibility in their healthcare

In recent years, there has been a decided shift towards patient centred care driven by various stakeholders from policy to patients (Department of Health, 2012). Therefore, patients are expected to take on a progressively more active role in their healthcare. In the United Kingdom (UK), the National Health Service (NHS) aims to enhance shared decision-making, patient access to care records, offer greater patient choice, and personalised care (Department of Health, 2010). The Five Year Forward view sets out that people will have access to clinical advice, information about their condition and history (NHS England, 2014). Subsequently, the NHS Long Term Plan re-iterated the move towards more personalised care and giving patients more control over their own health and care (NHS England, 2019). The focus on patient centricity comes as benefits of patients' engagement in health, like

improved health outcomes, patient experiences (Hibbard & Greene, 2013) and health risk factors (Simmons et al., 2014), are increasingly recognised.

Patient engagement

Patient engagement refers to an extensive notion including interventions to increase activation and patients' resulting behaviour such as taking preventive measures or regularly exercising (Hibbard & Greene, 2013). It has behavioural, cognitive, and emotional dimensions which need to be taken into account when monitoring outcomes of interventions (Barello et al., 2016). However, studies tend to not consider all aspects of patient engagement (Barello et al., 2016).

Patient engagement has become a frequently used term as part of the journey towards patient-centric care; with a marked increase in the number of publications concerning patient engagement starting from 2010 (Xu & Wong, 2017). The Care Act 2014 Section 1 provides the legal basis and need for individuals to participate in their care recognising an individual is usually best placed to appraise their wellbeing (Great Britain. Care Act 2014, 2014). While policy and law are driving towards patient engagement in care, the research literature overflows with various terms and concepts.

Unfortunately, it is not always clear what someone means by the terms they use and how the terms relate to each other. Hence, uncertainty exists in the literature (Grande et al., 2014). Although, according to Xu and Wong (2017), thirty percent (*i.e.*, 15 out of 50) of the most cited articles concerning patient engagement address the development of a model or framework for it, the term '*patient engagement*' can be taken to mean differing things, as

there is no one definition or terminology consistently used (Barello et al., 2014; Gallivan et al., 2012).

The various concepts and terms in the context of patient engagement in health care (see *Figure 1*) tend to overlap and be used synonymously to each other (Fumagalli et al., 2015). This ambiguity and lack of clarity has created an interwoven net of terms that are tangled with each other and cannot easily be separated or assessed individually. Given the complex maze of concepts, definitions, and terms surrounding patients' engagement in health and care, communication about patient engagement and related issues is challenging (Gallivan et al., 2012). Nevertheless, a clear definition is needed to effectively measure the impact of '*patient engagement*' interventions (Higgins et al., 2017), avoid misunderstandings between stakeholders, and enhance comparability of studies and interventions targeted at patient engagement. The next section will discuss current conceptual difficulties regarding patient engagement in further detail. Awareness of potential conceptual pitfalls is paramount to discussing issues around patient engagement.

Debated patient engagement concept

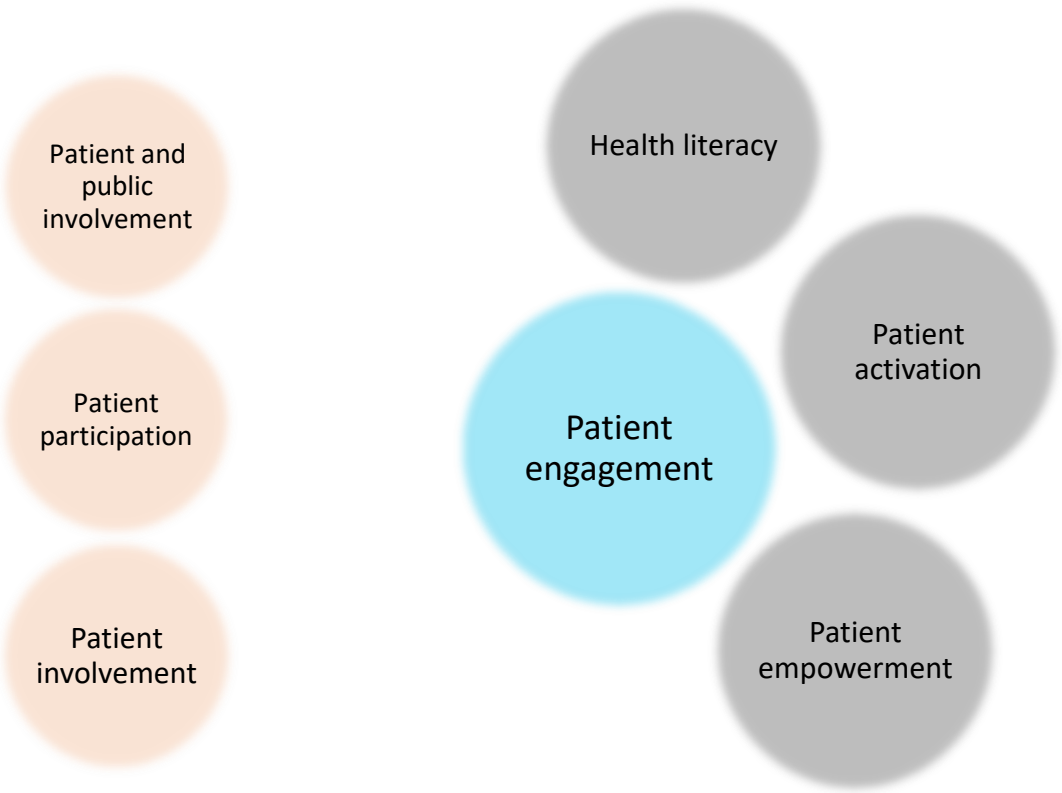


Figure 1. Concepts surrounding patient engagement in the literature. Dark grey circles denote related concepts discussed in more detail, while light orange circles are mentioned for the sake of providing an overview of existing terms.

In this section, patient engagement will be introduced and discussed as if independent from other concepts and terms, such as patient activation, initially, though it is tightly interwoven within the literature (see *Figure 1*). Hence, this separation does not come naturally. However, without it the consideration of patient engagement would be even more unclear. Subsequently, the relation between patient engagement and other terms will be deliberated in the following section.

The multitude of 'patient engagement' interpretations is exemplified by descriptions and definitions from additional sources:

- actions one must take to achieve the maximum benefit from the available health services (Center for Advancing Health, 2010),
- effective self-management (Barello et al., 2014),
- a 'therapeutic alliance' (Barello et al., 2014; Higgins et al., 2017), and
- a tool for health self-management in terms of information, communication, and education concerning processes of care relevant to patients' health (Barello et al., 2014).

Moreover, the definitions of patient engagement differ depending on time and contexts (Higgins et al., 2017): for example, in nursing research the focus is on patients' self-awareness whereas in biomedical research patient engagement is seen as a tool for effective health self-management (Barello et al., 2014). Furthermore, patient engagement is thought to have four defining attributes, namely personalization, access, commitment, and therapeutic alliance (Higgins et al., 2017). On the other hand, according to the patient health engagement (PHE) model it is considered to be a process with four stages from blackout, arousal, and adhesion to eudaimonic[1] project on the responsive levels of feeling, thinking, and acting (Graffigna et al., 2014, 2015). The PHE model considers the interaction of its individual responsive levels with each other to form the process stages. Hence, over time one person's engagement in their health can change between the levels. The PHE model's components alone give an impression of the complexity of patient engagement without attempting to take external factors influencing and determining an individual's level of

[1]In psychology "eudaimonic" wellbeing is a happiness realised through self-actualisation with a meaningful purpose (American Psychological Association, n.d.).

engagement into account. Based on the PHE model the PHE-scale was devised to measure engagement and is aimed at patients with chronic conditions. The PHE-scale consists of five-items measuring the level of engagement along the lines of the model's proposed stages of patient engagement (Graffigna, Barello, Bonanomi, & Lozza, 2015).

Synonymous use and overlap of patient engagement with other terms

Health literacy

Health literacy is the '*degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions*' (U.S. Department of Health and Human Services, 2000). There are various definitions and conceptualisations of health literacy in the literature (Sørensen et al., 2012; WHO, 2013). The conceptual model of health literacy by Sørensen et al. (2012), underlying the European Health Literacy Survey, integrates peer-reviewed definitions and conceptual frameworks resulting in a comprehensive basis (WHO, 2013).

The model considers health literacy as a process involving several steps including the access, understanding, appraisal, and application of information (Sørensen et al., 2012). The core competence, knowledge, and motivation are influenced by proximal and distal factors impacting on the pathways linking the health literacy components to resulting health outcomes (Sørensen et al., 2012). The four dimensions of health literacy can be applied to the three health domains of health care, disease prevention and health promotion (Sørensen et al., 2012).

Depending on an individual's health literacy, health related behaviours and health outcomes differ. Patients with lower health literacy are more likely to be hospitalised and use

emergency care while being less likely to engage with preventive services such as mammography screening and influenza immunisations (Berkman et al., 2011). Additionally, elderly people with lower health literacy report poorer health status and their all-cause mortality rates are higher (Berkman et al., 2011). Consistently, health literacy together with trust in science is positively related to health promoting behaviours such as physical activity and stress management (Plohl & Musil, 2022).

In the digital context health literacy gains additional complexity. Six skills have been identified as components of digital health literacy: traditional literacy, health literacy, information literacy, scientific literacy, media literacy, and computer literacy (Chung & Nahm, 2015). Hence, to support literacy in the digital health context several additional components must be taken into account.

Patient activation

Patient activation is a concept related to health literacy (Smith et al., 2013), describing '*the knowledge, skills and confidence a person has in managing their own health and health care*' (Hibbard & Gilburt, 2014, p. 3). This is in contrast to patient engagement which is taken to refer to a wider concept including activation, interventions to increase activation, and resulting patient behaviours (Hibbard & Greene, 2013).

Similarly to health literacy, patient activation is related to health outcomes. Patients with low activation levels are more likely to attend accident and emergency departments, be hospitalized or re-admitted to hospital after being discharged in comparison to patients with high activation levels (Begum et al., 2011). Hence, they are likely to lead to higher health care costs compared to patients with high activation levels (Hibbard & Gilburt, 2014).

Interventions to increase activation can improve a patient's engagement and, consequently, health outcomes relatively independent of population and condition (Hibbard & Gilburt, 2014).

The level of an individual's patient activation is commonly measured using the Patient Activation Measure (PAM) either in its original form with 22 items or its 13-item short version (Hibbard et al., 2004, 2005). The PAM measures patients' self-reported knowledge, skills, and confidence for managing their personal health (Hibbard et al., 2004). Almost half of the items refer to "my health condition" (Hibbard et al., 2005, p. 1923), hence, postulating the existence of a pre-existing health condition for any individual.

While patient engagement and activation are considered to conceptually overlap, they are also presumed to vary in their scope (Graffigna et al., 2015). Patient engagement as an entity is separate from activation, therefore, using it as a measure of activation is not feasible. Since the terms 'patient engagement' and 'patient activation' are regularly used synonymously (Fumagalli et al., 2015; Rieckmann et al., 2015), it becomes difficult to ascertain when reviewing studies which concept authors actually intended to measure.

Patient empowerment

Patient empowerment refers to the ability and motivation of patients to participate in their health and care as needed (Fumagalli et al., 2015). Patient engagement has been described as a consequence of empowerment (Fumagalli et al., 2015); however, patient empowerment can also be used synonymously with patient engagement and in other instances considered to be a lever for engagement (Fumagalli et al., 2015; Higgins et al., 2017).

Patient engagement, patient activation, patient empowerment, and health literacy

Patient activation and empowerment can be viewed as recursive with patient engagement as all concepts may present as antecedents and consequences of patient engagement (Higgins et al., 2017). Patient activation and empowerment could be an outcome of patient engagement. It also could be understood that these actions contribute to patient engagement (Higgins et al., 2017). The interweaving of concepts and actions makes it difficult to assess definite borders. The aspect of patient engagement which includes the relationship between patients and healthcare professionals is not part of the concepts of patient activation and empowerment (Higgins et al., 2017).

Increasing patient engagement must also include health literacy because the concepts are related (Coulter & Ellins, 2007). However, the relationship of patient activation being a subdomain of patient engagement and patient health literacy can be debated. Similarities and differences do exist in the association of health behaviours and outcomes with health literacy and patient activation respectively.

While health literacy and patient activation overlap in various ways, the concepts and behaviours are not the same and are independently correlated with health outcomes (Smith et al., 2013) being distinct constructs. However, while patient activation is almost exclusively measured using the PAM there are various measures of health literacy which differ in their focus on the individual health literacy domains.

As demonstrated, patient engagement has multiple meanings depending on the context and shares commonalities with several concepts. When concepts are used synonymously it suggests an equality or at least close similarity in meaning. However, in case of patient engagement, activation, and empowerment the conceptualisations do not necessarily support this. Empowerment has been indicated in the literature as both an antecedent and

as an outcome of patient engagement (Higgins et al., 2017). Empowerment and engagement can be interconnected but are not equal. Using patient activation and patient engagement interchangeably does not represent their relationship since engagement can be included with activation (Hibbard & Greene, 2013). Subsequently, the relationship between patient engagement, patient activation, and patient empowerment are dependent on how the terms are used.

Impact of the patient engagement concept issues

As understanding patient engagement is central to patient centred care and important for all stakeholders involved, a common and more intuitive terminology than seems to currently exist could prevent probable misunderstandings. Due to the interweaving concepts and indefinite borders, the language used when discussing patient engagement is essential.

The demonstrated current lack of clarity and confusion in the literature concerning patient engagement impacts the research into related areas and the targeting of quality improvement interventions including the measurement of their success. Generally, targeting interventions and measuring their influence is beneficial, if not vital, in order to know as much as possible about the variables affected. Similarly, quality improvement interventions in health services require clearly defined aims that are specific, measurable, achievable, realistic, and timely (Crowe & Sharma, 2017). Without being aware of the variables influencing patient engagement, interventions will not reach their full potential. Measuring the impact of a variable, such as health literacy, will be ineffective without understanding patients' actions and behaviours as a result of their health literacy.

Measuring patient engagement

The two main measures currently used to quantify a patient's level of involvement are the Patient Activation Measure (PAM) (Hibbard et al., 2004, 2005) and the patient health engagement (PHE) scale (Graffigna et al., 2015). As discussed, patient engagement is not equal to patient activation. Thus, a potential direct measure for patient engagement in contrast to the proxy of activation could be more informative for interventions. The PHE was created for patients with chronic conditions (Graffigna et al., 2015). Since the PHE scale focuses on a patient's chronic disease and reaction to the disease (Graffigna et al., 2015) the scale is not applicable for patients with non-chronic health issues. Moreover, PHE is best when measuring the 'disease reactive' nature of the patient and reaches its limits when trying to measure the effectiveness of preventative services.

Common language concerning what is the patient's and what is the public's role in health care is beneficial. Achieving a common language with clear cut, measurable concepts, however, has proven to be challenging (Barello et al., 2014; Fumagalli et al., 2015; Gallivan et al., 2012; Higgins et al., 2017; Xu & Wong, 2017).

Reoccurring themes from the patient engagement context

When considering patient engagement and its context, several themes reoccur as fundamental to the various concepts being used. The three core dimensions emerging from the reviewed literature seem to relate to patients' motivation, ability, and opportunity to engage with their health and care, which are also influenced by various additional factors discussed in later paragraphs. *Figure 2* gives an overview over the dimensions and corresponding terms from the literature. For clarification each of the three dimensions will be deliberated in the following paragraph.

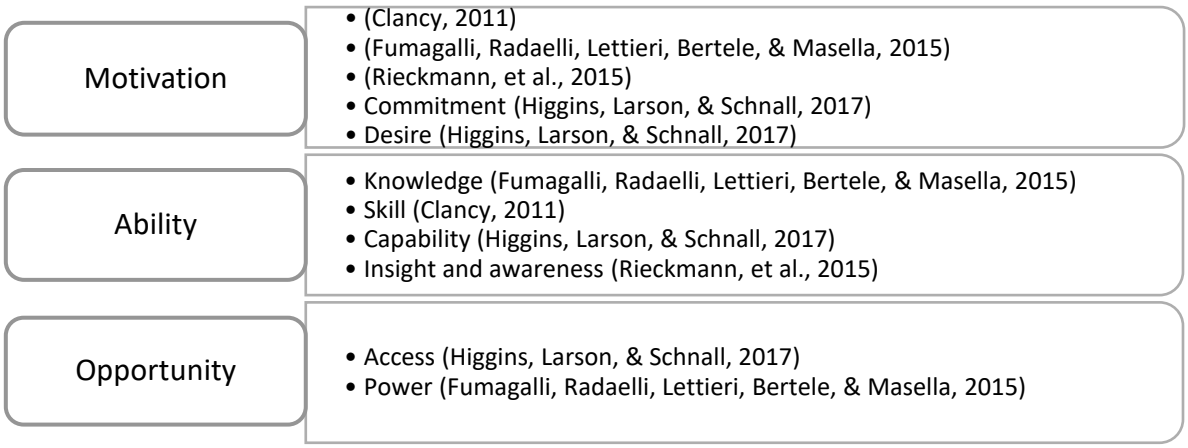


Figure 2. Patient engagement dimensions with corresponding terms and references

Patients' motivation to be engaged with their health and care is repeatedly discussed in the literature surrounding patient engagement (Clancy, 2011; Fumagalli et al., 2015; Rieckmann et al., 2015) and acts as driver for patients' engagement. In addition, other authors refer to patients' commitment or desire to be engaged (Higgins et al., 2017) which group well with motivation in terms of being drivers for engagement. Moreover, the ability to engage with one's health has been amply discussed in the literature using various terms. Here, the ability to engage as dimension of patient engagement is based on the facets of skills (Clancy, 2011), knowledge (Fumagalli et al., 2015), capability (Higgins et al., 2017), and insight and awareness (Rieckmann et al., 2015) necessary for proficient engagement in personal health and care. Finally, the last component in *Figure 2*, the opportunity dimension, relates to the access (Higgins et al., 2017) and power (Fumagalli et al., 2015) required for engagement in health.

Considering that patient engagement has no commonly used clear definition, its precursors are uncertain as well. However, several possible associations can be identified in the reoccurring themes surrounding patient engagement (see *Figure 3*).

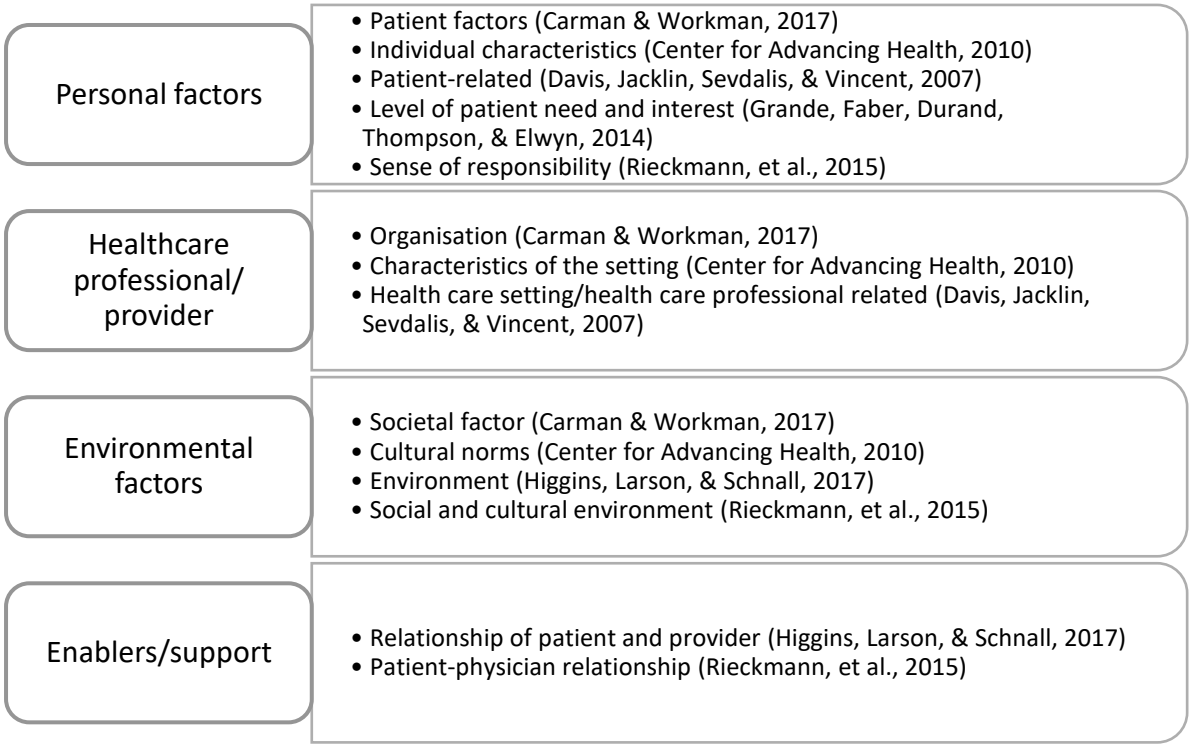


Figure 3. Factors associated with patient engagement with literature references.

The literature indicates factors as associated with patient engagement that can be roughly grouped into four themes: personal factors (Carman & Workman, 2017; Center for Advancing Health, 2010; Davis et al., 2007; Grande et al., 2014; Rieckmann et al., 2015), healthcare professional/provider (Carman & Workman, 2017; Center for Advancing Health, 2010; Davis et al., 2007), environmental factors (Carman & Workman, 2017; Higgins et al., 2017; Holmes Rovner et al., 2010; Rieckmann et al., 2015), and enablers/support (Higgins et al., 2017; Rieckmann et al., 2015). From the factors associated with patient engagement and its previously deliberated dimensions results in high-level structure shown in *Figure 4* which serves as visualisation of factors when considering patient engagement, along with the associated aspects and dimensions.

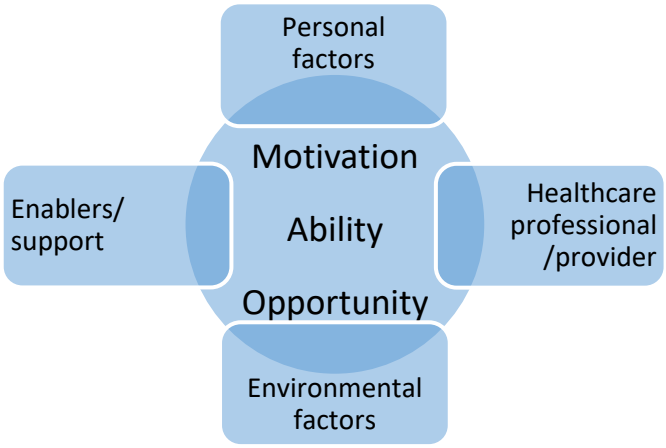


Figure 4. Core dimensions of patients' engagement with personal health (inner circle) and associated factors (four outer squares).

Reocurring themes in context of the COM-B system

The COM-B system refers to a framework for understanding behaviour based on the three factors capability, motivation, and opportunity (Michie et al., 2011). According to Michie et al. (2011) capability, motivation, and opportunity interact with each other in forming a behaviour which in turn again impacts the three factors. Based on the COM-B system any intervention might impact one or more of the components of the behaviour system potentially influencing the given behaviour (Michie et al., 2011).

The three factors of the COM-B system correspond to the three dimensions identified here as reocurring in the patient engagement literature. As such patient engagement might be viewed as a behaviour based on capability, motivation, and opportunity whereas each of them is influenced by the behaviour itself.

From the COM-B system at the centre the authors describe the behaviour change wheel (BCW) consisting of nine surrounding intervention functions which are again surrounded by

seven categories of policy potentially impacting the occurrence of an intervention (Michie et al., 2011). The nine intervention functions are:

- Education,
- Persuasion,
- Incentivisation,
- Coercion,
- Training,
- Enablement,
- Modelling,
- Environmental restructuring, and
- Restrictions.

While the seven policy categories discussed are:

- Environmental/social planning,
- Communication/marketing,
- Legislation,
- Service provision,
- Regulation,
- Fiscal measures, and
- Guidelines.

Hence, the BCW offers further insights into how policy and interventions might impact a behaviour based on their influence on the behaviour factors of capability, opportunity, and motivation than the discussion of the reocurring themes of factors associated with patient engagement and its three dimensions discussed above. Nevertheless, the three dimensions

identified as reocurring in the patient engagement context remain useful and can be said to be supported as relevant in light of the close resemblance to the COM-B system.

Considering patient engagement to consist out of motivation, ability, and opportunity to act for one's personal health and care, the opportunity dimension can be embodied manifold. Patients can take an active role in their health and care through various means and supported by different levers. The following sections introduce health record access as one such opportunity.

Patient engagement through health record access

Electronic health records (EHR)

With digitisation of information now being commonplace in the healthcare context patient records are kept digitally in the form of electronic healthcare records (EHR). EHR systems from different providers with varying usability strengths and weaknesses are utilized across the UK (Bloom et al., 2021). A key issue of the multitude of EHR systems in use, is the limited interoperability between the systems chosen by healthcare providers (Bouamrane et al., 2015; Warren et al., 2019). Hence, while digital documentation in theory should be easily shared between the healthcare providers a patient sees, record sharing is not always straightforward.

The patients themselves are the one constant throughout their life's health and care. Healthcare providers certainly change based on patients' circumstances and needs. The digitalisation of medical information in EHR has the potential to make health knowledge more accessible to patients and empower them to take charge of their health and care. Evidence suggests that tools are best suited to improve patient care when they support

rather than replace interactions with healthcare professionals (Coulter & Ellins, 2007). Hence, the following portions are discussing the concept of personal health records (PHR) in contrast to EHR.

Personal health records (PHR)

Instead of directly sharing EHR with patients, PHR integrating information from various health and care providers, can be shared. PHR are systems based on patients' medical records, which allow patients to access, control and share information as required. According to ISO Technical Report: ISO/TR 14292, 1st edition, 2012, as cited by Wyatt et al. (2017, p. 13), PHR are "*a representation of information regarding* […] *the health, including wellness, development and welfare of that individual, which may* […] *integrate health information from multiple sources, and for which the individual* […] *manages and controls the PHR content and grants permissions for access by, and/or sharing with, other parties*".

Although patients' interaction with and use of PHR depends on various factors, it has been argued that PHR access can play a beneficial role for patients' health and care (Symons et al., 2019; Wyatt et al., 2017). Since the ability of the patients to efficiently use the PHR and understand its functionalities impacts its usefulness, knowing what patients need for successful interactions with PHR systems is important. One opportunity to test the ability of patients interacting with their PHR is for them to be able to spot and correct any errors in the record. Error correction could lead to enhanced patient safety and experience, although this concept has not been conclusive in the research. The identification of errors in PHR by patients could potentially reduce the number of patient safety incidents. However, it is not clear whether the expectations of patients regarding PHR functionalities differ from those of healthcare professionals and providers.

Care Information Exchange (CIE)

The Care Information Exchange (CIE) is a patient-controlled PHR system operated by Patients Know Best (PKB). In 2014 the CIE Programme was launched in North West London. The CIE Programme was led by Imperial College Healthcare NHS Trust and initially funded by Imperial Health Charity. The progress was monitored through monthly steering group meetings. While the implementation encountered challenges and delays at the beginning, by March 2022 300,000 patients were registered to the system from across four North West London acute NHS trusts.

The first formal assessment of the CIE roll-out was completed in 2017. The results were presented in two reports focusing on a qualitative evaluation of the implementation and the creation of a framework to measure its economic impact respectively (Neves et al., 2017; Poovendran et al., 2017). The CIE implementation was a complex process that needed to continuously adapt to the requirements of all stakeholders (Poovendran et al., 2017).

The functionalities offered to patients by CIE vary between services depending on the specific needs of a service and its patients. Offered functionalities range from communication with the healthcare team and appointment schedules to viewing test results and hospital letters. Medical record systems that allow patient modification, such as CIE, incorporate a patient error identification functionality in their systems. Error identification by patients can potentially reduce the number of patient safety incidents by enhancing record quality. Expectations by patients for PHR functionalities could differ from those of healthcare professionals and providers because of the different perspectives on the processes and responsibilities.

PHR based data sharing with patients and quality of care

Sharing medical data with patients via PHR access can impact the quality of care received. The Institute of Medicine (IOM) categorises quality of care into six domains: effectiveness, patient-centredness, efficiency, timeliness, equity, and safety (Institute of Medicine (US) Committee on Quality of Health Care in America, 2001). Taken together the six domains form a useful structure to assess the impact of interventions on overall quality of care.

The results of a systematic review on the impact of sharing EHR information with patients, mapped to the IOM domains, are mixed (Neves et al., 2018, 2020). While some domains are commonly assessed by studies (*e.g.*, effectiveness, *n*=14) others are not represented at all (*i.e.*, timeliness and equity, *n*=0), showing a comparative research focus on effectiveness, patient-centredness (*n*=11), efficiency (*n*=5), and safety (*n*=4). Especially when considering digital interventions, equity is an important issue to explore in the context of the existing inequality in terms of the digital divide (Litchfield et al., 2021). To maximise the benefits of sharing EHR information with patients, the contained information needs to be accessible and understandable to patients. However, to be appropriate and useful for patients' medical care, EHR information cannot be overly simplified or condensed.

Posited impact of patient PHR access on patient engagement

Insights into how patients interact with health informatics applications are essential for designing effective interventions for patient engagement using electronic health records. The term '*consumer health informatics*' (CHI) has been described by Eysenbach (2000) as '*the branch of medical informatics that analyses consumers' needs for information; studies and implements methods of making information accessible to consumers; and models and*

integrates consumers' preferences into medical information systems' (p. 1713). Furthermore, according to the American Medical Informatics Association, CHI is concerned with consumer empowerment to manage their own health (American Medical Informatics Association, n.d.). While the term '*consumer*' is not generally used to describe patients in the NHS, the concept is increasingly applicable as patients gain greater choice in decisions around their healthcare provider.

Coulter and Ellins (2007) found that '*health information materials, decision aids, self-management action plans, and other "technologies" of patient engagement are most effective when they supplement or augment, rather than replace, interactions between patients and professionals*' (p. 27). Hence, any intervention using a digital information tool, such as PHR, to increase patient engagement needs to be carefully planned for the different levels of health literacy, needs and abilities of patients. PHR cannot replace face-to-face consultations with healthcare professionals even though it could have a positive influence on patient safety.

To assess the existing knowledge base, the following chapter systematically reviews and appraises the research literature around the impact of patients' access to their medical records on patient engagement in their health.

Thesis aims and objectives

The aim of the research project is to investigate how access to personal PHR information can facilitate patient engagement in an individual's health and care. Towards the assessment, the overall research project is guided by four objectives.

Objectives and corresponding dissertation components are as follows:

1. Review existing knowledge of patient PHR access' impact on patient engagement
    a. Narrative literature review for broad context on concepts
    b. Systematic literature review for relevant specific study results and approaches
2. Explore patients' use of a PHR system as baseline
    a. Data analytics case study for impression on registrations and access to Care Information Exchange with cross-sectional survey to assess patient expectations regarding CIE functionalities
    b. Cross-sectional survey to assess patients' perceived level of understanding, barriers to it and types of errors identified in CIE information
3. Investigate patient expectations and needs for using a PHR
    a. Semi-structured interviews to identify and explore themes relevant to patients regarding CIE
4. Examine patient needs for understanding of information presented in PHR, using PHR to engage in healthcare, and the perceived impact of PHR use
    a. Cross-sectional survey to quantify prevalence of patient expectations and ability to use CIE for engagement in health and care with regards to patient demographics and CIE use's perceived impact

Figure 5 shows an overview of the project studies and their underlying objectives. It clarifies the project flow by illustrating how the individual studies are building on each other.

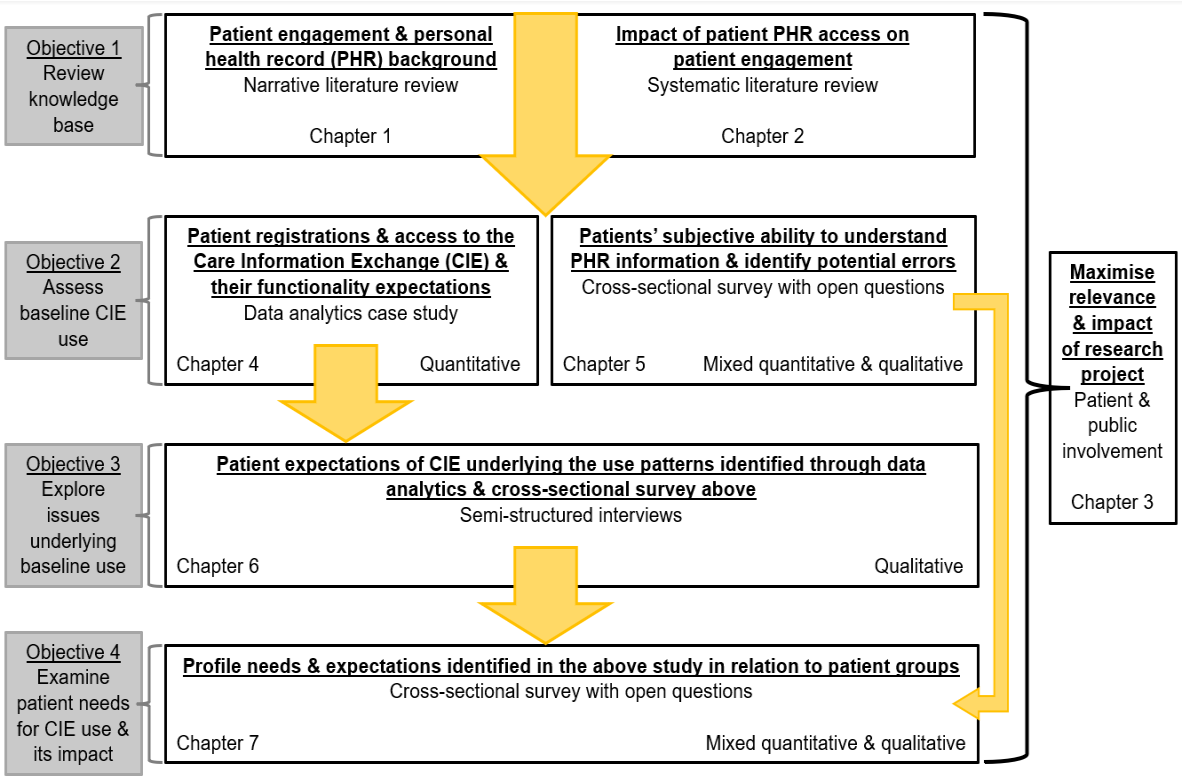


Figure 5. Research project overview detailing the research objectives and studies.

Firstly, the aim of the systematic and narrative reviews in *Chapter 1* and *Chapter 2* is to establish background and contextual knowledge for the following chapters. The reviews provide the initial basis upon which the following studies are designed and discussed.

Secondly, the data analytics case study in *Chapter 4* aims to clarify if, or how, patients at specific clinical services (*e.g.*, Rheumatology or Multiple Sclerosis) use the opportunity of accessing their medical records via a personal health record using the example of the Care Information Exchange (CIE). Initial feedback on patient expectations regarding CIE functionalities is collected as a point of reference for the following studies. The cross-sectional CIE survey study in *Chapter 5* explores patient's perceived level of understanding

of information contained in their PHR as well as the potential impact of said information understanding by assessing unprompted error identification in PHR data.

Moving on to the third objective of the project, the semi-structured interview study in *Chapter 6* elaborates on the underlying reasons for the data in *Chapter 4*. The results from the case study guide the subsequent semi-structured interview study in two ways. Firstly, the services selected for the interview study are based upon the findings of the registration and access data analysed in *Chapter 4*. Secondly, the interview guide questions are designed to further investigate patients' views on the functionalities the CIE offers them.

Finally, the cross-sectional survey in *Chapter 7* addresses the fourth objective. The chapter relates patient perceptions and preferences to socio-demographic information such as age, gender, education, and digital health literacy. Hence, providing information for future improvements and facilitation of patient engagement through PHR access.

Research strategy

Research paradigm

The research project is based in pragmatism. Linguistically pragmatism is centred around approaching problems practically (Merriam-Webster, n.d.). In the research context, Morgan (2014, p. 1051) describes pragmatism as

> *"treating research as a human experience that is based on the beliefs and actions of actual researchers".*

Hence, the researcher and their research are not entirely separate entities, but any research will be influenced by the researchers, their experiences, and actions. The given research

project does not claim to identify an absolute truth. Instead, it considers phenomena as set within contexts (Morgan, 2014) and aims to provide useful knowledge by contemplating layers of phenomena (Feilzer, 2010). Depending on the context of an intervention, its impact and outcomes may vary. Methods are chosen based on their suitability in answering the posed questions (Kivunja & Kuyini, 2017). Hence, no method is categorically excluded or preferred initially. Any choices in terms of method selection are made with a view on

1. the specific aims and objectives of the individual studies, and
2. the aims and objectives of the overarching research project.

Depending on the individual studies' and overarching research project's needs, methods are selected freely from quantitative, qualitative, and mixed methods backgrounds. The sections below provide a first insight into the chosen methods and underlying reasoning which will then be expanded upon in the relevant chapters.

Mixed methods research

Given the aims and objectives of the research project, a mixed methods approach is deemed most suitable throughout the research conducted. There has been debate on making mixed methods the standard approach for interventional evaluations (Fetters & Molina-Azorin, 2020). In this instance, mixed methods are selected as the questions at hand can be approached from several directions both quantitatively and qualitatively allowing for more in-depth investigation and interpretation (Almalki, 2016; Almeida, 2018; Doyle et al., 2009). While every method has its advantages and disadvantages, mixed methods are applied to alleviate some of the inherent disadvantages to using quantitative or qualitative methods in isolation (Almalki, 2016; Almeida, 2018; Doyle et al., 2009).

The overall research project follows a multiphase mixed methods approach where multiple studies build upon each other over time using differing methodological approaches (Creswell et al., 2011). The results from the opening quantitative data analysis on the use of the CIE are taken as basis for the following interview study in a sequential mixed methods design. On the other hand, the initial survey on CIE information understanding and error identification embeds both quantitative and qualitative data with each other to support interpretation of the data. Lastly, the interview study results guide the development of the final survey questionnaire. Hence, the research project employs mixed methods across the project and in parts within studies as needed to answer the relevant research questions. However, individual studies, *i.e.*, *Chapter 4* and *Chapter 6*, are based solely on quantitative and qualitative methods respectively.

Quantitative research

Based on the aims of any research study, the methods will be selected accordingly. As the name states, quantitative research deals with quantities and statistics. To begin understanding of the status-quo for the specific implementation of the CIE, a data analytics case study (see *Chapter 4*) was deemed the best first step. Quantitative data was used to create a baseline awareness of CIE use across several settings which could then be used to select settings for qualitative, more in depth analysis and exploration. Without the baseline CIE implementation knowledge, later studies could not have been as focused. Hence, starting with a more general, quantitative overview was favoured.

Qualitative research

Qualitative research is based less on numbers and statistics but more on language and interpretation. Instead of providing overview over large sets of numbers, issues can be explored focusing on their '*quality*' as perceived by relevant groups or individuals. Following from the overview provided by the quantitative data analytics, to enable a deeper exploration of patients' views and expectations regarding the CIE, an interview study (see *Chapter 6*) was conducted. The aim of the interview study was to provide a better understanding of the reasons underlying the quantitative data assessed in the previous data analysis and support future assessment of identified issues.

Patient and public involvement (PPI)

To maximise the relevance and impact of the research, input from patients and the public is a vital component. PPI is recognised as adding value to research (Duffett, 2017; Faulkner et al., 2015; National Institute for Health Research, 2015) and PPI strategies are increasingly expected by research funders (National Institute for Health Research, 2014). As PPI can vary between low level involvement to active co-production of research projects (Carman & Workman, 2017; Duffett, 2017), PPI needs to be carefully planned. Hence, guidance from the Imperial Patient Safety Translational Research Centre's Research Partners Group (RPG) supported the research project's patient and public involvement approach. The research project has been co-designed and conducted together with an especially recruited Project Partner Group (PPG). *Chapter 3: Patient and public involvement* provides a detailed PPI account across the whole project. Furthermore, PPI is mentioned and discussed in the individual chapters wherever relevant.

Chapter 2: A systematic review of the literature on the impact of patients' access to health records on patient engagement

Introduction

Patients' uptake of PHR access opportunities has been widely discussed in the literature. A multitude of barriers to using PHR have been identified from technical to literacy issues (Showell, 2017). To properly make use of access to PHR for engaging in personal health and care, patients need a certain level of health literacy (Noblin et al., 2012) and digital skills.

However, the possibility of how PHR access may facilitate patient engagement in personal care by providing an opportunity for patients to act is less clear. Due to the absence of an agreed upon, clear definition of patient engagement, a direct common measure is lacking as well. The most frequently used way of assessing patient engagement may be via the proxy of patient activation using the PAM. The given systematic review seeks to add to the literature in these areas of patient engagement in personal care through PHR access and the applied measures of patient engagement.

Aims and objectives

The systematic review aimed to assess the knowledge base on the impact of patients' access to personal health records on their engagement in their personal health and care. Specifically, the objectives were to:

- Evaluate the impact of patient health record access on patient engagement.

- Identify the measures used to assess patient engagement.

Methods

The Preferred Reporting Items for Systematic Reviews, *i.e.*, PRISMA, guidelines were followed in conducting this review (Moher et al., 2009; Page, McKenzie, et al., 2021; Page, Moher, et al., 2021). Based on the research question and the kind of evidence available in the literature, no quantitative meta-analyses were possible. Hence, not all PRISMA checklist items were applicable. The filled in PRISMA 2020 checklist is provided in *Appendix A*: *Table 38-Table 41*. Due to the differing study types included in the review, the Mixed Methods Appraisal Tool (MMAT) version 2018 (Hong et al., 2018, 2019) was used to critically assess the studies' quality. A systematic review protocol was decided on with the research team and the institutional librarian. A review registration was not completed.

Search strategy

The systematic literature search was run on 8th October 2018 in the Healthcare Management Information Consortium (HMIC), Medline, Embase, and PsycINFO databases via Ovid. LF discussed the initial search strategy and selection of databases with the institutional librarian (JK) and Ana Luisa Neves (ALN) and refined them in an iterative process according to the combined expertise.

In agreement with JK, CINAHL was not included in the search, as the 263 results (as of 15.10.2018) of a preliminary search did not appear to match the research question based on a rapid review of a random subset of results. On the other hand, a Google Scholar scoping search (run 15.10.2018) returned disproportionally many (ca. 15000) articles when

running a full text search. Restricted to title search only, the number of results went down to 28. However, as this search method did not match the search strategy for the other databases, LF and JK decided the best choice was excluding Google Scholar from the search.

The systematic search used a combination of free text terms and Medical Subject Headings (MeSH) to identify relevant literature. The systematic search strategies adjusted for the individual databases can be seen in *Table 1*. The subject headings were adapted for each database as the applicable subject headings differed between databases.

Assessing studies relating to the impact of patients using health records on patient engagement in their personal care was the aim of the literature search. No publication date, article type, or language restrictions were applied at the time of searching. LF screened the reference lists of relevant literature reviews identified in the database search results and the included studies for any potentially missed additional studies.

Table 1. Systematic search terms for Medline, HMIC, Embase, and PsycINFO via Ovid.

Data base	Systematic search terms
Medline	1. Patient Participation/ 2. (patient* adj3 (engag* or activation or empower* or involv* or participat*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 3. 1 or 2 4. Electronic Health Records/ or Health Information Exchange/ 5. (electronic health record* or electronic medical record* or personal health record* or EHR* or EMR* or PHR*).mp. [mp=title, other title, abstract, heading words] 6. 4 or 5 7. 3 and 6
HMIC	1. Patient Participation/ or empowerment/ or Patient empowerment/ 2. (patient* adj3 (engag* or activation or empower* or involv* or participat*)).mp. [mp=title, other title, abstract, heading words] 3. 1 or 2 4. Electronic patient records/ or Lifelong electronic health records/ or Summary care records/ 5. (electronic health record* or electronic medical record* or personal health record* or EHR* or EMR* or PHR*).mp. [mp=title, other title, abstract, heading words] 6. 4 or 5 7. 3 and 6
Embase	1. Patient Participation/ or empowerment/ 2. (patient* adj3 (engag* or activation or empower* or involv* or participat*)).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word] 3. 1 or 2 4. Electronic Health Record/ 5. (electronic health record* or electronic medical record* or personal health record* or EHR* or EMR* or PHR*).mp. [mp=title, other title, abstract, heading words] 6. 4 or 5 7. 3 and 6
PsycINFO	1. Client Participation/ or involvement/ or empowerment/ 2. (patient* adj3 (engag* or activation or empower* or involv* or participat*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] 3. 1 or 2 4. Medical records/ or Client Records/ 5. (electronic health record* or electronic medical record* or personal health record* or EHR* or EMR* or PHR*).mp. [mp=title, other title, abstract, heading words] 6. 4 or 5 7. 3 and 6

Study selection criteria

The inclusion and exclusion criteria considered for the article selection related to the studies' population, intervention, comparison, outcomes, and study types. Quasi-experimental studies were included in the review as argued for by Rockers et al. (2015). Qualitative studies were excluded due to the difficulties in comparing outcomes across studies. Both inclusion and exclusion criteria are detailed accordingly in *Table 2*. Articles were included if the inclusion criteria were met. Otherwise, articles were excluded.

Table 2. Inclusion and exclusion criteria for the systematic search results on the impact of patient electronic health record (EHR) access on patient engagement related variables.

	Inclusion	Exclusion
Population	Adult subjects (patients and carers including parents)	Individuals below 18 years of age
Intervention	EHR (electronic health record) / PHR (personal health record) access for patients, including interventions with EHR-based messaging or communication with healthcare professionals	EHR access for healthcare professionals only, access to health portal without personal health record access, health reminders only
Comparison	Any comparison or control group	No comparison or control group
Outcomes	Any measure or variables related to patient engagement, activation, empowerment, involvement, or participation	Studies that report only healthcare professionals' or patients' anticipations or opinions of potential patient EHR/PHR access impact on patient engagement, activation, empowerment, involvement, or participation; or studies that do not consider these variables at all
Study and publication type	Original research (apart from qualitative studies), randomized controlled trials, cluster randomized trials, cohort studies, case-control studies, quasi-experimental studies	Protocols, ongoing research, conference proceedings, purely qualitative studies, commentaries, editorials

Screening

Two independent reviewers screened all titles and abstracts for inclusion. Due to the number of abstracts and availability of the second reviewers LF reviewed all abstracts while Lily

Roberts (LR) reviewed abstracts 1-1713 and ALN reviewed 1714-3427. Disagreements regarding inclusion or exclusion of papers were settled through appraisal by a third reviewer (ALN and LR respectively). Cohen's kappa, κ, was calculated to assess agreement rates between first and second reviewers. Once the screening of abstracts was complete, the full texts were collated and reviewed independently by two reviewers according to the inclusion and exclusion criteria. Cohen's kappa, κ, was calculated for the full-text review. The reviewers (LF and ALN) settled disagreements through discussion. For additional information on the search and screening process, see *Figure 6* in the *Results* section.

The reference lists of included studies and the relevant literature reviews identified during the abstract screening were then screened for any possible further pertinent publications. Any articles LF identified as potentially relevant to the review were cross-referenced to the database search results. If the articles were present in the previously screened content, they were excluded.

Data extraction

The data from the articles was collated into a table by LF and reviewed for consistency by ALN. The information extracted from the included studies was: first author's name and year of publication, participant information (numbers consented and population), study duration, retention rates based on ratio from consented participants to those included in analysis, intervention information, outcome measures, and results.

Data synthesis

A narrative data synthesis was conducted based on the extracted data. A meta-analysis was deemed inappropriate due to the varying interventions, study types, and outcomes. Instead, an overview table of trends, *i.e.*, increase, decrease or no change, was created for an at glance impression of health record access impact on patient engagement related variables (see *Table 9*). As an extension to the PRISMA guideline the adherence to the Synthesis Without Meta-analysis (SWiM) reporting guideline (Campbell et al., 2020) was logged in *Appendix A: Table 42*.

Quality appraisal with risk of bias assessment

Pre-post-studies were considered as cross-sectional if the relevant results were based solely on the post timepoint. As quasi-experimental studies were included in the systematic review the risk of bias assessment tool needed to be selected accordingly. The commonly used tools ROB 2 (Sterne et al., 2019) and ROBINS-I (Sterne et al., 2016) are limited to randomised trials and non-randomised trials respectively. Hence, ROB 2 and ROBINS-I were not the most appropriate tools to achieve a comparable assessment across the study types included in the review. However, as comparable outcomes for the risk of bias assessments across all studies were deemed important, the Mixed Methods Appraisal Tool (Hong et al., 2018, 2019), short MMAT, was selected to assess risk of bias.

The MMAT consists of five questions for each study type. Depending on the study type different criteria are addressed. For the given review, the criteria for three study types, *i.e.*, quantitative randomised controlled trials, quantitative non-randomised and quantitative

descriptive, are relevant. For quantitative randomised controlled trials, the assessed criteria are:

- appropriate randomisation,
- comparableness of groups at baseline,
- completeness of outcome data,
- blinding of outcome assessors, and
- participant adherence to intervention (Hong et al., 2018, 2019).

Quantitative non-randomised studies are scored on:

- representativeness of participants for target population,
- appropriateness of measurements regarding outcomes and intervention,
- completeness of outcome data,
- accounting for confounders in design and analysis, and
- the administration of intervention as intended (Hong et al., 2018, 2019).

Finally, quantitative descriptive studies are appraised based on:

- relevance of sampling strategy to research question,
- representativeness of sample for target population,
- appropriateness of measurements,
- low risk of nonresponse bias, and
- appropriateness of statistical analysis for the research question.

The risk of bias for all included studies was assessed by LF using the MMAT. The results of the assessment were then checked by ALN. Any disagreements were discussed and re-assessed accordingly.

Results

The given systematic literature search identified 4471 articles. After duplicate removal, 3427 articles remained. During abstract screening 3323 articles that did not meet inclusion criteria (*n*=3264) or were additional duplicates (*n*=59) were excluded. The agreement rate was fair with *κ*=.35 (89% agreement) for the first half of articles screened by LF and LR and *κ*=.26 (95% agreement) for the second screened by LF and ALN. During full text screening 61 out of 73 original articles were removed by LF and ALN (almost perfect agreement *κ*=.86, 96% agreement). Reasons for exclusion were the following:

- 13 qualitative studies
- 46 studies not relevant according to selection criteria, and
- 2 studies of uncertain scientific standards.

The articles excluded due to concerns regarding their scientific integrity were: "*The Role of PAEHRs in Patient Involvement*" by Wass and Vimarlund (2018) and "*Exploring patients' perceptions of accessing electronic health records: Innovation in healthcare*" by Wass, Vimarlund, and Ros (2019). The two articles reported the same data sets with extremely similar content along with several identical passages without any acknowledgement of a correlation between the publications. The results were reported slightly differently in the articles as the agreement and disagreement items on a five-point Likert scale were aggregated in one publication (Wass & Vimarlund, 2018) but not in the other (Wass et al., 2019). Overall, the disregard of scientific standards in regards to publication and reporting caused LF and ALN to agree on excluding both articles as it was not possible to ensure the integrity of the underlying research. *Figure 6* illustrates the search and screening process.

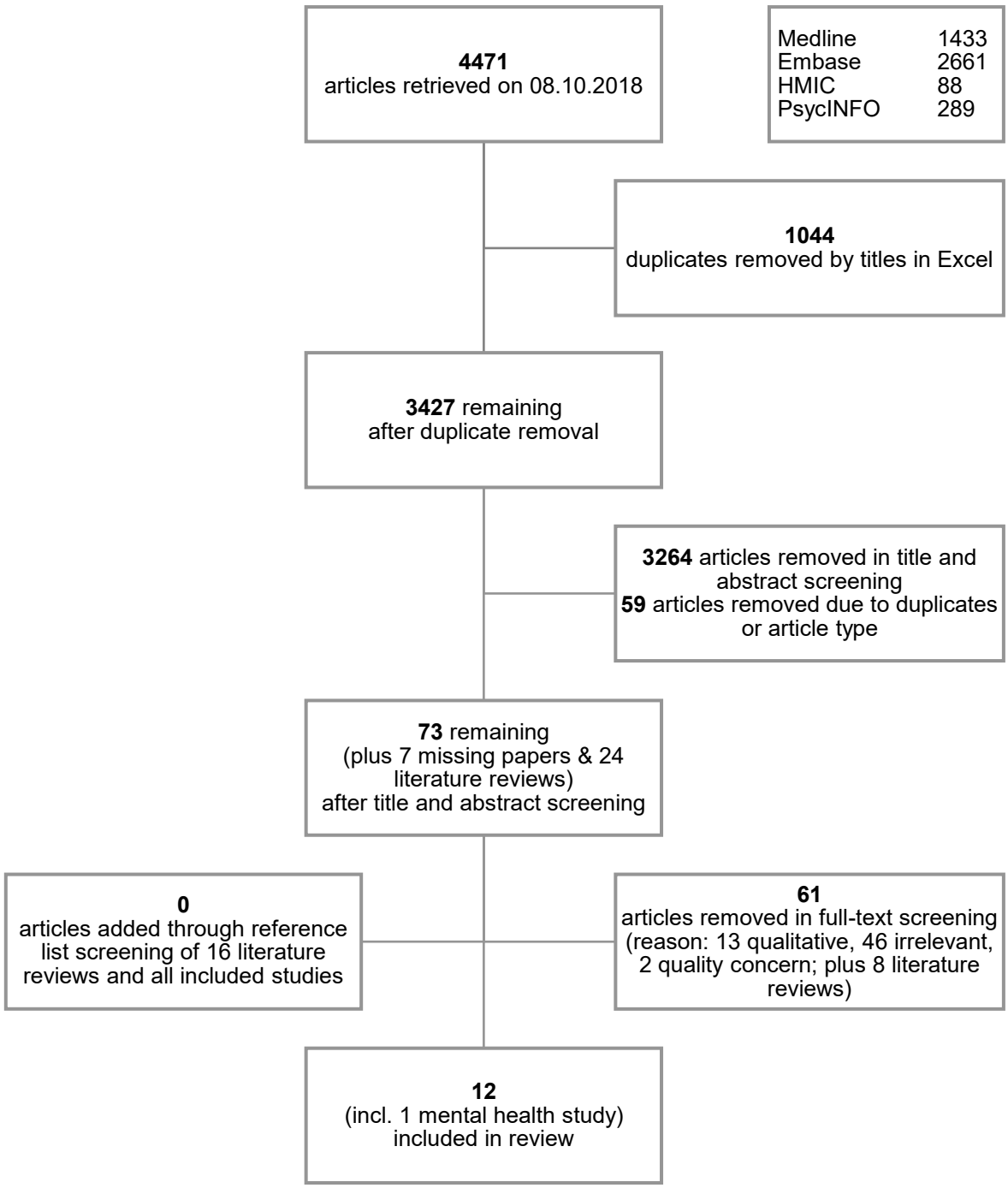


Figure 6. Systematic search schema for the literature search run on 08.10.2018 in Medline, Embase, HMIC, and PsycINFO via Ovid.

In total, 12 articles reporting on 13 studies with 9787 patients, published between 2007 and 2018, from four countries (USA: *n*=7, Netherlands: *n*=3, Canada: *n*=1, Finland: *n*=1) met the inclusion criteria. All included articles were written in English. Two randomised controlled trials (RCT), one cluster randomised controlled trial (cRCT), four cross-sectional surveys, and six quasi-experimental studies were described in the included articles. As Nagykaldi et al. (2012) report on both a pilot and full study including the same intervention but with different outcome measures, their intervention is counted twice below for the purpose of this evaluation.

The interventions and settings varied considerably across the included studies. Access to personal health records or medical history was provided most, *i.e.*, in ten out of thirteen interventions (Crouch et al., 2015; Kipping et al., 2016; Kuijpers et al., 2016; Nagykaldi et al., 2012; Riippa et al., 2014; Toscos et al., 2016; Tuil et al., 2007; van der Vaart et al., 2014; Wright et al., 2014). As Nagykaldi et al. (2012) report on a pilot and full study including the same intervention but with different outcome measures, their intervention is counted twice for the purpose of this evaluation. Interventions that did not provide access to the medical records directly, integrated information from EHR in the intervention (Fauer et al., 2019; Krist et al., 2012; Milani et al., 2017). Fauer et al. (2019) visualised EHR content in their intervention and Krist et al.'s (2012) intervention drew information from the EHR to provide an interactive preventative health record. Finally, Milani et al. (2017) uploaded patient blood pressure readings into the EHR. Hence, while not all interventions directly displayed EHR content as a whole, all interventions were connected to EHR information and provided some form of PHR.

The second most common intervention feature was communication with healthcare professionals, which was present in seven out of thirteen studies (Crouch et al., 2015;

Kipping et al., 2016; Nagykaldi et al., 2012; Riippa et al., 2014; Toscos et al., 2016; Tuil et al., 2007). Tuil et al. (2007) added an option for patients to communicate with each other facilitated by healthcare professionals (HCP). While two interventions included co-created care or treatment plans (Milani et al., 2017; Riippa et al., 2014), another contained personal information regarding treatment (Tuil et al., 2007).

Compared to record access less commonly, access to test results was provided specifically in several interventions (Crouch et al., 2015; Fauer et al., 2019; Nagykaldi et al., 2012; van der Vaart et al., 2014). Provision of educational materials was not uncommon. However, while some interventions included general educational materials (Riippa et al., 2014; Tuil et al., 2007; van der Vaart et al., 2014), others utilised personalised educational materials and recommendations (Krist et al., 2012; Milani et al., 2017). Overall, more than one intervention contained progress information (Crouch et al., 2015; Milani et al., 2017), prescription renewals (Crouch et al., 2015; Kipping et al., 2016), appointment information (Kipping et al., 2016; Kuijpers et al., 2016), and reminders (Milani et al., 2017; Toscos et al., 2016). Toscos et al. (2016) trained participants on the use of the intervention's system with an optional refresher session. For further information and details on the included studies, see *Table 3-Table 5* for the data extraction table and *Table 7* and *Table 8* for the reported outcomes.

Table 3. Details of the studies regarding the impact of patient access to their electronic health records on engagement in their health included in the systematic review, part 1.

1st author	*study type*	*intervention*	*study duration*	*participant number**	*retention rate***	*population*	*outcome measure*
Crouch 2015	cross-sec	ePHR access minimum twice within the last year for user group; system includes test results, progress notes, and prescription renewals, messaging with HCP	n/a[+]	40	n/a[-]	HIV infected veterans	PAM, HCEI
Fauer 2019	quasi-exp	Access to real-time test results, medications, clinical trial enrolment, healthcare professional contacts and discharge checklist through app on a tablet	100 days[1]	32	76.2%	Caregivers of adult & paediatric hematopoietic stem cell transplantation patients	PAM-C
Kipping 2016	quasi-exp	portal featuring prescription renewal, appointment, communication with HCP, and educational functionalities	6-10 mos	79 baseline, 54 follow-up[~]	68.4%[~]	Patients with serious or persistent mental illness	MHRM as proxy for activation
Krist 2012	RCT	Portal provided a list of recommended prevention services personalised to patients using EHR data and offered health risk assessment, additional tailored explanatory and educational material available	66 wks	4500	n/a[2]	Primary care patients (18-75 yrs) needing range of prevention services	Screening uptake

Note. Study types are abbreviated as follows: quasi-experimental pre-post study (quasi-exp), cluster randomised controlled trial (cRCT), randomised controlled trial (RCT), & cross-sectional survey (cross-sec). Technology types are abbreviated as follows: web-based patient portal (portal), electronic personal health record (ePHR). The duration of studies is stated in days, weeks (wks), or months (mos). Age of study participants is stated in years (yrs).
*Number of participants included in the data analysis, **Retention rate of participants from consented participants to those included in the data analysis, [1]post haematopoietic stem cell transplantation, [2]data extraction from EHR, [3]based on number of participants completing 12-month survey, [~]based on participants responding to relevant measure, [+]one-off survey, [-]20 users & 20 non-users recruited, [#]survey response rate given instead, [x]responses included in analysis.

Table 4. Details of the studies regarding the impact of patient access to their electronic health records on engagement in their health included in the systematic review, part 2.

1st author	*study type*	*intervention*	*study duration*	*participant number**	*retention rate***	*population*	*outcome measure*
Kuijpers 2016	quasi-exp	Portal contained educational material, appointment overview, patient reported outcomes, feedback, physical activity support, in addition to EHR access	4 mos	73	79.3%	Women with histologically confirmed breast cancer currently receiving treatment or having received treatment within 3-12 mos	PAM
Milani 2017	quasi-exp	Co-created treatment plan, provision of personalized recommendations and educational material, blood pressure reading reminders, monthly progress reports through portal	90 days	556 (of which 400 usual care)	100%	Patients with uncontrolled hypertension	PAM
Nagykaldi 2012	cRCT	Portal contained features focussed on preventive services and wellness such as prevention history, tailored wellness plans, personal risk factors and preferences in addition to test results, medical history, and secure messaging with HCP	12 mos	384	71.4%	patients (40-75 yrs) & parents of patients (2-5 yrs) in primary care	PAM, prevention uptake
	cross-sec		6 mos intervention access	30	n/a[+]	Primary care patients (23-83 yrs)	Subjective involvement perception

Note. Study types are abbreviated as follows: quasi-experimental pre-post study (quasi-exp), cluster randomised controlled trial (cRCT), randomised controlled trial (RCT), & cross-sectional survey (cross-sec). Technology types are abbreviated as follows: web-based patient portal (portal), electronic personal health record (ePHR). The duration of studies is stated in days, weeks (wks), or months (mos). Age of study participants is stated in years (yrs).
*Number of participants included in the data analysis, **Retention rate of participants from consented participants to those included in the data analysis, [1]post haematopoietic stem cell transplantation, [2]data extraction from EHR, [3]based on number of participants completing 12-month survey, [~]based on participants responding to relevant measure, [+]one-off survey, [-]20 users & 20 non-users recruited, [#]survey response rate given instead, [x]responses included in analysis.

Table 5. Details of the studies regarding the impact of patient access to their electronic health records on engagement in their health included in the systematic review, part 3.

1st author	*study type*	*intervention*	*study duration*	*participant number**	*retention rate***	*population*	*outcome measure*
Riippa 2014	quasi-exp	Creation of care plan with HCP for all participants, control group received hard copy, intervention group had online access to the plan, portal with links to further information, messaging with HCP	6 mos	137	62.3%	Chronically ill patients from primary care	PAM
Toscos 2016	quasi-exp	ePHR with secure messaging with HCP and educational material, initial patient training on system use with optional refresher course, option for patients to upload information on blood pressure, heart rate, blood glucose, weight, and BMI, reminders to upload possible on request,	12 mos	173	86.5%[3]	Coronary artery disease patients	PAM
Tuil 2007	RCT	ePHR providing general and personal information about treatment and messaging with other patients and HCP	Unspeci-fied	180	73.8%	Patients undergoing in vitro fertilisation (IVF) or intracytoplasmic sperm injection (ICSI)	Self-efficacy, knowledge, involvement in decision-making
van der Vaart 2014	cross-sec	Portal includes educational material (without login), and after login also medical history, blood test results, quality of measures	5 mos	214	59.4%	Patients with rheumatoid arthritis	perceived impact on involvement
Wright 2014	cross-sec	Viewing of a personal problem list through ePHR as recorded within EHR	n/a[+]	3389	42.1%[#], 93.4%[x]	Patients of a large integrated care delivery system with EHR access	actions taken after viewing problem lists

Note. Study types are abbreviated as follows: quasi-experimental pre-post study (quasi-exp), cluster randomised controlled trial (cRCT), randomised controlled trial (RCT), & cross-sectional survey (cross-sec). Technology types are abbreviated as follows: web-based patient portal (portal), electronic personal health record (ePHR). The duration of studies is stated in days, weeks (wks), or months (mos). Age of study participants is stated in years (yrs).

*Number of participants included in the data analysis, **Retention rate of participants from consented participants to those included in the data analysis, [1]post haematopoietic stem cell transplantation, [2]data extraction from EHR, [3]based on number of participants completing 12-month survey, [~]based on participants responding to relevant measure, [+]one-off survey, [-]20 users & 20 non-users recruited, [#]survey response rate given instead, [x]responses included in analysis.

Risk of bias assessment results

The results of the MMAT risk of bias assessment are shown in *Table 6*. Ten out of thirteen studies had one or more potential risk of bias areas (rated either “no” or “cannot tell”). Five studies did not provide sufficient information to ascertain if risk of bias existed in one or more areas. Overall, three studies were evaluated as having no risk of bias issues or unanswered questions. As advised by the MMAT authors, no studies were excluded based on the risk of bias assessment results (Hong et al., 2018).

Table 6. Overview of the Mixed Methods Appraisal Tool risk of bias assessment results grouped by study category.

Study category	1st author	Question 1	Question 2	Question 3	Question 4	Question 5
Quantitative randomised controlled	*Question topic*	Appropriate randomi-sation	Baseline groups comparable	Complete outcome data	Blinded outcome assessors	Intervention adherence
	Nagykaldi 2012	■	■	■	■	■
	Krist	■	■	■	■	■
	Tuil 2007	■	■	■	□	□
Quantitative non-randomised	*Question topic*	Target population represented	Measure-ments appropriate	Complete outcome data	Confounders accounted for	Intervention proceeded as intended
	Fauer 2019	■	■	■	■	■
	Milani 2017	■	■	■	■	□
	Toscos 2016	■	■	■	■	■
	Kipping 2016	■	■	■	■	□
	Kuijpers 2016	■	■	■	■	■
	Riippa 2014	□	■	■	■	■
Quantitative descriptive	*Question topic*	Sampling relevant	Sample represent-tative	Measure-ments appro-priate	Low non-response bias	Statistical analysis appropriate
	Crouch 2015	■	■	■	■	■
	Wright 2014	■	■	■	■	■
	Nagykaldi 2012	■	■	■	□	■
	van der Vaart 2014	■	■	■	■	■

Note. Questions for each study category as described in Hong, Q. N., Pluye, P., Fàbregues, S., Bartlett, G., Boardman, F., Cargo, M., Dagenais, P., Gagnon, M.-P., Griffiths, F., Nicolau, B., Rousseau, M.-C., & Vedel, I. (2018). *Mixed Methods Appraisal Tool (MMAT), version 2018 user guide*. http://mixedmethodsappraisaltoolpublic.pbworks.com/
Questions were answered as either ‘■’ yes, ‘■’ no, or ‘□’ cannot tell.

Measurements of patients' engagement in their health and care

Nine studies used validated measures to assess patients' engagement. Seven of the 13 studies used the PAM or PAM-C to assess patients' engagement in their health and care (Crouch et al., 2015; Fauer et al., 2019; Kuijpers et al., 2016; Milani et al., 2017; Nagykaldi et al., 2012; Riippa et al., 2014; Toscos et al., 2016). Crouch et al. (2015) additionally used the Health Care Empowerment Inventory (HCEI). Kipping et al. (2016) utilised only the total score of the Mental Health Recovery Measure (MHRM) as a proxy for patient activation.

Overall, six studies assessed perceived involvement in personal care or behaviour and behaviour changes related to patient engagement. Two studies assessed prevention or screening uptake (Krist et al., 2012; Nagykaldi et al., 2012). One study considered actions patients took after viewing problem lists in their PHR (Wright et al., 2014). Another two studies recorded patients' subjective perceived involvement (Nagykaldi et al., 2012; van der Vaart et al., 2014). Tuil et al. (2007) measured patient empowerment as a mixture of self-efficacy, actual and perceived knowledge, and patients' involvement in decision making processes.

Results measuring patient engagement in personal care

In the following paragraphs the outcomes reported in the included studies are presented according to the applied measurements of patient engagement with personal care discussed above. *Table 7* and *Table 8* provide details on the reported outcomes. An initial at a glance overview of the trends of the recorded results is presented in *Table 9*.

Table 7. Results table presenting the reported outcomes from the 12 articles included in the systematic review, part 1.

1st author	*outcome measure*	*outcomes*
Fauer 2018	• PAM-C	• determinants of activation by caregiver group over time (controlled for vigour & perceived usefulness): ○ activation increase from baseline to discharge (baseline to discharge: 8.3 (2.5 SE), p=.001) ○ stable at 100 days (baseline to D100: 5.4 (2.6 SE), p=.04) • overall sample: ○ activation increased from mean=72.3 (12.5 SD) at baseline to 78.8 (14.0 SD) at discharge & mean=77.9 (14.0 SD) at 100 days • adult caregivers: ○ baseline mean=70.7 (12.8 SD) ○ discharge mean=76.0 (13.8 SD) ○ 100 days mean=73.5 (13.5 SD) • paediatric caregivers: ○ baseline mean=73.9 (12.8 SD) ○ discharge mean=81.9 (14.0 SD) ○ 100 days mean=83.5 (13.0 SD)
Milani 2017	• PAM • Behaviour	• Increase of mean patient activation from 41.9 (6.6 SD) to 44.1 (6.7 SD), p=.008 • Decrease of low patient activation levels from 15% to 6% at 90 days, p=.03 • At 90 days: 71% of intervention patients achieve BP control versus 31% of control group, p<.001
Toscos 2016	• PAM	• patient activation increase baseline to 6 & 12 months not statistically significant, p=.22 ○ Baseline: 67.24 (14.80 SD) ○ 6 months: 68.13 (15.21 SD) ○ 12 months: 68.41 (14.89 SD) • usage of system & activation: ○ no statistically significant differences between low, active & super user groups, p>.43 ○ higher number of logins correlated to higher PAM score at 12 months (correlation=.17, p=.0213) but no significant correlation between usage (logins) and change in PAM score (r=.03, p=.71)
Kipping 2016	• MHRM as activation proxy	• significant increase of MHRM from baseline 70.4 (SD 23.6; n=79) to follow-up 81.7 (SD 25.1; n=54), p=.01 • self-empowerment subdomain increase from 10.1 (SD 3.8, n=90) to 11.5 (SD 4.0, n=55), p=.04
Crouch 2015	• PAM • HCEI	• Mean PAM score was 67.99 (12.47 SD) • Intervention group had significantly higher mean PAM scores (72.5, 11.27 SD) compared to control (63.49, 12.23 SD), p=.03 • HCEI informed, committed, collaborative, and engaged subscale (ICEE) mean score 17.35 (2.33 SD) ○ no significant difference between groups: intervention 17.80, 2.33 SD; control 16.90, 2.29 SD; p=.22
van der Vaart 2014	• perceived involvement	• No significant differences in empowerment related variables such as self-efficacy between groups • Descriptive statistics indicate 44% (38 of 86 respondents) of EHR users feel more involved in their treatment

Note. Patient Activation Measure (PAM), carer version of the PAM (PAM-C), Mental Health Recovery Measure (MHRM), Health Care Empowerment Inventory (HCEI).

Table 8. Results table presenting the reported outcomes from the 12 articles included in the systematic review, part 2.

1st author	*outcome measure*	*outcomes*
Wright 2014	• actions taken	• 56.1% (n=1901) took one or more action(s) after viewing their problem list ○ 32.4% (n=1098) looked up information on a condition online ○ 12.9% (n=437) discussed a condition with family or friends ○ 12% (n=406) adapted a health behaviour ○ 10.6% (n=359) messaged their HCP ○ 6.8% (n=231) set up an appointment with HCP ○ 5.8% (n=197) planned to adapt a health behaviour ○ 5.2% (n=177) called their HCP ○ 4.2% (n=142) looked up information on a condition offline
Riippa 2014	• PAM	• No significant effect of EHR access on PAM score, p=.17 ○ intervention group: mean PAM score increased from 63.74 (15.37 SD) to 64.79 (15.20 SD) ○ control group: mean PAM score decreased from 63.39 (14.51 SD) to 61.80 (14.17 SD)
Nagykaldi 2012	• PAM • Prevention uptake	• Significant increase in PAM score in intervention group versus control group: 47 versus 45 points, p=.0014 • Significantly larger portion of adult intervention group received all recommended prevention services compared to control (84.4% vs. 67.6%, p<.0001)
	• perceived involvement	• 80% agreed the intervention facilitated their participation in their care
Tuil 2007	• Self-efficacy • Knowledge • Decision-making involvement	• Patient empowerment measured as combination of ○ self-efficacy (General Self-Efficacy Scale, specific IVF self-efficacy) ○ actual and perceived knowledge (10 multiple choice questions & Visual Analogue Scale on IVF treatment) ○ patient involvement in decision processes (three items of Problem-Solving Decision-Making Scale) • No significant change in patient empowerment (time by group)
Krist 2012	• Screening uptake	• Significant increase of patients in the intervention group up-to-date with all prevention services between baseline & 16 months (11.4% to 15.2%, p<.001) • No significant difference for control group (11.1% to 12.6%, p=.07) • Significant difference in change from baseline to 16 months between groups (2.3%, p=.05) • Analysis of the intervention group differentiated by use-status of the portal: users had a 9.3% higher increase in being up-to-date on all prevention services than non-users, p<.02
Kuijpers 2016	• PAM	• No significant changes in PAM scores: ○ baseline 62.7, 13.1 SD; post 60.9, 15.4 SD

Note. Patient Activation Measure (PAM), carer version of the PAM (PAM-C), Mental Health Recovery Measure (MHRM), Health Care Empowerment Inventory (HCEI).

Table 9. Overview of recorded results measuring patients' engagement in their health and care.

1st author, year of publication	Patient activation (PAM)	Screening/prevention uptake	Behaviour change	Subjective involvement
Fauer 2018	▲*			
Milani 2017	▲		▲	
Toscos 2016	—			
Kipping 2016	(▲+)			
Crouch 2015	▲/(—#)			
van der Vaart 2014				▲ / —
Wright 2014			n/a-	
Riippa 2014	—			
Nagykaldi 2012	▲	▲		
				▲
Tuil 2007				—
Krist 2012		▲		
Kuijpers 2016	—			

Note. Where applicable (*i.e.*, not blank) the symbols used mean improvement (▲), no significant change (—), decrease (▼). Patient Activation Measure (PAM), carer version of the PAM (PAM-C), Mental Health Recovery Measure (MHRM), Health Care Empowerment Inventory (HCEI), *PAM-C, +MHRM as activation proxy, #HCEI, -cannot be described as behaviour change as no time comparison possible.

Patient activation measure, Healthcare empowerment inventory and Mental health recovery measure as patient engagement measures

Significant increases in PAM scores related to patient health record access were registered in several of the studies. Several pre-post-test and control group studies demonstrated a positive impact of PHR access on patient engagement. In one case, the mean patient activation increased from 41.9 (6.6 SD) to 44.1 (6.7 SD), *p*=.008, while the prevalence of low patient activation levels decreased from 15% to 6% at 90 days, *p*=.03 (Milani et al., 2017). Similarly, the PAM-C scores increased from *mean*=72.3 (12.5 SD) at baseline to *mean*=78.8 (14.0 SD) at discharge, *p*=.001, and *mean*=77.9 (14.0 SD) at 100 days (Fauer et al., 2019). Comparing intervention group and control group, the intervention group's PAM

scores were significantly higher at 47 versus 45 points, *p*=.0014 (Nagykaldi et al., 2012). Lastly, while the mean PAM score was 68.0 (12.5 SD), the intervention group had significantly higher mean PAM scores (72.5, 11.3 SD) compared to control (63.5, 12.2 SD), *p*=.03 (Crouch et al., 2015).

However, not all studies identified significant changes in patient activation. Toscos et al. (2016) found no significant increase from baseline (67.2, 14.8 SD) to six (68.1, 15.2 SD) and 12 months (68.4, 14.9 SD), *p*=.22. Likewise, Kuijpers et al. (2016) identified no significant changes in PAM scores from baseline (62.7, 13.1 SD) to post intervention (60.9, 15.4 SD). When comparing intervention and control groups, no significant effect of PHR access on PAM score, *p*=.17, was seen by Riippa et al. (2014). The intervention group's mean PAM score increased from 63.7 (15.4 SD) to 64.8 (15.2 SD), while the control group's mean PAM score decreased from 63.4 (14.5 SD) to 61.8 (14.2 SD) (Riippa et al., 2014).

The one study using the HCEI as measure found no significant differences. The HCEI informed, committed, collaborative, and engaged subscale (ICEE) mean score was 17.4 (2.3 SD) with no significant difference between groups. The intervention group's mean score was 17.8 (2.3 SD) with the control group's score at 16.9 (2.3 SD), *p*=.22 (Crouch et al., 2015). In contrast, there was a significant MHRM score increase from baseline 70.4 (SD 23.6; *n*=79) to follow-up 81.7 (SD 25.1; *n*=54), *p*=.01, with a self-empowerment subdomain increase from 10.1 (SD 3.8, *n*=90) to 11.5 (SD 4.0, *n*=55), *p*=.04 (Kipping et al., 2016).

Considering self-efficacy as patient empowerment related variable, no significant differences between groups was observed (van der Vaart et al., 2014). Concordantly, patient empowerment measured as combination of self-efficacy, actual and perceived knowledge, and patient involvement in decision processes did not show significant change in patient empowerment in time by group (Tuil et al., 2007).

Patient engagement by perceived involvement

Perceived involvement was measured by asking about patients' subjective level of involvement in their personal healthcare. In one instance, 80% agreed the intervention facilitated participation in their care (Nagykaldi et al., 2012). In the second study, 44% (38 of *n*=86) of EHR users felt more involved in their treatment (van der Vaart et al., 2014). Overall, the inferences possible from these findings were limited by the subjective and high-level nature of the variables.

Patient behaviour and behaviour changes as indicators for patient engagement

EHR access had a positive impact on patient behaviours. Patients adhered to instructions and recommendations for their health and care more closely. Blood pressure control was achieved at 90 days by 71% of intervention patients versus 31% of control group participants, $p<.001$ (Milani et al., 2017). In Nagykaldi et al.'s (2012) study a significantly larger portion of the intervention group (84.4%) received all recommended prevention services compared to the control group (67.6%, $p<.0001$). Krist et al. (2012) investigated the uptake of prevention services. Patients in the intervention group were likelier to be up to date with all prevention services by 16 months (11.4% to 15.2%, $p<.001$), while no significant difference existed for the control group from baseline to 16 months (11.1% to 12.6%, $p=.07$). The difference in change from baseline to 16 months between groups was significant (2.3%, $p=.05$). The use of the PHR portal impacted the uptake of prevention services within the intervention group. Users had a 9.3% higher increase in being up to date on all prevention services than non-users, $p<.02$ (Krist et al., 2012).

The final study exploring patient behaviour related to PHR access took a different approach (Wright et al., 2014). The authors assessed if patients took actions after viewing their

problem lists and found that 56.1% (*n*=1901) did react with one or more action(s). Wright et al. (2014) recorded the actions of:

- looking up information on a condition online (32.4%, *n*=1098),
- discussing a condition with family or friends (12.9%, *n*=437),
- adapting a health behaviour (12%, *n*=406),
- messaging the HCP (10.6%, *n*=359),
- setting up an appointment (6.8%, *n*=231),
- planning to adapt a health behaviour (5.8%, *n*=197),
- calling the HCP (5.2%, *n*=177), and
- looking up information on a condition offline (4.2%, *n*=142).

Discussion

Summary of key findings

The most common measures for patient engagement, the PAM measure and its variant for carers, the PAM-C, were used in seven of the 13 included studies (Crouch et al., 2015; Fauer et al., 2019; Kuijpers et al., 2016; Milani et al., 2017; Nagykaldi et al., 2012; Riippa et al., 2014; Toscos et al., 2016). Improvements in PAM scores were present in four out of seven studies (Crouch et al., 2015; Fauer et al., 2019; Milani et al., 2017; Nagykaldi et al., 2012) with the other three reporting no significant changes (Kuijpers et al., 2016; Riippa et al., 2014; Toscos et al., 2016).

Other measures of engagement showed mixed results with no significant changes in the HCEI (Crouch et al., 2015) but significant improvements in the MHRM (Kipping et al., 2016). Self-efficacy related measures showed no significant changes (Tuil et al., 2007; van der

Vaart et al., 2014). The uptake of prevention or screening improved in both cases (Krist et al., 2012; Nagykaldi et al., 2012). The subjective involvement of patients increased as well (Nagykaldi et al., 2012; van der Vaart et al., 2014).

No study reported a decrease in patient engagement or related variables after an EHR based intervention. Overall, the results indicate a potential for PHR access to benefit patient engagement likely depending on implementations and circumstances. Given the mixed findings and paucity of evidence, an evidence gap remains.

Results in context

There is no consistent patient engagement definition (see *Chapter 1: Introduction*). As such there is also no consistency in measurement of patient engagement in the literature. While some of the measures used, *i.e.*, PAM, MHRM, and HCEI, are validated (Hibbard et al., 2004; Johnson et al., 2012; van Nieuwenhuizen et al., 2014), others such as subjective involvement levels (Nagykaldi et al., 2012; van der Vaart et al., 2014) are not. Furthermore, the assessed patient behaviours depend largely on the interventional contexts and aims. In the included studies, the behaviours ranged from uptake of preventative measures (Krist et al., 2012; Nagykaldi et al., 2012) to achieving blood pressure control (Milani et al., 2017). The descriptions of the interventions varied in their level of detail hindering replication of and building on previous research (Hoffmann et al., 2014). Hence, the comparability of interventions and their impact is limited based on their context and the definitions and measures used. Consistent reporting of interventions according to for instance the TIDieR checklist and guide (Hoffmann et al., 2014) could be beneficial in achieving more comparability across interventions and, thus supporting future systematic reviews.

The intention to use PHR interventions is related to various factors such as system and patient characteristics (Showell, 2017). Hence, patients that lack the necessary skills or knowledge to understand and use PHR information, would be less likely to try in the first place (Noblin et al., 2012; Showell, 2017). While the volume of logins to a PHR system did not significantly correlate with changes in PAM score by the post-intervention timepoint, a higher number of logins was correlated to a higher PAM score after 12 months (Toscos et al., 2016). Patients with higher PAM scores are more likely to use a PHR system more frequently.

Considering patient EHR information access can positively impact the quality of care (Neves et al., 2020; Pagliari et al., 2007; Sarkar & Lyles, 2020), a positive impact on patient engagement seems reasonable. Collating and comparing results from various studies is complicated by the scarcity of comparability of the selected measures and interventions. The lack of a common patient engagement definition (Higgins et al., 2017; Xu & Wong, 2017) is noticeable in the literature around PHR access. From the selection of the systematic search terms to the measures used to assess patient engagement, the indistinct patient engagement term is represented. The search terms needed to be adjusted to cover a wide range of related concepts as otherwise relevant publications would have been missed. In the included studies patient engagement is measured solely by proxy measures such as PAM (Hibbard et al., 2004, 2005) and perceived involvement.

PAM scores can give an indication of how patient engagement may be influenced by patient PHR access. However, patient activation does not equal patient engagement even according to the first author of the PAM development articles (Hibbard et al., 2004, 2005; Hibbard & Greene, 2013). Proposed direct measures for patient engagement, such as the PHE scale (Graffigna et al., 2015), are not represented in the reviewed studies' measures.

Patients' perceived involvement in healthcare has limited informational value as it is a very subjective and not standardised measure. However, in lieu of a convenient better measure, perceived engagement is still assessed (Nagykaldi et al., 2012; van der Vaart et al., 2014).

Drawing meaningful, transferable conclusions about the impact of patient PHR access on patient engagement is difficult. Across the thirteen studies included in the review, three different validated measures and several unvalidated ones were assessed. Few studies had no risk of bias and the interventional contexts differed strongly. Therefore, the mixed results with some studies reporting benefits to patient engagement and some finding no significant changes, are unsurprising as neither the measures, nor the interventions, nor the contexts are consistent.

Strengths and limitations

The strengths of the literature review laid in its rigorous methodology. The literature review was performed systematically with the approach being well documented throughout. The search strategy was developed and refined with support from an institutional librarian. Hence, ensuring the most relevant databases (Medline, Embase, HMIC, and PsycINFO) were searched using a combination of free text search and MeSH terms. The PRISMA guidelines (Page, McKenzie, et al., 2021; Page, Moher, et al., 2021) for reporting systematic review results were followed (see *Appendix A*: *Table 38* for the PRISMA 2020 checklist with item locations).

All screening stages, *i.e.*, of titles, abstracts, and full texts, were completed by two researchers independent of each other. While the assessment by two independent researchers can be considered a strength, the interrater-reliability variation from $\kappa = .26$ in

the first screening step to κ = .86 in the full text screening was large. The wide range might have at least partially resulted from the unclear definition of what constitutes 'patient engagement' and related concepts. Furthermore, it was not always apparent if patient engagement was considered a predictor of EHR access or as result thereof. Therefore, the tendency was to include ambiguous studies in the earlier screening stages and exclude irrelevant studies in later stages.

Future work

The non-existent agreed upon definition of patient engagement made the selection of relevant studies difficult. Adoption of consistent terminology around patient engagement would be highly beneficial. Common terminology is a foundation for standardised measurements based on validated measurement tools. Both conventional language and measurements would support evaluations of the impact interventions have on patient engagement, comparability of interventions, and transferability of findings. In future, assessing the impact of PHR access on patient engagement may be more effective in light of a consistent definition. Hence, a subsequent systematic review might be better placed to further assess results using meta-analyses. Furthermore, the systematic review should be updated in intervals to assess the current state of the literature including any new publications.

Conclusion

The measures used to assess patient engagement ranged from activation proxies, such as MHRM and PAM, to behaviour changes and perceived involvement in personal care. PHR

access did not have any negative impact on patient engagement in personal care. Although not all results showed clear evidence of positive changes in patient engagement levels through PHR access, the results tended towards improvements in patient engagement related variables. Hence, further investigation on how PHR access can be leveraged to support patient engagement is worthwhile.

Chapter 3: Patient and public involvement

Rationale for patient and public involvement in the project

The value added by involving members of the public and patients throughout all research stages and its importance has become increasingly recognised internationally (Duffett, 2017; Faulkner et al., 2015; National Institute for Health Research, 2015). Hence, research funders progressively expect applicants to be able to demonstrate clear strategies for projects' patient and public involvement (PPI) and engagement at the application stage (National Institute for Health Research, 2014). Furthermore, researchers may receive training on how to involve patients and members of the public in research (Yu et al., 2021).

Involving patients and members of the public has been advised and implemented across all stages of the research cycle from study conception to result dissemination (Brett et al., 2014; Carman & Workman, 2017; Duffett, 2017; National Institute for Health Research, 2014). For instance, enrolment rates in clinical trials can be enhanced by patient and

Chapter terminology

Imperial PSTRC – Imperial Patient Safety Translational Research Centre: Research centre at Imperial College London funded by the National Institute for Health Research (NIHR)

PPI – Patient and public involvement: Working with patients and members of the public on research projects across all stages of the research cycle

RPG – Research Partners Group: Imperial PSTRC group consisting of lay members advising researchers on PPI for their research projects

PPG – Project Partner Group: Group of three lay partners recruited specifically for the given research project

public involvement, while the evidence is less clear for participant retention rates (Crocker et al., 2018). Additionally, the dissemination of research results can be facilitated by patients involved in the research (Schandl et al., 2022). However, not every project necessarily involves patients at each research stage.

PPI can range across a continuum from a relatively tokenistic patient voice representation to active co-production or leadership of research projects (Carman & Workman, 2017; Duffett, 2017). Depending on the research stage, the type, and the level of involvement chosen, the outcomes and impact vary respectively. Thus, a certain amount of planning precedes thought through PPI activities to ensure the involvement suits the members of the public and patients, the research project, and its aims. However, it has been argued that there remains a level of unpredictability of PPI impact as researchers '*don't know what they don't know*' prior to initiating projects (Staley, 2015, p. 2).

The evaluation of PPI impact is not always straightforward even if attempted and reported by researchers (Mockford et al., 2012). According to a review of the literature for Involve, PPI impacts not only every stage of research on all levels, but also the patients and public members involved, the researchers, participants, organisations, and the wider community (Staley, 2009). To support reporting of PPI impact, the *Guidance for Reporting Involvement of Patients and Public* (GRIPP) checklist was developed and updated in a second version (Staniszewska et al., 2011, 2017). The items constituting the GRIPP and GRIPP2 checklists are intended to guide authors and peer reviewers in their critical appraisal of PPI in research projects (Staniszewska et al., 2011, 2017). The GRIPP2 checklist exists in two versions, one long and the other short. The long version targets studies with a principal focus on PPI including items on abstract contents. The authors note that not all checklist items are applicable or necessary in every instance and the checklist continues to be developed

(Staniszewska et al., 2017). The GRIPP2 checklist has been criticised for potentially fostering a false sense of objectivity and the need for justification of PPI (Scholz & Bevan, 2021). Hence, while a long form of the GRIPP2 is completed (see *Appendix A*: *Chapter 3: Patient and public involvement*), more emphasis is placed on reflective considerations in accordance with Scholz and Bevan (2021).

Considering the given research project is strongly concerned with patients' engagement in their health, a high level of patient involvement throughout the project was especially invaluable. As described by Gonzales et al. (2023), it was expected that the relevance for and alignment of the research questions and patient priorities would be enhanced by incorporating the patient voice in the research design phase. Furthermore, drafting study materials, such as participant information sheets, with patients and the public should make the materials more accessible to participants (Brett et al., 2022). Similarly, the assumption was that adding the patient perspective to the analysis of qualitative data would broaden the insights gained from the analysis. Hence, the patient perspective remained a point of focus throughout. Patients and members of the public were involved in this project as research partners to increase project relevance and its impact on future service provision. To establish the most suitable approach to the project's PPI the Research Partners Group was consulted initially. An overview over the PPI activities is shown in *Figure 7*.

	CONTRIBUTORS	ACTIVITY	TIMING
	Research Partners Group & Researcher	Discussion of • Patient and Public Involvement (PPI) plans throughout project • One constant group for whole project or new study partners for each study • Recruitment strategies for PPI project partners	Sep 2017
	Researcher with PPI manager	Planning for and recruitment of Project Partner Group (PPG)	Up to Jan 2018
	PPG & Researcher	1st PPG meeting • Introducing meeting attendees and agreeing principles (*e.g.*, confidentiality) • Introduction to and consideration of the project plans and aims • Discussion of project priorities and group's involvement preferences	Jan 2018
	PPG & Researcher	• Email update on project progress • PPG input on interview study materials such as participant information sheet and consent forms	Mar 2018
	PPG & Researchers	Interview data analysis training day	Jul 2018
	PPG & Researcher	Independent analysis of interviews by researcher and project partners • Opportunity to ask and discuss questions in regard to the analysis at any time	Aug-Dec 2018
	PPG & Researcher	PPG meeting to discuss interview analysis results • Prior to the meeting preliminary themes from the researcher were shared as basis for discussion • Themes were considered and adapted accordingly	Aug 2019

Figure 7. Overview of Patient and Public Involvement activities throughout the research project.

Research Partners Group (RPG)

The Research Partners Group (RPG) of the Patient Safety Translational Research Centre (PSTRC) at Imperial College London consists of eleven members of the public (Imperial PSTRC, 2018). The RPG was set up in August 2017 as part of the Imperial PSTRC PPI strategy and aimed to ensure researchers embed PPI within all stages of their research (Imperial PSTRC, 2018).

The RPG provides feedback to researchers to achieve the best possible PPI and engagement for their research projects. Researchers present their projects (*e.g.*, plan, documentation, overview of the study) and can ask specific questions to the group. The RPG advises for instance on recruitment of project PPI partners and which PPI strategies might be most suitable for a specific project and aim. Members of the RPG will raise any issues they see within a project and comment on the presented projects' overall PPI plans. Furthermore, the RPG members help raise the profile of Imperial PSTRC PPI work through blog posts and their participation in events (Kendall, 2018; Norton, 2017; Taylor, 2018).

RPG project involvement

LF initially presented the project plan to the RPG on 25 September 2017. In preparation for the meeting, a short lay summary was sent to the group to introduce the research project. Using the lay summary, the group members could start to familiarize themselves with the project plans, scope and aims. Furthermore, the group noted questions to ask during the meeting. After the researcher (LF) presented the project plans in the meeting, the group asked questions concerning the literature background, existing research in the project area, and the PPI plans.

Project feedback and recommendations

The RPG's feedback was wide in scope and went beyond advice on only the PPI elements of the project. The RPG noted that a representation of views from a spectrum of patients across language, experience, and ethnicity was important for the impact of the research project. Moreover, the group emphasized the importance of being clear on the interpretation and definitions of EHR and patient engagement used in the context of the project. Potential concerns stated by the RPG related to the interoperability of EHR systems and the confidentiality of contained information. Hence, including issues beyond the focus of the specific project.

One group member did not particularly like the project title 'Engaging patients in their care through electronic health record access' and suggested several alternatives. The two main ones were 'How do patients use EHRs to manage their health?' and 'Patients managing their health through EHR access'. However, the rest of the group did not share the concern and voiced no preference for any of the suggestions. Thus, the working title remained as it was for the time being.

The RPG encouraged the researcher (LF) in her intention of involving the same partners throughout the project instead of recruiting PPI partners for individual studies. In terms of the project's PPI, the researcher requested advice on characteristics and recruitment of Project Partner Group (PPG) members. The feedback from the RPG was to recruit a minimum of four people from diverse backgrounds while taking into account their professional skill sets, as it would be important for their involvement in the research project. The minimum of four members was suggested to ensure several people would attend each meeting. In addition, even if someone dropped out from the PPG for whatever reason there would still be several members present from start to end of the project.

Reflection on impact of Research Partners Group's contribution

The preparation of the lay summary in advance of the RPG meeting provided an initial opportunity for the researcher to practice communicating her project in a succinct manner accessible to lay members. This writing to a lay audience was helpful in shaping the project as it allowed for taking a step away from the project plans and looking at them through the eyes of someone new to the project.

The discussion with the RPG was valuable as it ranged from challenging to supporting the ideas and thoughts of the researcher on various issues. The feedback prompted further thought on project details leading to more robust study design. The RPG's emphasis on ensuring EHR impact was assessed for a wide spectrum of patients was recognized. Hence, the survey section on patient profiles in *Chapter 7: A cross-sectional survey outlining patients' motivation and abilities for using a PHR and the patient perceived impact of PHR access on care quality* was extended accordingly. The definitions of EHR and patient engagement were clarified in *Chapter 1: Introduction* to provide the level of information requested by the RPG.

Regarding the number of PPG members, the researcher decided together with the Imperial PSTRC Patient and Public Involvement and Engagement (PPIE) Manager ALJ to recruit only three members for the PPG instead of the advised minimum of four. This smaller number of PPG members was due to budgeting limitations and ease of scheduling for meetings. The more PPG members, the higher the workload for organizing meetings and scheduling would have been. As, even with three PPG members, one could have dropped out from the project while still having two consistent PPG members remaining recruiting three members was considered acceptable.

Project Partner Group (PPG)

Recruitment process

Based on the RPG feedback and discussions with the Imperial PSTRC PPIE manager ALJ recruitment for the project partner group (PPG) started in December 2017. To recruit members for the PPG an advert, informed by the guidance from the NIHR '*Patient and public involvement in health and social care research: handbook for researchers*' (2014), was written which detailed the expected tasks and prerequisites for the role. The advertisement was sent out together with an application form (see *Appendix A: Chapter 3: Patient and public involvement*) via ALJ's network of email contacts as well as advertised via the Imperial PSTRC's twitter account (@Imperial_PSTRC) (see *Figure 8*). The application deadline was set several weeks later at the beginning of January 2018 after the Christmas Holidays. In the meantime, LF and ALJ answered any queries about the project and application process as promptly as possible via email.

Figure 8. Tweet from Imperial PSTRC account advertising for patient and public representatives to join the research study.

Ten applications were received and reviewed independently by ALJ and LF based on applicants' motivation, skills, and experience relevant to the given project. After the independent scoring of the applications LF and ALJ discussed the results until they reached a consensus. Finally, applicants were notified of the outcome of their applications via email. More detailed application feedback was offered at the time of outcome notification and provided to the applicants upon request. Two applicants requested feedback. ALJ and LF first agreed on the written comments and then sent them to the applicants within a few days via email.

Group members

Two women and one man from working age to retiree were recruited. As advised by the RPG, the group had varying life experiences with different health experiences and status, professional and educational backgrounds. The members had previously contributed to PPI for research projects to varying degrees. However, none of the group had heretofore analysed research data in course of PPI or been trained to do so. The three group members were all present for every meeting and remained involved throughout the project duration as initially intended and recommended by the RPG.

Involvement throughout the project

The PPG's involvement in the project began with an introductory meeting consisting of ALJ, LF and the three group members. During the first meeting, after an introductory round and a description of the project plans, everyone's ideas and wishes for general base rules of conduct were discussed to ensure a comfortable and productive environment for collaboration. Moreover, the group's preferences for communication and meetings were established to be via email for organisational issues and in person for meetings whenever possible.

In some instances, when there were longer periods of time without a face-to-face meeting of the PPG email updates on the project progress with requests for input were sent. The same applied to smaller items such as questions and feedback regarding study materials, such as survey questions or participant information and consent sheets.

Co-researchers in interview study

Study preparation and planning

The plans for the interview study including its potential aims and methods were discussed initially during the first PPG meeting. Prior to requesting service evaluation approval, the study materials (*i.e.,* participant information sheet, consent form, semi-structured interview guide, and study methodology) were drafted by LF and reviewed with the PPG. Any issues raised were discussed so that LF could make the according changes to the documents and study procedures before submission for service evaluation approval. One comment made by a PPG member suggested having a short plain English guide on the CIE available when speaking to potential participants. This guide could support introducing the study to any patients who might take part.

As part of their involvement in the interview study the PPG wished to be part of the interview data analysis. Most of the group did not have any prior experience with qualitative data analysis. Hence, interview data analysis training was planned for the whole group and offered in collaboration with LD who had prior experience in training lay partners for research activities.

Training for data analysis

After discussion with the PPG a date for the training session was set that suited everyone involved. The training content and format was conceptualised and formed by LD, ALJ and LF. The whole day training took place from 9.30am to 4.30pm, 26.07.2018. The training was organised according to the agenda in *Table 10*. At the beginning everyone present (PPG members, ALJ, LD, and LF) introduced themselves. The learning objectives and expectations for the day were discussed and LF emphasised questions were welcome at

any time throughout the day. To begin with the interview study methodology was briefly recapitulated and debated before the topic of data analysis was approached. Tea, coffee, and snacks were available throughout the day and small breaks were encouraged.

Table 10. Meeting agenda for the Project Partner Group training day on interview data analysis on 26.07.2018.

Item	Time
Learning objectives and expectations	09:30
Project recap	10:00
Theoretical steps for interview analysis	10:15
Working example of interview data analysis	10:30
Practice coding of an interview	11:00
Lunch	12:00
Continuation of coding practice	12:30
Discussion of experiences and questions	15:15
Feedback	16:00
Close	16:15

The theoretical steps of thematic interview data analysis (see *Figure 9*) and relevant terms based on Braun and Clarke (2006) were introduced before LD showed a working example of one of her interview data analyses as illustration of the analysis steps. The thematic analysis steps of 1) familiarisation, 2) initial coding, 3) searching for themes, 4) reviewing themes, 5) defining and naming themes, and 6) writing the report were described. Consequently, LD answered questions from the group.

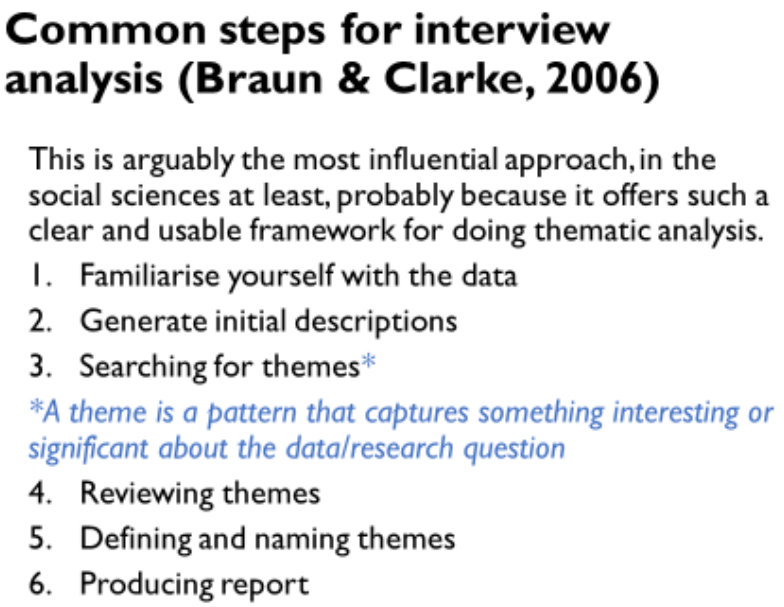


Figure 9. Project Partner Group interview data analysis training day (26.07.2018) overview slide about thematic analysis steps according to Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77–101. https://doi.org/10.1191/1478088706qp063oa.

Once all initial theoretical questions were answered, the researchers and PPG members endeavoured to perform the first two steps of the thematic analysis on two of the 31 interview transcripts. Everyone individually read the interviews and made comments in the page margins. Whenever there were questions related to the process of the analysis, they were solved by discussing the problem. During the individual working time participants took short breaks as they needed.

Towards the end of the afternoon, the group came together again and deliberated the codes everyone had come up with for the first two interviews. During this discussion many of the researchers' and PPG members' codes were very similar. However, the PPG members identified some codes from their point of view, which the researchers did not pick out.

To conclude the training day, the group went back to the expectations for the day they had written down in the morning. The group reviewed how their expectations of the training day mirrored their actual experiences. After the day, LF provided the group with a summary of the discussed codes and thanked the PPG again for their time. Furthermore, LF asked for feedback on the training day from the participants.

Reflection on data analysis training and expectations of the day

Many of the group's expectations gathered in the morning appeared to ring true when discussed at the end of the day. In addition to the expected items around making the analysis more comprehensive by adding the patient and public angle to it, the feeling in the afternoon was that everyone worked well as a group. Notably, the PPG did not necessarily expect the analysis and staying concentrated throughout it to be as challenging and tiring as it was.

After the training, the PPG members provided some comments on their experiences of the analysis training day via email. Based on this feedback, the PPG seemed to have enjoyed the training day and felt it was an interesting programme set within a productive atmosphere.

'I really enjoyed our day together and it was most instructive particularly being quite new to analysis of data. What made it especially good was that we had adequate time really to go into things in detail without too much pressure.' (PPG member 1, 27.07.2018)

'Just like to thank you […] for an interesting and stimulating training day. I feel more confident about analysing the interview data now. I look forward to receiving interviews to analyse and trust I can do justice to and help with this valuable research.' (PPG member 2, 27.07.2018)

In terms of coding together it was a very satisfying group experience with useful discussions that helped clarify our thinking and assumptions for certain codes. Together with the group, the codes were extended and clarified beyond what the researcher could have compiled otherwise. LF wrote down some reflections on how the process of coding with the PPG affected her own coding of the data at the end of the training day:

> *'To myself some things may have appeared obvious in their meaning, however, knowing I would discuss the codes with the group made me more aware in the way I coded the data. Hence, I coded more 'down to earth' without using terms from the literature that might have been unknown to the group.' (LF, 26.07.2018)*

For the training, a larger emphasis on keeping to the data might have been helpful from the start as the PPG sometimes tended to interpret meaning into the data that was not necessarily obvious within it.

For future training days, it would be good to clearly restate the rules for conversation at the beginning of the day as the group had agreed on during the first meeting. This reminder might have helped to keep everyone aware of staying on topic and avoided some communication difficulties caused by off-topic discussions.

Data analysis

Coding of data

After the training day, each PPG member was sent the discussed codes from the first two interviews as well as additional interviews to code at home. LF encouraged the group to ask her any questions that may arise during coding. However, the PPG did not require extended

support throughout the individual coding of the additional interviews. The group was aware that codes and themes would be discussed in a meeting once all data was reviewed and an appointment agreed.

Concerns regarding data security needed to be discussed with the Big Data & Analytical Unit (BDAU) director prior to sharing the interview data with the PPG. After the discussion, it was decided that the interviews had been sufficiently anonymised to avoid any potential re-identification of study participants. Hence, the interviews were emailed to the respective PPG members who then sent their codes and impressions back to LF. Once LF received all codes, she compiled them as basis for the next stage of theme identification.

Theme identification and discussion

As foundation for the discussion of themes, a preliminary thematic map was created by LF together with ALN based on the codes from all coders and interviews. LF initially wrote out all codes onto individual sticky notes. Once all codes were written, LF and ALN used a large whiteboard to group similar codes together and name the developing themes. Finally, once all codes were allocated the thematic map was photographed. LF created a digital version of the thematic map for ease of data storage and sharing.

The initial thematic map (see *Chapter 6*) was then shared with the PPG via email as a basis for future discussion. The choice if this discussion should take place face-to-face or via online meeting or email was left to the PPG members to suit their convenience. While most preferred a face-to-face meeting to online discussions, the scheduling was problematic to the work schedule of one PPG member. Hence, finally the decision was made to meet on a Saturday as this was the only option suiting the schedules of all PPG members.

To prepare for the meeting all attendees, PPG members and the researcher, reviewed the interviews, codes and initial thematic map. To support discussion during the meeting, notes were made in advance on quotes considered as illustrating a code especially well or contradicting it. Furthermore, the PPG were asked to record any quotes or codes that may not be represented in the initial thematic map or changes they would make to the thematic map with reasons why. On the day of the meeting, everyone brought their materials such as notes and coded interviews. The thematic map, themes and corresponding quotes were shown on a large screen and adapted based on the discussion. First, the main themes were discussed and contrasted with everyone's overall impression of the data. Subsequently, the quotes for each theme and subtheme were inspected and debated. Notes were made on any changes to the themes and important issues to be included in the write-up were highlighted.

The PPG and researcher agreed on all main themes and most of the subthemes of the initial thematic map. Overall, only in two out of four themes changes were made to the subthemes. Adjustments were made for subthemes of the *strengths and preferences* and *concerns and weaknesses* themes. In case of the *concerns and weaknesses* the *data privacy* subtheme was expanded by the mention of *patient control of access rights* as the PPG argued for the importance of directly representing this issue within the thematic map. Just discussing control over access rights within the topic of privacy was considered insufficient. The most modifications were made to the subthemes of the *strengths and preferences* theme. *Quality of care records* was merged with the *data accuracy* subtheme in *concerns and weaknesses* as it was a small subtheme, that presented the flipside of the matter. *Accessibility and empowerment* became *empowerment*, while its previous subthemes *access* and *information* became *speed and ease of access* and *personal health information* respectively. The

argument for not combining empowerment and accessibility was based on the themes' individual importance independent of each other. Accordingly, the theme with two subthemes was re-structured into three individual themes.

Reflection on data analysis

The analysis of the interview data was enriched by the PPG. The evaluation of the importance of quotes and themes were impacted significantly. Furthermore, while all main themes and the majority of the initial subthemes were confirmed, the adjusted themes were better defined and clearer than before. The discussion was insightful, friendly, and respectful. Although months passed between the initial analysis of the interviews and the discussion of the themes, everyone came to the meeting well prepared and motivated.

Feedback from the group regarding the data analysis both for the coding of the data and the theme discussion was positive.

> *'[The interview coding] did not take me as long as I expected […] I have used the codes we agreed but I am conscious that I have not really combined them into themes. However, I felt that a short summary of the main points from each interview might be useful […] All these participants were mainly concerned with test results so I suppose that is the overarching theme from all [coded interviews].' (PPG member 1, 02.08.2018)*

The prepared short summaries were part of the materials the PPG member used to prepare for the theme discussion meeting as a reminder of the general information across interviews

and to refer back to when discussing specific quotes and their interpretation during the meeting.

> *'I thought the [theme discussion] meeting went well - there was broad agreement for all the data analysis categories by us all. Where there were questions or divergence we were able to constructively discuss them and come to relevant conclusions or you [i.e., LF] will consider further. The project is developing well and it is interesting to see the proportion of interviews bringing up similar comments and others that had completely different comments that only they commented on.' (PPG member 2, 24.08.2019)*

The discussion atmosphere was constructive as in previous meetings but required some reminders to stay on topic and not get too lost in the interpretation of a single quote, as time was limited.

Reflection on the interview study co-research process

The PPG and researcher worked together well. The group had a strong interest in the project and was motivated to be as involved as possible. Everyone took part in discussions creating a rich insight into issues by highlighting varying perspectives. The face-to-face meetings had a constructive, respectful, and friendly atmosphere. The researcher needed to occasionally ensure that all group members voiced their opinions semi-equally. In some instances, discussions veered off topic or someone got slightly lost in the details. However, overall, everyone paid close attention and questions were answered or debated as required. The PPG's insights and feedback were extremely beneficial in preparing the study materials such

as participant information and consent sheets and the semi-structured interview guide. Unclear or difficult to understand phrasing could be flagged up and altered prior to commencing of the study.

Organising, preparing, and running meetings took up a lot of time. Due to the very different schedules of the group members in combination with a preference for in person meetings, scheduling meetings everyone could attend was difficult. In hindsight, keeping the number of PPG members at three instead of the initially recommended four, was likely helpful in terms of scheduling. More group members would have probably made scheduling even more complicated. Furthermore, because of sudden illness the data analysis training day needed to be cancelled on the day. Re-scheduling was again not straightforward. Hence, the discussion of the data analysis results was finally scheduled on a Saturday instead of a weekday.

Patient and public involvement throughout the project

Overview of patient and public involvement impact on the research project

Given the extensive occurrences of PPI throughout the project, an overview of the impact of PPI is provided below in *Table 11*. For lack of a better term the individual input from a PPI instance is listed in the column as “recommendation”. Especially in terms of, for instance, the interview analysis, “recommendation” does not quite fit the role of the provided input as the PPG members were co-researchers. However, as not all PPI input led to the exact suggested changes, the term “recommendation” was selected as label. “Changes made” was not applicable in all instances as decisions were often taken together, hence, defining what “*would have happened without PPI input*” was somewhat arbitrary.

Table 11. Overview of impact of patient and public involvement throughout the research project with justification for any deviations from PPI recommendations.

Topic	PPI body	Recommendation	Actions taken/ changes made	Justification for deviation
PPG recruitment	RPG	Recruit one, diverse PPG for the whole project with at least four members	Recruited one, diverse PPG for the whole project with three members	Budgetary, scheduling, & organisational limitations
Project write-up	RPG	Provide clear definitions on terms such as patient engagement and EHR	Terms are discussed and clarified in *Chapter 1*	n/a
EHR impact assessment population	RPG	EHR impact assessment for a wide spectrum of patients	*Chapter 7* survey section on patient characteristics extended accordingly	n/a
Interview study materials	PPG	Have plain English summary on CIE available when inviting potential participants to take part	Plain English CIE information was provided in participant information sheets, further information was available as needed, participants could ask the researcher questions before and after the interviews	n/a
Interview data analysis	PPG	Make some theme names clearer	Some themes and subthemes were re-named	n/a
	PPG	Merge two subthemes (*quality of care records* and *data accuracy*)	Subthemes were merged into *data accuracy*	n/a
Study contents and order	PPG	Agreement on starting with quantitative analysis of CIE status quo and using interviews to explore patient experiences and identify topics for quantitative survey	Proceeded as discussed	n/a

Note. Research partners group (RPG), project partner group (PPG), electronic health record (EHR), Care Information Exchange (CIE).

Reflection on patient and public involvement

Benefits

The opportunity to receive support from patients and the public via the RPG to start planning the PPI across the project and consider recruitment of project partners, was a privilege. Otherwise, the initial decisions on PPI would have been entirely one-sided. Through the RPG, the thoughts and ideas regarding potential PPI throughout the project could be amended to be viable but ambitious. There was a balance to be found between wanting to

coproduce the research while keeping the project manageable. Hence, the RPG meeting provided direction and parameters for the recruitment of a dedicated project partner group and their future project involvement.

The insights provided by the PPG were invaluable. Through the integration of their point of view within the project, the studies were shaped, and their results interpreted with heightened regard of patient perspectives and relevance for direct patient impact. Even more involvement from the group would have been optimal, but their involvement was maximised based on the given constraints. One instance of the PPG's impact was the creation of more inclusive, less literature driven codes during the interview data analysis with the group. Such codes then influenced the interpretation of the data accordingly as it was more data driven than based upon prior literature and pre-conceptions of the researcher. Furthermore, the themes' connection to their corresponding codes and quotes was strengthened by the critical discussions of the PPG members and researcher.

Considerations, potential pitfalls, and obstacles

From the experience of PPI in the given project there seem to be several things to consider when planning PPI. For one, involving patients in research can be quite resource intensive in terms of time and budget. If the aim is a close cooperation with patients and the public throughout a research project, a significant amount of time is necessary to organise and schedule meetings, attend them, keep everyone informed between meetings, and document the feedback and work completed. Additionally, the more people are involved in a project the more complex the task of finding times for meetings and assuring attendance becomes. Hence, while maximum coproduction for all decisions and every stage of each study may be the optimal aim, PPI will be limited by both researcher and lay partner resource

restrictions. Realistically, neither party can commit unlimited time, funding, or attention to a project.

As the members of the public are usually paid for their time spent on a project according to Involve and Imperial PSTRC guidance (Imperial PSTRC, 2016; INVOLVE, 2016a, 2016b), budgeting and organising payments beyond just refreshments at meetings is necessary. Hence, a significant amount of the researcher's time will be spent on the organisational tasks related to the PPI activities. Collating travel receipts, completing and submitting payment forms, potentially chasing payments all combined to take up more time than anticipated.

Discussion

Reflection on the impact of PPI within the project can be guided by the Health Inequalities Assessment Tool (HIAT) which aims at supporting the integration of equity into applied health research (FOR EQUITY, n.d.; Popay et al., 2023; Porroche-Escudero & Popay, 2020). The HIAT consists of five sections, the first four of which are concerned with the research process (Popay et al., 2023). The fifth section, on the other hand highlights researchers' responsibilities for research that is sensitive to potential inequalities (Popay et al., 2023). Using the PPI components of the HIAT as a guide to consider the implications of this project's PPI for inequalities provides a structured mode of reflection (see *Table 12*).

Table 12. The Health Inequalities Assessment Tool's patient and public involvement (PPI) components adapted from FOR EQUITY. (n.d.). Health Inequalities Assessment Tool (HIAT). Retrieved December 21, 2024, from https://forequity.uk/hiat/ with corresponding reflections on the project's PPI.

	Topic – PPI component	Corresponding reflection
1	Involvement of patients and members of the public in identifying the addressed problem and relevant dimensions of inequality	The Research Partners Group and Project Partner Group were involved in clarifying the research problem and ensuring clear and understandable participant information materials.
2	Involvement of patients and members of the public in shaping research questions	The research approach and studies were jointly discussed accordingly.
3	Involvement of patients and members of the public in shaping study design, analysis and data interpretation	The Project Partner Group was especially involved in the analysis and interpretation of the interview study (see *Chapter 6*) and for instance adapted the thematic map.
4	Involvement of patients and members of the public in planning and dissemination of findings	The planning and dissemination of findings could have been addressed more specifically with the Project Partner Group and should be considered in future work.
5	Transparency of involvement processes and feedback/complaints process for involved patients and members of the public	Feedback, both positive and negative, was actively sought out by the researcher and offered by the Project Partner Group. How the involvement was structured (*e.g.*, online or in person) and which activities were included (*e.g.*, data collection, analysis or interpretation) were jointly discussed and decided upon at the beginning.

According to the time and budget implications, achieving a balance between the project's PPI expectations or needs and resource limitations has to be considered – optimally before recruitment of PPI partners. Logically, with higher levels of patient and public involvement in a project come higher resource demands. Resource demands have been previously identified as a challenging impact of PPI (Brett et al., 2014). As such, it will depend on each project, its topic, and its resources to which degree patients and the public can and need to be involved. For this project, as it was inherently concerned with patients' engagement with their health, a concerted approach to PPI was essential. The point of view from the project partners was highly valuable in ensuring the quality and real life translatability of the research project and its outcomes.

Finding the right people to involve in the way most beneficial for a project is another issue to consider (Brett et al., 2014). Depending on the tasks patients and the public are predicted to be involved with, *i.e.,* providing feedback on study results or actually analysing data, different skills will be necessary. Hence, one needs to provide appropriate training to the PPI members or recruit those who already possess the relevant skills. However, the latter option will limit the diversity of research partners recruited.

Training provision might also depend on the duration for which individuals are involved in a project, from one-off feedback to all stages of a research project across several years. Furthermore, patients' and publics' experiences, knowledge and attitudes towards involvement can be vital for successful collaboration. While for this thesis project, for instance, no experience of a specific disease was pertinent, for some studies investigating symptoms of a specific disease, it might be critical for patients to have personal experience of it. Gauging the motivation of potential project partners for involvement was deemed more important in case of the given project as they were involved over a longer time period.

The reporting of PPI is not straightforward. Attempts have been made to provide guidance for reporting of PPI via, for instance, checklists (Staniszewska et al., 2011, 2017). However, these do not address issues like power imbalances and tokenism entirely and lack depth in terms of reflection on PPI (Scholz & Bevan, 2021). Furthermore, not all checklist items are applicable or necessary in every instance (Staniszewska et al., 2017). The GRIPP2 checklist does not appear to account for PPI extending beyond a single study to a series of studies as in this instance, further complicating its use. Moreover, the checklist appears most appropriate for publications "studying" PPI instead of reporting a co-produced research study. However, it is debatable in how far PPI impact can be investigated without affecting the co-production of research.

Conclusion

Working together with patients and members of the public throughout a research project can be incredibly rewarding and insightful. PPI needs to be well planned and organised to work smoothly. While sharing responsibilities with the lay partners may reduce researcher workload, the organisational burden PPI can create for the researcher, should not be underestimated. Although, there are issues to consider when organising PPI, such as resources in terms of for instance time and funding, the unique knowledge and insight added by the inclusion of the patients' and public's point of view within the research process makes it certainly worthwhile.

Chapter 4: Analysing patient registrations and access to a personal health record: Care Information Exchange case study

Introduction

There is rising focus on sharing information with patients and making care patient-centric (Department of Health, 2012). One opportunity to keep patients up to date with their health information is via personal health record (PHR) based data sharing. Sharing information from EHR, for instance via PHR, influences quality of care, such as patient-centredness (Neves et al., 2020) and patient engagement in their health can be positively affected (see *Chapter 2*: *Results*). The benefit of patient access to their PHR depends on patients' registration to and subsequent use of PHR systems. Logically, if patients do not access available shared electronic health records, the records cannot have any resulting impact. Thus, understanding if patients interested in accessing their PHR are completing the registration process and actually accessing their PHR is important.

Furthermore, investigating reasons underlying access and registration rates will be vital to identify levers to enhance PHR registration and access rates in future. The registration and access rates to PHRs likely differ between medical specialties and services considering their healthcare needs' differences and commonalities. Hence, data on the Care Information Exchange (CIE), a patient-controlled PHR, is used to assess the registration and access rates across medical services. These differences could possibly depend on the available personal health record functionalities in each service.

Aims and objectives

The aim of the study is to understand the patient use of the Care Information Exchange (CIE), a PHR intervention in North West London. Hence, the objectives are to:

1. Investigate patients' uptake of the intervention by
    a. Determining patient registration rates across different clinical specialties
    b. Assessing how frequently registered patients access their PHR
2. Explore the perceived usefulness of PHR system functionalities to patients
3. Provide basis insights for subsequent study design

A case study is conducted to establish a baseline of patients' registrations to and access of the Care Information Exchange (CIE) and their preferred system functionalities. The analysed data is collected from two sources. First, the percentage of patients completing the registration process for the CIE, as well as of those accessing it needs to be assessed to investigate in how far patients take advantage

Chapter terminology

Access rate: Percentage of registered users accessing the CIE within the month prior to 29.01.2018

Conversion rate: Percentage of patients invited to use CIE who complete registration

Early Intervention Services A-C: Early Intervention Services at three different locations

Higher access: Logging on the CIE at least twice within the month prior to 29.01.2018

Invited patients: Patients asked to register for the CIE

Renal Dialysis A-D: Renal dialysis services at four different locations

Registered patients: Invited patients who completed the registration process

of available PHR access. Second, patient perspectives on the most important functionalities of the CIE are assessed to illuminate possible reasons for registration and access rates among services analysed in part 1 of the case study.

The results of this study then inform the following studies. The information gained from *Part 1* of this study informs the selection of services for in depth exploration of reasons underlying the identified access and registration patterns. Results of *Part 2* provide insights for the design of the interview guide and survey questions for subsequent studies.

Methods

Part 1 – CIE registrations and access

The study was approved as a service evaluation of the CIE (reference number: 675796). Patient access to their electronic health records was analysed descriptively using data from the CIE, which is implemented by PKB. Specifically, for each service the following information was evaluated:

- Registration percentage, in terms of invited patients completing the registration for the CIE,
- percentage of registered patients accessing the CIE at least once in a given four week period, and
- percentage of patients accessing the CIE twice or more in a given four week period.

For the number of patients completing the registration for the CIE at the individual services the total numbers of patients invited to access the CIE was compared to the total number of patients who completed the registration process. The conversion percentage from invited to

registered users was calculated to enhance comparability between services irrespective of their total number of patients approached regarding CIE access. Access was defined as having one or more logins to the system within the four weeks preceding the data download. Users with two or more logins in the same time period were defined as 'higher access' users. The usage of the CIE was then compared among the services signing up patients to the system.

Results are based on data up to 29th January 2018. The services using the CIE in North West London by that date were as follows:

- Colposcopy
- Interstitial Lung Disease
- Major Trauma
- Multiple Sclerosis
- Neuro-oncology
- Oncology
- Renal Dialysis A[2]
- Renal Dialysis B
- Renal Dialysis C
- Renal Dialysis D
- Renal Transplant
- Rheumatology
- HIV
- Early Intervention Service A[3]

[2] Letters A to D denote renal dialysis services at different locations.
[3] Letters A to C denote early intervention services at different locations.

- Early Intervention Service B
- Early Intervention Service C.

Only data from services that actively recruited patients to the Care Information Exchange and had at least ten registered patients at the time was analysed. Services that were not recruiting patients at the time of data analysis were excluded for reasons of system access comparability. The services with less than ten registered patients were excluded for identifying the services with the highest and lowest registration and access rates to the CIE due to issues of their representativeness. Namely, the three Early Intervention Services A-C, Major Trauma, Renal Dialysis A, and Renal Dialysis D were disregarded for the sake of the given analysis. Hence, data from ten services was included for the purpose of this analysis.

Part 2 – CIE functionalities perceived as important by patients

The web-based cross-sectional survey, implemented in Qualtrics, was conducted between March 2017 and September 2017. In a convenience sampling approach, interested CIE users who accessed their CIE records during the data collection period were involved in the study. A message regarding the survey was displayed on all CIE users' homepage after log-in stating their views on the CIE would be appreciated. Further, it asked patients to follow the given link if they were willing to complete a short survey which they could take wherever they were at the time.

The survey question was based on the Care Information Exchange: Standard Operating Protocol developed from the literature (Jilka, 2016). Replies were not mandated. The assessed survey question was: "*Thinking about the features of the Care Information*

Exchange (CIE), what do you find most useful, and what would you like to see introduced in the future?". Participants could select all relevant options from a multiple-choice list covering all available functionalities across all services. To provide additional opinions especially regarding future additions to the system, participants could select the option "*other, please specify*" to enter free text suggestions.

Patients could fill in the survey more than once as it was posed to relate to a particular instance of using the CIE website and additional ideas regarding useful functionalities were possible. Thus, no attempts were made to prevent multiple entries from the same individuals. At no time during data collection did participants have direct contact to the survey team. Hence, no reviews or changes of completed survey responses were possible. The quantitative data was analysed descriptively in regard to patients' opinions on the most important CIE functionalities. No participant characteristics or personal data were collected in the survey. In the interest of proper reporting a Checklist for Reporting Results of Internet E-Surveys, short CHERRIES checklist, (Eysenbach, 2004) was completed (see *Appendix A: Chapter 4: CHERRIES checklist*).

Results

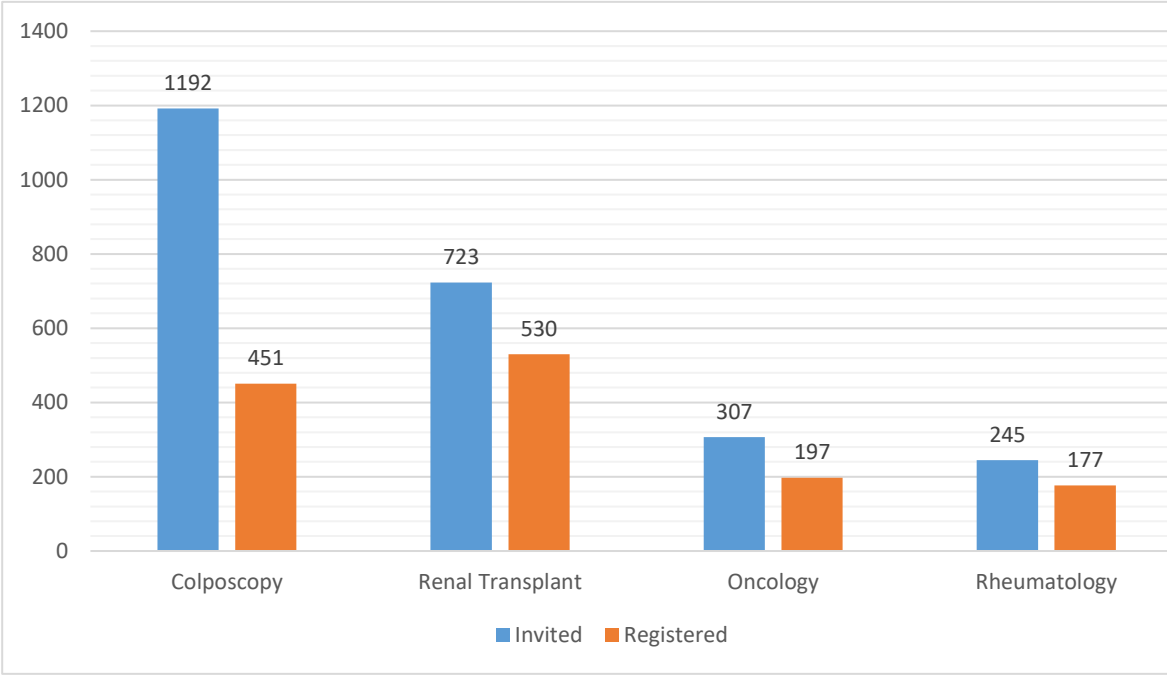
Part 1 – CIE registrations and access

Registration rates

The services with the highest total number of patients registered for the Care Information Exchange were Renal Transplant, *n*=530, Colposcopy, *n*=451, Oncology, *n*=197, and Rheumatology, *n*=177 (see *a)* in *Figure 10*). The number of patients registered to the services, which had more than ten registrations (compare *Methods*), ranged between

$r_{minimum}=r_{min}=15$ and $r_{maximum}=r_{max}=530$ (see *Table 13*) while the number of patients invited to the individual services ranged between $r_{min}=26$ and $r_{max}=1192$. Of the four services with more than one hundred registered patients the conversion rates of invited patients completing the registration to use the CIE varied. The conversion rates were at Renal Transplant, 73%, Colposcopy, 38%, Oncology, 64%, and Rheumatology, 72% respectively (see *b)* in *Figure 10*).

a)



b)

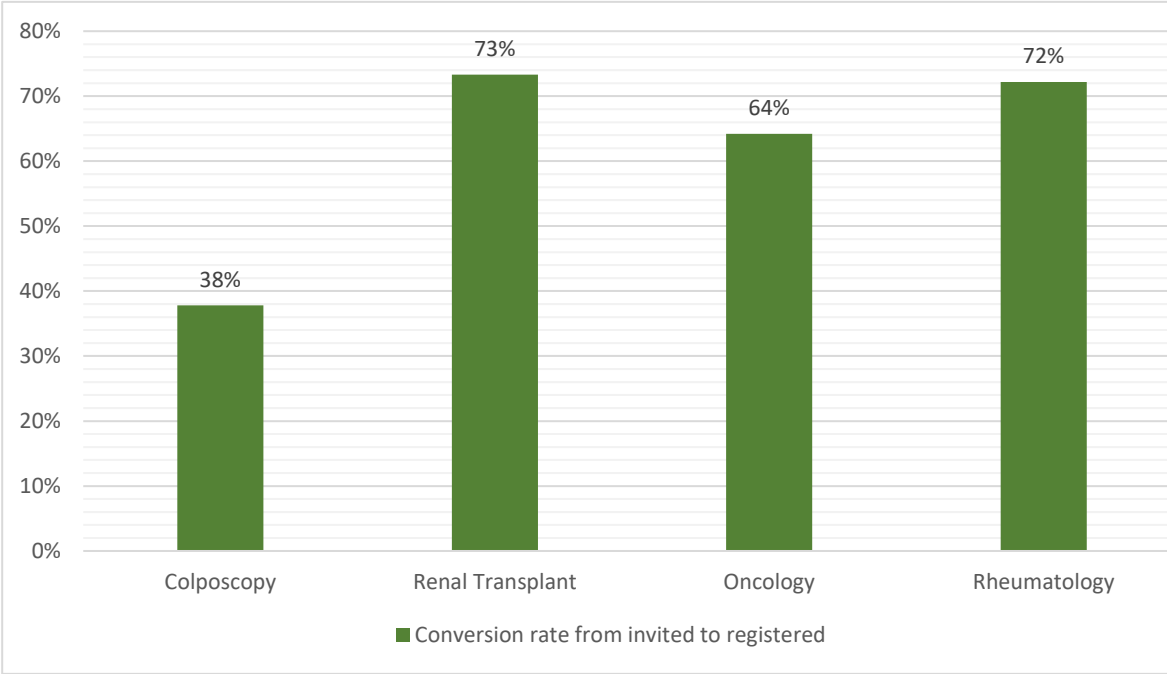


Figure 10. The four services with more than 100 registered patients with: a) the number of invited and registered patients and b) the percentage with which invited users completed the registration process for the Care Information Exchange at each of them.

The highest conversion rate from invited to registered patients was at Interstitial Lung Disease with 77%, *n*=20 (see *Table 13*). In comparison, the other services with between 11 and 100 registered users did not show particularly low or high conversion rates.

Table 13. Imperial College Healthcare NHS Trust services using the Care Information Exchange with respective go live dates and registration information on 29.01.2018.

Service	Go Live Date	Invited	Registered (*n*)	Conversion Rate
Colposcopy	03.10.16	1192	451	38%
Interstitial Lung Disease	12.12.16	26	20	77%
Multiple Sclerosis	21.08.17	142	52	37%
Neuro-oncology	05.09.16	84	47	56%
Oncology	28.11.16	307	197	64%
Renal Dialysis B	24.07.17	30	17	57%
Renal Dialysis C	10.07.17	36	15	42%
Renal Transplant	05.09.16	723	530	73%
Rheumatology	05.09.16	245	177	72%
HIV	05.09.16	100	60	60%

Note. Renal Dialysis B and C refer to services at different locations. Services with less than 10 registrations were excluded.

Patient access to the CIE

The number and percentage of users that logged on to the Care Information Exchange once or more during the four weeks preceding 29.01.2018 are given in *Figure 11*. Among these services all but Renal Dialysis C had more than ten patients who accessed the Care Information Exchange in the specified time frame (see *Figure 11*).

Colposcopy had the second highest number of users accessing CIE, *n*=119, after Renal Transplant, *n*=350, and before Oncology, *n*=117. However, in regards to the rate of users accessing CIE in relation to registered users at the service, Renal Transplant and Oncology had a rate of 66% and 59% respectively in comparison to Colposcopy's 26% (see *Figure 11*

and *Table 14*). The highest percentage of users accessing CIE were found at Neuro-oncology with 72%, Renal Dialysis B with 71%, and Multiple Sclerosis with 69% (see *Table 14*).

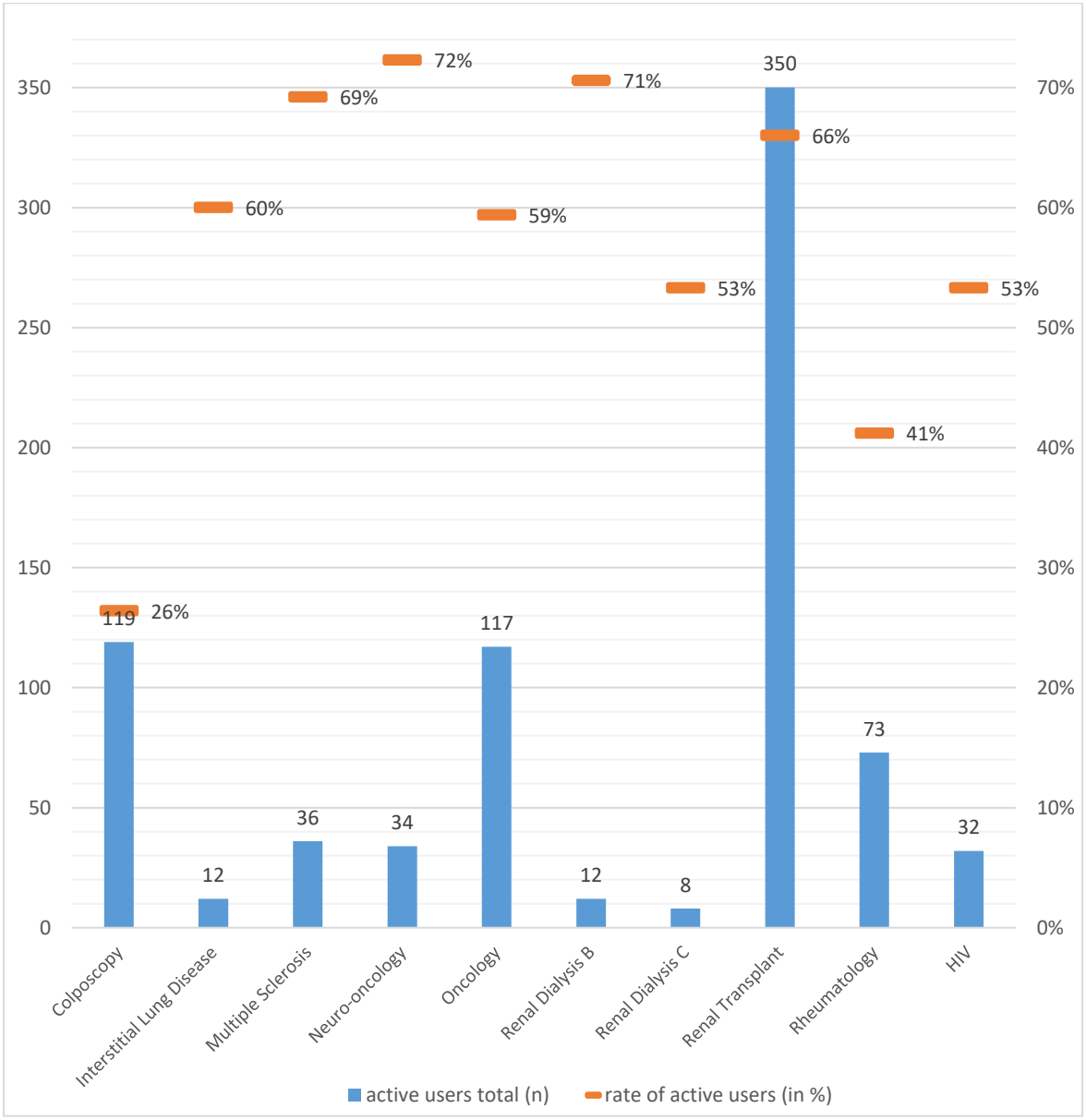


Figure 11. The number of users accessing the system at least once in the four weeks preceding 29.01.2018 and the according percentage of active users to registered users.

Higher access users in the same ten services logged on at least twice in the given four weeks (see *Table 14*). Colposcopy showed the lowest rate at 16%, followed by Rheumatology with 28%, HIV with 40%, and Oncology with 45%. Higher levels of access were most prominent at Renal Dialysis B with 65%, Multiple Sclerosis with 58%, Renal Transplant with 54%, Neuro-oncology with 53%, and Interstitial Lung Disease with 50% (see *Table 14*).

Table 14. Care Information Exchange access and higher access by service.

Service	Access	Rate with 1+ login	Higher Access	Rate with 2+ logins
Colposcopy	119	26%	72	16%
Interstitial Lung Disease	12	60%	10	50%
Multiple Sclerosis	36	69%	30	58%
Neuro-oncology	34	72%	25	53%
Oncology	117	59%	88	45%
Renal Dialysis B	12	71%	11	65%
Renal Dialysis C	8	53%	8	53%
Renal Transplant	350	66%	286	54%
Rheumatology	73	41%	50	28%
HIV	32	53%	24	40%

Note. Access refers to one or more logins within the four weeks preceding 29.01.2018. Higher access signifies two or more logins in the same period. Marked in light grey is the service with less than ten users in the access category. Renal Dialysis B and C refer to services at different locations.

Registration and access comparison

The services with the highest conversion rates were not the same as the ones with the highest percentage of users accessing CIE (see *Table 15*). For instance, Rheumatology had the third highest conversion rate paired with the second lowest access rate. Of the two services with the lowest conversion rates, namely Colposcopy and Multiple Sclerosis, the first also had the lowest access rate while the latter had one of the highest access rates.

Table 15. Services sorted from highest to lowest conversion rate from invited to registered patients.

	Service	Invited	Registered	Conversion Rate	Access Rate	Higher Access Rate
1	Interstitial Lung Disease	26	20	77%	60%	50%
2	Renal Transplant	723	530	73%	66%	54%
3	Rheumatology	245	177	72%	41%	28%
4	Oncology	307	197	64%	59%	45%
5	HIV	100	60	60%	53%	40%
6	Renal Dialysis B	30	17	57%	71%	65%
7	Neuro-oncology	84	47	56%	72%	53%
8	Renal Dialysis C	36	15	42%	53%	53%
9	Colposcopy	1192	451	38%	26%	16%
10	Multiple Sclerosis	142	52	37%	69%	58%

Note. Green marks the two highest percentages and red the two lowest ones. If the third highest or lowest values differed from the second ones by less than 2% it was marked as well. Renal Dialysis B and C refer to services at different locations.

Figure 12 shows the services with the most and least congruence between registrations and access based on data from *Table 15*. Renal Transplant had the highest registration in terms of total user numbers with relatively high access (*i.e.*, 66%). Even though the access was high it was not amongst the highest three access percentages (see *Table 15*). Hence, the high registration and high access field of *Figure 12* remained blank (*i.e.,* 'no service'). Colposcopy had low rates in both registrations and access. Rheumatology had low access but high registration rates and for Multiple Sclerosis the opposite was the case.

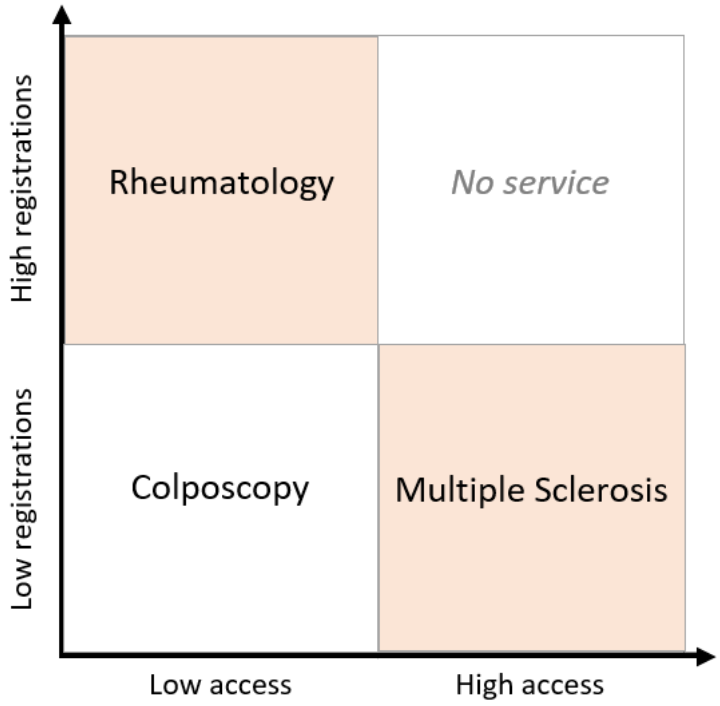


Figure 12. Congruence and incongruity between high and low Care Information Exchange registrations and access based on conversion rates from invited to registered patients and percentage of CIE accessing users out of the registered ones (see Table 15). Fields with incongruent registration and access rates are marked in red.

Part 2 – CIE functionalities perceived as important by patients

Participant characteristics

A total of 194 responses to the survey were completed. Overall, a minimum of 154 patients replied to the survey, while the additional responses may have been made by patients responding more than once. Patients from three trusts responded. On average six minutes were needed to fill in the survey. Most responses (*n*=131, 68%) came from services within one trust. Sixty-one responses (31%) did not specify which trust or service enrolled them.

Patients from the Renal service (*n*=69, 36%) markedly replied to the survey more frequently than patients from any other service (see *Table 16*). However, the patients (*n*=61, 31%) who

did not specify which service enrolled them may have come from any of the trusts and services enrolling patients to the CIE before and during the data collection timeframe.

Table 16. Number and percentage of survey responses regarding Care Information Exchange functionalities by registering department.

Department	Percentage	Count
Colposcopy	3.6%	7
Early Intervention Service A	0.5%	1
Early Intervention Service B	0.5%	1
HIV	2.1%	4
Interstitial Lung Disease	2.6%	5
Neuro-oncology	3.1%	6
Oncology	8.2%	16
Renal	35.6%	69
Rheumatology	12.4%	24
Unspecified	31.4%	61
Total	100%	194

Note. Early intervention service A and B refer to services at different locations.

CIE functionalities' perceived usefulness to patients

In total *n*=194 responses were collected regarding the CIE functionalities patients found most useful. *Table 17* shows the percentage and number of patients perceiving the given CIE functionalities as useful. While a clear majority of responses identified viewing of test results (83%) and appointment schedules (70%) as useful CIE functionalities, the usefulness of the other functionalities was supported by considerably fewer patients ranging from 8% to 27% (see *Table 17*).

In contrast to current useful functionalities, the differences between the CIE functionalities patients wanted to see in future were less clear cut (see *Table 17*). The requested future functionalities' support ranged from 32% for a video consultation to 65% for viewing hospital letters to the GP with an average of 49%. After the viewing of hospital letters to the GP the most requested functionalities were viewing diagnostic reports, 57%, and viewing

information about GP consultations, 56%. Adding information to one's own record was the second least requested, 37%, after video consultations.

Table 17. Percentage and number of patients (n=194) perceiving Care Information Exchange functionalities as useful.

Functionality	Current most useful functionalities		Requested future functionalities	
	percentage	number	percentage	number
Viewing test results	82.5%	160	48.5%	94
Viewing scheduled appointments	69.6%	135	43.3%	84
Viewing diagnostic reports	27.3%	53	57.2%	111
Viewing letters from hospital doctor to GP about clinic appointments	24.2%	47	65.4%	127
Adding information to own record	21.6%	42	37.1%	72
Viewing reports about discharge from hospital	16.5%	32	47.4%	92
Viewing information about GP consultations	16.5%	32	56.2%	109
Exchanging written messages or emails with a doctor	14.9%	29	51.0%	99
Viewing care plans	14.4%	28	49.0%	95
Having a video conversation with a doctor	7.7%	15	32.0%	62

Note. More than one functionality could be selected. 'Requested future functionalities' were responses to the question about which CIE functionalities patients wanted to be able to use in future.

Discussion

Under consideration in the given analysis was how the registrations and access to the CIE rollout in North West London went in the individual participating services up to January 2018. It was posited that both registration and access would differ between services as implementation in them varied as well. To this end, the services with the highest and lowest registration and access rates were identified from the available data. Afterwards the identified services are discussed in the context of the functionalities perceived as useful and those offered.

Part 1 – CIE registrations and access

CIE registrations

The process of patient enrolment differed from service to service. Most services offered the Care Information Exchange to all patients. However, at Neuro-oncology, Rheumatology, and Interstitial Lung Disease enrolment was more selective due to clinicians being the ones who informed patients about the Care Information Exchange. However, this did not seem to impact the percentage of patients accessing the Care Information Exchange in each service, as all of the four services were in the middle range concerning their patients' system access. Nevertheless, the role and status of the professional informing patients of the CIE may potentially have impacted on the number of patients that completed the registration in comparison to those invited per service. Two of the services where clinicians informed patients about the CIE, Rheumatology (3rd) and Interstitial Lung Disease (1st), were among the three services with the highest conversion rate from invited to registered patients. Considering Graffigna et al.'s (2016) findings that healthcare professionals can have a motivating impact on patients regarding mHealth and eHealth interventions, this hypothesis seems plausible.

The noticeable difference in the total numbers of invited patients between services, range r_{min}=26 and r_{max}=1192, may have been caused by a combination of several factors such as the total amount of patients using a service, patient and staff characteristics, go live dates, and enrolment process used. The services with the lowest and highest numbers of invited patients tended to also be the ones with the highest and lowest total numbers in terms of patients registered to use the CIE. However, the same was not true in regards to the conversion rates from invited to registered patients. Especially, while Colposcopy had the highest number of invited patients with the second highest number of registered patients, it

had the second lowest conversion rate. In contrast, Interstitial Lung Disease, the service with the lowest number of invited patients, had the highest conversion rate of all services at 77%. Potentially, the clinicians inviting patients to use the CIE pre-selected the interested patients. The recommendation of using the CIE coming from a clinician at the service, likely increased patients' motivation for the using the system (Graffigna et al., 2016).

In some cases, the conversion rates might have been impacted by how much patients were using digital technologies in their everyday lives. Hence, patients who were using digital technologies less such as for instance older patients (Harding et al., 2012) might have been less likely to register. As patient use of PHR depends on digital literacy, patients may need training or support in digital literacy to use PHR (Gellner et al., 2021). Furthermore, while digital literacy levels are increasing, digital literacy together with a lack of internet access still results in digital inclusion remaining an important issue (Honeyman et al., 2016).

Patient access to the CIE

Multiple Sclerosis had one of the highest access rates among all ten services assessed while Colposcopy had the lowest ones. Factors that might have influenced the percentage of patients accessing CIE versus patients registered could have been the duration and frequency with which patients engage with specific services. Some services, such as Multiple Sclerosis, may require more long term or repeated interactions with the specific service. Hence, these services might have had fewer patients who were registered but were no longer or not currently accessing the system in comparison to others. Conversely, services with a comparatively short or interspersed interaction period such as Colposcopy, in case of an inconspicuous result (*i.e.*, annually), might have had more patients who did not need to access their account within the assessed month while remaining registered. Thus,

differences in service use duration and frequency might have led to varying percentages of registered patients not accessing CIE.

However, contrary to the above example, Rheumatology also had low access rates. Hence, while parts of the access differences might have been due to the duration and frequency of patient service use, another influence would have been involved. Markedly, both Colposcopy and Rheumatology offered the use of six functionalities to their patients. These were: pathology results, radiology reports, appointments, library, inpatient activity, and messaging with the Patient Advice and Liaison Service team. Multiple Sclerosis, on the other hand, provided ten functionalities. In addition to the functionalities offered by Colposcopy and Rheumatology, the Multiple Sclerosis service made use of the medication, diagnoses, symptoms, and care plan functionalities. Moreover, their messaging functionality was not limited to the Patient Advice and Liaison Service team but extended to the clinical team which allowed patients to contact their clinical team directly via CIE. The four additional functionalities as well as the advanced messaging might have been more conducive for self-management activities which can be supported by digital health interventions in chronic conditions (Morrison et al., 2012; M. L. Taylor et al., 2022). A care plan and diary function, such as recording symptoms, can support self-reflection and awareness (Hui et al., 2017; Lau et al., 2013) which are also relevant for self-management. However, these functions do not necessarily motivate patients to register to and continuously use a PHR (Hui et al., 2017).

Nevertheless, in contrast to the six functionalities offered by all three services, the four additional functionalities of the Multiple Sclerosis service might have induced more continuous patient access to the CIE. Partly, because care plans would have been referred to repeatedly and symptoms would potentially have required updating by patients as they

changed. Thus, the number and type of functionalities offered to patients likely influenced the access rates (Morrison et al., 2012).

CIE registration and access rates congruence and incongruity

Colposcopy had the lowest access rate (*i.e.*, 26%) with a slightly indistinct registration rate, due to the second highest number of registered users being in combination with the second lowest conversion rate. Since clinicians did not approach patients about CIE at Colposcopy, the conversion rate could not have been enhanced by clinician recommendation, as potentially the case at Rheumatology. Moreover, the need for CIE access might have been more short-term compared to other services and more restricted by the functionalities available in comparison to Multiple Sclerosis.

With regards to the conversion rate, Interstitial Lung Disease, Renal Transplant, and Rheumatology were the strongest services (see *Table 15*), with the latter two only differing by 1.1%. Interstitial Lung Disease and Renal Transplant had medium levels of CIE access, while Rheumatology had the second lowest access rate. As mentioned before, at Rheumatology patients were informed about the CIE by their clinicians. This enrolment process might have caused patients who otherwise would not have signed up to the CIE to complete the registration. However, based on digital competences, health literacy and other factors, patients might not have started or continued using CIE (Sarkar et al., 2010).

The weakest conversion rates were present at Colposcopy and Multiple Sclerosis (see *Table 15*). Nevertheless, Multiple Sclerosis had some of the highest access values among all ten services assessed while Colposcopy had the lowest ones. As mentioned before, this might have been due to differences in service use duration and necessary self-management

leading to varying percentages of registered patients accessing CIE (Morrison et al., 2012; Yamin et al., 2011). Since only data covering the preceding four weeks was available for analysis, the system access data had limited informational value for understanding whether patients used the CIE during the periods of their service usage. Furthermore, the high usage in Multiple Sclerosis might have been due to its additional functionalities which might have induced prolonged patient access to the CIE.

Part 2 – CIE functionalities perceived as important by patients

Across all services the most useful functionalities were clearly demarcated from the less useful ones. The gap between the two functionalities selected most frequently as 'useful', *i.e.*, test results (*n*=160, 83%) and appointment schedules (*n*=135, 70%), and the third ranking one, *i.e.*, viewing diagnostic reports (*n*=53, 27%), was 82 (42%) out of a range of 145 (75%). This result portrays strong agreement between the participants in terms of the usefulness of the available CIE functionalities as evidenced by the strong distinction between the functionalities rated 'most useful'.

Viewing of test results and appointment schedules might be the two functionalities which alleviate the most organisational burden from patients. Being automatically notified by the CIE of available test results means calling the service to find out results becomes unnecessary. Furthermore, the current test results can be viewed in context of previous ones potentially providing a helpful overview of symptom development. Similarly, having a digital calendar of appointments providing a future and past overview of care means less paper-based organisation may be needed and the information can be accessed when- and wherever at a moment's notice.

While test results (83%) and appointment schedules (70%) were clearly the functionalities perceived as most useful of all available ones at the time, the most requested future functionalities differed. CIE users most frequently requested to view hospital letters to the GP in future (65%). The fact that both the test results (49%) and appointment schedules (43%) were at around 45% in terms of being requested in future, might be due to participants interpreting the question diversely. While some might have selected all features they wanted to keep in addition to 'new' ones for the future, others might have only selected those they wanted to be added in future. Hence, the less demarcated selection of features requested for the future in comparison to the current useful ones, might be due to participants' varying interpretation of the question. This varying interpretation represents a limitation of the study design which should be avoided in any future work.

Patient CIE access and available functionalities in context

How much patients choose to access the CIE might very well depend on the added value they perceive it to have (Fuji et al., 2014). This added value in turn is likely closely related to the functionalities the system offers patients as these define what patients can use the CIE for, *i.e.*, just viewing test results or consulting physicians via video streams and adding their own information. Functionalities supporting self-management seem to be important to patients (Hui et al., 2017; Morrison et al., 2012; Taylor et al., 2022) and may result in more frequent and persistent use of a PHR system. However, the use of CIE likely depends on more than the offered functionalities. Hence, investigating preferences of CIE use and functionalities in connection to access rates might offer further insights into reasons behind access rates and opportunities for future access enhancement through adjustments of CIE functionalities.

Generalisability and transferability

The generalisability of the results to a broader context may be limited by both sample size and variations in the offered functionalities from service to service. Hence, further insights into the topic are required. Furthermore, considering the differences between the services and their registration and access rates together with the likely impact of the offered functionalities on both, it could be posited that:

- The setting, *i.e.*, the specific service or speciality, and intervention itself, *i.e.*, the functionalities offered at an individual service, influence registration and access rates of a PHR.

However, transferability might be limited as clear impact of individual factors on for instance a specific service level cannot be established from the given results.

Strengths and limitations

Analysis of data regarding registrations and use of a system, here the CIE, provides a defined starting point for additional studies. The inclusion of data relating to several services gives a broader insight into the topic than focusing on users from a single service and their perspective from the start. Hence, the information from this study will provide guidance for the selection of the target population for future work. Moreover, the functionalities of a system can impact its use (Morrison et al., 2012). Hence, considering the access to a PHR together with its functionalities is useful.

In terms of *Part 2* of the study, considering that the given short survey was aimed at providing an initial starting point for further, more in depth studies, the lack of piloting, while still a limitation, should not be problematic. The reporting of *Part 2* was supported by the

completion of a CHERRIES checklist (see *Appendix A: CHERRIES checklist*). One limitation regarding participants' potentially differing interpretation of the question which functionalities they wish to see in CIE in future, has been discussed above. Furthermore, as no information on the participant characteristics was collected, the findings cannot be interpreted on how they might be influenced by these factors.

Conclusion

Registrations and access to the CIE at the individual services varied strongly. Multiple Sclerosis and Colposcopy were the services with the lowest registration rates based on the conversion rate while Interstitial Lung Disease, Renal Transplant, and Rheumatology were the ones with the highest values. In terms of access, Rheumatology and Colposcopy had the lowest percentages of active users. The highest rates of active users were found at Renal Dialysis B, Neuro-oncology, and Multiple Sclerosis. In *Part 2*, viewing test results and appointment schedules were perceived as most useful current CIE functionalities by a large margin. In future, the most requested functionality was viewing of hospital letters to the GP.

As PHR's potential for quality of care benefits cannot be fully exploited if registrations and access are suboptimal, it is vital to find approaches to improve both. Identifying the services with the lowest and highest registrations provided the first step in examining patients' engagement in their health through personal health record access. In future, patients' perspectives regarding their motivation, ability, and preferences to use the CIE and its perceived usefulness to them can be explored using the identified services as exemplars to, in turn, understand and explain the observed patterns and enhance the future CIE offer based on it. This work provided initial insights needed to further enhance the understanding

of personal health record registrations and access supported by the usefulness of individual functionalities as explored in *Part 2* of the case study.

Chapter 5: A cross-sectional survey on patients' perceived ability to understand PHR information and identify potential errors

Introduction

Patient access to health records can positively impact quality and safety of care (Neves et al., 2020). Furthermore, patient engagement in their health and care can be positively affected by access to health record information (see *Chapter 2*: *Results*). Regarding patient engagement as consisting of the dimensions of motivation, ability, and opportunity (see *Chapter 1*), PHR access can be taken as representing the opportunity dimension. Given the option to access PHR information, patients have an opportunity to engage with their health and care. The Care Information Exchange (CIE), a patient controlled personal health record (PHR), has been established at the Imperial College Healthcare NHS Trust (Poovendran et al., 2017). Once patients are registered to use the CIE system as discussed in *Chapter 4*, in how far this opportunity can be successfully utilized, depends on both the system and the patient. If patients register to and use the CIE as well as understand their record information, then they would be well placed to mitigate potential patient safety risks such as errors in their PHR. However, limited information is available on patients' ability to potentially identify errors in their PHR based on their understanding of the contained information (Bell, Mejilla, et al., 2017; Lam et al., 2021; Ross & Lin, 2003).

Aims and objectives

The given study aims to enhance the knowledge of patient PHR information understanding and its implications. Its objectives are to evaluate and assess:

1. Patients' perceived ability to understand their PHR information,
2. Barriers to information understanding,
3. Patient error identification, and
4. Types of errors identified by patients.

Methods

Study design and setting

A cross-sectional study on electronic survey data collected on patients' usage of the CIE was performed. The study reporting was based on the Consolidated criteria for reporting qualitative research, short COREQ checklist (Tong et al., 2007), and the CHERRIES checklist (Eysenbach, 2004) included in *Appendix A: COREQ checklist* and *CHERRIES checklist.* The CIE is a patient controlled PHR implementation in North-West London allowing for patient directed data sharing between patients and their healthcare professionals (Jilka, 2016; Poovendran et al., 2017). It provides patients with access to information on, for instance, their care plans, medications, test results, and medical history. The CIE integrates data from sources across healthcare trusts and care settings.

Ethics

The survey was run as part of a trust based service evaluation. Consequently, the survey underwent the appropriate service evaluation approval processes at Imperial College Healthcare NHS Trust. As such no further formal ethical consideration was required. The survey was approved by the Imperial College Healthcare NHS Trust's audit and information governance and assigned the reference number 675796.

Participants and sampling

In the given study a convenience sample of CIE users who accessed their CIE records during the data collection period was assessed. After log-in to the system a message inviting all active CIE users (*n*=682) to take part in the survey was displayed on the homepage. The message stated patient views would be appreciated and provided a link to the online survey which patients were asked to follow if they were willing to complete the short survey. As the survey was online it could be completed at any time or place according to patients' convenience.

Data collection

The data collection ran between March 2017 and September 2017. The online survey was implemented using the web-based survey software Qualtrics. The survey contained both quantitative (multiple choice) and qualitative (free text) elements providing complementing levels of information. The survey questions were based on the Care Information Exchange: Standard Operating Protocol developed from the literature (Jilka, 2016).

The quantitative data was used to assess patients' perceived ability to understand the information within their PHR (*i.e.*, "Did you find any information in your record difficult to understand today?") as well as identify errors (*i.e.*, "When using CIE today, did you notice any errors in your record?"). The qualitative data, on the other hand, provided information on the barriers to understanding and the type of errors patients identified in their PHR, if any. The use of both free text and multiple-choice questions was due to the complementary information gained from them. The free text fields allowed patients to expand on the reasons underlying their problems with understanding their PHR information and specify the type of errors they identified in their PHR.

No personal data was collected and at no time during data collection did participants have direct contact to the survey team. Patients did not have to reply to all questions and could complete the survey multiple times as it was posed to relate to a particular instance of using the CIE website.

Data analysis

The quantitative and qualitative data was analysed using Microsoft Excel 2013. Patients' registering clinical service and trust were analysed descriptively together with the quantitative data, while the qualitative data was analysed inductively according to the framework analysis method by Ritchie and Spencer (1994). Framework analysis is a six stage approach: 1) familiarisation, 2) identification of a thematic framework, 3) indexing, 4) charting, 5) mapping, and 6) interpretation (Ritchie & Spencer, 1994). Two researchers with previous experience in qualitative data analysis (LF and ALN) independently analysed the data. Afterwards, the two discussed their themes together and developed the thematic maps for a) the barriers to PHR information understanding and b) the type of errors patients

identified in their PHR, respectively. The themes were supported by quotes from the free text replies. Data saturation was reached. As there was no contact information or permission available to ask the participants for feedback on the results, they were not returned to patients for comments or discussion.

Results

Participant characteristics

In total the *n*=682 active CIE users submitted 210 survey responses (31% response rate). Out of the 210 responses, 160 stated that it was their first time responding to the survey (adjusted response rate of 24%). The additional 50 responses may have been made by patients responding two or more times as not all respondents specified how many times they had completed the survey already. The survey took an average time of six minutes to fill in.

Respondents came from three trusts, though most responses (*n*=134, 64%) came from services within one of the trusts. Patients from the Renal service (*n*=70, 33%) markedly replied to the survey more frequently than patients from any other service (see *Table 18*). However, 74 respondents (35%) potentially could have come from any of the trusts or services enrolling patients to the CIE before and within the data collection timeframe as they did not specify which trust or service enrolled them.

Table 18. Number and percentage of survey respondents by department registering them to the Care Information Exchange.

Department	Percentage	Count
Early Intervention Service A	0.5%	1
Early Intervention Service B	0.5%	1
HIV	1.9%	4
Interstitial Lung Disease	2.4%	5
Neuro-oncology	2.9%	6
Colposcopy	3.3%	7
Cancer Oncology	7.6%	16
Rheumatology	12.4%	26
Renal	33.3%	70
Unspecified	35.2%	74
Total	100%	210

Note. Early Intervention Service A and B refer to services at different locations.

Patients' ability to understand PHR information

Participants' ability to understand PHR information in this survey was self-estimated. Participants responded to the question if they found any information they saw in their record during their current visit to the site difficult to understand. In total 179 patients replied to the question. The majority (*n*=123, 69%) stated they had no difficulties understanding the information they saw within their PHR on that day. However, the remaining 56 participants (31%) indicated some difficulties with understanding the information. These difficulties were based on the barriers considered in the following paragraphs.

Perceived barriers to PHR information understanding

Participants described their difficulties with understanding the information in their PHR. From the given descriptions the researchers identified two main themes relating to: 1) difficulties with the information itself and 2) difficulties based on the technology or system relaying the information to them. The thematic map with the main and subthemes derived from the survey

responses is shown in *Figure 13*. The thematic map provides an overview of the information based and system-based factors influencing patients' PHR information understanding. The prevalence of system-based barriers indicates the importance of the technology usability for PHR usefulness to patients.

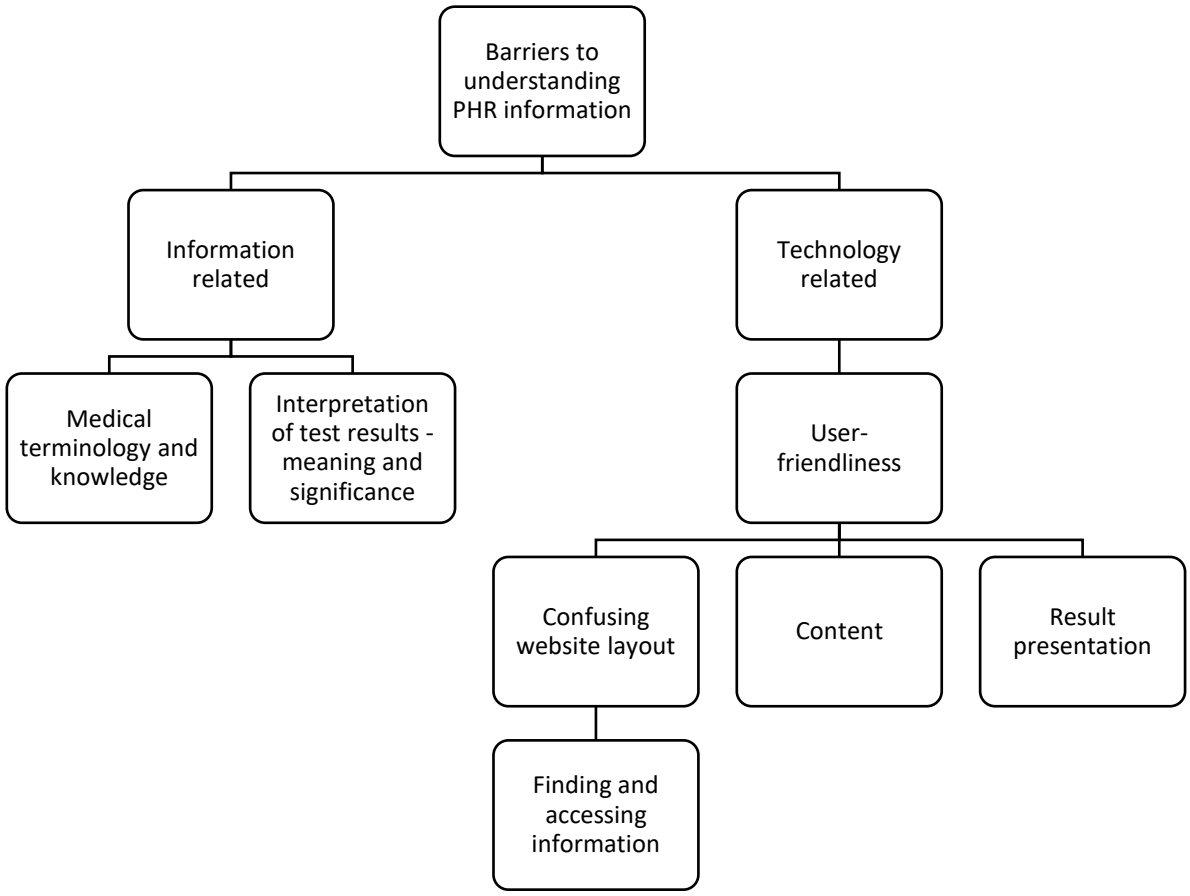


Figure 13. Thematic map of barriers to patients' understanding of personal health record (PHR) information.

The theme of information-based barriers had two subthemes, namely 1) medical terminology and knowledge and 2) interpretation of test results – meaning and significance (see *Table*

19 for quotes). The subtheme of *Medical terminology and knowledge* was based on participants' mention of needing a certain level of knowledge regarding medicine and its terms to understand test results, as well as abbreviations and jargon used when presenting PHR information. Hence, medical terminology and knowledge were perceived as prerequisites for understanding PHR information and a lack of it posed a potential problem.

Following the *Medical terminology and knowledge*, the subtheme of *Interpretation of test results – meaning and significance* is more specialised but likely related to the *Medical terminology and knowledge* subtheme. *Interpretation of test results – meaning and significance* is based on participants' issues with interpreting the meaning of test results and the impact results might have in terms of for instance actions needed in response to them (see *Table 19* for quotes). It seems probable that problems in understanding the medical content due to terminology and knowledge issues, would impact patients' interpretation of their PHR information.

Table 19. Information-based barriers to understanding personal health record information.

Information-based
Medical terminology and knowledge
- *'You obviously need reasonable medical knowledge to understand results.'* (ID 89)
- *'Plain English needed against various medical terms / acronyms used'* (ID 1)
- *'I do not understand the names of the test'* (ID 204)
- *'When jargon is used [information is difficult to understand]'* (ID 159)
- *'blood test result abbreviations'* (ID 185)
Interpretation of test results – meaning and significance
- *'All test results should have an information sheet attached explaining in layman's terms what it means and if any action is required.'* (ID 94)
- '[difficulty understanding] *blood test results, as some of the categories do not seem to correspond with the parameters laid down in my results history booklet'* (ID 104)
- *'I am a bit vague on some of the results. But clear about the most important ones'* (ID 192)
- *'I do not understand* […] *how worried I need to be when test results are out of range'* (ID 204)
- *'I don't know what the results mean'* (ID 91)
- *'Some of the results* [I am] *not sure what is good and what is not good* [I] *need to know more for myself'*
- *'It is difficult to understand the significance of some tests even when accessing the help feature'* (ID 37)

In addition to and potentially perpetuating the information-based barriers, the researchers identified a technology-based theme of *User-friendliness* (see *Table 20*). For one, patients seemed to struggle with a *Confusing website layout*. The confusion created by the website layout meant patients could not easily find and access the information they wanted to review. In addition to the *Confusing website layout*, the *Content* of messages did not necessarily support understanding either as some perceived it as unclear or repetitive. Finally, yet importantly, patients suggested the *Result presentation* could be improved to meet their information needs regarding for instance the normal ranges for blood test results.

Table 20. Technology-based barriers to understanding personal health record information.

Technology-based
User-friendliness
- Confusing website layout '*The website is confusing. Too many functions.'* (ID 123) *'Menu options needs to be clearer'* (ID 107) *'Not very intuitive display of actions to navigate the site.'* (ID 140) *'I don't find the site easy to navigate and the blood results which* […] *most interest me aren't easy to review and understand.'* (ID 164) o Finding and accessing information '*Cannot access latest test results*' (ID 102) '*Having difficulty finding anything'* (ID 23) *'Having received an email stating that my records have been updated, I cannot find the stated change once logged in.'* (ID 136) *'I received an email telling me that radiology data had been uploaded to my account, but I was not able to find it. It would have been easier if there had been a pathfinding link.'* (ID 146) *'I do not know how to access information correctly'* (ID 81) *'I couldn't find the data'* (ID 113)
- Content *'The Notifications do not always make sense'* (ID 210) *'All the message contents don't make sense'* (ID 46) *'Notifications too repetitive and not well read.'* (ID 107) *'The same message content comes up in all the messages.'* (ID 46)
- Result presentation *'Would like results in text as well as graph.'* (ID 119) *'I would like to see all my blood results each time to be submitted in excel sheet'* (ID 17) *'I would like to see numbers not* […] *graphs for blood tests.'* (ID 100) *'I would prefer all bloods to be grouped better, rather than spread over numerous pages'* (ID 129) *'All information is in graph form, can I have them in Text form please?'* (ID 171) *'Some blood results don't show the normal range'* (ID 99)

The individual barriers to patients' understanding of their PHR information likely interrelate with each other and together support or impede the ease of PHR information understanding.

Patients' ability to identify errors in their PHR

Out of 186 respondents to the question asking if any errors were noticed in the PHR information during the current visit to the system, the majority of patients (*n*=160, 86%) reported not observing any errors. Even though patients were not prompted to look for errors within their records prior to completing the survey, 14% of respondents (*n*=26) indicated they noticed some form of error within their record. The types of errors flagged by the patients are detailed in the following section.

Types of errors patients identified in their PHR

According to the researchers' analysis of the unstructured free text responses, the types of errors patients identified within their PHR records fell within either of two main themes relating to: 1) incorrect information and 2) incomplete information (see *Figure 14*). As *Figure 14* illustrates, there were more subthemes relating to the theme of *Incorrect information* than the *Incomplete information* theme. The subthemes mostly relate to the type of data being incomplete or incorrect.

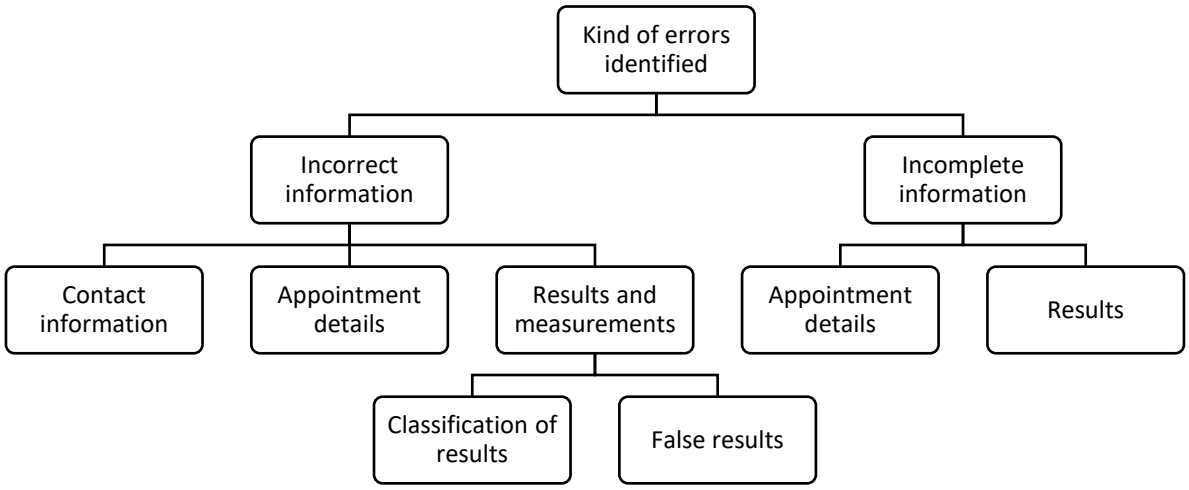


Figure 14. Thematic map of the kind of errors identified by patients in their personal health record (PHR).

The theme of *Incorrect information* was identified based on patients' comments on details regarding their *Contact information*, *Appointment details*, or *Results and measurements* being inaccurate (see *Table 21*). In case of the *Results and measurements* subtheme, either the *Classification of the result*, for instance an x-ray recorded as a CT scan, or the result itself was described as false (see *False results* in *Table 21*). Especially the inclusion of *False results* in a patient's PHR may present a patient safety threat as ongoing patient treatment and future care is based on their medical history. Thus, the differentiation of incorrect *Results and measurements* into *Classification of results* and *False results* was seen as necessary.

The *Incomplete information* theme and its subthemes of *Appointment details* and *Results* are based on patients' comments that not all their appointments or results were visible on the system (see *Table 21*). Most patients seemed to have access to at least some information regarding their appointments, but some were not able to access any information

on their test results. The lack of test result data may have limited the CIE access usefulness for the affected patients.

Table 21. Errors found in their personal health records by patients.

Information-based
Incorrect information
- Contact information *'incorrect address'* (ID 147 and ID 163)
- Appointment details *'Not all my appointments are accurate'* (ID 180) *'My appointment admission and discharge times are not accurate'* (ID 140)
- Results and measurements o Classification of results and measurements *'An x-ray scan* […] *was recorded as a CT scan.'* (ID 186) *'I had a HRCT scan which had been recorded as an x-ray'* (ID 3) o False results and measurements *'Ward glucose of another patient maybe with the same name seem to be there.'* (ID 199)
Incomplete information
- Appointment details *'Not all my appointments are recorded so I can't rely on this so I have to keep a separate record myself'* (ID 99) *'Some* [appointments] *are totally missing'* (ID 180) *'Not all my appointments show up in my calendar'* (ID 115)
- Results *'doctors' letters haven't been uploaded'* (ID 180) *'Lots of things missing'* (ID 68) *'My test results are not complete'* (ID 91) *'No information shown on blood test results or anything other than hospital appointments'* (ID 144)

Discussion

Summary of key findings

While the majority of surveyed patients (69%) did not report problems with understanding their PHR information, those who did faced several barriers hindering their understanding. These barriers were identified to relate to the information presented (*i.e.,* terminology and significance) or to technology or system-based issues (*i.e.*, layout, message content, and result presentation). Additionally, patients (14%) had noticed issues of incorrect and

incomplete information in their records without being prompted to look for them prior to using the CIE website and filling in the survey.

Results in context

Once patients have taken the first step and are registered to use the CIE (see *Chapter 4*), its usefulness to them depends on the system and their ability to utilise it effectively. A majority of patients (69%) felt they were able to understand the information within their PHR. This might be because the likelihood of patients using a PHR is linked to digital health literacy, which refers to their ability to understand online health information (Noblin et al., 2012). Noblin, Wan, and Fottler (2012) tested patients' willingness to use a PHR in relation to their perceived digital health literacy. They found that higher digital health literacy levels were associated with greater willingness to use PHR (Noblin et al., 2012). The results were supported by further studies subsequently (Davis et al., 2015; Irizarry et al., 2015). Hence, it is possible that the patients using interventions such as the CIE and replying to the survey may have been relatively well placed to comprehend their PHR information from the beginning.

Amongst other dimensions, health literacy refers to patients' knowledge and ability to understand and act upon health information (Sørensen et al., 2012). Hence, it follows that patients who identify problems in understanding their CIE information may refer to medical terminology and knowledge as hindrances as found in the given study. This might be related to these patients' health related knowledge possibly being lower in comparison to other respondents.

The high rate of patients reporting themselves as being able to understand their PHR information is consistent with findings from other studies (Pyper et al., 2004; Zanaboni et al., 2020). In one study, 73% of patients agreed that the health record information was overall easy to understand (Pyper et al., 2004). Zanaboni et al. (2020) reported 85% of patients understood the information in their health record, even though more than half was at some point troubled by medical jargon. However, the authors noted that 25% of patients did not have any documents in their record at all (Zanaboni et al., 2020). Hence, these patients would not have any information available that might be difficult to comprehend. Interpretation of patient reported PHR information understanding may be hindered by differing expectations regarding what level of insight is sufficient to count as 'understanding' across patient populations.

In terms of understanding, the information-based subthemes probably interact with each other as the medical terminology and knowledge will likely impact the interpretation of test results. The technology-based barriers also likely further perpetuate the identified information-based barriers. The way medical information, such as test results, is presented has been found to influence patients' ability to interpret its significance and actions needed as a result (Fraccaro et al., 2018). There is an opportunity for PHR to support understanding of health information through its presentation and provision of linked, easily accessible, additional clarifying information resources.

Similarly to the current study, technology design issues have previously been identified as inhibiting patients' use of health records (Fuji et al., 2014). The navigation of the system as well as the ease of use were criticised by patients regarding their PHR (Fuji et al., 2014). These findings are consistent with the results of this study showing that patients' ability to use their PHR effectively is related to the subthemes 'user-friendliness' and 'website layout'

(see *Figure 13*). The perceived added value of a PHR has been suggested to influence patients' likelihood to use it (Fuji et al., 2014). Hence, ensuring errors relating to incorrect and incomplete information are identified and corrected may indirectly lead to enhanced perceived value of PHR and patient use beyond solely increasing record accuracy.

The potential severity and impact of the different error types identified varied. While a misclassification of a result (*i.e.*, ID 186: '*An x-ray scan* […] *was recorded as a CT scan*.') may be inconvenient for finding it on the CIE, this does not necessarily directly pose a threat to patient safety. On the other hand, test results from another patient (*i.e.*, ID 199: '*Ward glucose of another patient* […] *seem to be there*.') may directly impact future care provision by providing false data to healthcare professionals. Thus, patients monitoring the contents of their PHR and flagging up potential inconsistencies, could enhance quality of care in future care instances and offers an opportunity for patients to engage with their healthcare.

Consistent with UK policy guidance emphasising patient-centricity (Department of Health, 2010, 2012; NHS England, 2019), clinic letters were recently advised to be directed at patients and written in appropriate language (Academy of Medical Royal Colleges, 2018). This too will help overcome some of the information- and knowledge-based barriers to understanding information. Hence, it might mitigate some barriers to patient error identification supporting future patient error identification effectiveness and impact in instances related to clinic letter data. Especially, receiving clinic letters almost immediately gives patients the means to keep a convenient record of the letters and ensure actions advised in them are followed through, both by themselves and the healthcare professionals involved in their care.

Strengths and limitations

The study had several strengths. The survey questions were based on the Care Information Exchange: Standard Operating Protocol developed from existing evidence about PHR system characteristics and functionalities (Jilka, 2016). The combination of structured (quantitative multiple-choice data) and unstructured (qualitative free text data) data complimented the aims of the study (see *Aims and objectives*). To ensure the quality of the work and meet best practice recommendations, the CHERRIES checklist (Eysenbach, 2004) was completed and the qualitative data was handled and reported according to the COREQ checklist (Tong et al., 2007) included in *Appendix A: CHERRIES checklist* and *COREQ checklist*. Data analysis was performed by a team with multi-disciplinary experiences in qualitative and clinical research and cognitive science. Thus, including varying perspectives and allowing for triangulation of interpretations among the researchers. Similarly, the participant sample was diverse in terms of the medical specialities that participating patients were seen under.

A limiting factor on the generalisability of the survey results was the sparse available information on participant demographics and characteristics and the context of CIE access. In a conscious decision, only little information on participant characteristics and CIE access context was collected to keep the survey length short. The purpose of this choice was to encourage responses and minimise the risk of patient re-identification. The interpretation of the data was limited by the opportunity for patients to fill in the survey repeatedly. However, as the questionnaire referred to a specific instance of CIE access, the richness of the data would have been constrained by allowing only single participation. With more experience in using the system, patient feedback could potentially evolve. Patients' ability to understand the PHR information was based on their self-reported estimation instead of an objective

measure due to the ease of surveying and varying participant healthcare backgrounds. There was no objective information available on errors existing in patients' PHR. Hence, the interpretation of the error detection rate was limited by being participant self-reported.

Future work

Some demographic factors, such as gender, age below 60 years, and higher educational level, can influence patients' likelihood of even reading their PHR information (Mossaed et al., 2015). Investigating the association between additional factors and patient ability to understand PHR information and identify errors is essential in supporting patients to effectively use PHR access to engage in their health and care. Future studies need to examine factors like digital health literacy, socio-demographic variables, and health status in relation to patient motivation to access PHR and their understanding of PHR information. Thus, enabling targeted support for patients' use of PHR without disadvantaging any patient groups.

Furthermore, patients' detection of errors in their PHR needs additional investigation. Analogue to motivation to read and ability to understand PHR information, factors influencing patient error detection should be assessed. Errors in PHR as identified by patients, compared to those identified by healthcare professionals, should be studied in future research.

Conclusion

Making personal health information accessible to patients via PHR systems can support patient engagement in healthcare. However, while a majority of patients declare

understanding their PHR information, technology- and information-based barriers seem to persist. Addressing these barriers by, for instance, enhancing system design is necessary in order to support patients in taking on an increased share of responsibility for their healthcare. Furthermore, a better understanding of variables influencing patients' motivation and ability to access and utilise PHR to engage with their health and care will make more effective patient support and minimising the risk of disadvantaging any patient groups possible.

Chapter 6: A semi-structured interview study on patient expectations of the Care Information Exchange, its functionalities, and their usefulness

Introduction

As a prerequisite for patients to effectively use PHR as examined in *Chapter 5*, they need to register for and access PHR systems in the first place. In accordance with studies investigating registrations and access to other PHR systems (Shimada et al., 2014; Yamin et al., 2011), previous work has demonstrated that overall completed registrations and access to the Care Information Exchange have been relatively low (see *Chapter 4*). Hence, patients' perspectives on the CIE system needed to be explored to assess the underlying reasons for this status quo and to make targeted improvements possible.

Aims and objectives

The aim of the given study was to explore patient perspectives on accessing and using their PHR. In particular, the semi-structured interviews queried patients' views on CIE functionalities, their usefulness, and reasons for accessing their records. Consequently, the insights from the interviews were intended to form the basis of the next survey-based study to support quantification and characterisation of patient PHR access.

Methods

Study design and setting

In the exploratory qualitative study, a convenience sample of consenting patients from two services, Rheumatology and Colposcopy, was interviewed with regards to their CIE experiences and opinions when attending their appointments. An exploratory design was selected to explore patients' perspectives on PHRs since there was little coverage of this phenomenon in the existing literature and to uncover topics of interest for the subsequent survey study. The study population of Rheumatology and Colposcopy patients was chosen based on the results of the case study in *Chapter 4*. The Colposcopy service was chosen for the relatively low completed registration and access rates. There was no service with both high registration and access rates. Moreover, the service with low registrations but high access rates was comparatively niche as Multiple Sclerosis had a total of *n*=52 registered users. Hence, the Rheumatology service was selected due to its low access but high registration rates as contrast to the Colposcopy service. Furthermore, the interview guide was informed by the literature, the CIE Standard Operating Protocol which sets out procedures and objectives regarding CIE (Jilka, 2016), and the case study results and reviewed by the PPG. Semi-structured interviews were chosen as method of data collection as they presented as the most appropriate choice according to the study aim of gaining a more detailed insight into patients' CIE expectations and experiences. The COREQ checklist guided the reporting of the study (see *Appendix A: Chapter 6: COREQ checklist*).

Patient and public involvement

The PPG was involved throughout all stages of the study based on their preferences to maximise its relevance and impact (see *Chapter 3: Project Partner Group (PPG)*). The study design was initially discussed with the project partner group prior to seeking service evaluation approval. Later the group fed into the patient information sheet and consent forms (see *Appendix A: Chapter 6: Participant information and consent forms*) as well as the interview guide. As the group was particularly keen to be involved in the interview data analysis but largely had no prior experience in qualitative data analysis, they were trained in the thematic analysis method accordingly (see *Chapter 3: Training for data analysis*). Only anonymised transcripts were shared with the group as agreed with the data controller (Big Data & Analytical Unit (BDAU)).

After the coding of all transcripts was completed, two researchers, LF and ALN, created an initial thematic map as basis for future discussion. The PPG and researcher discussed the initial thematic map and corresponding quotes together. Agreed changes to the themes of the initial thematic map were implemented to create the final thematic map.

Ethics

The interview study was conducted and approved according to the relevant ethical processes, *i.e.,* a service evaluation. Imperial College Healthcare NHS Trust's audit, information governance, and communication teams reviewed the interview study for service evaluation approval. It was approved by the appropriate audit leads for the concerned divisions and registered with the audit team under the service evaluation registration number 259. The patient information sheets, consent forms, and interview guide were agreed with

the Imperial College Healthcare NHS Trust Communications Manager responsible for CIE related matters.

Information governance was approached to clarify potential data storage issues. The handling of the data was approved by the Information Governance team at Imperial College Healthcare NHS Trust prior to data collection with the reference number 1109268. It was arranged that paper records would be held in a locked drawer in an office with pin-code access located in a swipe card access controlled area. The audio recordings were stored on a device from the BDAU until the transcripts were completed and saved in the BDAU Secure Environment (SE).

The audio recordings were transcribed by LF using a BDAU desktop computer. The transcripts were anonymised and any potentially identifiable information was redacted by the researcher at point of transcription. After the transcription process and checking of the audio recordings was complete, the recordings were deleted from the BDAU device as set out in the service evaluation documentation.

Participants and sampling

A convenience sample of patients above 18 years of age attending appointments at Rheumatology or Colposcopy on days the researcher was present for data collection, were invited to give their views about the CIE through a semi-structured interview. Convenience sampling was chosen for pragmatic reasons as it required the least amount of patient information to be implemented. Both patients registered to use the CIE and patients without CIE use experience were included. Patients were informed about the study by nurses or clinicians at the services. If patients were open to speaking to the researcher, they would

meet LF after their appointment to discuss the details of participation and if consenting complete the interview. The purpose of the study was described as follows: "We want to investigate the impact of the Care Information Exchange to enhance experiences with it. We are interested to learn about your perception of the Care Information Exchange which will inform us on how to improve it." (see *Appendix A: Participant information and consent forms*).

Due to the relatively open, exploratory nature of the survey guide and varied population of CIE users as well as non-users to be interviewed, a sample size of approximately 30 participants was set as goal. Considering that studies with relatively homogenous study population and narrowly defined objectives seem to require between nine and 17 interviews to reach saturation (Hennink & Kaiser, 2022), here more interviews were deemed necessary.

Data collection

The interview study with notes on observational data was conducted between 12th April and 19th June 2018. Patient perspectives were assessed through one-off semi-structured interviews led by the researcher, LF. The interview guide used is shown in *Table 22*. Participant information and consent sheets are provided in *Appendix A*: *Figure 30*, *Figure 31*, and *Figure 32*. Data was collected in a Colposcopy department at a central London hospital, and the Rheumatology department at a different central London hospital, as identified by the prior data analysis presented in *Chapter 4*. The researcher was allocated an empty room to use for conducting the interviews. Hence, only the interviewee and interviewer were present during the interviews unless an interviewee requested to have a companion in the room.

Table 22. Interview guide with questions regarding patients' perspectives on the perceived usefulness of the Care Information Exchange, and their willingness, ability, and preferences for using it.

Theme	Patients using CIE	Patients without CIE experiences
Usefulness	• How useful is the CIE to you?	• How useful would the CIE be to you?
Willingness	• Do you use it? • Why (not)?	• Would you use it? • Why (not)?
Ability	• Are you be able to use it? • What impacts your ability to use it? (Problems?)	• Would you be able to use it? • What might impact your ability to use it? (Foreseeable problems?)
Preferences	• What do you use it for? • What other activities would you like to be able to do with it?	• What activities or tasks would you use it for?

Note. Care Information Exchange (CIE)

With patients' explicit consent the interviews were audio recorded to allow for documenting as many details as possible. Observational notes taken while the researcher was present at the services were used to supplement the audio data. As no contact information and consent for follow-up was collected, transcripts and results were not returned to participants for comments.

Data analysis

Data collection and interview timings were analysed descriptively. The researchers and Project Partner Group (PPG) jointly coded and thematically analysed the transcripts and observational notes in accordance with Braun and Clarke (2006). The approach by Braun and Clarke (2006) was selected as it allowed for flexible, inductive analysis of the data. Furthermore, this thematic analysis method was well suited to be taught to and implemented by the PPG. The six steps of thematic analysis below were followed:

1) familiarisation with the data,

2) generation of initial codes,
3) searching for themes,
4) reviewing themes,
5) defining and naming themes, and
6) producing the report (Braun & Clarke, 2006).

The data coding for the first two interviews was done by two researchers, LF and LD, and the three members of the PPG simultaneously in the afternoon of the thematic analysis training meeting (see *Chapter 3: Training for data analysis*). After everyone had coded the initial two interviews the codes were discussed, added to, adapted, and combined until the group was content the codes were comprehensive and representative of the data.

A list of the codes resulting from the discussion of the first two interviews was sent to the project partner group to refer to during the coding of their additional interviews at home. Interviews three to 31 were all coded by the lead researcher (LF) and one member of the PPG each. In the latter half of the interviews, few new codes were identified, suggesting data saturation was reached. After all interviews were coded LF collated the codes covering all interviews and coders. Together with ALN, LF then created an initial thematic map by grouping codes written on post-its. Finally, the PPG and LF met to discuss the themes of the initial thematic map in relation to the interview data and create the final thematic map. The coherence of the themes and the distinction between themes was challenged and expanded upon during this joint discussion.

Results

Participants

Patients (*n*=31) were approached by their healthcare professionals at the departments of Colposcopy and Rheumatology at the Imperial College Healthcare NHS Trust after their appointments. Participant characteristics can be seen in *Table 23*. Note, that at Colposcopy only women were interviewed due to the nature of the service. Hence, the overall male to female ratio was roughly 1:6 (*n*=5, 16% male participants). According to the researcher's observational notes, participants came from various age groups, however, all participants were at least eighteen years of age. The majority (*n*=22, 71%) had no experience of using the CIE prior to the interview (see *Table 23*).

Table 23. Interviewee characteristics in the Care Information Exchange (CIE) experiences and expectations study.

	Colposcopy	Rheumatology	Overall
Gender	• 100% female, *n*=15 • 0% male, *n*=0*	• 69% female, *n*=11 • 31% male, *n*=5	• 84% female, *n*=26 • 16% male, *n*=5
Age	• Above 18	• Above 18	• Above 18
CIE user status	• 27% have used CIE, *n*=4 • 73% never used CIE, *n*=11	• 31% have used CIE, *n*=5 (1 male, 4 female) • 69% never used CIE, *n*=11 (4 male, 7 female)	• 29% have used CIE, *n*=9 (1 male, 8 female) • 71% never used CIE, *n*=22 (4 male, 18 female)

Note. * Gynaecology service – females only, Care Information Exchange (CIE).

Interviews

The researcher spent a total of 35.5 hours at the two services for data collection. The data collection time was divided across five data collection sessions per service. Fifteen

interviews were conducted at the Colposcopy service and 16 at the Rheumatology service. The mean interview duration was four minutes and 32 seconds.

Initial interview data themes

The initial grouping of codes from all interviews and coders resulted in four main categories with regards to using CIE:

- motivation,
- ability,
- concerns and weaknesses, and
- strengths and preferences.

A photograph of the results of the mapping and labelling exercise using post-its and a whiteboard can be seen in *Figure 15*. LF refined and condensed these results under consideration of the interview data to create the preliminary thematic map shown in *Figure 16*.

Figure 15. Picture of the initial thematic map creation by LF and ALN using codes written on post-its.

Due to scheduling and timing issues the preliminary thematic map informed the follow-up survey of CIE users. Interviewees' initial motivation to start using CIE relied on their perceived need to do so and any approval or recommendation of the system by healthcare professionals. While the ability to make efficient use of CIE was supported or inhibited by levels of technological and informational variables.

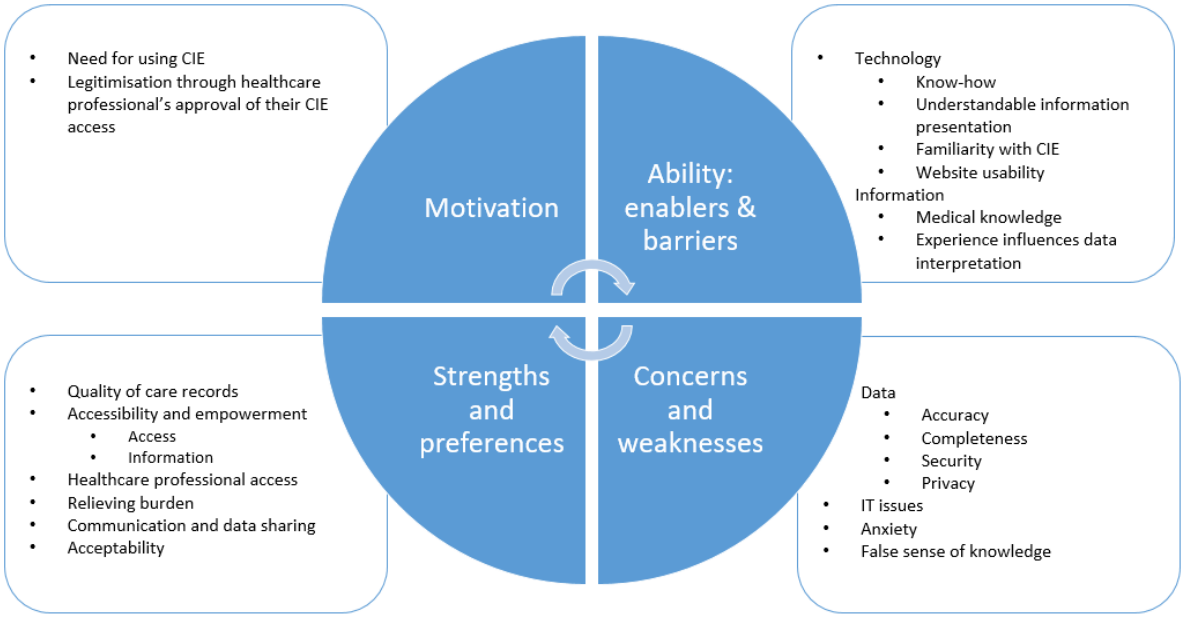


Figure 16. Preliminary thematic map identified from the interview data created by two researchers.

Changes to initial thematic map based on PPG coding and discussion

The PPG and researcher agreed on the four main themes which, hence, remained unchanged. Adjustments to the initial thematic map were made for subthemes of the *strengths and preferences* and *concerns and weaknesses* themes as discussed in *Chapter 3: Theme identification and discussion*. The changes made to subthemes from the preliminary thematic map are marked by an asterisk in the final thematic map (see *Figure 17*).

Final interview data themes

The final thematic map consists of four main themes: motivation to use a system such as CIE, the ability to do so with its enablers and barriers, concerns and weaknesses, and strengths and preferences of a PHR system (see *Figure 17*). However, all four themes are

interconnected to a certain degree as for instance the motivation to use CIE will depend on patients' ability to do so. This interdependent relationship of the themes will become clear during the detailed introduction of the themes and their subthemes below.

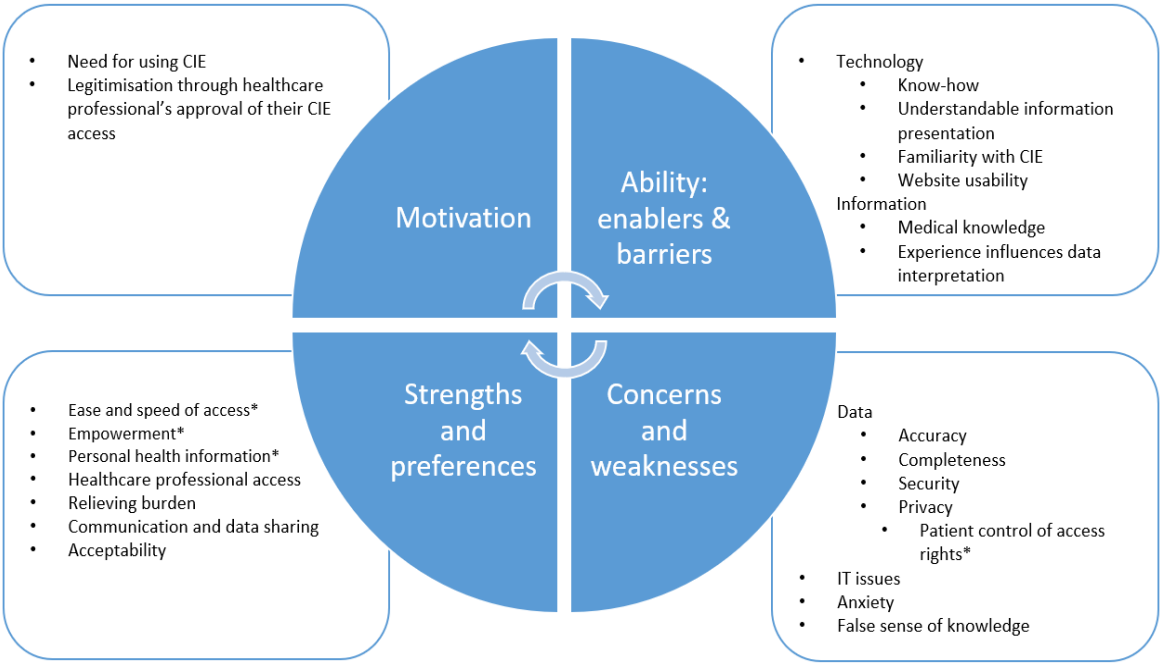


Figure 17. Final thematic map of interview themes as discussed and agreed by the project partner group and the researcher. Changes compared to the preliminary map are marked by an asterisk (*).

Motivation

The theme of motivation was grounded in patients' drive to use the CIE or lack thereof. It depended on their *Need for using CIE* which varied based on patients' circumstances and the frequency with which they engaged with the healthcare system.

> *"To be honest, I don't think I've been on the system since I looked up my results probably about 10 or 11 months ago." (ID 10)*

"I would just use it before I attend the appointment just to briefly see what happened last time and then after the appointment, let's say a month after, because then everything is uploaded there so that's the only time I actually use it. So it's a shame it can't be more useful. But maybe there are people who are coming here more frequently than I am so." (ID 12)

"I think it would only be useful to me if I did have an illness that required ongoing treatment and there were various professionals involved in that. Then I would find it useful but if one is generally healthy and has the odd appointment here or there, then I probably wouldn't want access by various different people." (ID 14)

Hence, interviewees' comments suggested that they would be most motivated to use CIE if they experienced an ongoing health problem that required medical appointments on a regular basis. Otherwise, it was a recognised opportunity which had limited usefulness.

Furthermore, patients were motivated to use the system by *Legitimisation through healthcare professional's approval of their CIE access*. Patients trusted their healthcare professional's advice on whether they should use the CIE to decide if they wanted to start or continue accessing their records via CIE.

"[The doctor] recommended it as a way to share information and, so I read – he gave me an invitation and I joined it." (ID 2)

"Even my doctor said, cause he wasn't too sure about it at first and then I showed him, and then he asked me to show it to him, and then even he said he likes it. So if the doctor likes it, then there must be something good about it, if the doctor likes it. My doctor just, he is one of the doctors

if he likes, he likes if he don't, he don't. But he likes it and I'm happy. If he's happy I'm happy." (ID 21)

For the purpose of this analysis the statements related to the system functionalities such as ease of data access, while related to motivating patients to use CIE, are being considered in the other themes to avoid disproportionate overlap between themes.

Ability: enablers and barriers

The second theme revolved around patients' ability to use the CIE and variables supporting or hindering it. Potential enablers and barriers could be described as sides of the same coin as a specific subtheme could present as either a barrier or an enabler depending on its state and perception by the interviewee.

The *Ability: enablers and barriers* theme was split into two main areas, namely *Technology* and *Information*. While *Technology* referred to the system itself and its use, how the content of the CIE was perceived also strongly depended on the *Information* subtheme. The *Technology* subtheme was made up of: *Know-how*, *Website usability*, *Familiarity with CIE*, and *Understandable information presentation*. *Technology Know-how* referred to the general ability and skills needed to operate any information technology system. Interviewees assumed that some groups such as older people might struggle more in this area than others.

"So [not knowing how to use the system]'s the only weakness that could be initially when you start something new and innovative." (ID 3)

"You see I'm an IT literate because I worked in the information technology business as a youngster and it doesn't frighten me. But I can

imagine older people who are not as used to working with a system, might need a bit more introduction." (ID 26)

"You'd have to look at the demographic though. Because obviously some people are less techy than others." (ID 20)

The *Website usability* in turn could either support or hinder efficient CIE use from the interviewees' point of view. Experiences differed: some interviewees had a positive view of CIE usability and the ease of finding information. Others, on the other hand, were not as satisfied as they encountered complications in accessing what they wanted.

"I like the way all of it works. If I want to go to like appointments I just go straight to appointments and same like the blood test results and everything I just get to them." (ID 21)

"[There] are some cases where you have to click from one to another to another one to another one, which is opening a hundred pages which I don't like. So I better open one page, go directly to my name and there I can see all my details." (ID 7)

However, according to several interviewees the *Website usability* depended on one's *Familiarity with CIE*. While certain problems in navigating the system were encountered when first starting to use the CIE, once some familiarity with the system existed, a part of these issues were solved.

"The first time I went on, it was a little bit confusing which section you have to go to but it's fine." (ID 1)

"It's easy to access, easy to use. Well, once you've learned how it works. The cascade structure of screens and how they come up together. They could be more comprehensively used." (ID 26)

One example of a website usability issue that could be resolved based on system familiarity was the following:

"I've learnt how to change the time scale on the blood, because I have blood tests every month and when you try to get that up and running to get a year, a year and a half of blood tests onto one screen it's very compressed. But you can change it to monthly or weekly or daily or all of it, every one you've ever taken that's on the system." (ID 26)

The final *Technology* subtheme was *Understandable information presentation* which described in how far the system's presentation of information may support users' understanding of the conveyed information. Blood test results were the main example of information presentation discussed by interviewees.

"If I get a load of blood test results and there's a lot of numbers to it I won't necessarily know what I'm looking at." (ID 17)

"I can see from the way it's portrayed that all my bloods are within normal range and things like that." (ID 2)

"I like the little graphs that are on the blood test results so you can see how things have gone. Then whether they are out of range." (ID 25)

"I think it would be a huge challenge to make it, for results particularly, to make it clear and communicated in a way that as I say isn't going to potentially alarm some patients or be meaningless." (ID 20)

The *Understandable information presentation* provides an apparent link between the *Technology* and *Information* subthemes. While the presentation of information could support patients' understanding of their personal health information displayed on CIE, other factors that affected their level of understanding are contained in the *Information* subtheme. *Medical knowledge* was a prerequisite to understanding and interpreting any health information.

"We don't understand the medical terms" (ID 19)

"If I could learn what the various indicators were, then I could actually extract some useful information from the blood tests. Like you know my cholesterol is high or the markers for [inaudible] is high or something there was abnormal." (ID 17)

"Any information that I don't understand and that are quite often a lot of things because I'm not a medic at all. So there are bits of jargon in there that I may not understand." (ID 31)

However, *Medical knowledge* was facilitated by *Experience influences data interpretation*. Patients learned to understand and interpret their health information with time and experience. Depending on their interactions with health information and their environment they gained experience necessary to make use of CIE information.

"[Understanding CIE content is] fine. But then I have had years of looking at my blood results." (ID 1)

"There's certain things that I'll know because [my mom] used to work in the NHS. So, it's quite easy for me because of that as well." (ID 21)

"It helps you get acquainted with the right buzz words and the medical terminology that they use. Because you can look it up you see you can tap on a word and say 'Oh, I'll look that up' and go into Wikipedia and find out what it means. And then you go back into the radiology test results and continue your reading. So you can get a better understanding of what is coming, the picture is coming out of." (ID 26)

Strengths and preferences

The overall *Strengths and preferences* theme was split into seven subthemes. These subthemes were:

- *Ease and speed of access*,
- *Empowerment*,
- *Personal health information*,
- *Healthcare professional access*,
- *Relieving burden*,
- *Communication and data sharing*, and
- *Acceptability*.

The *Ease and speed of access* to their personal health information was praised by interviewees. Coming out as an especially prevalent benefit was easy and fast access to test results.

"Normally you have to wait a couple of weeks for a letter or if you have any results or anything, so yeah, it would be great if it was much quicker and more accessible." (ID 8)

"I suppose you have access to it straight away so there is no kind of like waiting around or anything or you don't need to get into contact with the GP or trying to get through to the hospital which is not always so convenient sometimes." (ID 27)

"I mean when I get the test results, the blood test results, three hours after the blood test. It goes 'ping' and the results are there. And I go through them quite carefully." (ID 26)

CIE access empowered interviewees to act and take on responsibility for their health. The *Empowerment* subtheme illustrates the feeling of control and responsibility interviewees perceived resulting from CIE information.

"I like to be in control in my health. To me it's a very good opportunity to get all the information at a time." (ID 18)

"I think the way the NHS is progressing it will be important for people to take control of their own notes really." (ID 23)

"I think it's less burden on the NHS maybe. Or GPs. And take some more responsibility of your own health." (ID 27)

However, *Personal health information* was discussed frequently beyond just the empowerment resulting from it. Having a general overview over health information was appreciated as interviewees regarded the opportunity to view and monitor their information

as useful. Interviewees felt they could refresh their memories prior to healthcare appointments to make the most out of them.

"Obviously, if there are any issues then the hospital, my GP, would phone – but it's quite useful to monitor what's going on and also, like I was in A&E recently with a bad virus and stuff, so it's quite useful to see what, you know, the discharge notes are and things." (ID 1)

"I would just use it before I attend the appointment just to briefly see what happened last time and then after the appointment, let's say a month after, because then everything is uploaded there" (ID 12)

"Before I come back to a clinic I'll be able to refresh myself on what I've had done, what my results were." (ID 24)

Taking it further, one interviewee requested the system could provide personalised advice regarding minor issues such as a low grade vitamin deficiency. In contrast to the internet at large CIE was considered a trusted information source.

"If it was like a minor thing like if there was something specific going wrong, going on in your blood if like a thing flagged up where it was like 'your such, certain vitamin is low' or whatever. Maybe like, maybe just kinda, if there was a link to what's good to have in your diet for that. That would be good. Because you hear so many, like if it's from [medical professionals] I'm gonna trust it more than anything that you can kind of read on the internet." (ID 5)

Healthcare professional access to this information source was important. For the purpose of healthcare professionals having as complete information about a patient's health as possible interviewees wanted their care team to have access to the necessary information.

"Hopefully a better access, not just for myself but for the different healthcare professionals that I've been, might need to speak to and for them to access my files." (ID 15)

"I think [the doctors] should be able to get into [the CIE record]" (ID 2)

Yet, an invitation to access a patient's CIE information sent by them was not always accepted by healthcare professionals outside the service providing CIE in the first place.

"I did invite my GP to have access to it. But unfortunately she doesn't seem to have responded." (ID 25)

Notably, CIE access was thought to relieve the burden on patients, healthcare professionals, and NHS alike. Hence, the *Relieving burden* subtheme was identified as crucial strength of CIE.

"My generation is not really paper based. So anything online is my time and I believe it takes a lot of time from the hospital as well." (ID 12)

"Rather than having to come and sit with the doctor, I can just log on, you know, at my own convenience." (ID 22)

"I just think that because we're so busy and the NHS is so stretched, the less we can hassle clinics and doctors, and as long as we take information correctly, I think [the CIE]'s really, really, good." (ID 24)

Beyond one patient's current use of the system, they suggested future functionalities maximising the efficient use of everyone's time and resources:

> *"I've just today travelled on a train 2 hours to get to London, spend the afternoon in London, apart from the smoke inhalation and everything else I'm going to spend another 2 hours to get back, having had 10 minutes talking to a nurse. If I could make an appointment and speak to her on Skype and then if she has any concerns, so yeah, well okay, I will see you next week and I come up to the hospital. It would relieve both of us from a lot of aggro and free up my time and hers. Same with the specialist, the consultants are the same, right. I'll see him, so long as there are no problems with my health, then that's fine. It's really, basically I come in on a 6 monthly check up. There's no reason why that shouldn't be done on Skype or some kind of internet connection." (ID 31)*

Connected to this idea of potentially communicating via a Skype-like online service, *Communication and data sharing* presented an advantage of CIE. Interviewees expected CIE to be beneficial in supporting their interactions with healthcare professionals by facilitating data sharing between both parties.

> *"When it comes to different doctors and different specialists everything is in the same place. So you don't actually have to just make sure that the communication flows because everything is in one just system. Everything is centralised." (ID 3)*

> *"More when I go and see a new doctor. Obviously, here in the GP it's never the same doctor, so sometimes they will ask you things and I might*

not remember. So for me to see it or for that doctor to have access to it. Instead of me just responding random, you know, just giving random answers. That I think is helpful." (ID 13)

"I've got a bag full of different blood tests that I've done with my GP, then things that I've done in the [hospital] as well. So me being able to access the information, then I can bring it with me and then I can show the other hospitals or doctors as well." (ID 28)

The *Communication and data sharing* went beyond the relationship between patients' and their healthcare professionals to keeping family informed on patients' health or the presence of medical issues running in a family.

"One of the things I do think is extremely useful, I'd never thought about it, is my own medical history, is how much of that is genetic and how much of it actually will pass and be relevant to my daughter and is relevant to my cousins and nephews and nieces for example. So, my nephew talking about an issue he's got with cholesterol. Well, you know, what I have, I've got familial hypolipidemia. So it makes sense. But it would be useful for him to know that, cause he could've managed his diet I guess appropriately because he would be aware of the sensitivity.

So, I think things like that where you do realise that there are familial issues I think is extremely powerful. If you can then help you know the next generation learn and prepare for things" (ID 30)

The final subtheme regarding CIE *Strengths and preferences* was its *Acceptability*. A sense of enthusiasm for the perceived opportunities offered by CIE was present in many interviews. Interviewees seemed to be generally open towards using CIE and positive about its (anticipated) impact.

> *"Although I do realise that some people don't want that kind of data shared, I can't see the disadvantage and I can see benefit of the healthcare professional that's treating me being able to [see] what other medications that I'm on." (ID 2)*

> *"It's great that things go more online in terms of getting feedback and results." (ID 8)*

> *"As long as I know the access was only to me and obviously the healthcare provider, then no, I think I'd be fine with that. I know you've got to share it with you know departments and things like that but, yeah, as long as I wasn't suddenly being hassled by a drug company or something like that, then no, I'd be fine. I think it's all good. I think it's the way it should move forward." (ID 24)*

Concerns and weaknesses

The *Concerns and weaknesses* theme consisted of the below subthemes:

- *Data*
    - *Accuracy*
    - *Completeness*
    - *Security*
    - *Privacy*
        - *Patient control of access rights*
- *IT issues*
- *Anxiety*
- *False sense of knowledge*.

Interviewees discussed a range of concerns related to the *Data* on the CIE. First, the data contained in the system needed to be accurate and as they expected. However, the actions taken to adapt incorrect information depended on its perceived urgency.

> *"I've really been on there just to check the information that's on there is the information that I thought that is going to be there about me" (ID 31)*

> *"I did just flag up to [doctor] that the, when I saw the nurse last time, the letter that got sent to my GP and to me, and I think it's going to be on the system as well. I think that's how it works. So it said I've had a cough for months whereas I've had a cough for a couple of weeks. But I didn't feel the need to flag that up. You know because I thought I'd let them know when I come back. It wasn't anything about actual consequence." (ID 25)*

Second, the CIE was expected to provide a complete record of medical information. The *Completeness* subtheme represented the repeated references to the expectation of having access to 'all information' via CIE.

"I expect all information about my condition, my diseases, my analyses, results, anything that concerns my health and anything that has been discussed in different appointments or meeting with doctors [to be on the system]. That's the minimum." (ID 3)

"[I want to see] the test results, everything, all my history, medical history." (ID 7)

"To me it's a very good opportunity to get all the information at a time." (ID 18)

However, the *Completeness* of the CIE data was still an ongoing process as further data was added to the system and information exchange between providers' online platforms was challenging. Hence, *Completeness* of data at the time was better placed in the *Concerns and weaknesses* than the *Strengths and preferences*.

"They're adding historic records cause there seems to be more historic data coming on. So I presume they are moving it onto the system." (ID 2)

"It would be ideal if it would be connected to my GP which it's not because they're using a slightly different platform which is online as well but it's not connected at all so it's slightly tricky that you need to remember where you've been treated for what." (ID 12)

Third, CIE information *Security* protecting from hacking was seen as vital. Nevertheless, interviewees acknowledged that no system could be entirely secure. While many referred to the security of data, the level of personal concern about it was varied.

> *"I guess information, data protection, I guess is the main thing. I mean it would have to be secure but other than that -, I guess data protection is probably the biggest issue." (ID 11)*

> *"Once it's online, it's there for the taking no matter how strict the security is. There'll be someone with the ability to go around that, probably." (ID 4)*

> *"These days if somebody wants to hack your information it can happen anywhere. But for me as a patient if it helps, no, I don't think I am worried because it can happen anywhere. Yeah, anything can be stolen. Your data, what are they going to do with it?" (ID 28)*

Connected to data *Security*, *Privacy* was another concern. Though, some interviewees speculated about others' perception of privacy while stating they themselves did not mind their data being in CIE.

> *"I suppose people are going to be reticent about people having access to their information but I'm not one of those people. I mean it's all to do with my health history and my treatment for health so I don't have a problem with anybody accessing it." (ID 17)*

> *"I will be very, very upset if the information goes somewhere else. I mean outside. If I receive calls or if I am annoyed with different kinds of emails*

coming from, I don't know, pharmacies or different kind of other industry or companies." (ID 18)

"I might be a little bit concerned about privacy, I might be concerned about the fact that my information is somehow out there rather than confidential between me and the team treating me. But I'm not so paranoid that it worries me a great deal. I'd be more concerned about my bank details as I'm quite happy to use online banking. So why shouldn't I use online facilities for accessing my health details?" (ID 31)

In terms of privacy, *Patient control of access rights* to their CIE data was raised repeatedly. Being able to restrict access to certain information for specific persons seemed reassuring and useful for interviewees.

"My only concern would be privacy. And can I control who looks at it and who doesn't? And what's the definition of healthcare professional? So if I want, there's certain things I wouldn't want accessible to my GP and that would, and I normally would say 'I don't want my GP to have access to that'. Only because he's a family friend. So I kind of restrict what he knows and what he doesn't. So, yeah, I would have that concern. That there are some part of my information that I don't want available to my GP and other people. So I'd have to restrict parts. I don't want everybody to handle literally everything." (ID 14)

"Access is only going to the people that should be getting it. That I would be happy for them to see." (ID 15)

As CIE is an IT system, potential *IT issues* were considered to be likely but not overly concerning. While some, like interoperability issues of systems used by different providers, may impact the information available on CIE.

> *"Standard problems that we always face a little bit with technology where things can go wrong. So maybe there will be blips with the system, teething problems, problems getting access even for people that have the access potentially, but there are always these issues." (ID 15)*

> *"It would be ideal if it would be connected to my GP which it's not because they're using a slightly different platform which is online as well but it's not connected at all so it's slightly tricky that you need to remember where you've been treated for what." (ID 12)*

Speculation about *Anxiety* caused by CIE information was abundant. While most interviewees reported they themselves were unlikely to worry overly, they suggested that many people may be alarmed unduly. This supposed worry was assigned to people not understanding information or interpreting it incorrectly based on additional information obtained from other sources in an attempt to understand the information.

> *"We don't understand the medical terms so maybe you, we always see everything and we expect the worst and we always google everything before calling someone and we always think like we're dying and so maybe that's not that good." (ID 19)*

> *"There is a risk perhaps of receiving results and not having an explanation around it. And, you know, if you have something a bit negative it might kind of panic some patients." (ID 20)*

"The only thing is, I guess, generally this concern about people over-analysing their own health. Yeah, you see something on there and start panicking. I am personally fairly chilled about things. I don't overreact but I guess the hypochondriacs in this world might end up stressing themselves if they've got too much access to data which then you know gives them concerns." (ID 30)

Apart from this type of worry and anxiety over information on the system, there was also concern about having contact persons to reach out to as needed. Both to ensure CIE did not replace face-to-face care where necessary and to answer to any questions or concerns caused by records.

"Hopefully there would be people to communicate to if there were errors. Or if there seemed confusion or problems so there would be someone to then discuss that with so that people weren't left at home worrying about their records" (ID 15)

"In terms of diagnosing problems and explaining your symptoms that's really important that that's face-to-face." (ID 8)

The *False sense of knowledge* represented the flipside of the *Empowerment* subtheme. It was based on a perceived risk of patients over-estimating their knowledge and abilities. Hence, potentially making (ill advised) decisions which they might otherwise not have made.

"I do think there is a risk. I do think in the world that we work that actually the more information you give patients, the more we might start thinking we do know what we're talking about. And I do think there is a bit of a temptation to try and take the information and then start googling and

things like that. So I just think there is something about, and I could imagine that could create problems, is that, I mean I am very mindful of that, but I do think some people might suddenly start self-medicating or second-guessing around all of that." (ID 2)

Discussion

Summary of key findings

While most interviewees (71%) had not previously used the CIE system, most were interested in their PHR. The four main themes relating to CIE use identified in the data were: *Motivation*, *Ability: enablers and barriers*, *Strengths and preferences*, and *Concerns and weaknesses*. Patient motivation to use the PHR was based on their need for CIE access and their attending healthcare professionals' approval thereof. The ability to effectively utilise CIE was impacted by both technology and information related issues. Potential benefits from empowerment to data sharing, were preferred or expected strengths of CIE. On the other hand, potential issues relating to the data contained in the PHR itself, such as accuracy or completeness, and patients' reaction to it, were seen as weaknesses.

Results in context

Upon consideration of the themes from the interview analysis (see *Figure 17*), a number of similarities exist to the patient engagement dimensions identified in *Chapter 1* (see *Figure 2* and *Figure 4*). Several dimensions are analogous between the patient engagement literature commonalities and the interview themes. Opportunity is a commonly referred to dimension to patient engagement and PHR access can be seen as just such an opportunity through

which a patient can engage in their health and care. *Figure 18* illustrates the high-level commonalities between the patient engagement dimensions and the interview themes.

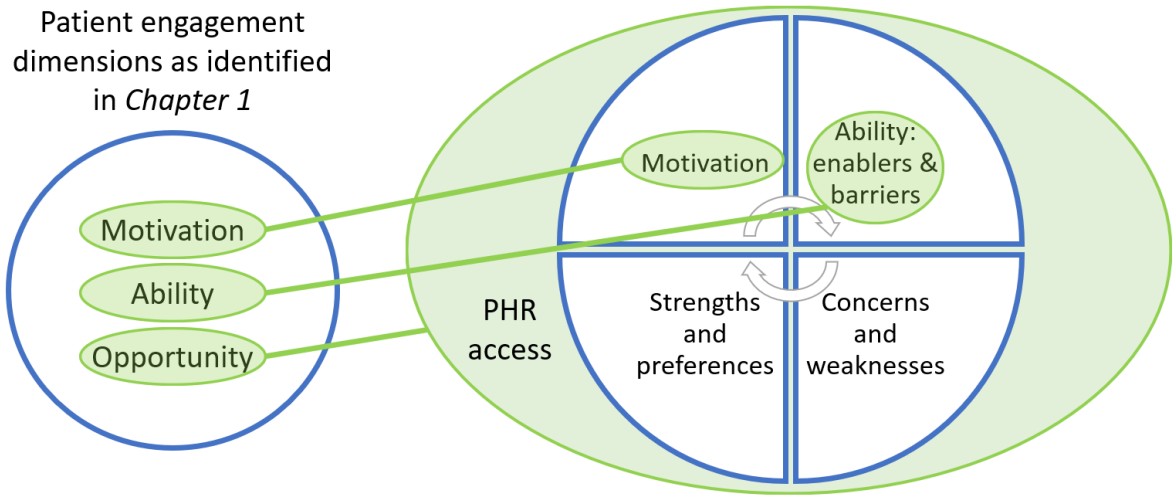


Figure 18. Comparison between patient engagement dimensions identified in Chapter 1 and the themes impacting personal health record (PHR) access.

When viewing the option to access the PHR as the patient engagement opportunity dimension, the motivation and ability to make use of the opportunity remain partly comparable. However, the 'strengths and preferences' and 'concerns and weaknesses' are more innate to the specific patient engagement opportunity offered by the PHR system and access to it. The perceived strengths and weaknesses may also vary depending on patients' socio-demographic backgrounds. However, as this study did not collect sociodemographic information on its participants, it remains speculation in this instance. Furthermore, the ability theme from the interviews illustrates the impact technology- and information-based concerns can have on patients' ability to use or understand PHR information as previously discussed in *Chapter 5*.

Motivation

As a first step, patients need to choose to make use of a PHR. Since '*to be motivated means to be moved to do something*' (Ryan & Deci, 2000a, p. 54), without any *motivation* to access and use a PHR, no action will be taken. Patients' *motivation* to use the CIE is based on their perceived *need for using CIE* and the *legitimisation through healthcare professional's approval of their CIE access*. The idea of motivation to access and use CIE being dependent on a *need for using CIE* seems straightforward as motivation may arise from a feeling of need.

A theory on motivation, which has been applied across various domains from education to sport to healthcare, is the Self-Determination Theory, short SDT (Ryan & Deci, 2000b). SDT considers motivation types to range between intrinsic motivation and extrinsic motivation (Ryan & Deci, 2000a). While intrinsic motivation, the most autonomous type of motivation, relies on an individual's own interests and values, extrinsic motivation results from external pressures or rewards (Ng et al., 2012). According to SDT three needs must be satisfied; autonomy – feeling responsible for one's own behaviour, competence – feeling useful, and relatedness – feeling understood by others (Ng et al., 2012; Ryan & Deci, 2000b). Hence, not only the quantity of motivation but the quality of motivation matter (Vallerand et al., 2008). The more autonomously motivated someone is, the more likely one is to exhibit healthy behaviours and psychological well-being (Ng et al., 2012). Furthermore, including a combination of techniques to promote needs satisfaction and autonomous motivation in interventions, can enhance health behaviour change and health outcomes (Gillison et al., 2019). Autonomy can be supported through the health care climate created for instance by the healthcare professionals facilitating feelings of competence and relatedness (Ng et al., 2012).

The *need for using CIE* can reflect intrinsic or extrinsic motivation as patients can be innately interested in their health records (*e.g.*, "*I would just use it before I attend the appointment just to briefly see what happened last time and then after the appointment*", ID 12) or be motivated by external factors (*e.g.*, "*I think it would only be useful to me if I did have an illness that required ongoing treatment and there were various professionals involved in that.*", ID 14).

The *legitimisation through healthcare professional's approval of their CIE access* can be argued to relate to the healthcare climate of supporting patients to feel competent, understood, and autonomous. If healthcare professionals support patients in viewing their healthcare records and test results, it implies a certain level of trust in patients' ability to understand the contents. As such patients' wish for *legitimisation through healthcare professional's approval of their CIE access* seems reasonable. Graffigna et al. (2016) found that healthcare professionals do affect type 2 diabetes patients' motivation for and their subsequent engagement with an eHealth intervention. Hence, arguing that healthcare professionals' ability to support patients' use of eHealth interventions plays an important role in eHealth uptake (Graffigna et al., 2016). Since healthcare professionals historically are persons of trust (Coulter, 2002) which is beneficial in healthcare provision (Birkhäuer et al., 2017), their approval is important to patients (*e.g.*, "*if the doctor likes it, then there must be something good about it* […] *he likes it and I'm happy. If he's happy I'm happy.*", ID 21).

Ability

Patient access to PHR has been discussed in the wider literature (*e.g.*, see *Chapter 2*). The ability to understand PHR information and use the PHR system depended on technology- and information-based factors in this study. Both information- and technology-factors are

consistent with variables identified in previous studies (Fraccaro et al., 2018; Fuji et al., 2014; Zanaboni et al., 2020). The technology subthemes identified here are *know-how*, *understandable information presentation*, *familiarity with CIE*, and *website usability*. Consistent with the *know-how* subtheme, without at least basic digital literacy accessing and using a PHR is problematic (Gellner et al., 2021). The influence of information presentation on understanding is recognised beyond the digital health context (Moseley et al., 2006). For example, Moseley et al. (2006) found the understanding and recall of information for informed consent was influenced by how the information was presented to patients.

As identified in the interview data, the more familiar users are with a system, the easier its navigation can become (*e.g.*, "*I've learnt how to change the time scale on the blood, because I have blood tests every month and when you try to get that up and running to get a year* […] *of blood tests onto one screen it's very compressed. But you can change it to monthly or weekly or daily or all of it* […] *that's on the system.*", ID 26). Hence, even if the design of a system has issues, once an awareness of these issues exists, users can overcome them to a degree (*e.g.*, "*The first time I went on, it was a little bit confusing which section you have to go to*", ID 1).

For the information-based factors impacting the use and understanding of the CIE, the identified subthemes were *medical knowledge* and *experience influences data interpretation*. As a PHR contains medical information, a certain degree of knowledge related to medical matters is required to understand and interpret its content. An explanation of medical terms as included on CIE is not always sufficient. In the context of digital health interventions, the health literacy concept alone does not cover the necessary skills and knowledge. Hence, health literacy needs to include an additional IT usage related component to suit digital health literacy (Norman, 2011). The eHealth literacy concept and

its measure the eHealth Literacy Scale (eHEALS) consider the "*knowledge, comfort, and perceived skills at finding, evaluating, and applying electronic health information to health problems*" (Norman & Skinner, 2006a, p. 1). Previous research has shown that eHealth literacy plays a part in patients' use of PHR systems (Holt et al., 2019). Individually health literacy impacts patient PHR use (Sarkar et al., 2010). It stands to reason the same may be true for digital literacy. Analogous to the impact of *familiarity with CIE* discussed above, *experience influences data interpretation* in the CIE. With experience regarding medical issues, knowledge for and practice in dealing with said issues is developed. For instance, if a patient has been getting regular blood tests for years, they will eventually know when values are out of their normal range and how they need to react under such circumstances.

Opportunity: strengths and preferences in contrast to concerns and weaknesses

Considering not all interviewees had used the CIE before, expectations of and experiences with the CIE are contained in the themes of *strengths and preferences* and *concerns and weaknesses*. *Strengths and preferences* cover *ease and speed of access*, *empowerment*, *personal health information*, *healthcare professional access*, *relieving burden*, *communication and data sharing*, and *acceptability*. The *ease and speed of access* to PHR information is part of the benefits commonly ascribed to PHR systems (Bhavnani et al., 2011; Wyatt et al., 2017). For instance, keeping patients from having to phone a service or wait for a letter to arrive to receive test results (*e.g.*, "*I get the* […] *blood test results, three hours after the blood test. It goes 'ping' and the results are there*", ID 26).

Using CIE led to a feeling of *empowerment* as patients felt they had more control over their health and care by being better informed. This result is consistent with other studies showing patients with access to their PHR feel more in control and engaged in decision making

(Blease et al., 2021; Moll et al., 2018; Oster et al., 2015; Walker et al., 2019; Weinert, 2017). Additionally, evidence is growing that more engaged patients act more beneficially for their health by, for instance, better adhering to medication or treatment plans, screening or prevention recommendations, and adopting strategies for managing chronic conditions (Bell et al., 2015; Náfrádi et al., 2017; Walker et al., 2019; Yeom & Lee, 2022). Moreover, the *access to personal health information* is commonly perceived as beneficial by patients, likely in part due to its influence on the feeling of empowerment. Being able to access up to date health information has been identified as a design feature influencing the effectiveness of eHealth interventions (Morrison et al., 2012).

The *healthcare professional access* is an expected benefit for patient care as healthcare professionals require health records for efficient and effective care. Furthermore, both patient's and healthcare professionals' access to the records was perceived as *relieving burden* from the healthcare system. Consistently with this study's findings, Graham et al. (2020) found patients reported time savings when booking appointments via their PHR, less repetition being required during appointments, and some appointments not being necessary at all, thus saving their own and the healthcare system's resources. Furthermore, evidence from analysing randomized trials implies patients having access to a form of PHR can reduce their overall health care use (Neves et al., 2020), hence, freeing resources needed elsewhere.

CIE based *communication and data sharing* being appreciated aligns with the design feature of social context, that supports the effectiveness of eHealth interventions (Morrison et al., 2012). According to Morrison et al. (2012), human interaction and support can facilitate effective interventions. Moreover, sharing PHR information has been previously found to lead to perceived benefits in the relation between patients and healthcare professionals

(Bell, Mejilla, et al., 2017). Nevertheless, without a level of *acceptability* an intervention will not be used. In this study CIE was deemed to be an acceptable intervention. However, CIE *acceptability* will be closely tied to the concerns and weaknesses patients perceive relating to CIE.

The *concerns and weaknesses* theme relates to the contained *data* with its *accuracy*, *completeness*, *security*, and *privacy*, especially in terms of *patient control of access rights*. Further subthemes of *concerns and weaknesses* are *IT issues*, *anxiety*, and a *false sense of knowledge*. That the *data* within a PHR is vital seems straightforward with its implications for patient safety (Bowman, 2013). The importance of the *accuracy* of health records is undisputed (Abdelrahman & Abdelmageed, 2014). Hence, patients being concerned about the *accuracy* of their health records is to be expected and potentially beneficial as patients may help to ensure health record accuracy by reviewing their health records (Bell et al., 2020; Bell, Mejilla, et al., 2017). *Completeness* of records is related to their *accuracy* as missing information may have similar consequences to incorrect information. If, for instance, an allergy to penicillin is missing from the health record, it being recorded as an allergy to ibuprofen would, in this instance, have a similar effect as no allergy being recorded at all. The concern regarding the *completeness* of health records matches patients' perception of missing information as errors seen in *Chapter 5*.

Security of the PHR data was perceived as important but patients compared the security of their health record data to other personal data available online (*e.g.*, "*These days if somebody wants to hack your information it can happen anywhere.*", ID 28). Hence, while security measures were important to patients, they were aware of the inherent risk that their data may be accessed by unauthorised persons breaching these measures. In contrast, the *privacy* theme regarding the PHR data was concerned with more people having access to

a patient's health information than strictly necessary (*e.g.*, "*people are going to be reticent about people having access to their information*", ID 17). Privacy is an issue frequently discussed in regards to data (Wieringa et al., 2021). However, *patient control of access rights* may mitigate some of the anticipated privacy issues and allow patients to feel more in control of their PHR as patients can then decide who may access their PHR.

IT issues were another concern regarding CIE use since, as with any digital offering, *IT issues* can hinder its use. Both software and hardware issues can affect using any website of programme. Nevertheless, compared to *security* and *privacy* of data *IT issues* were not perceived as overly problematic but more par for the course.

Patients feared some information in their health records might lead to *anxiety* (*e.g.*, "*There is a risk perhaps of receiving results and not having an explanation around it.* […] *if you have something a bit negative it might kind of panic some patients*", ID 20). Interestingly, several patients stated this as a concern for other patients but not themselves. In contrast, previous research found that patients were rarely anxious about the information they read in their record (Walker et al., 2019).

Understanding part of the health records was posited to potentially give some patients a *false sense of knowledge*. However, this concern was something interviewees suggested as potentially applying to other patients (*e.g.*, "*I do think there is a risk* […] *the more information you give patients, the more we might start thinking we do know what we're talking about.* […] *I could imagine that could create problems* […] *I mean I am very mindful of that, but I do think some people might suddenly start self-medicating or second-guessing around all of that.*", ID 2). Other research showed, however, that health outcomes and adherence to medication or treatment plans improved with PHR access (Bell et al., 2015;

Neves et al., 2020; Walker et al., 2019). Hence, the concern about the creation of a *false sense of knowledge* might be comparatively unfounded.

Overall, several potential strengths of CIE can be flipped upside down to turn into concerns or weaknesses and vice versa. Hence, while some subthemes were represented in one theme, depending on the circumstances, it could possibly present as part of the other. For instance, while *communication and data sharing* is considered a strength of the CIE, if something went wrong in sharing data, it could become a concern regarding *privacy*. Hence, the *strengths and preferences* are inherently connected to the *concerns and weaknesses*.

Trustworthiness of the thematic analysis

The trustworthiness of a thematic analysis is assessed based on its credibility, dependability, confirmability, and transferability (Forero et al., 2018; Nowell et al., 2017). Analysis process' audit trails with, for instance, self-critical journaling of the research process can be used to enhance or support the trustworthiness of an analysis (Forero et al., 2018; Nowell et al., 2017). In the following paragraphs the trustworthiness of the given thematic analysis is discussed focusing on each dimension one after the other.

Credibility

Here the thematic data analysis was completed by researchers and members of the PPG collaboratively. The joint work of researchers and PPG from establishing the interview guide up to and including the result discussion with repeated touchpoints on the process and progress strengthens the credibility of the interview study. Furthermore, researchers were

experienced in thematic analysis and the PPG members were supported in their analysis lending additional confidence that the results are true, credible and believable.

Dependability

Dependability, referring to the repeatability of the study within the same context, requires a clear documentation of the study process (Forero et al., 2018; Nowell et al., 2017). Using the COREQ checklist (see *Appendix A: Chapter 6: COREQ checklist*) a dependable account of the given study process and analysis was pursued. Additionally, the interview guide (see *Table 22*) and patient information materials (see *Appendix A: Participant information and consent forms*) were provided for reference purposes.

Confirmability

Providing a detailed account of how the findings were derived from the data together with quotes for each theme and subtheme was the basis for the confirmability dimension in the given study. Research cannot be entirely separated from the researchers conducting it (Morgan, 2014). Nevertheless, the ongoing discussion of codes and themes as well as the challenging of assumptions across the involved researchers and PPG should have bolstered its confirmability.

Transferability

The transferability of the study results to a different context may be limited. However, the descriptions of the methodology, context, and results were kept as detailed as feasible.

Therefore, enabling readers, such as other researchers, to assess for themselves in how far the findings may be transferable to their own context.

Strengths and limitations

The qualitative data was handled and reported according to the COREQ checklist (see *Appendix A: Chapter 6: COREQ checklist*) to confirm the quality of the work and meet best practice recommendations (Tong et al., 2007). Furthermore, a short form of the GRIPP2 checklist was completed for the same reasons (see *Appendix A: Chapter 6: GRIPP2 short form*). As a long version GRIPP2 checklist has been filled in for the project wide PPI in *Chapter 3: Patient and public involvement*, a short version was considered sufficient for the given study. The strong coproduction of the study with the PPG was a clear strength of the study (Brett et al., 2022; Crocker et al., 2018; Gonzalez et al., 2023). The PPI ensured the collection and interpretation of the data was completed without being solely coloured by the researcher's perspective and expectations (see *Chapter 3: Co-researchers in interview study* and *Chapter 6: Patient and public involvement*). While overall the strong PPI was a definite strength of the study, there were difficulties connected to it. For one, scheduling the meetings for the data analysis training and the final theme discussion to suit everyone's availability was problematic, even with the option of meeting on the weekend.

Recruitment of patients to take part in the interviews was slow and relied on the healthcare professionals' schedules and openness to invite patients to participate and patients' availability and willingness to stay for an interview. Furthermore, as an empty room at the services was needed for the interviews, the researcher could only visit on days that were expected to be less busy. As patients already spent quite an amount of time at the services waiting for their appointments and travelling to their appointments and back, many did not

have additional time or patience for an interview. Even patients agreeing to be interviewed, had very limited time available as many had taken time off from work for their appointments. Hence, the duration of the interviews was very short. On the positive side, the short interviews resulted in manageable amounts of data for the PPI members to handle timewise.

A roughly even split between interviewees being CIE users and non-users was aimed at initially. However, due to the use of a convenience sample and the already existing difficulties in recruitment, the rate being skewed towards non-users (71%) was accepted. The higher rate of non-users in the sample might have impacted the findings as expectations of non-users instead of experiences of users were more strongly represented. The achieved rate of users and non-users might also be caused by the prevalence of patient CIE registrations in the given services. Hence, achieving a roughly equal mix might have been unrealistic from the beginning. User and non-user interviews formed one data set. The different perspectives were considered as two sides of a coin with subthemes having the possibility to have either a positive or negative impact on patients' perspectives on CIE. Hence, no theme differentiation was made based on CIE user status.

Future work

The given interview study provided an insight into themes relevant to patients with regards to using the CIE. However, the identified themes of motivation and ability to use CIE as well as the CIE opportunity-based facilitators and barriers require further investigation. The prevalence of these perspectives should be explored in future research in relation to demographic factors. Considering demographic factors is important to assess CIE use equity and understand the impact of the digital divide on CIE use. Moreover, the impact of

using CIE on the quality of care as perceived by patients should be examined to ascertain how long-term motivation to use CIE may be supported.

Conclusion

The coproduced semi-structured interview study illustrated patients' motivation to engage with their health and care through PHR access. However, their ability to use a PHR system depended on both facilitators and barriers to effective use of the system. Furthermore, patients perceived both potential strengths and weaknesses related to PHR access which need to be further explored. The coproduction of the study was worthwhile though time consuming.

Chapter 7: A cross-sectional survey outlining patients' motivation and abilities for using a PHR and the patient perceived impact of PHR access on care quality

Introduction

In the previous chapter the overlap between patient engagement dimensions identified in *Chapter 1* and the themes impacting PHR access were discussed. Namely, motivation and ability were acknowledged as important factors determining use of PHR. The impact of digital health interventions depends on factors such as patients' motivation and abilities to use them (Goel et al., 2011; Holt et al., 2019). Motivation is a complex construct consisting of intrinsic and extrinsic components (Ryan & Deci, 2000a). Similarly, abilities and factors affecting the use of PHR are manyfold (Holt et al., 2019; Ronda et al., 2013). To the author's knowledge, few studies assess both factors determining PHR use and the impact of PHR use on patients' health and care together. Based on the themes from the preceding interview study, the given chapter assesses patients' motivation and abilities to use PHR and its perceived impact on care quality using CIE as an exemplary PHR engagement opportunity.

Aims and objectives

This survey aimed to examine patients' perspectives on PHR by exploring patients' motivation to use a PHR, their ability to do so, and how they perceive PHR use impacts on their care. The objectives were to:

1. Describe patients' reasons for either using or not using CIE.
2. Explore patients' ability to make use of the CIE and factors that influence this ability.
3. Examine the perceived impact of CIE use on quality of care and identify the characteristics of patients who perceive the greatest benefits from CIE use.

Methods

Study design and setting

A cross-sectional web-based survey study was performed to evaluate patients' perspectives on, and experiences of, using the Care Information Exchange (CIE) which was previously described and integrates data from sources across healthcare trusts and care settings. To enhance the quality of reporting a CHERRIES checklist (Eysenbach, 2004) was completed (see *Appendix A: Chapter 7: CHERRIES checklist*).

Ethics

The survey data collection was conducted and approved according to service evaluation processes by Imperial College Healthcare NHS Trust's audit, information governance, and communication teams. It was approved by the appropriate audit leads for the concerned division and registered with the audit team under the service evaluation registration number 296. Furthermore, feedback from the communications team was integrated into the questionnaire. All data was stored and analysed securely in the BDAU SE according to the approved survey documentation.

Participants and sampling

A cross-sectional sample of CIE users who accessed their CIE records during the data collection period was assessed in the given study. CIE was offered to patients from various services and specialties situated across North West London. Patients who consented to being contacted via a mailing list at the trust, were informed about the study by an email and invited to participate in the survey. Furthermore, after log-in to the system a message inviting all CIE users who logged in at least once during the study period (*n*=27,411) to take part in the survey was displayed on the homepage. The message stated patient views on the CIE would be appreciated and provided a link to the online survey which patients were asked to follow if they were willing to complete the survey. At the beginning of the survey general information on its purpose was provided and informed consent sought. As the survey was online it could be completed at any time or place according to patients' convenience.

Not all patients registered with the CIE had used the portal; only respondents who indicated that they had used the CIE were included for the quantitative analyses presented. Patients who did not provide basic demographics regarding age and gender were excluded. For the given population, a confidence level of 95%, and a 5% margin of error, the minimum sample size for representativeness was calculated to be *n*=379 participants.

Data collection

The data collection took place between July 1, 2018, and July 1, 2019. The online survey was implemented using the web-based survey software Qualtrics. A bespoke questionnaire co-designed through cooperation between researchers, the NHS trust-based CIE project team including implementation and communication teams, and clinicians. The questionnaire

items were based on the preliminary themes from the interviews in the previous chapter, understanding of information and error identification questions from *Chapter 5*, as well as the CIE Standard Operating Protocol (Jilka, 2016) which set out plans and assessment intentions for the CIE implementation. Key themes addressed by the questionnaire were patient needs for understanding information presented in PHR, the impact of PHR access on patient engagement in health and care, and sociodemographic information. Several iterations of the questionnaire were produced before the final version was implemented.

The final version included a maximum of 50 questionnaire items for users and 19 for non-users. However, based on the survey logic 14 items related to user perceived impact were only displayed if specific answers were selected to previous questions. Apart from the first question assessing the use status of participants, participants could choose to omit questions as the survey did not force responses. The questionnaire contained both quantitative (multiple choice) and qualitative (free text) items providing complementing types of information. Furthermore, the questionnaire relied on existing literature to include the eHealth Literacy Scale, eHEALS for short, a validated measure of digital health literacy (Chung & Nahm, 2015; Norman & Skinner, 2006a). Digital health literacy needed to be assessed as underpinning of participants' ability to use digital health resources in general compared to the CIE specifically. The eHEALS tool is an 8-item measure of patients' combined knowledge, comfort, and perceived skills in finding, evaluating, and using internet health resources for health concerns (Norman & Skinner, 2006a). The items are answered on a five-point Likert scale (from one "strongly disagree" to five "strongly agree") with total eHEALS scores ranging from eight to 40. A higher score indicates higher digital health literacy.

To be registered for the CIE meant having had a CIE account created disregarding of its usage. Respondents were asked to self-report if they were CIE users or not ("*Have you ever used the CIE?*"). Dependent on the response participants were categorised as users or non-users and the subsequent survey blocks were presented accordingly apart from the participant characteristics, which were queried for all respondents. The collected participant characteristics included:

- age bracket (*i.e.*, <30, 31-40, 41-50, 51-65, or ≥65years),
- gender (*i.e.*, male, female, other [free text], or prefer not to say),
- ethnicity (*i.e.*, white or ethnic minority),
- if English was the native language,
- highest level of education (*i.e.*, GCSE/NVQ/apprenticeship, AS-levels/A-levels/equivalent, undergraduate degree, postgraduate degree, professional degree, doctorate, or prefer not to answer),
- perceived health status (*i.e.*, very poor, somewhat poor, neither good nor poor, somewhat good, or very good),
- motivation to be involved in healthcare (*i.e.*, very much, a lot, a moderate amount, a little, or not at all), and
- the first section of the postcode.

The complete questionnaire with the split for CIE users and non-users can be found in the appendix (see *Appendix A: Chapter 7: Chapter 7: A cross-sectional survey outlining patients' motivation and* abilities for using a PHR and the patient perceived impact of PHR access on care quality

Questionnaire – Personal health records and care quality and safety).

Data analysis

Participant characteristics

Descriptive information, such as counts and percentages, on sociodemographic factors, user status and postcodes, was compiled to characterise the participant sample. Due to the strongly skewed distribution towards West London and North West London, postcode areas were categorised as “West London”, “North West London”, “other London” or “other”. Maps of the total participant numbers and the proportion of CIE users by postcode areas were created using Tableau software.

Objective 1: describe motivation to use a PHR based on reasons for using or not using CIE

Considering the complexity of motivation, qualitative data regarding reasons to use CIE or not was analysed as a proxy for motivation. The analysis was based on respondents’ free-text elaborations on the reasons why they had or had not used the CIE (see *Appendix A: Chapter 7: Questionnaire – Personal health records and care quality and safety* for full questionnaire). Thematic analysis according to Braun and Clarke (2006) was conducted as it allowed for flexible, inductive analysis of the data. The six steps of thematic analysis below were followed:

1) familiarisation with the data,
2) generation of initial codes,
3) searching for themes,
4) reviewing themes,

5) defining and naming themes, and
6) producing the report (Braun & Clarke, 2006).

Separate thematic analyses were performed for self-proclaimed CIE users and non-users. LF coded all responses and RL second coded a subset of the quotes to sense check the first coder's work. All disagreements were discussed and resolved jointly by the coders. Based on the codes, themes were created, and a thematic map formed which again was jointly discussed and refined.

Objective 2: explore patients' ability to make use of a PHR

The survey explored patients' ability to make use of a PHR (*i.e.*, CIE) with consideration of factors impacting patient ability to make use of it. *Table 24* includes the survey items related to patients' ability to use a PHR and its impacting factors. The ability to make use of a PHR refers to several levels and is based on understanding the information contained in a PHR. Understanding and using a PHR may be supported or hindered by impacting factors such as system usability and patient perceptions. Responses concerning the experience of navigating CIE and participants' problems and concerns were analysed descriptively.

Building on the understanding of PHR information, actions may be taken by patients in response to the available information. For instance, PHR offer the opportunity for patients to actively contribute to patient safety by identifying errors in their records and taking action to ensure that these are corrected. As an initial assessment of the acceptability and feasibility of this patient safety strategy, the CIE users' willingness and ability to identify and respond to errors in their PHR was appraised.

Table 24. Survey questions regarding the ability to make use of a personal health record (PHR) and its impacting factors.

Survey questions		**Response options**
Users	Non-users	
How was your experience of navigating your CIE record?	-	• Very difficult • Difficult • Easy • Very easy • Not applicable
Did you understand the information that you saw on CIE?	-	• Yes, definitely • Yes, to some extent • No, please specify [free text] • Not sure, please specify [free text]
When using CIE, did you notice any errors in your record?	-	• No, I did not notice any errors • Yes, I did notice errors. Please specify [free text]
If you were to see an error in your medical records, what would you like to be able to do?	-	• Nothing • Flag it up to my healthcare professional for correction • Correct it myself • Unsure
Which type of errors would you personally feel comfortable correcting? Tick all that apply.	-	• Personal information • Medication names • Medication doses • Doctor's notes • Dates of appointments • Diagnosis • Other, please specify [free text]
Did/Do you have any of the following problems or concerns when using CIE? Tick all that apply.		• Finding information • Understanding information • Problems using PC or tablet • Problems with internet connection • Concerns about confidentiality • Concerns about data security

Note. Care Information Exchange (CIE).

Quantitative analyses for missing data and participant characteristics

To assess the effects of excluding patients with missing data regarding age and gender (*n*=78 out of 523, 15%), a Pearson chi-square test of homogeneity (χ^2) was run. The distribution of responses to survey items was compared between the analysis sample and the missing data sample. Descriptive statistics were used to quantitatively summarize respondent characteristics and users' responses to structured survey items. Counts and

proportions were calculated for categorical variables. Means and SDs were calculated for continuous variables.

Analysis of free-text responses using framework analysis method

The framework analysis method by Ritchie and Spencer (1994) was used to analyse the unstructured, free-text responses. Framework analysis is a transparent and systematic approach to qualitative data analysis that allows for data to be interpreted through a five-step process:

1) familiarization with data,
2) identification of a thematic framework - themes were either identified a priori or detected in the data itself,
3) indexing - to explore the fit of the theoretical framework to the data,
4) charting - which involves summarizing the data into theoretical charts, and
5) mapping and interpretation - which involves checking or reviewing and synthesizing the data set as a whole (Ritchie & Spencer, 1994).

Two researchers experienced in framework analysis (RL and LF) coded the data independently. Differences in coding were discussed by the coders to reach a consensus. Organized frameworks of inductively and deductively derived themes and subthemes were generated and applied across free-text responses. The coders worked together to complete the other stages of the analysis. Quotes from the free-text responses from the CIE users were presented to illustrate each theme and subtheme.

Multinomial Regression Analysis

Multinomial regression analyses were conducted to identify the characteristics of patients predicting:

1) their ability to identify errors in their records
   (*i.e.*, to what extent did they understand their records?) and
2) their willingness to respond to errors in their records
   (*i.e.*, what action would they like to be able to take once errors in their records were noticed?).

To facilitate regression analyses in the context of sparse counts (*Appendix A: Table 58* and *Table 59*), age, motivation to be involved in own care, and digital health literacy were treated as dichotomous variables and respondents reporting gender as "other" were excluded. Based on existing literature, an eHEALS score ≥26 was chosen to indicate higher digital health literacy and <26 to indicate lower digital health literacy (Milne et al., 2015; Richtering et al., 2017). Univariate multinomial logistic analyses were initially performed to identify potential predictors to include in the multivariable model. As suggested by Hosmer et al. (2013; Zhang, 2016), the following approach to variable selection was adopted:

1) variables that demonstrated significance (p<.25) in the univariate analyses were entered into the preliminary multivariable model,
2) variables that were nonsignificant at p>.05 according to the likelihood ratio test were then removed one at a time according to the variable with the highest P value (backward elimination), and
3) to check for suppressor effects, variables excluded during backward selection were re-entered separately into the regression model (forward selection).

Only variables that were significant at $p<.05$ (likelihood ratio test) were retained in the final multinomial regression models. Model quality comparisons were conducted using the Akaike Information Criterion (Snipes & Taylor, 2014), and the goodness of fit was assessed using Pearson chi-square statistic (Zhang, 2016). Effect estimates are presented as odds ratios (ORs) with 95% CIs. Analyses were conducted using Microsoft Excel (version 16.54, Microsoft Corporation) and SPSS (version 27, IBM Corp).

Objective 3: investigate the impact of PHR access on perceived quality of care

The impact of CIE access on the perceived quality of care was assessed with regards to the survey items in *Table 25*. The survey items were mapped to five out of six of the Institute of Medicine's domains of quality of care: effectiveness, safety, timeliness, efficiency, and patient centredness (Institute of Medicine (US), 2012; Institute of Medicine (US) Committee on Quality of Health Care in America, 2001). In contrast to the other domains of the Institute of Medicine's domains of quality of care, the equity domain was not assessed using survey items and is instead based on multivariable regression analyses. Hence, no mapping is included for this domain in *Table 25*. Participants' responses to the 12 multiple-choice, closed-ended items displayed below in *Table 25* were analysed.

Table 25. Survey questions regarding the impact of personal health record access as opportunity for patient engagement on perceived quality of care.

Domain	Survey questions	Response options
Patient centred-ness	Has CIE changed your role when making decisions about your health care?	• Yes, I feel I have more of a role • Yes, I feel I have less of a role • No
	Has CIE changed how much you feel in control about your health care?	• Yes, I feel I have more control • Yes, I feel I have less control • No
	Has CIE changed any of the following for you?	
Effective-ness	• Accessibility of my personal health history • Health conditions	• Much worse • Somewhat worse • About the same • Somewhat better • Much better
Efficiency	• Workload for HCP involved in my care • My own workload relating to my health and care	
Safety	• Safety of care • Accuracy of my health information • Detection of errors in my health records	
Timeliness	• Quickness of appointments/diagnosis/treatment	
Overall care quality	• Overall quality of care received • Satisfaction with care received	

Note. Care Information Exchange (CIE).

Only participants who had previously accessed and used the CIE as well as provided basic demographic information regarding age and gender were included for these analyses. To evaluate equity, multivariable regression analyses were conducted to determine associations between patients' sociodemographic characteristics and perceptions of the impact of CIE on overall care quality and satisfaction with care. The following information was used for multivariable analyses: age, gender, ethnicity, native language, education level, digital health literacy, motivation to be involved in own care, and health status. Respondents' level of motivation to be involved in their own care was assessed via a multiple-choice question (*i.e.*, "In general, how motivated to be involved in your healthcare are you?" Possible responses: "A little," "A moderate amount", "A lot", and "Very much").

Digital health literacy was assessed using eHEALS, developed and validated by Norman and Skinner (2006a).

Descriptive statistics were used to summarize respondent characteristics and patients' responses to survey items. Counts and proportions were calculated for categorical variables; means and SDs were calculated for continuous variables. Multinomial regression analyses were conducted to identify sociodemographic characteristics that predict patient-perceived improvement in overall care quality and greater satisfaction with care. To overcome the issue of sparse counts in multivariable modelling (see *Appendix A*: *Table 62* and *Table 63*), "age", "motivation to be involved in own care", "digital health literacy", and "frequency of CIE use" were treated as dichotomous variables, and respondents reporting gender as "other" were excluded. Again, an eHEALS score ≥26 to indicate higher digital health literacy and <26 to indicate lower digital health literacy were selected (Milne et al., 2015; Mitsutake et al., 2011; Richtering et al., 2017; Shiferaw & Mehari, 2019; Van Der Vaart et al., 2011). Categories of the dependent variable were combined (*i.e.*, "much worse" and "somewhat worse" as well as "somewhat better" and "much better" were analysed as a single category, respectively). Univariate multinomial logistic analyses were performed to identify possible predictors to include in the multivariable model. As for the analysis for Objective 2, the approach by Hosmer et al. (2013; Zhang, 2016), was adopted for variable selection.

Only variables that were significant at $p<.05$ (Likelihood Ratio Test) were retained in the final multinomial regression models. Model quality comparisons were conducted as previously described. Effect estimates are presented as odds ratios (ORs) with their 95% CIs. To assess the effects of excluding patients with missing data regarding age and gender, the sociodemographic characteristics of the missing data sample (n=78) and the analysis sample (n=445) were compared. Additionally, the distribution of item responses between

the analysis sample and the missing data sample for the perceived impact of CIE on the overall quality of care and satisfaction with care was compared using a Pearson chi-square test of homogeneity ($\chi 2$). Analyses were conducted using Microsoft Excel (version 16.54) and SPSS software (version 27; IBM Corp).

Results

Participant characteristics

The survey link was shared with a total of 27,411 patients that logged in at least once (*i.e.*, were accredited to use the system) between July 1, 2018, and July 1, 2019. A total of 1083 subjects replied to the survey (186% of the estimated target sample). The proportion of users was 61.58% (667/1083), and among these, more than half (385/667, 57.7%) used the portal at least once a month. Self-identified users and non-users of CIE were more likely to provide demographic information (for age: 251/667, 37.6% and 152/416, 36.5%, respectively; for gender: 246/667, 36.9% and 36.6%, 152/416). Of them, 650 participants provided information regarding their gender and age. The analysis was limited to these individuals (+71.5% of the estimated target sample).

In the sub analysis of patients who provided basic characteristics regarding gender and age category, 59.8% (389/650) were women, and 84.8% (551/650) were ≥40 years old. Most participants were White (498/650, 76.6%) and resided in London (651/1006, 64.7%). Among them, 55.9% (363/651) were from North West London. A more detailed overview of the distribution of participants by postcode area is provided in *Figure 19*. The mean literacy score assessed by the eHEALS tool was 31.5 (SD 7.9), and 22.3% (145/651) had a postgraduate degree or higher. A majority of participants considered themselves very

motivated to be involved in their own care (374/651, 57.5%), and 41.8% (272/651) considered themselves to have a good or very good health status. A full description of the analysed sample and the characteristics of the non-user and user groups is provided in *Table 26*.

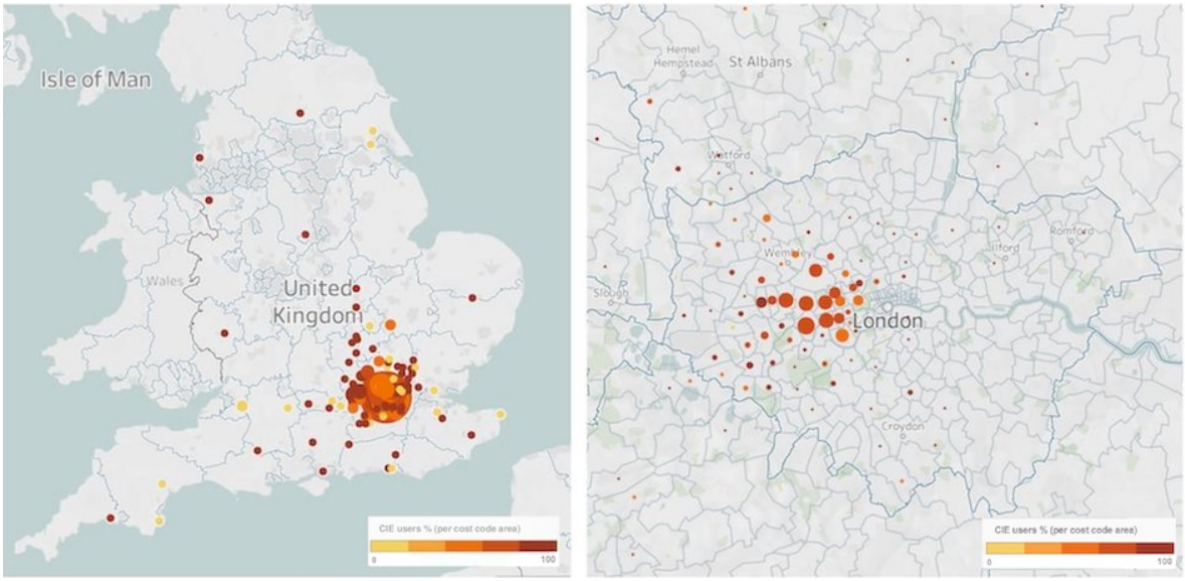


Figure 19. Geographic location overview: general overview of England (left) and Central London (right, representing 64.7% of the subjects). Circle size represents the total number of respondents per postcode area, and colour code represents the percentage of Care Information Exchange users per postcode area. The right-side image shows the stronger representation of North West London in the sample. Figure source is an open-access article distributed under the terms of the Creative Commons Attribution License: Neves, A. L., Smalley, K. R., Freise, L., Harrison, P., Darzi, A., & Mayer, E. K. (2021). Determinants of use of the care information exchange portal: Cross-sectional study. Journal of Medical Internet Research, 23(11), e23481, p.4., https://doi.org/10.2196/23481

Table 26. Characteristics of the participants according to their system use (n=650).

Characteristics	Non-users (*n*=205)	Users (*n*=445)	Total (*n*=650)
Gender, n (%)			
Female	113 (55.1)	276 (61.7)	389 (59.8)
Male	91 (44.4)	167 (37.4)	258 (39.7)
Other	1 (0.5)	2 (0.4)	3 (0.5)
No response	0 (0)	0 (0)	0 (0)
Age band (years), n (%)			
<30	9 (4.4)	22 (4.9)	31 (4.8)
31-40	20 (9.8)	48 (10.7)	68 (10.5)
41-50	23 (11.2)	62 (13.9)	85 (13.1)
51-65	72 (35.1)	166 (37.1)	238 (36.6)
≥65	81 (39.5)	147 (32.9)	228 (35.1)
No response	0 (0)	0 (0)	0 (0)
Ethnicity, n (%)			
BAME[a]	34 (16.6)	75 (16.8)	109 (16.8)
White	155 (75.6)	343 (76.7)	498 (76.6)
Other	16 (7.8)	22 (4.9)	38 (5.8)
No response	0 (0)	5 (1.1)	5 (0.8)
Geographic location, n (%)			
London			
East	2 (0.9)	2 (0.5)	4 (0.6)
East Central	0 (0)	0 (0)	0 (0)
North	0 (0)	7 (1.6)	7 (1.1)
North West	15 (7.3)	40 (8.9)	55 (8.5)
South East	0 (0)	5 (1.1)	5 (0.7)
South West	20 (9.8)	28 (6.3)	48 (7.4)
West	96 (46.8)	203 (45.4)	299 (46)
West Central	1 (0.5)	1 (0.2)	2 (0.3)
Other	62 (30.2)	146 (32.7)	208 (31.8)
No response	9 (4.4)	13 (2.9)	22 (3.5)
Educational degree, n (%)			
Secondary school or below	75 (36.6)	118 (61.1)	193 (29.7)
Undergraduate or professional degree	77 (37.6)	180 (40.3)	257 (39.5)
Postgraduate or higher	33 (16.1)	112 (25.1)	145 (22.3)
No response	20 (9.8)	35 (7.8)	55 (8.5)
Digital literacy (eHEALS[b] score), mean (SD)	28.4 (8.1)	32.9 (7.4)	31.5 (7.9)
Overall health status, n (%)			
Good or very good	95 (46.3)	177 (39.6)	272 (41.8)
Neither good nor poor	55 (26.8)	106 (23.7)	161 (24.8)
Poor or very poor	55 (26.8)	162 (36.2)	217 (33.3)
No response	0 (0)	0 (0)	0 (0)
Motivation to be involved in own care, n (%)			
Not very much	7 (3.4)	6 (1.34)	13 (2)
A moderate amount	40 (19.5)	43 (9.6)	83 (12.7)
A lot	61 (29.8)	116 (25.9)	177 (27.2)
Very much	96 (46.8)	278 (62.2)	374 (57.5)
No response	1 (0.5)	2 (0.5)	3 (0.5)

Note. [a]BAME: Black, Asian, and minority ethnic. [b]eHEALS: eHealth Literacy Scale.

User status self-reporting

The user status was self-reported by the survey participants. Patients' response to the question if they "*had ever used the CIE*" defined the further survey blocks as questions for users and non-users differed apart from the demographic information block at the end of the survey (see *Appendix A: Chapter 7: Questionnaire – Personal health records and care quality and safety*).

Objective 1: describe motivation to use a PHR based on reasons for using or not using CIE

Users

A total of 503 participants provided free-text descriptions about their main reasons for using CIE. User responses regarding their reasons for using CIE were categorised into four main themes: *involvement in own care*, *access to medical care information*, *communication*, and *other reason*. The complete thematic map with themes and subthemes is provided in *Figure 20*. Each main theme and its subthemes will be discussed in the following paragraphs and related quotes presented.

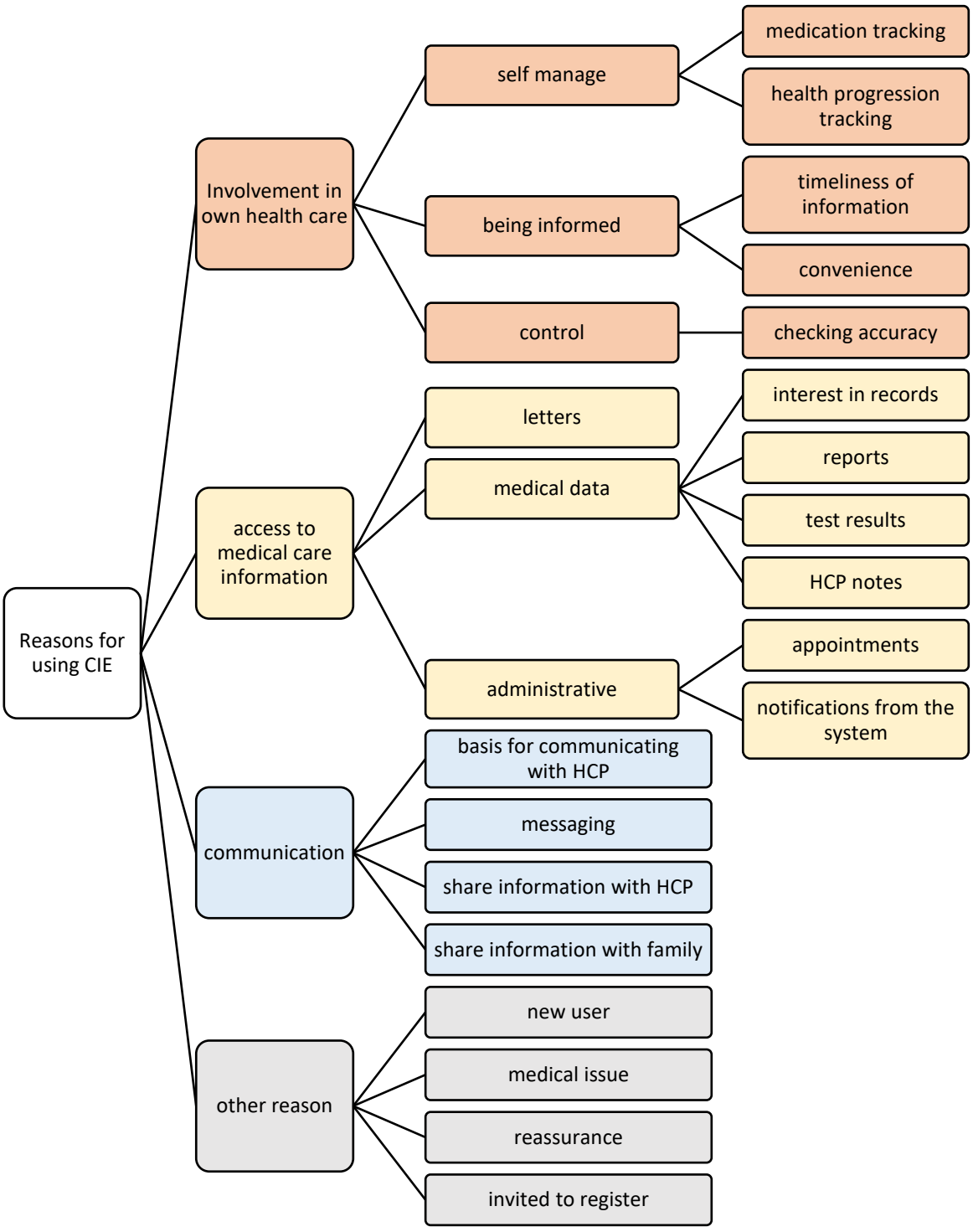


Figure 20.Thematic map of reasons participants stated for using the Care Information Exchange (CIE). HCP stands for healthcare professional.

Access to medical care information

The opportunity to *access medical care information* was discussed by participants with mention to three main areas. The issues identified in the analysis related to *letters*, *medical data*, and *administrative* matters. The types of *letters* were not consistently specified but ranged from clinic appointment letters to letters from consultants. As the mentions of letters by participants were sometimes vague and neither purely related to *medical data* nor *administrative* in nature, *letters* was declared its own theme.

"Check on letters (which arrive weeks before snail mail) […]" [ID 12]

"[…] Re-reading letters from consultants very useful" [ID 284]

"[…] Also to keep track of correspondence." [ID 292]

"Clinic appointment letters" [ID 503]

Medical data related to the information concerning a participant's health contained in the record.

"At present to follow all results for ongoing treatment" [ID 59]

"centralised record" [ID 440]

Medical data had four subthemes of *interest in record*, *reports*, *test results*, and *HCP notes*. Access to *test results* was by far the most frequently mentioned issue in the analysed responses.

"[…] Check medical tests results" [ID 46]

"To be able to get test results quickly and to be able to reference back when I know things have changed for me" [ID 68]

"to find out results of tests" [ID 87]

The subthemes *interest in record*, *reports*, and *HCP notes* were expressed less often but are still not to be neglected. *Interest in record* represented participants' general interest in accessing their medical records.

"Interested to build and see my record" [ID 16]

"Interest" [ID 327]

In addition to test results, respondents highlighted their wish to access medical reports from various services.

"To view […] radiology reports" [ID 406]

"Check bloods/urine/radiological reports following [outpatient appointment]" [ID 394]

"Xrays reports, observations reports, all other health issues reports" [ID 279]

Furthermore, the insight *HCP notes* on the medical records could potentially offer seemed to be interesting for participants.

"[…] Specialists notes on my case" [ID 119]

"To check appointments and doctors entries" [ID 419]

The more *administrative* matters identified were information related to *appointments* and *reactions to notifications from the system*. *Administrative* reasons to use CIE were of a more organisational nature than *letters* and *medical data* with their subthemes.

"[…] take control of medical records (which previously have been repeatedly lost as I moved around the country)" [ID 143]

"[…] Record information." [ID 425]

Appointments was the second most frequently mentioned theme in the analysis. In terms of appointments, participants appreciated being able to keep track of upcoming and past appointments.

"Checking appointments" [ID 14]

"to confirm appointments and locations […]" [ID 93]

"To look up my upcoming appointments […]" [ID 197]

Moreover, participants stated using the CIE in response to *notifications from the system* to check updates to their uploaded information.

"In response to email nitification [sic]." [ID 110]

"to check notifications of results or appointments" [ID 495]

"prompted by an email saying my records have been updated" [ID 471]

Involvement in own health care

Participant responses indicated their intention for *involvement in own health care*. For instance, one response stated:

"As I can see what's going on and I feel apart [sic] of my health journey […]" [ID 185]

However, the *involvement in own health care* theme extended beyond feeling like a part of the health care journey and included the three subthemes *self manage*, *being informed*, and *control*. The opportunity to *self manage* was expressed repeatedly.

"to self manage [long term conditions] and multimorbidities" [ID 41]

"Manage chronic health" [ID 129]

Furthermore, two more specific examples of self management activities were described. One was *medication tracking* with some using it to contextualise changes in medications.

"[…] tracking medication […]" [ID 37]

"[…] to see how I am responding to changes in medication" [ID 203]

The other subtheme was *health progression tracking* for which information from the record was used to compare one's health status across different points in time.

"To track my progress […]" [ID 213]

"[…] To look at historic trends in results, as very easy to see, e.g. for specific blood test results" [ID 251]

"[…] to be able to reference back when I know things have changed for me" [ID 68]

Being informed as a theme related to participants information needs concerning their health and care.

"Just to keep on track and in the know about my healthcare" [ID 200]

"To be fully informed of my health issues.." [ID 325]

Similarly, the subtheme of *being informed* was further specified regarding the *timeliness of information* obtained and the *convenience* of receiving information. The *timeliness of information* was valued.

"I can get my test results quicker online her [sic] than my GP or consultants. It reassures me faster so I [don't] have to wait." [ID 102]

"fast accurate information on my health issues […]" [ID 321]

Moreover, the *convenience* of receiving information was appreciated as well.

"It's convenient." [ID 266]

"Because it's difficult to get feedback by phone or e-mail" [ID 1]

Lastly, *control* over personal care and medical records and the opportunity for *checking accuracy* of information was valued. *Control* may have been based on the overview of the whole healthcare journey provided by CIE information. However, not many participants further specified how they connected control with using CIE.

"To check on my health and clinic appointment findings. Giving me the opportunity to take control of my treatment process" [ID 175]

"Taking control" [ID 323]

In contrast, *checking accuracy* was more straightforward. Respondents wanted to ensure that the information within their medical record was correct and CIE gave them an opportunity to do so.

"To check and re-read my medical records" [ID 364]

"To check information is correct […]" [ID 27]

Communication

The third theme of reasons to use CIE was *communication*. Participants used CIE in course of communication as *basis for communicating with HCP*, for *messaging*, to *share information with HCP* or to *share information with family*. Information from CIE was taken as *basis for communicating with HCP* for instance to inform discussions with medical professionals. Being able to correlate experiences with medical data supported participants in communicating with their HCP and was perceived as useful.

"Allows me to correlate my own experience with diagnostic test information and have a much more informed exchange with the medical professionals, as well as providing them with more relevant symptom details." [ID 113]

"[…] helps me think […] of questions to ask at appointments" [ID 156]

"[…] to inform discussions with doctors who are treating me" [ID 478]

Moreover, the *messaging* was providing contact with HCP teams beyond the usual channels such as telephone calls.

"Maintain contact with my Asthma team - messages, letters, instructions, etc" [ID 409]

"Contact with consultant or medical team" [ID 417]

Information sharing was an important benefit discussed by participants. On the one hand, data could be more efficiently shared with additional medical professionals than previously without CIE. To easily *share information with HCP* was considered a benefit of CIE.

"[…] Use when seeing other clinicians from other Trusts who do not have access to these records." [ID 394]

"To get test results for my GP." [ID 340]

"Share information between care providers. I am currently serving in HM Forces, this platform is vital for showing GPs information when we move around the country." [ID 319]

On the other hand, participants valued the opportunity to *share information with family* members or having a family member's record shared with them. Especially, children appreciated checking their potentially elderly parents' records.

"[…] sharing info with my family member" [ID 51]

"To check on my elderly parents [sic] medical info - test results, letters and appt [appointments]" [ID 361]

"To check my mother's test results, appointments and documents" [ID 212]

Other reason

The group *other reason* contains subthemes of more unspecific and variable nature, any more specific labels would have been inaccurate. The subthemes of this theme are less

related to each other than the subthemes of the previous three themes. *New user*, *reassurance*, *medical issue*, and *invited to register* were the subthemes of *other reason*. Some participants stated as they just recently registered to CIE they were a *new user*, and, hence, felt unable to comment on their reasons for using it.

"New to the system." [ID 11]

"Don't know as I only joined today. But think it is going to be v[ery] useful" [ID 306]

On the other hand, other participants simply stated that they were *invited to register* without further explaining why they had decided to follow the invitation. Though, some respondents were unsure what CIE might be useful for.

"I was told to" [ID 80]

"curiosity, received an email telling me to activate my account. not really sure what i [sic] need it for" [ID 502]

Another small group of participants referred to a *medical issue* as their reason for using CIE. However, no explanations as to how CIE was useful specifically was provided. Thus, it was sorted to the *other reason* theme.

"Had infusion" [ID 481]

"Because I was in hospital with a [sic] infection" [ID 100]

Lastly, *reassurance* was an expected benefit from using CIE for some respondents. These considered CIE to provide information more quickly and, hence, give reassurance of, for instance, test results being within normal ranges, earlier.

"I can get my test results quicker online her [sic] than my GP or consultants. It reassures me faster so I don't have to wait." [ID 102]

"To check my blood results to give me peace of mind. […]" [ID 292]

However, this expectation did not prove correct for all respondents as one described:

"I thought it would reduce time in finding out results and make me less anxious waiting for letters in the post. But actually I find it makes me more anxious!" [ID 412]

Contrasting to other participants, a single respondent wished to have their record removed. Hence, the participant, who described themselves as a user, accessed the system aiming to achieve a record removal.

"To try to remove my records" [ID 404]

Non-users

A total of 147 participants provided free-text descriptions regarding their main reasons for not using CIE. These reasons were split into the three main themes *unaware of CIE existence*, *no need*, and *problems using CIE*. The *unaware of CIE existence* theme contained the subtheme of *not invited to use CIE*. The thematic map is presented below in *Figure 21*. The themes and subthemes will be discussed in more detail below.

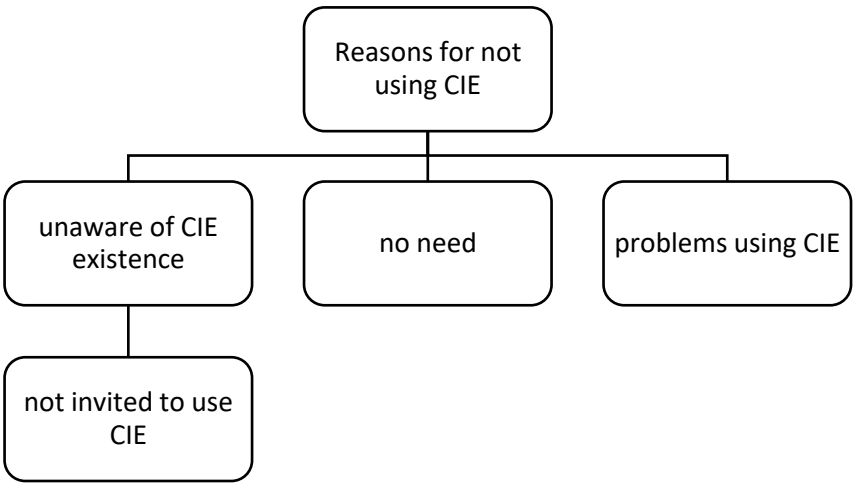


Figure 21. Thematic map of reasons participants provided for not using the Care Information Exchange (CIE).

Being *unaware of CIE existence* was reported repeatedly by participants. In the below quotes "it" refers to CIE.

"I never heard of it" [ID 35]

"I didn't realise it was available to me" [ID 50]

"did not know of its existence" [ID 95]

Moreover, the *unaware of CIE existence* theme contained the subtheme *not invited to use CIE*. Participants mentioned not having been invited or asked to join CIE previously.

"Not been offered before" [ID 65]

"Never been asked to do so [i.e., use CIE]" [ID 105]

In terms of motivation, a perception of need can bring someone to act (Ryan & Deci, 2017). Therefore, if *no need* is perceived, no action such as using a PHR is taken. Some participants stated not to have needed to use CIE previously.

"I have not had the need to [use CIE]" [ID 63]

Other participants elaborated further. For instance, as they had not required medical care where CIE would have been offered.

"Not needed to visit hospital before" [ID 147]

Or, on the other hand, one patient mentioned they already had access to all information CIE provided.

"It just has information that I already have." [ID 17]

Moreover, several participants described *problems using CIE*. The mentioned problems ranged from poor website usability to difficulties understanding information and situations CIE could be useful.

"Only just been emailed about it and have found the site impossible to use, […] very poorly designed to maximise frustration for the user,. [sic] As a professional I tried for 10 m[i]ns to get my latest report and failed completly [sic]. I wont [sic] be using this site again, and will use my GP instead." [ID 120]

"I have looked at my results but I don't actually understand what they mean" [ID 68]

"No[t] sure how to use or under which circumstances it woul[d] be appropriate for me to input information. I only access when I recieve [sic] notifications of test results or appointments" [ID 25]

In response to being asked about their reasons for not using CIE, a total of three respondents were either unsure of their registration status [ID 56, ID 86] or stated they were not registered [ID 6]. These replies did not quite answer the question posed and as such were not represented as themes in the thematic map in *Figure 21*.

Importantly, contrary to their response to the question regarding their user status, a substantial number (*n*=53, 36.1%) of participants claimed to actually be existing or new CIE users. Even though these responses did not answer the question regarding reasons for not using CIE, due to the prevalence of the issue, a separate thematic map was prepared (see *Figure 22*). The thematic map for the misidentified non-users consisted of the themes of *new users* and *users* who selected the wrong answer to the preceding survey question. Some of the *users* expressed *branding confusion* regarding CIE and PKB.

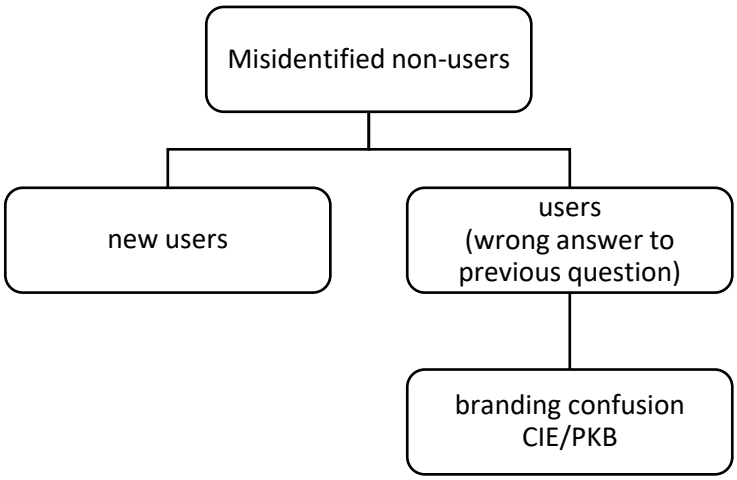


Figure 22. Thematic map regarding reasons for participants to identify themselves as (potential) Care Information Exchange (CIE) users in their free-text responses. PKB stands for Patients Know Best.

New users might not have felt comfortable categorising themselves as having used CIE. Hence, proclaiming themselves to be non-users while stating to have just registered in their reasons for not using CIE previously.

"I have only just registered" [ID 69]

"I have been member for 2 weeks" [ID 96]

In contrast, several *users* apparently answered the previous survey question (*i.e.*, "*Have you ever used CIE?*") incorrectly. The survey did not allow for participants to go back and change their responses to previous survey sections. As a negative response to the aforementioned question initiated a new survey block, respondents could not correct their answer afterwards.

"I made a mistake, I have been using it." [ID 102]

"Sorry, I pressed the wrong option on the firs[t] question. I do use the CIE, and it is very helpful." [ID 90]

Furthermore, some users described *branding confusion* between CIE and PKB. It appeared that patients knew the CIE by the name of the platform provider (*i.e.*, PKB) instead of the trust programme name CIE. As the survey was run as a trust based service evaluation, the trust name for the programme, CIE, was used throughout the survey and its documentation. However, some patients seemed to be unsure if PKB and CIE referred to the same matter or not. As with the *user* theme, participants could not go back to change their answer once they realised that CIE and PKB referred to the same system.

"I use and access patients know best, regularly, is this the same as CIE? I don't know if I misunderstood previous question." [ID 60]

"I have used it but at first did not know what was meant by CIE" [ID 54]

"I have used CIE but I didn't realise this was the application as I always log in via Patient Knows Best and the previous question was not clear that it was the same thing." [ID 30]

Objective 2: explore patients' ability to make use of a PHR

Participant characteristics for sub analysis

Of 1083 patients who responded to the survey, 674 (62.2%) patients indicated that they had previously used the CIE, and of these CIE users, 523 (77.6%) went on to complete some or all of the questionnaire. Only the CIE users who provided basic demographic details regarding both age and gender were included in the analysis (445/523, 85.1%; +117% of the minimum target sample size) while 14.9% (78/523) of respondents with missing data for either age or gender were excluded.

Of the 445 respondents, 276 (62%) were women and most were aged ≥51 years (313/445, 70.3%). Approximately two-thirds (284/445, 63.8%) of the respondents resided in London and a further 32.6% (145/445) of the respondents lived in other geographical locations in England. More than one in five (97/445, 21.8%) participants belonged to an ethnic minority group. Most were educated to a degree level or higher (292/445, 65.6%), and the mean digital literacy (eHEALS) score was 33.6 (SD 6.4). Most patients (278/445, 62.5%) considered themselves to be highly motivated for their own care. Approximately one-third (162/445, 36.4%) of the patients reported poor health status, whereas 39.8% (177/445) reported being in good health. Most patients (284/445, 63.8%) reported using the CIE at least once a month. Patient characteristics are shown in *Table 27*.

Table 27. Respondent characteristics for personal health record use ability, n=445.

Characteristics	Respondents
Gender, n (%)	
Male	167 (37.5)
Female	276 (62)
Other	2 (0.4)
No response	N/A[a]
Age group (years), n (%)	
<30	22 (4.9)
31 to 40	48 (10.8)
41 to 50	62 (13.9)
51 to 64	166 (37.3)
>65	147 (33)
No response	N/A
Ethnicity, n (%)	
Ethnic minority	97 (21.8)
White	343 (77.1)
No response	5 (1.1)
Geographic location, n (%)	
London	284 (63.8)
Other location in England	145 (32.6)
No response	16 (3.6)
Education, n (%)	
Secondary school or below	118 (26.5)
Undergraduate or professional degree	180 (40.4)
Postgraduate or higher	112 (25.2)
No response	35 (7.9)
Language, n (%)	
English	379 (85.2)
Non-English	58 (13)
No response	8 (1.8)
eHealth literacy (eHEALS[b] score), mean (SD; range)	33.6 (6.4; 8-40)
Overall health status, n (%)	
Good or very good	177 (39.8)
Neither good nor poor	106 (23.8)
Poor or very poor	162 (36.4)
No response	0 (0)
Motivation to be involved in own care, n (%)	
Not very much	6 (1.3)
A moderate amount	43 (9.7)
A lot	116 (26.1)
Very much	278 (62.5)
No response	2 (0.4)

Note. [a]N/A: not applicable, [b]eHEALS: eHealth Literacy Scale.

Missing data analysis

Meaningful comparisons of sociodemographic characteristics between the analysis sample and the missing data sample were not possible because of considerable missing data in the group of 15% (78/523) of respondents excluded from this analysis (*Appendix A: Table 60*). There were no differences in the distribution of structured questionnaire responses between the analysis sample and the missing data sample (*Appendix A: Table 61*).

Patients' understanding of information in the CIE

Of the 445 respondents, 181 (41%) reported that they "definitely" understood the CIE information and 220 (49%) reported understanding the CIE information "to some extent". Few patients answered "No" (31/445, 7%) or "Not sure" (13/445, 3%); these patients were asked to elaborate on their responses and 93% (41/44) of patients provided free-text comments. Through the mapping and interpretation of coded responses, two primary categories of barriers to understanding the CIE information were identified:

1) information-related barriers (*i.e.*, users have difficulty understanding the information itself) and
2) system-related barriers (*i.e.*, problems related to the CIE system impeding users' understanding of information).

These categories consist of several themes and subthemes as outlined in *Figure 23*.

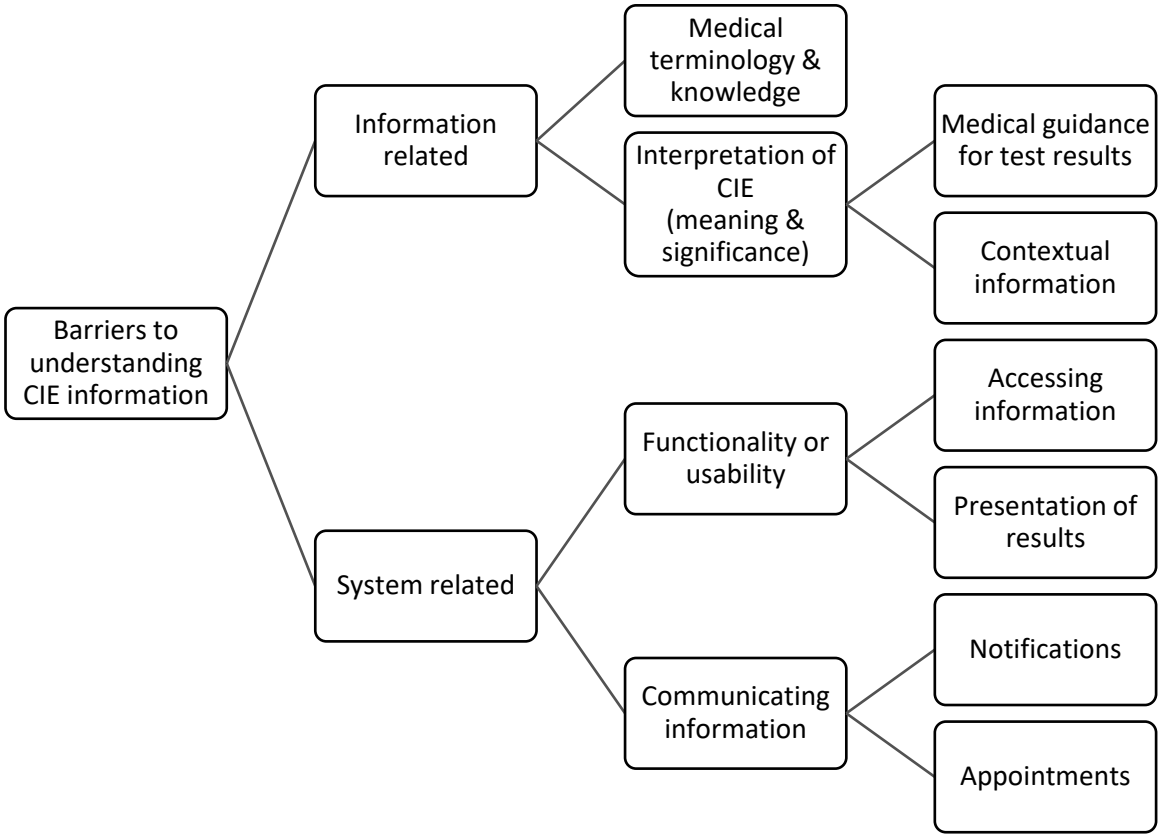


Figure 23. Thematic map of barriers to understanding the Care Information Exchange (CIE) information.

Regarding information-related barriers, medical terminology or users' lack of medical knowledge were identified as barriers to understanding the CIE information as articulated by two patients:

> *"[…] when it is hugely medical, as one would expect for Doctors records, then I don't always understand what I am looking at, or the relevance of its meaning. [ID 280]*

> *"It's great having access to blood results and radiology reports but the jargon. I don't understand much of it." [ID 376]*

Patients often struggled to interpret the meaning or significance of information on the CIE, particularly in relation to the interpretation of test results.

"Didn't know whether a test result mattered or not" [ID 282]

Some patients would like more medical guidance to help with understanding the CIE information, as articulated by a patient:

"There is no room or option for doctor comments so I do not understand my test results and this makes me worried when I can see them but do not understand if they are ok or not!" [ID 412]

For other patients, additional contextual information would have assisted with understanding information.

"Blood tests results out of range and not knowing context" [ID 363]

In terms of *system-related* barriers to understanding the CIE information, patients described problems with the way in which test results were presented, including how results are displayed (*"Results are virtually unreadable" [ID 57]*) or how they are listed in the CIE:

"[...] difficult to find some test results as they are listed under the medical name and the patient may not recognize the test under these names" [ID 195].

Being able to access information was problematic for some patients; for example, a patient [ID 153] pointed out that the CIE system is not accessible to screen reader users; another patient reported that *"Information is too difficult to navigate when loaded separately" [ID 235]*. Some patients reported that the CIE notifications were confusing (*"All these messages and*

they were not clear what they were for" [ID 428]), whereas others reported problems with how appointment information is communicated on the CIE, such as the following:

> *"Often no detail given so it says I have an appointment, but I don't know who with or why" [ID 302].*

Overall, patients' free-text responses provided fewer examples of system-related barriers than information-related barriers and a significant proportion of responses related to difficulties in understanding the test results.

Patient characteristics associated with understanding information on the CIE

Patient characteristics and responses to the question "*Did you understand the information you saw on CIE?*" were entered into univariate and multivariable multinomial regression models to identify patient characteristics that predicted the perceived ability to understand information in the electronic record. The final multivariable multinomial regression model with two predictor variables (digital health literacy and motivation) predicted significantly better than the null (intercept) model ($p<.001$), and Pearson chi-square statistic suggested that the model fit the data well ($\chi^2_2=2.4$; $p=.30$). In the final multivariable model, digital health literacy was the only variable independently associated with understanding the CIE information (*Table 28*). Patients with higher digital health literacy (eHEALS score ≥26) were six times more likely to report "definitely" understanding the CIE information, compared with patients with lower digital health literacy (OR 6.07, 95% CI 1.70-21.57; $p=.005$). Sensitivity analyses assessing the effects of including or excluding predictor variables that demonstrated significance in the univariate analyses did not alter this result.

Table 28. Multinomial regression results of users' sociodemographic characteristics and perceived level of understanding of information in the Care Information Exchange.

	Yes, to some extent vs no		Yes, definitely vs no		Yes, to some extent vs no		Yes, definitely vs no	
	Univariate odds ratio (95% CI)	*p* value	Univariate odds ratio (95% CI)	*p* value	Multivariable odds ratio (95% CI)	*p* value	Multivariable odds ratio (95% CI)	*p* value
Gender								
Female				Reference				
Male	0.76 (0.36-1.61)	.47	0.49 (0.23-1.06)	.07	—[a]	—	—	—
Age (years)								
≥65				Reference				
≤64	1.33 (0.60-2.96)	.48	1.58 (0.70-3.57)	.27	N/A[b]	N/A	N/A	N/A[b]
Ethnicity								
White				Reference				
Ethnic minority	2.48 (0.72-8.53)	.15	3.18 (0.92-10.97)	.07	—	—	—	—
Native language								
Non-English				Reference				
English	0.41 (0.09-1.78)	.23	0.45 (0.10-2.00)	.29	—	—	—	—
Education								
Secondary or below				Reference				
Undergraduate or professional	0.47 (0.16-1.82)	.18	0.66 (0.22-1.96)	.45	—	—	—	—
Postgraduate or higher	0.33 (0.12-1.04)	.06	0.58 (0.18-1.82)	.35	—	—	—	—
Digital literacy								
Lower digital health literacy				Reference				
Higher digital health literacy	1.47 (0.51-4.18)	.48	6.23 (1.76-22.06)	.005	1.51 (0.53-4.34)	.44	6.07 (1.70-21.57)	.005
Health status								
Neither good nor poor				Reference				
Poor	1.48 (0.51-4.29)	.48	2.58 (0.86-7.75)	.09	N/A	N/A	N/A	N/A
Good	0.63 (0.25-1.57)	.32	1.29 (0.86-7.75)	.60	N/A	N/A	N/A	N/A
Motivation to be involved in own care								
Not very much or a moderate amount				Reference				
A lot or very much	1.08 (0.39-3.01)	.89	3.29 (1.04-10.39)	.04	0.93 (0.30-2.88)	.90	2.99 (0.85-10.61)	.09

Note. [a]Variable excluded from the final multivariable model using a backward elimination approach, [b]N/A: not applicable (variable excluded from the multivariable analyses because of nonsignificance [$p>.25$] in the univariate analyses).

Experience navigating the CIE

A total of 504 participants specified their experience of the CIE record in response to the question "*How was your experience of navigating your CIE record?*". The vast majority of participants reported navigating their record was "very easy" (*n*=254, 50%) or "easy" (*n*=130, 26%). However, roughly a quarter reported navigating CIE to be "difficult" (*n*=87, 17%) or "very difficult" (*n*=33, 7%).

Problems or concerns with CIE use

Given a list with potential problems or concerns, participants were asked to select all options that applied for them. The following problems or concerns when using CIE were specified a total of 414 times by the CIE users responding to the question. Finding information was declared difficult by numerous participants, *n*=132 (32%). Beyond the navigation to specific information, 36% of participants (*n*=150) reported problems understanding information contained in CIE. Comparatively few respondents had described problems using a PC or tablet, 5.1% (*n*=21), or with their internet connections, 2.7% (*n*=11). Concerns about confidentiality and data security were not uncommon with *n*=50 occurrences (12%) each.

In contrast, the problems and concerns regarding CIE foreseen by non-users were as follows. A total of 141 instances of the given problems or concerns were proclaimed by the CIE non-user respondents. Not unexpectedly, finding information, 17% (*n*=24), and understanding information, 16% (*n*=23), were predicted to be difficult. Very few participants expected problems using a PC or tablet, 3.5% (*n*=5), or with the internet connection, 1.4% (*n*=2). However, in relation to the total number of problems reported or expected by users and non-users, concerns about confidentiality, 31% (*n*=43), and concerns about data security, 31% (*n*=44), were more prevalent for non-users.

Errors that patients noticed in their records

Nearly one in five patients (79/445, 18%) reported that they had noticed errors in their medical records. In all, 97% (77/79) of the patients provided further information regarding the nature of these errors. The themes and subthemes that were identified in the analysis of these free-text responses are presented in *Figure 24*. The most prominent theme emerging from patients' free-text responses was *incorrect information*. This theme described six categories of *incorrect information*: *patient details*, *appointments*, *medical history or diagnoses*, *measurements or results*, *medications*, and *letters or correspondence*.

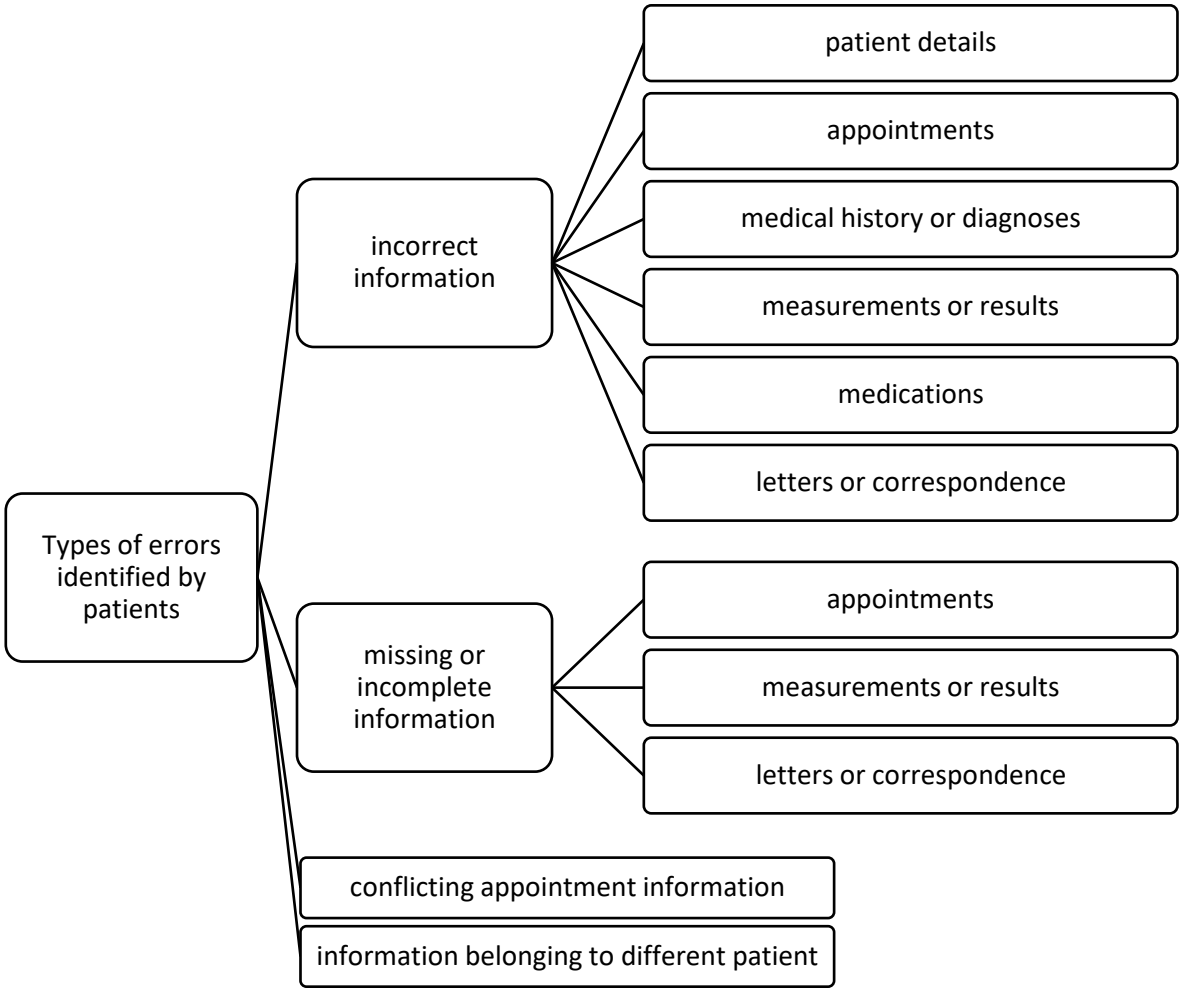


Figure 24. Thematic map of types of errors identified by patients.

Patient details referred to patients' personal information such as identifying details or contact information being inaccurate. Hence, potentially resulting in problems on delivering information to the patient or correctly assigning information to a specific patient.

"incorrect NHS number" [ID 77]

"My address is wrong" [ID 79]

Similarly, errors concerning the details or tracking of *appointments* were repeatedly described in the participants' replies.

"Appointment times are incorrect" [ID 117]

"On one occasion, the system indicated that I had missed an appointment when I was definitely there" [ID 178]

In some instances, the *medical history or diagnoses* of participants was misrepresented potentially causing initial anxiety until incongruencies can be assessed.

"Diagnosis of cancer which I do not have" [ID 317]

"my GP [general practitioner] said, 'he became depressed.' No, I didn't" [ID 120]

Measurements or results were reported as containing errors as well. While sometimes only details such as times were incorrect, some tests had never been performed in the first place.

"A time on a test was wrong" [ID 304]

"MRSA result appeared on my record for a test I never took" [ID 95]

Another part of the CIE, errors were identified in, related to *medications*. In line with the *measurements and results* subtheme, the *medications* subtheme had instances of medication entries including incorrect details as well as completely incorrect medication entries.

"An error on the dosage of one of my medications" [ID 280]

"I have never received ibuprofen on prescription" [ID 128]

Finally, participants described errors in their *letters and correspondence* accessible via CIE.

"Incorrect information on discharge notice from A&E [accident and emergency]" [ID 173]

"Errors in my consultants [sic] letter" [ID 271]

A smaller number of respondents described information that was either incomplete or missing from the record entirely. A few patients noted instances where results or letters were missing from the record.

"Blood test and urine results are missing" [ID 413]

"2 notifications disappeared" [ID 264]

However, most patients noted instances of *missing or incomplete information* related to *appointments* (*e.g.*, *"Some appointments are not shown" [ID 406]*).

Conflicting appointment information also emerged as a distinct theme; several users described instances of the CIE appointment information that did not match information communicated via other means (*e.g.*, through phone calls or letters). There appears to be a general lack of trust in appointment information listed on the CIE as articulated by a user:

"I don't know. Hard to confirm whether an appointment is real or a mistake as I have not received a letter or email notification to confirm appointment listed" [ID 303].

"I am shown as having multiple appointments at different dates at the same clinic. The last time I turned up for one of these I was told there was no appointment [...] very confusing!" [ID 226]

The final theme *information belonging to a different patient* contained only two responses: a CIE user had noticed *"another patient's clinic letter—major breach of confidence" [ID 164]* in their record, whereas another respondent reported that information belonging to a different patient had appeared in her midwifery notes.

Responding to errors in the medical record

When asked to consider how they would like to respond to errors in their records, most patients (272/445, 61%) would like to flag up errors to their health professionals for correction. Although some patients (57/445, 13%) were unsure what action they would like to take, only a small proportion (16/445, 3.6%) said they would not take any action. Approximately one-fifth (91/445, 20%) of the respondents were willing to correct errors themselves. Of the 91 CIE patients who were willing to correct errors themselves, most were comfortable correcting errors in their personal information (88/91, 97%), and approximately two-thirds were willing to correct medication doses (58/91, 64%) or medication names (56/91, 62%). A smaller proportion reported willingness to correct physicians' notes (33/91, 36%) or diagnoses (31/91, 34%).

Patient characteristics associated with willingness to correct errors

Patient characteristics and responses to the question, "*If you were to see an error in your medical record, what would you like to be able to do?*" were entered into univariate and multivariable multinomial regression models to identify patient characteristics that predicted willingness to take action to address errors in the record. The reference category for these analyses was do nothing. The results are presented in *Table 29*. The final multivariable

multinomial regression model with two predictor variables (language and health status) predicted significantly better than the null (intercept) model (p=.04) and the model fit the data well (χ^2_4=6.7; p=.16). In multivariable analyses, users' native language and health status predicted their willingness to take action to address errors in the record. Native English speakers were more likely to select flag up errors to health professionals (OR 3.45, 95% CI 1.11-10.78; p=.03). Native English speakers were also more likely to be willing to correct errors in their medical records themselves (OR 5.65,95% CI 1.33-24.03; p=.02). Compared with patients reporting that their health was neither good nor poor (reference group), patients reporting good health status were more likely to correct errors themselves (OR 3.84, 95% CI 1.07-13.75; p=.04). However, there was no convincing evidence that poor health status increased the odds of being willing to correct errors (OR 3.35, 95% CI 0.89-12.61; p=.08). Post hoc sensitivity analyses did not affect any of these findings.

Table 29. Multinomial regression results of users' sociodemographic characteristics and willingness to flag up or correct errors in the Care Information Exchange.

Characteristics	Flag it up[a] vs do nothing		Correct it myself vs do nothing		Flag it up[a] vs do nothing		Correct it myself vs do nothing	
	Univariate odds ratio (95% CI)	*p* value	Univariate odds ratio (95% CI)	*p* value	Multivariable odds ratio (95% CI)	*p* value	Multivariable odds ratio (95% CI)	*p* value
Gender								
Female	Reference							
Male	0.71 (0.25-2.02)	.52	0.59 (0.20-1.78)	.35	N/A[b]	N/A	N/A	N/A
Age (years)								
≥65	Reference							
≤64	0.81 (0.25-2.64)	.72	0.73 (0.21-2.54)	.62	N/A	N/A	N/A	N/A
Ethnicity								
White	Reference							
Ethnic minority	0.48 (0.16-1.50)	.21	0.48 (0.14-1.58)	.23	—[c]	—	—	—
Native language								
Non-English	Reference							
English	3.13 (1.02-9.56)	.05	3.59 (0.51-2.69)	.04	3.45 (1.11-10.78)	.03	5.65 (1.33-24.03)	.02
Education								
Secondary or below	Reference							
Undergraduate or professional	1.57 (0.44-5.6)	.49	1.36 (0.36-5.21)	.65	N/A	N/A	N/A	N/A
Postgraduate or higher	1.55 (0.36-6.75)	.56	1.80 (0.39-8.32)	.45	N/A	N/A	N/A	N/A
Digital health literacy								
Low digital health literacy	Reference							
High digital health literacy	2.25 (0.47-10.83)	.31	144 (0.28-7.51)	.66	N/A	N/A	N/A	N/A
Health status								
Neither good nor poor	Reference							
Poor	1.45 (0.45-4.68)	.54	3.73 (1.00-13.85)	.05	1.34 (0.41-4.41)	.63	3.35 (0.89-12.61)	.08
Good	2.61 (0.71-9.58)	.15	5.32 (1.27-22.25)	.02	2.82 (0.76-10.54)	.12	3.84 (1.07-13.75)	.04
Motivation to be involved in own care								
Not very much or a moderate amount	Reference							
A lot or very much	2.09 (0.56-7.78)	.27	2.37 (0.56-10.09)	.25	—	—	—	—

Note. [a]Flag it up to my health care professional for correction, [b]N/A: not applicable (variable excluded from the multivariable analyses because of nonsignificance [*P*<.25] in univariate analyses), [c]Variable excluded from the final multivariable model using a backward elimination approach.

Objective 3: investigate the impact of PHR access

The same subgroup was analysed as for Objective 2. Hence, participant characteristics can be found in this chapter's *Results: Objective 2: Participant characteristics for sub analysis*.

Patients' perceptions of the impact of CIE on the overall quality of care

Patients were asked to consider how CIE has changed the overall quality of care they receive. Of 429 patients who answered this question, 172 (39%) reported that the quality of their care was better with CIE. A further 55% (243/445) said that their care was about the same, and 3.2% (14/445) of patients said their care was worse (see *Table 30*).

Table 30. Patients' perceptions of the impact of the Care Information Exchange (CIE) on overall quality of care and satisfaction with care.

	Missing data *n* (%)	Much worse *n* (%)	Somewhat worse *n* (%)	About the same *n* (%)	Somewhat better *n* (%)	Much better *n* (%)
How has CIE changed the overall quality of care you have received?	16 (3.6)	7 (1.6)	7 (1.6)	243 (54.6)	93 (20.9)	79 (17.8)
How has CIE changed how satisfied you are with your care?	20 (4.5)	7 (1.6)	12 (2.7)	212 (47.6)	97 (21.8)	97 (21.8)

Patients' perceptions of the impact of CIE on satisfaction with care

When asked to consider how CIE has changed how satisfied they are with their care, 44% (194/445) of patients said their care was better, 48% (212/445) said their care was the same, and 4.3% (19/445) said their care was worse. In addition, 4.5% (20/445) of patients did not respond to this question (*Table 30*).

Patients' perceptions of the impact of CIE across six domains of care quality

Overview

Patients' responses to a further ten survey items revealed their perceptions of how CIE use has changed the care they receive across the following domains of quality of care: effectiveness, safety, timeliness, efficiency, and patient centredness (see *Table 31*).

Table 31. Survey items and participants' responses to "Has CIE changed any of the following...?" mapped to the Institute of Medicine's domains of health care quality (n=445).

	Missing data, *n* (%)	Much worse, *n* (%)	Somewhat worse, *n* (%)	About the same, *n* (%)	Somewhat better, *n* (%)	Much better, *n* (%)
Effective						
Health conditions	30 (6.7)	7 (1.6)	9 (2)	276 (62)	61 (13.7)	62 (13.9)
Safe						
Safety of care	33 (7.4)	7 (1.6)	7 (1.6)	260 (58.4)	68 (15.3)	70 (15.7)
Accuracy of health information	25 (5.6)	9 (2)	11 (2.5)	187 (42.0)	117 (26.3)	96 (21.6)
Detection of errors in health records	32 (7.2)	8 (1.8)	13 (2.9)	246 (55.3)	70 (15.7)	76 (17.1)
Timely						
Quickness of appointments, diagnosis, and/or treatment	29 (6.5)	13 (2.9)	12 (2.7)	212 (47.6)	77 (17.3)	102 (22.9)
Efficient						
Workload for health care professionals involved in my care	31 (7.0)	7 (1.6)	15 (3.4)	265 (59.6)	63 (14.2)	64 (14.4)
My own workload relating to my care	28 (6.3)	11 (2.5)	23 (5.2)	209 (47)	92 (20.7)	82 (18.4)
Patient centredness						
Accessibility of my personal health records	16 (3.6)	6 (1.3)	9 (2.0)	72 (16.2)	112 (25.2)	230 (51.7)
My role when making decisions about my health care	6 (1.3)	11 (2.5)[a]	11 (2.5)[a]	188 (42.2)[b]	240 (53.9)[c]	240 (53.9)[c]
How much I feel in control of my health care	6 (1.3)	19 (4.3)[d]	19 (4.3)[d]	147 (33)[b]	273 (61.2)[e]	273 (61.2)[e]

Note. [a]I feel I have less of a role, [b]No change, [c]I feel I have more of a role, [d]I feel I have less control, [e]I feel I have more control, Care Information Exchange (CIE).

Effectiveness

Patients were asked whether CIE use had changed their health condition. Most (276/445, 62%) patients responded that their health condition was about the same; however, 28% (123/445) patients reported that their health condition had improved with CIE use. Only 3.6% (16/445) said their health condition was worse.

Safety

Although many (260/445, 58%) patients reported that the safety of the care was the same with CIE; 31% (138/445) felt that their care was safer. Approximately half (213/445, 48%) believed that CIE had led to improvements in the accuracy of their health information, and 33% (146/445) of patients felt CIE was associated with better detection of errors in the health record. Only 3.2% (14/445) of patients felt the safety of their care was worse with CIE.

Timeliness

Approximately 40% (179/445) of patients felt that the timeliness of their care (being able to access appointments, diagnoses, and treatment quickly) had improved with CIE. Only 5.6% (25/445) said the timeliness of their care was worse, and 48% (212/445) said the timeliness of their care was about the same.

Efficiency

Patients were asked whether CIE had changed the workload relating to their health, including both patients' own workload and the workload of health professionals involved in their care. Many (209/445, 47%) patients reported that their own workload was about the

same; however, 29% (174/445) felt that their workload was better, and 7.7% (34/445) felt their workload was worse. Regarding the impact of CIE on the workload of health professionals, 39% (174/445) of patients perceived that this had improved, 60% (265/445) believed it to be about the same, and 4.9% (22/445) thought that it was worse.

Patient centredness

Most (342/445, 77%) patients reported that CIE had improved the accessibility of their personal health records. A few (72/445,16%) patients felt that the accessibility of their records was about the same with CIE, whereas only 3.3% (15/445) said their records were less accessible. More than half (240/445, 54%) of the survey respondents reported that CIE had led to them having more of a role in decision making, and 61% (273/445) felt they had more control of their health care. Only 2.5% (11/445) of patients reported feeling they had less of a role, and 4.3% (19/445) felt they had less control of their healthcare with CIE.

Equity

To identify the characteristics of CIE users who perceived better overall quality of care and greater satisfaction with care with portal use, patient characteristics and survey responses were entered into univariate and multivariable multinomial regression models. For the survey item "*How has CIE changed the overall quality of care you have received?*" the final multivariable multinomial regression model with three predictor variables (ethnicity, digital health literacy, and frequency of CIE use) predicted significantly better than the null (intercept) model (p<.001) and Pearson chi-square statistic indicated satisfactory model fit (χ^2_8=14.4; p=.07). The results of the regression are presented in *Table 32*. Patients with

higher digital health literacy (eHEALS score ≥26) were more likely to report that the overall quality of their care was better with CIE use (OR 2.40, 95% CI 1.07-5.42; *p*=.03). Compared with their White counterparts, patients self-identifying to an ethnic minority group were also more likely to perceive improvements in care quality based on CIE use (OR 2.27, 95% CI 1.26-3.73; *p*=.005). Across ethnic groups, 68% (30/44) of Asian and British Asian patients reported better overall quality of care with CIE use, compared with 45% (9/20) of Black or African or Caribbean or Black British patients, 37% (120/328; missing data, *n*=15) of White patients, and 36% (4/11) of patients from mixed or multiple ethnic groups (see *Table 33*).

Table 32. Multinomial regression results of patient characteristics and perceived change in overall quality of care with Care Information Exchange use.

	Univariate[a]				Multivariable[a]			
	Worse care quality vs about the same		Better care quality vs about the same		Worse care quality vs about the same		Better care quality vs about the same	
	OR[d] (95% CI)	*p* value	OR[d] (95% CI)	*p* value	OR[d] (95% CI)	*p* value	OR[d] (95% CI)	*p* value
Gender								
Female	Reference							
Male	0.47 (0.13-1.74)	.26	1.26 (0.84-1.88)	.26	N/A[b]	N/A	N/A	N/A
Age (years)								
≥65	Reference							
≤64	1.35 (0.41-4.42)	.63	1.28 (0.84-1.94)	.26	N/A	N/A	N/A	N/A
Ethnicity								
White	Reference							
Ethnic minority	1.88 (0.49-7.18)	.36	2.27 (1.37-3.78)	.002	2.44 (0.61-9.80)	.21	2.27 (1.26-3.73)	.005
Native language								
English	Reference							
Non-English	2.56 (0.66-9.91)	.18	1.81 (1.02-3.21)	.04	—[c]	—	—	—
Education								
Secondary or below	Reference							
Undergraduate or professional	4.60 (0.55-38.23)	.16	0.85 (0.53-1.38)	.51	—	—	—	—
Postgraduate or higher	4.00 (0.44-36.76)	.22	0.73 (0.42-1.25)	.25	—	—	—	—
Digital literacy								
Lower digital health literacy	Reference							
Higher digital health literacy	1.57 (0.20-12.63)	.67	2.51 (1.15-5.45)	.02	1.51 (0.18-12.42)	.70	2.40 (1.07-5.42)	.03
Health status								
Neither good nor poor	Reference							
Poor	0.72 (0.20-2.60)	.62	1.29 (0.77-2.16)	.34	N/A	N/A	N/A	N/A
Good	0.52 (0.14-2.02)	.35	1.22 (0.73-2.03)	.45	N/A	N/A	N/A	N/A
Motivation to be involved in own care								
Not very much or a moderate amount	Reference							
A lot or very much	1.92 (0.24-15.19)	.54	1.67 (0.86-3.24)	.13	—	—	—	—
Frequency of Care Information Exchange use								
≤ once a month	Reference							
≥ once a week	1.05 (0.32-3.45)	.94	2.40 (1.59-3.63)	<.001	0.92 (0.24-3.60)	.90	2.31 (1.49-3.58)	<.001

Note. [a]Goodness-of-fit: χ^2_8=14.5; p=.07, [b]N/A: not applicable, variable not entered into multivariable analyses due to nonsignificance (p>.25) in univariate analyses, [c]Variable excluded from final multivariable model using backward elimination approach, [d]odds ratio: OR.

Table 33. Cross-tabulation of patients' ethnicity and their perceived change in overall quality of care with Care Information Exchange (CIE) use.

Survey item: *Has CIE changed overall quality of care received?*	Much worse *n* (%)	Somewhat worse *n* (%)	About the same *n* (%)	Somewhat better *n* (%)	Much better *n* (%)
Asian/British Asian	0 (0.0)	0 (0.0)	14 (31.8)	14 (31.8)	16 (36.4)
Black/African/Caribbean/ Black British	0 (0.0)	1 (5.0)	10 (50.0)	4 (20.0)	5 (25.0)
Mixed/multiple ethnic groups	0 (0.0)	2 (18.2)	5 (45.5)	2 (18.2)	2 (18.2)
Other	0 (0.0)	0 (0.0)	14 (66.7)	4 (19.0)	3 (14.3)
White	6 (1.8)	4 (1.2)	198 (60.4)	67 (20.4)	53 (16.2)
No response for ethnicity	1 (20.0)	0 (0.0)	2 (40.0)	2 (40.0)	0 (0.0)

Frequency of CIE use

Patients using CIE at least once per week were more likely to perceive improved care quality compared with patients using CIE less frequently (OR 2.31, 95% CI 1.49-3.58; $p<.001$). Sensitivity analyses assessing the effects of including or excluding predictor variables that had demonstrated significance in univariate analyses did not alter the results of the multivariable regression. For the survey item "*How has CIE changed how satisfied you are with your care?*" the final multivariable model with three predictor variables (ethnicity, digital health literacy, and frequency of CIE use) predicted significantly better than the null (intercept) model ($p <.001$) and Pearson chi-square statistic suggested that the model fit the data well ($\chi^2_8=5.6$; $p=.69$). Patients with higher digital health literacy (eHEALS score ≥26) were more likely to report greater satisfaction with their care with CIE use, compared with those with lower digital health literacy (OR 2.35, 95% CI 1.09-5.04; $p=.03$; see *Table 34* and *Table 35*). CIE use was also associated with greater satisfaction with care among patients belonging to an ethnic minority group compared with White patients (OR 2.12, 95% CI 1.22-3.67; $p=.007$).

Table 34. Multinomial regression results of patients' sociodemographic characteristics and the perceived impact of the Care Information Exchange on patient's satisfaction with care, part 1.

	Univariate[a]				Multivariable[a]			
	Worse satisfaction vs about the same		Better satisfaction vs about the same		Worse satisfaction vs about the same		Better satisfaction vs about the same	
	Odds ratio (95% CI)	*p* value	Odds ratio (95% CI)	*p* value	Odds ratio (95% CI)	*p* value	Odds ratio (95% CI)	*p* value
Gender								
Female	Reference							
Male	0.84 (0.31-2.31)	.74	1.32 (0.88-1.97)	.17	—[b]	—	—	—
Age (years)								
≥65	Reference							
≤64	0.69 (0.27-1.80)	.45	1.215 (0.76-1.75)	.51	N/A[c]	N/A	N/A	N/A
Ethnicity								
White	Reference							
Ethnic minority	1.30 (0.35-4.78)	.70	2.32 (1.38-3.90)	.002	1.68 (0.44-6.41)	.45	2.12 (1.22-3.67)	.007
Native language								
English	Reference							
Non-English	1.74 (0.47-6.52)	.41	1.63 (0.91-2.89)	.10	—	—	—	—
Education								
Secondary or below	Reference							
Undergraduate/ Professional	8.15 (1.03-64.80)	.05	1.14 (0.67-1.96)	.63	—	—	—	—
Postgraduate/higher	5.94 (0.67-52.47)	.11	1.11 (0.69-1.80)	.67	—	—	—	—

Note. [a]Goodness-of-fit: χ^2_8=5.6; p=.69, [b]Variable excluded from final multivariable model using backward elimination approach, [c]N/A: not applicable as variable not entered into multivariable analyses due to nonsignificance (p>.25) in univariate analyses.

Table 35. Multinomial regression results of patients' sociodemographic characteristics and the perceived impact of the Care Information Exchange on patient's satisfaction with care, part 2.

	Univariate[a]				Multivariable[a]			
	Worse satisfaction vs about the same		Better satisfaction vs about the same		Worse satisfaction vs about the same		Better satisfaction vs about the same	
	Odds ratio (95% CI)	*p* value	Odds ratio (95% CI)	*p* value	Odds ratio (95% CI)	*p* value	Odds ratio (95% CI)	*p* value
Digital literacy								
Lower digital health literacy	Reference							
Higher digital health literacy	2.29 (0.29-18.03)	.43	2.47 (1.19-5.13)	.02	2.17 (0.27-17.35)	.46	2.35 (1.09-5.04)	.03
Health status								
Neither good nor poor	Reference							
Poor	0.92 (0.27-3.16)	.89	1.34 (0.80-2.23)	.27	N/A[b]	N/A	N/A	N/A
Good	1.04 (0.32-3.33)	.95	1.07 (0.65-1.78)	.78	N/A	N/A	N/A	N/A
Motivation to be involved in own care								
Not very much/a moderate amount	Reference							
A lot/very much	3.00 (0.39-23.31)	.29	1.99 (1.04-3.82)	.04	X[c]	X	X	X
Frequency of CIE use								
≤ once a month	Reference							
≥ once a week	0.92 (0.32-2.67)	.88	2.13 (1.41-3.23)	<.001	0.90 (0.27-2.95)	.86	2.03 (1.31-3.13)	.002

Note. [a]Goodness-of-fit: χ^2_8=5.6; p=.69, [b]N/A: not applicable as variable not entered into multivariable analyses due to nonsignificance (p>.25) in univariate analyses, [c]Variable excluded from final multivariable model due to 0 cell counts producing unstable estimates.

Cross-tabulation of patients' ethnicity and perceived change in satisfaction with care revealed that 77% (34/44) of Asian or British Asian patients reported greater satisfaction with care with CIE use, compared with 55% (11/20) of Black or African or Caribbean or Black British patients, 36% (4/11) of patients from mixed or multiple ethnic groups, and 42% (137/325; missing data *n*=18) of White patients (*Table 36*). Patients using CIE at least once per week were more likely to report greater satisfaction with care compared with patients using CIE less frequently (OR 2.03, 95% CI 1.31-3.14; *p*=.002). Sensitivity analyses assessing the effects of including or excluding predictor variables that had demonstrated significance in univariate analyses did not alter the results of the multivariable analyses.

Table 36. Cross-tabulation of patients' ethnicity and their perceived change in satisfaction with care with the Care Information Exchange (CIE) use.

Survey item: Has CIE changed satisfaction with care received?	Much worse *n* (%)	Somewhat worse *n* (%)	About the same *n* (%)	Somewhat better *n* (%)	Much better *n* (%)
Asian/British Asian	0 (0.0)	0 (0.0)	10 (22.7)	15 (34.1)	19 (43.2)
Black/African/Caribbean/ Black British	0 (0.0)	1 (5.0)	8 (40.0)	4 (20.0)	7 (35.0)
Mixed/multiple ethnic groups	0 (0.0)	2 (18.2)	5 (45.5)	3 (27.3)	1 (9.1)
Other	0 (0.0)	0 (0.0)	14 (70.0)	4 (20.0)	2 (10.0)
White	6 (1.8)	9 (2.8)	173 (53.2)	69 (21.2)	68 (20.9)
No response for ethnicity	1 (20.0)	0 (0.0)	2 (40.0)	2 (40.0)	0 (0.0)

Missing data analysis

Of 523 survey respondents, 78 (15%), who had previously used CIE, had missing data regarding age and gender, and these respondents were excluded from our analyses (see *Objective 2*: *Missing data analysis*). Meaningful comparisons of sociodemographic characteristics between the missing data sample and the analysis sample were not possible due to considerable additional missing data in the group of 78 respondents excluded from

this analysis. *Table 37* displays the missing data analysis for the questionnaire items regarding perceived satisfaction with care and quality of care. There were no differences in the distribution of responses between the analysis sample and the missing data sample for the questionnaire item "*How has CIE changed how satisfied you are with your care?*". However, patients included in the analysis were more likely to view the impact of CIE on overall quality of care favourably, compared with those in the missing data sample (χ^2_4=10.3; p=.04).

Table 37. Missing data analysis for questionnaire items regarding perceived satisfaction with care and quality of care.

	Missing data[a] sample, *n* (%)	Included sample, *n* (%)	χ^2_4	*p*
Has CIE changed satisfaction with care?			5.65	.28
Much worse	3 (6.8)	7 (1.6)		
Somewhat worse	2 (4.5)	12 (2.8)		
About the same	20 (45.5)	212 (49.9)		
Somewhat better	9 (20.5)	97 (22.8)		
Much better	10 (22.7)	97 (22.8)		
Has CIE changed overall quality of care received?			10.28	.04
Much worse	2 (4.2)	7 (1.6)		
Somewhat worse	4 (8.3)	7 (1.6)		
About the same	25 (52.1)	243 (56.6)		
Somewhat better	9 (18.8)	93 (21.7)		
Much better	8 (16.7)	79 (18.4)		

Note. Care Information Exchange (CIE), [a]Respondents who did not provide basic characterisation regarding age and gender.

Discussion

Summary of key findings

Reasons for using CIE

Users' main motivation for using CIE was related to accessing medical information, being involved in their own care, and communication. Conversely, non-users' reasons for not using CIE were based on being *unaware of CIE existence*, having *no need* to use it, and *problems using CIE*. However, it is important to note that a substantial part of non-users reported being registered to use the CIE and either confused by the CIE branding or newly registered without much experience using CIE.

Ability and expectations

While a large proportion of patients could understand their CIE health information fully or to some extent, a minority of patients with lower digital health literacy had difficulties understanding the CIE information. Approximately three quarters of respondents found CIE "easy" or "very easy" to navigate. However, 32% of participants reported finding information in CIE to pose a problem. Very few participants described problems with their internet connection (2.7%) or device usage (5.1%). Lacking medical knowledge or guidance, issues of CIE functionality and usability, and unclear presentation or communication of information were some of the barriers inhibiting CIE information understanding. Some patients stated they had found errors in their CIE information, including in patient details, diagnoses, medical history, results, medications, appointment information, and letters or correspondence. Almost two thirds of patients (*n*=272 out of 445, 61%) would like to have

the option of flagging errors in their records to healthcare professionals. Some patients, more likely native English speakers, would like to correct errors themselves.

Impact of PHR use

A large proportion of CIE users reported higher satisfaction with their care and better quality of care. However, many CIE users perceived no changes based on their CIE use. Improvements in overall care quality and better satisfaction with care were more likely to be perceived by patients from ethnic minority groups, those with higher digital health literacy, and those using CIE more frequently. The greatest benefits of using CIE regarding improvement in care quality and satisfaction with the care received were reported by patients of Asian or British Asian ethnicity.

The domain of patient centredness was perceived as benefitting the most from CIE use. Over half of CIE users felt they had increased control over their health care and played a greater role in decision making related to their health and care. Approximately a third of CIE users perceived their care to be more effective, efficient, and safer with CIE. Additionally, about 40% stated the timeliness of appointments, diagnoses, and treatments improved.

Results in context

Objective 1: describe motivation to use a PHR based on reasons for using or not using CIE

Users

Users' main motivation for using CIE was related to accessing medical information, involvement in their own care, and communication in general. Looking back at the

motivational theory, SDT, three motivational needs have to be satisfied: autonomy, feeling responsible for one's own behaviour; competence, feeling useful; and relatedness, feeling understood by others (Ng et al., 2012; Ryan & Deci, 2000b). Patients' aim to be involved in their own care via CIE access may be related to the autonomy domain. The described reasons for using CIE ranged from the comparatively limited level of autonomy of feeling informed, up to control of health records and self-management. The involvement of patients in their care, *e.g.*, via digital health interventions, has received increasing attention in research and health policy with supporting strategies being discussed frequently (Department of Health, 2012; Honeyman et al., 2016; Seventy-first World Health Assembly, 2018). Self-management might additionally relate to the domain of competence, while access to medical care information from administrative to medical data and letters might be prerequisites or early steps towards competence and autonomy.

Patients use CIE as a basis for communication and to share information with both family and healthcare professionals. The domain of relatedness may be linked to patients identifying communication as reason for using CIE since patients' access to PHR has been shown to support the relationship between patients and healthcare professionals (Bell, Mejilla, et al., 2017).

Finally, some users reported only being newly registered or invited to register when asked about their reasons for using CIE. Thus, patients might try CIE based on curiosity and then decide if they wish to continue using it. This would be in line with other research which identified various factors as important to patients, such as functionalities supporting self-management (Hui et al., 2017; Morrison et al., 2012; Taylor et al., 2022). These factors may impact sustained PHR use.

Non-users

Conversely, non-users' reasons for not using CIE were based on being unaware of CIE existence, having no need to use it, and problems using CIE. A lack of awareness of PHR offerings has been reported in other studies (Khan et al., 2020; Prinzivalli et al., 2022). According to SDT, motivation requires three motivational needs to be satisfied (Ng et al., 2012; Ryan & Deci, 2000b). But as long as no need is perceived, no drive to act will exist. Thus, if patients do not feel PHR access has any added value for them, they will not be moved to use available PHR (Fuji et al., 2014). Moreover, problems with a PHR, such as its usability, can be a barrier to PHR adoption and continued use as identified in this and previous studies (Fuji et al., 2014; Showell, 2017). Hence, barriers need to be addressed to encourage PHR adoption and usage.

A substantial number of the self-identified non-users reported being registered to use the CIE and either confused by the CIE branding or newly registered without much experience using CIE and, hence, identifying themselves as non-users at the start of the survey. The branding confusion regarding CIE might have been caused by patients thinking of the system by the name of PKB, the system provider, instead of CIE, the system's implementation ("*I have used CIE but I didn't realise this was the application as I always log in via Patient Knows Best*", ID 30). Surprisingly, this issue existed even though the invitation to take part in the survey about patient experiences with CIE was displayed while patients were logged into the CIE system.

Objective 2: explore patients' ability to make use of a PHR

For patient engagement via PHR to be equitable all patients need to be able to access and understand PHR information. Similarly to others, this study identified a distinct demographic

more likely to be portal users: female, older, highly educated, and with higher digital literacy (Bell, Mejilla, et al., 2017; DesRoches et al., 2019; Gerard et al., 2018; Neves et al., 2021). It has been demonstrated that lacking eHealth literacy skills not only inhibits the use of PHR systems but may also contribute to adverse health outcomes (Davis et al., 2015; Irizarry et al., 2015; Neves et al., 2021; Sanders et al., 2013). Here, it was revealed these patients are also less likely to understand the information provided in the PHR, possibly partly explaining worse health outcomes.

Information-related barriers such as lacking support for interpreting medical information as well as system- or technology-related barriers including issues with portal functionality, usability, and presentation of information were identified here and in previous research (see *Chapter 5*). Approximately a quarter of respondents described their experience of navigating CIE as “difficult” or “very difficult” and roughly a third of CIE users reported finding information to be difficult. Hence, highlighting the need for both system usability and digital literacy, even though problems with using a device (5.1%) or internet connection (2.7%) were rarely reported by CIE users in this study. Unless these barriers are addressed patients with lower digital health literacy will be disadvantaged by any system relying on digital information exchange (Cheng et al., 2020).

Non-users were comparatively more concerned than CIE users about confidentiality (31% vs. 12%) and data security (31% vs 12%). For one, patients who have concerns about PHR’s confidentiality and data security might be less likely to register for a PHR in the first place as from their perspective PHR risks might outweigh its benefits. A study in Sweden showed that trust levels in healthcare’s ability to protect health data influenced the perceived risks connected to unauthorised access to collected electronic health data and their severity (Belfrage et al., 2022). The trust levels were related to health status with those reporting

better health demonstrating higher levels of trust in healthcare (Belfrage et al., 2022). But the more serious an unauthorised access was perceived to be by the respondents (*e.g.*, staff versus hacker access), the more similar the seriousness was estimated to be by both those with higher and lower trust levels (Belfrage et al., 2022). The study, unfortunately, did not consider respondents' use of PHR offers, neither in terms of registration status nor use frequency (Belfrage et al., 2022), so the hypothesis that patients who have concerns about PHR's confidentiality and data security might be less likely to register for a PHR remains debateable.

Interestingly, digital health literacy, as measured by the eHEALS score, was not found to correlate to patients' willingness to take an active part in an error surveillance system in the PHR. Possibly, this is a matter of the eHEALS score being an imperfect measure for this task. The eHEALS has been criticised as not being comprehensive enough to measure the skills required to interact with and contribute to dynamic web-based health tools (Van Der Vaart et al., 2013). This is due to the eHEALS scale being developed on a static, read-only (Web 1.0) understanding of eHealth literacy with it being defined as "*the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem*" (Norman & Skinner, 2006b). In fact, one of the original authors of eHEALS has suggested to update the scale to reflect the modern state of the web (Norman, 2011).

While patient access to digital health records has been established (British Medical Association & NHS England, 2019; Department of Health and Social Care, 2021; NHS Digital, n.d.-a), close to no provider includes mechanisms that allow flagging or changing inaccuracies by patients reviewing their own health data. The findings in this study indicate that many, though not all, patients are willing and able to make use of error flagging or

correcting mechanisms if provided. These results are consistent with previous studies that further suggest that patients' involvement in their own care may help reduce medication errors, delays in their care, and redundant tests and procedures (Bell et al., 2020; Freise et al., 2021; Ross & Lin, 2003). Patients themselves are able to identify errors and omissions across various categories, such as diagnoses from both past and present, health or social histories, allergy or medication information, procedures, test results, and appointment schedules; many of these errors potentially affect care (Bell et al., 2020; Herlihy et al., 2019; Lam et al., 2021; Ross & Lin, 2003). Previous research indicates that serious errors with pertinent implications for medical care, which otherwise might remain unnoticed, can in many cases be identified by patients (Bell et al., 2020; Bell, Gerard, et al., 2017; Johansen et al., 2019; Lam et al., 2021; Ross & Lin, 2003). There is, thus, an as of now unused resource to increase patient safety by encouraging patients to actively participate in improving the accuracy of their own PHR by enabling such mechanisms. New data from this study suggest that approximately one in five (91/445, 20%) patients are willing to correct errors themselves. There have, however, been no previous studies to evaluate the feasibility of this option. One would have to consider several issues arising with this, most pressingly which types of errors one could reasonably expect to be accurately corrected by users without risking patient safety.

Furthermore, and although patients are generally interested in improving the accuracy of their PHRs, it is evident that not all sociodemographic groups are equally prepared to be actively involved in error identification. This survey identified patients' native language to be a predictor of their willingness to correct errors and even to report them to health care providers. This is in line with a US-based study finding that both primarily English- and Spanish-speaking patients were more likely to report mistakes in their records than speakers

of other languages (Bell et al., 2020). In this study there was no significant association between the willingness to act on medical record errors and age, gender, ethnicity, or educational level. However, some other studies did identify people that are male, younger, less educated, or of one of several ethnic minority backgrounds to be less likely to report mistakes (Bell et al., 2020; Lam et al., 2021). Hence, the given findings underscore the importance of considering equity in the design of patient-facing error surveillance systems for avoiding minority groups and patients choosing not to participate in addressing accuracy of medical records themselves being disadvantaged by a digital divide (Cheng et al., 2020).

Objective 3: investigate the impact of PHR access

As has been reported in other studies on different cohorts (Chu et al., 2022; Gerard et al., 2018; Kayastha et al., 2018; Mishra et al., 2019; Moll et al., 2018; Nazi et al., 2015; Oster et al., 2015; Peck et al., 2017; Walker et al., 2019; Weinert, 2017), this work found that patients in the UK experience several benefits when using a web-based PHR. To the author's knowledge, this is the first study mapping patients' experiences against the Institute of Medicine's (2001b) six quality of care domains. The aim was to provide a broader and more detailed insight into the effects of PHR use as perceived by the patients. In the next paragraphs the effects for each of the six domains will be discussed.

Concerning the effectiveness domain, in this study, approximately one quarter of participants stated that CIE use contributed to an improvement in their overall health; a finding that is consistent with meta-analyses of randomized trials and other survey studies (Neves et al., 2020; Reed et al., 2019). Since no information about medical histories was collected here, no statement about the accuracy of the respondents' judgments can be made. However, data available through other studies shows that there is a measurable

positive effect on health, particularly on chronic conditions such as diabetes and hypertension (Neves et al., 2020; Reed et al., 2019).

Safety concerns are prevalent in discussions about quality of care. PHR access provides patients with increased knowledge about their medicines thus increasing medication safety, medication adherence, as well as the likelihood of reporting medicine discrepancies (Blease et al., 2021; Chimowitz et al., 2018; DesRoches et al., 2019; Neves et al., 2020). Blease et al. (2021) reported that this is particularly true when informal carers gain access to the PHR of vulnerable patients (for instance those with serious mental illness) as patient safety risks such as errors in medications and delayed diagnoses could be prevented. These existing results are supplemented by this study showing that participants perceive greater safety in their care when using a PHR due to increased accuracy of their personal health information and detection of errors in their health records. As previously discussed (see *Discussion* of *Objective 2*), there is substantial interest among patients to partake in a patient-faced error surveillance system; likely due to this increase in perceived safety. As *Objective 2* and other research from the United States, have shown, approximately a fifth of patients accessing their PHR can, and do, notice errors in their health records with most patients wanting to participate in rectifying these errors (Bell et al., 2020; Lear et al., 2022).

Concerning the domain of efficiency, more than one in three patients in the study reported that their own workload relating to their health had changed for the better. Patients in another study specified saving time when scheduling appointments via PHR and, importantly, also needing to repeat themselves less in appointments or avoiding clinic visits altogether which saved not only their but also the care providers' resources (Graham et al., 2020). Evidence from analysing randomized trials implies furthermore that patients having access to a form

of PHR can reduce their overall health care use (Neves et al., 2020), thus freeing resources needed elsewhere.

As of now, there is no experimental evidence concerning the impact of PHR on the timeliness of care delivery (Neves et al., 2020). As a first indication that access to PHR can reduce waiting time and harmful delays, 40% of the participants of the survey at hand perceived that CIE enabled them to access appropriate care more quickly by receiving appointments, diagnoses, and treatments in a more timely fashion.

Regarding patient-centredness, the idea that high quality health care needs to be respectful of and responsive to patient preferences, needs, and values, the given study and numerous others found that patients feel more in control of and are more engaged in decision processes for their care when being provided access to their PHR (Blease et al., 2021; Moll et al., 2018; Oster et al., 2015; Walker et al., 2019; Weinert, 2017). With growing evidence it is becoming clear that the likelihood to adhere to medication and treatment plans, make use of screening offers and prevention practices, contribute to error and safety risk detection, and adopt effective management strategies for chronic conditions is greater for patients who are engaged in their care (Bell et al., 2015; Bell, Mejilla, et al., 2017; Náfrádi et al., 2017; Walker et al., 2019; Yeom & Lee, 2022).

Implications of this and other studies regarding equity in health care especially owing to a digital divide have been touched on above for *Objective 2*. The findings are consistent with other studies showing patients who experience barriers to accessing PHR, *e.g.*, low digital literacy, and patients with low levels of technology-enabled care engagement are less likely to report PHR based health improvements (Cross et al., 2021; Reed et al., 2019). Ethnic minority groups have been found to have lower uptake of PHR in previous research (Reed et al., 2019). However, consistent with survey studies of PHR users in the United States

(Gerard et al., 2018; Walker et al., 2019), CIE users who identified themselves as belonging to an ethnic minority group were more likely to perceive improvements in care quality and satisfaction with care. Gerard et al. (2018) found patients of Asian ethnicity were twice as likely as White patients to report these benefits of PHR use in the United States. This result is echoed in the given study for the United Kingdom.

This study highlights the challenges arising due to “the digital divide” in health care. That strategies to tackle this divide must be in place to ensure equitable access to the benefits of PHR for all patients (Maguire et al., 2021; NHS Digital, n.d.-b) is reaffirmed by this study. Several interventions such as a user-centric design ensuring accessibility, readability, and legibility, but also provision of low-cost mobile internet devices and patient outreach programmes have been proposed and could offer ways of access for underserved demographics (Blease et al., 2021; Grossman et al., 2019). The effectiveness of these interventions needs to be evaluated in the future. Additionally, these results suggest that beyond literacy and technology access, there are more untapped resources to increase portal use by underrepresented groups. It is worth enquiring on the reasons as to why some ethnic groups perceive greater benefits of PHR use than others. In this line, further research elucidating mechanisms of PHR adoption among ethnic minorities is needed.

Patient access to PHR seems to enhance transparency and trust as well as support the relationship between patients and healthcare professionals (Bell, Mejilla, et al., 2017). Possibly these benefits are especially vital for ethnic minority groups’ satisfaction with their care. However, to determine the mechanisms of PHR adoption across different ethnic minority groups additional research is required.

In general, the data collected suggests the likelihood of perceiving improvements in overall care quality and being more satisfied with that care is higher for patients who use CIE

regularly. Nevertheless, the causal relationship between the effects remains unclear. While a one directional causality cannot be excluded, this mechanism is likely to be circular. The initial PHR use may lead to perceived improvements in care quality, which may result in greater satisfaction with care, and, in turn, may prompt increased and sustained PHR use as the PHR is perceived to have started the positive development in care quality. As such the perceived care quality could act as a mechanism of sustained PHR adoption. This hypothesis is consistent with the Technology Acceptance Model's suggestion that the actual technology use behaviour is to a degree determined by the perceived benefits of using a technology (Venkatesh & Davis, 2000). The Technology Acceptance Model has been used previously to explore PHR use in older adults (Portz et al., 2019). The usefulness perceived by patients (*e.g.*, communication with healthcare professionals, saving of time and money, addressing concerns without clinic visits) was related to the frequent use of specific PHR functionalities, such as the message and pharmacy centres, and viewing of laboratory results (Portz et al., 2019). Future assessment of CIE should involve the development and testing of a "Theory of Change" to understand how and why PHR use leads to enhanced satisfaction with care in some patient groups (De Silva et al., 2014).

Strengths and limitations

The CHERRIES checklist was completed to ensure adequate reporting of the web survey (see *Appendix A: Chapter 7: CHERRIES checklist*). Representativeness and adequate statistical power were secured as a sample size 75% higher than the estimated minimum sample size was reached. The large sample size contributed to the robustness of the findings. Since the user and non-user groups were both registered at the CIE, the results highlight motivation to use CIE among those registered for the system. The study did not

investigate general determinants of initial engagement with CIE which should be taken into account for any attempt to perform external generalizations. Hence, future research should explore determinants of initial engagement, such as deciding to register with a PHR in the first instance.

The sample population was well characterised by the comprehensive collected characteristics and their analysis at the individual level. Hence, allowing for exploration of important variables such as overall health status, motivation to self-manage, and health literacy (measured by the validated eHEALS tool) in addition to classic demographic factors such as age, gender, ethnicity, and educational level. However, while the sample was diverse with a third of respondents living outside of London and one in five self-identifying as belonging to an ethnic minority group, the individual ethnic minority subgroups were small. Thus, the ethnicity categories were combined for the multivariable regression analyses. When investigating equity, ethnic categories should not be aggregated to ensure the different ethnic groups are properly represented (Kapadia et al., 2022). Though cross-tabulations exploring differences between ethnic groups were run, the groups were small and, hence, may lack generalisability to larger populations.

The survey questionnaire was established based on the (preliminary) thematic map from the interview study in *Chapter 6* and the survey on patients' ability to understand their PHR information and detect errors in *Chapter 5*. Thus, enhancing the relevance, applicability and targeting of survey items. Due to timing restrictions, the preliminary thematic map was the basis for the questionnaire instead of the final version. However, the changes in the thematic map from preliminary to final version would not have impacted the questionnaire items overly.

The mapping of survey items to the Institute of Medicine's six domains of care quality provided a broad overview of the impact of CIE as perceived by users. While initial insights could be gained, the questionnaire was not set up to assess the six domains of care quality as multidimensional constructs. Instruments for evaluating patients' subjective care quality perception are needed. Hence, future work should aim to develop and validate an according questionnaire.

Even though the sample size was substantially larger than the calculated minimum sample size, the overall response rate was relatively low at circa 4%, *n*=1083 out of a population of 27411. Due to the web-based recruitment strategy, a well-accepted method for data collection, selection bias may have been introduced as this approach may favour more tech-savvy and digital literate participants. These participants are also more likely to use PHR. The sample was limited to users of CIE and self-reported perceptions on motivation to use the system, understanding of PHR information, and impact on care quality. Thus, causal relationships regarding the impact of PHR use on care quality cannot be established due to the nature of the study design. Consequently, additional research should generate evidence concerning the relationship between PHR use and care quality using validated methods. A starting point can be the limited available evidence from controlled trials (Neves et al., 2020; NHS Digital, n.d.-a).

The PHR use was self-reported by participants in this study. Consequently, the presence of a potential information bias is possible. Alternatively, patient log-in data could be used as a measure of PHR use (Jung & Padman, 2014). Though, this approach would lack contextual information. Unexpectedly, there seemed to be an issue concerning the branding of CIE as participants stated knowing CIE by the provider's name, PKB. Hence, a contamination bias might have existed as participants that were users misidentified themselves as non-users

and responded to the non-user survey stream accordingly. Future research should classify PHR users and non-users more objectively, for instance, using PHR login data to investigate PHR related engagement in health care.

Conclusion

The ability and opportunity to use PHR for patient engagement in their personal health and its impact on care quality and satisfaction was investigated. PHR access allowed patients to use their information to act for the safety of their healthcare by identifying errors and could enhance perceived quality of care and satisfaction with the care received. Hence, it is worthwhile to further investigate and support patient engagement through PHR access.

Chapter 8: Discussion and conclusions

Summary of research project's main findings

The research focused on patients' engagement in their health and care facilitated through access to their PHR. While the terminology around patient engagement is indistinct, the dimensions of motivation, ability, and opportunity are commonalities throughout the literature (see *Chapter 1*). There is a growing body of evidence that patients engaging with their health and care through the opportunity of PHR access can be beneficial (see *Chapter 2*). While previous published studies reported mixed results on the impact of PHR access on patient engagement, the literature did not provide any examples of related negative implications. Instead, studies either showed benefits for patient engagement (Fauer et al., 2019; Kipping et al., 2016; Krist et al., 2012; Milani et al., 2017; Nagykaldi et al., 2012) or reported no improvements (Kuijpers et al., 2016; Riippa et al., 2014; Toscos et al., 2016; Tuil et al., 2007).

This study adds to the literature in identifying perceived barriers and facilitators to patients understanding and using PHR, both on a personal and IT system level (see *Chapter 5*, *Chapter 6*, and *Chapter 7*). The CIE was the specific PHR system investigated for the research project. Data regarding the preferences for as well as uptake and use of the CIE provided the basis for the following studies (see *Chapter 4*). Registrations and access to the CIE at the individual services varied strongly. The preferred CIE functionalities were viewing test results and appointment schedules as they were perceived as most useful current CIE functionalities by a large margin.

Analogously to the patient engagement literature (see *Chapter 1*), themes identified as important for patients' use of CIE related to their motivation, ability, and the CIE itself as an engagement opportunity with its inherent (perceived) strengths and weaknesses (see *Chapter 6*). Furthermore, using the example of error identification, patients' willingness as well as their ability to take action for their health and care, is demonstrated (see *Chapter 5* and *Chapter 7*). However, there were differences in who was able and willing to engage in improving record accuracy. Patients with higher digital health literacy were six times more likely to report "definitely" understanding the CIE information, compared with patients with lower digital health literacy. In terms of acting upon errors, native English speakers were more likely to want to flag up or correct errors themselves than non-native English speakers. Furthermore, patients with good health status were more likely to consider correcting errors themselves than those in the reference group with neither good nor poor health status.

Finally, the perceived positive impact of CIE use on satisfaction with and quality of care (see *Chapter 7*) further reinforces the benefits of patient engagement in their health and care through PHR access. The largest perceived improvement in care quality relates to the domain of patient centredness. With access to CIE, most patients reported improved accessibility of their health records, while over half the respondents felt they had more of a role in decision making and more control over their health and care.

Findings in the context of the broader literature

Patient engagement and PHR

The discussion of the various understandings and definitions of engagement in general and patient engagement specifically is still ongoing (Kelders et al., 2020). While a certain level

of agreement on the multidimensional nature of patient engagement seems to exist (Gallivan et al., 2012; Graffigna et al., 2015; Higgins et al., 2017), a common definition does not (Barello et al., 2014; Higgins et al., 2017; Kelders et al., 2020; Xu & Wong, 2017). Furthermore, the term patient engagement seems to continue to be used interchangeably with other terms, such as patient participation, for instance when reviewing related literature (Johansson et al., 2021; McCarron et al., 2019). Hence, when considering how patients may contribute as active partners in their healthcare, the consideration of patient engagement as a tripartite combination of motivation, ability, and opportunity, is a useful approach to assessing patient engagement. This approach is reflected in the search strategy for the review reported in *Chapter 2* and other reviews have adopted a similar approach by including interchangeable terms related to patient engagement in their literature search (Johansson et al., 2021; McCarron et al., 2019).

While assessing the impact of PHR on patient engagement remains relevant, studies focus on three main categories: increasing user engagement with PHR, testing usability of interfaces, and exploring barriers to PHR use (Lyles et al., 2020). For a PHR to impact on patients' engagement with their own healthcare, the PHR must be used by patients. As such, it makes sense to assess utilisation of PHR before moving on to address barriers and facilitators to PHR use, such as for instance usability. This research project followed a similar path by first exploring patients' use of a PHR system as a baseline for subsequent studies. Relatively few studies move beyond these three categories to consider the impact of PHR use on patient engagement in their healthcare (see *Chapter 2*). Thus, emphasising the need for addressing the specific impact of patients using PHR on their engagement in their health and care; also, in contrast to PHR use impact on, for instance, quality and safety of care (Neves et al., 2020). In this research project patient identification of errors in their PHR was

used as an exemplary way for patients to be engaged in their health and care by means of PHR use.

Patient motivation to use PHR

Patients' motivation to use CIE was based on their perceived need for it and legitimisation by healthcare professionals (see *Chapter 6*). Motivation ranges between intrinsic motivation and extrinsic motivation (Ryan & Deci, 2000a) with the perceived need to use CIE potentially reflecting anything along this spectrum. Motivational theory posits three needs must be satisfied: autonomy – feeling responsible for one's own behaviour, competence – feeling useful, and relatedness – feeling understood by others (Ng et al., 2012; Ryan & Deci, 2000b). Both the quantity and quality of motivation matter (Vallerand et al., 2008). With more autonomous motivation, one is more likely to exhibit healthy behaviours and psychological well-being (Ng et al., 2012). Additionally, a combination of techniques to promote needs satisfaction and autonomous motivation in interventions can enhance health behaviour change and health outcomes (Gillison et al., 2019). Autonomy can be supported through the healthcare climate created, for instance, by healthcare professionals facilitating feelings of competence and relatedness (Ng et al., 2012) or legitimising patient access to their PHR records. The influence of patient-healthcare professional interactions on motivation to use CIE was also present in *Chapter 7* as communication was one of the three main factors patients mentioned when asked about their reasons for using CIE.

How much patients choose to use a PHR may depend on the added value they perceive it to have (Fuji et al., 2014). This added value is likely closely related to the functionalities a PHR system offers patients as these define what patients can use a PHR for. Here, the CIE functionalities perceived as most useful were viewing test results and appointment

schedules (see *Chapter 4*) and patients mentioned access to their medical care information as another reason for using CIE (see *Chapter 7*). According to other research, functionalities supporting self-management seem to be important to patients (Hui et al., 2017; Morrison et al., 2012; Taylor et al., 2022) and may result in more frequent and persistent use of a PHR system. These findings are echoed in this research project since the third reason patients stated for using CIE was involvement in their own healthcare (see *Chapter 7*). The most valued functionalities in this research might be the two functionalities which alleviate the most organisational burden from patients on the one hand and hence, constituting an added value of CIE. While, on the other hand, CIE may be supporting self-management by allowing for test results to be put into the context of previous ones to provide a helpful overview of symptom development and allowing patients to feel more in control of their healthcare.

As discussed earlier, the perceived benefits of PHR use will impact sustained use. As has been reported by research on different cohorts (Chu et al., 2022; Gerard et al., 2018; Kayastha et al., 2018; Mishra et al., 2019; Moll et al., 2018; Nazi et al., 2015; Oster et al., 2015; Peck et al., 2017; Walker et al., 2019; Weinert, 2017), this research found that patients experience several benefits when using a web-based PHR. *Chapter 7*'s findings suggest the likelihood of perceiving improvements in overall care quality and being more satisfied with that care is higher for patients who use CIE regularly. The initial use of a PHR may lead to perceived improvements in care quality, which may result in greater satisfaction with care, and, in turn, may prompt increased and sustained PHR use as the PHR is perceived to have started the positive development in care quality. Hence, perceived care quality could act as a mechanism of sustained PHR adoption. This hypothesis is consistent with the Technology Acceptance Model's suggestion that the actual technology use behaviour is to a degree determined by the perceived benefits of using a technology (Venkatesh & Davis, 2000).

Patient ability to use PHR

PHR systems, as any other digital offering, need a certain level of usability to be functional and perceived as useful. According to the frequently applied technology acceptance model perceived usefulness and perceived ease of use are the main predictors of technology use (Marangunić & Granić, 2015). Surprisingly, in case of van der Nat et al.'s (2022) study regarding PHR based medication reconciliation no significant connection between PHR usability and patient, clinical, hospital, and ICT related factors was found. In contrast, issues on both the patient level (*e.g.*, medical knowledge) and IT system level (*e.g.*, presentation of information) were identified as potential barriers or facilitators for CIE use in the research project's qualitative analyses. The given discrepancy in results might be because only patients that had successfully completed the medication reconciliation were invited to participate; potentially also explaining the high perceived usability in the study (van der Nat et al., 2022).

Beyond any IT system's usability, people need to be able to effectively use IT systems. In line with other research *Chapter 7*'s study identified a distinct demographic more likely to be portal users: female, older, highly educated, and with higher digital literacy (Bell, Mejilla, et al., 2017; DesRoches et al., 2019; Gerard et al., 2018; Neves et al., 2021). While the majority of patients across this project's studies reported understanding the information in CIE, this understanding does relate to several factors. For one, the likelihood of patients to use a PHR in the first place is linked to their digital health literacy (Davis et al., 2015; Irizarry et al., 2015; Noblin et al., 2012), meaning patients more likely to use CIE would also be more likely to understand the provided information. Here, patients with higher digital health literacy were six times more likely to report "definitely" understanding the CIE information than those with lower digital health literacy. Consistent with variables identified in previous research

(Fraccaro et al., 2018; Fuji et al., 2014; Zanaboni et al., 2020), both information- and technology-factors impacted patient information understanding in this research project. Information-related barriers such as lacking support for interpreting medical information as well as system- or technology-related barriers including issues with portal functionality, usability, and presentation of information were identified in both *Chapter 5* and *Chapter 7*. Unless these barriers are addressed patients with lower digital health literacy will be disadvantaged by any system relying on digital information exchange (Cheng et al., 2020).

Opportunity to engage in care via PHR use by identifying errors in health records

To investigate patient engagement facilitated by PHR use, this research project used the identification of errors in CIE information as an exemplar opportunity. Patient access to PHR information and their willingness and ability to identify errors in their PHR has implications for patient safety and the relationship between patients and healthcare professionals (Bell et al., 2020; Bell, Mejilla, et al., 2017; Epner et al., 2017; Ross & Lin, 2003). Between 14% (see *Chapter 5*) and 18% (see *Chapter 7*) of patients stated to have identified errors in their CIE record without being prompted to look for them prior to the surveys. Consistently the described errors related to incorrect information and incomplete (or missing) information in both surveys.

According to *Chapter 7*'s findings, many, though not all, patients are willing and able to make use of error flagging or correcting mechanisms if available. Interestingly, digital health literacy, as measured by the eHEALS score, did not correlate to patients' willingness to take an active part in an error surveillance system in the PHR. Possibly, because the eHEALS

score is an imperfect measure for this task as it has been criticised as not being comprehensive enough to measure skills required to interact with and contribute to dynamic eHealth tools (Van Der Vaart et al., 2013). Patients being willing and able to act on errors they identify is consistent with previous studies that further suggest that patients' involvement in their own care may help reduce medication errors, delays in care, and redundant tests and procedures (Bell et al., 2020; Ross & Lin, 2003). Previous research indicates that serious errors with pertinent implications for medical care, which otherwise might remain unnoticed, can in many cases be identified by patients (Bell et al., 2020; Bell, Gerard, et al., 2017; Johansen et al., 2019; Lam et al., 2021; Ross & Lin, 2003). There is, thus, an as of now unused resource to increase patient safety by encouraging patients to actively participate in improving the accuracy of their own PHR. Data from *Chapter 7* suggests that approximately one in five patients is willing to correct errors themself. So far, no studies evaluated the feasibility of this option. One would have to consider several issues arising with this, most pressingly which types of errors patients could reasonably be expected to accurately correct without risking patient safety.

Furthermore, although patients are generally interested in improving the accuracy of their PHRs, it is evident that not all sociodemographic groups are equally well prepared to be actively involved in error identification. Patients' native language was a predictor of their willingness to correct errors and even to report them to health care providers in *Chapter 7*. This is in line with a US-based study in which primarily English- and Spanish-speaking patients were more likely to report mistakes in their records than speakers of other languages (Bell et al., 2020). In *Chapter 7* no significant association between the willingness to act on health record errors and age, gender, ethnicity, or educational level existed. However, some other studies did identify people that are male, younger, less educated, or

of one of several ethnic minority backgrounds to be less likely to report errors (Bell et al., 2020; Lam et al., 2021). Hence, considering equity in the design of patient-facing error surveillance systems is vital for avoiding minority groups and patients choosing not to participate in addressing accuracy of health records themselves being disadvantaged by a digital divide (Cheng et al., 2020).

Strengths and limitations of the research project

Research strategy

The research area was approached from various angles and assessed using several methods. The use of both quantitative and qualitative methods throughout the research project suited its aims (see *Thesis aims and objectives*) as the multidirectional approach allowed for in-depth investigation and interpretation (Almalki, 2016; Almeida, 2018; Doyle et al., 2009). The individual studies making up the research project built upon each other as much as possible (see *Figure 25*). In an emergent mixed methods design, the earlier studies provided guidance and direction for the later studies in the research project supporting the research's relevance (Creswell et al., 2011; De Allegri et al., 2020). *Figure 25* illustrates the main connections between the studies.

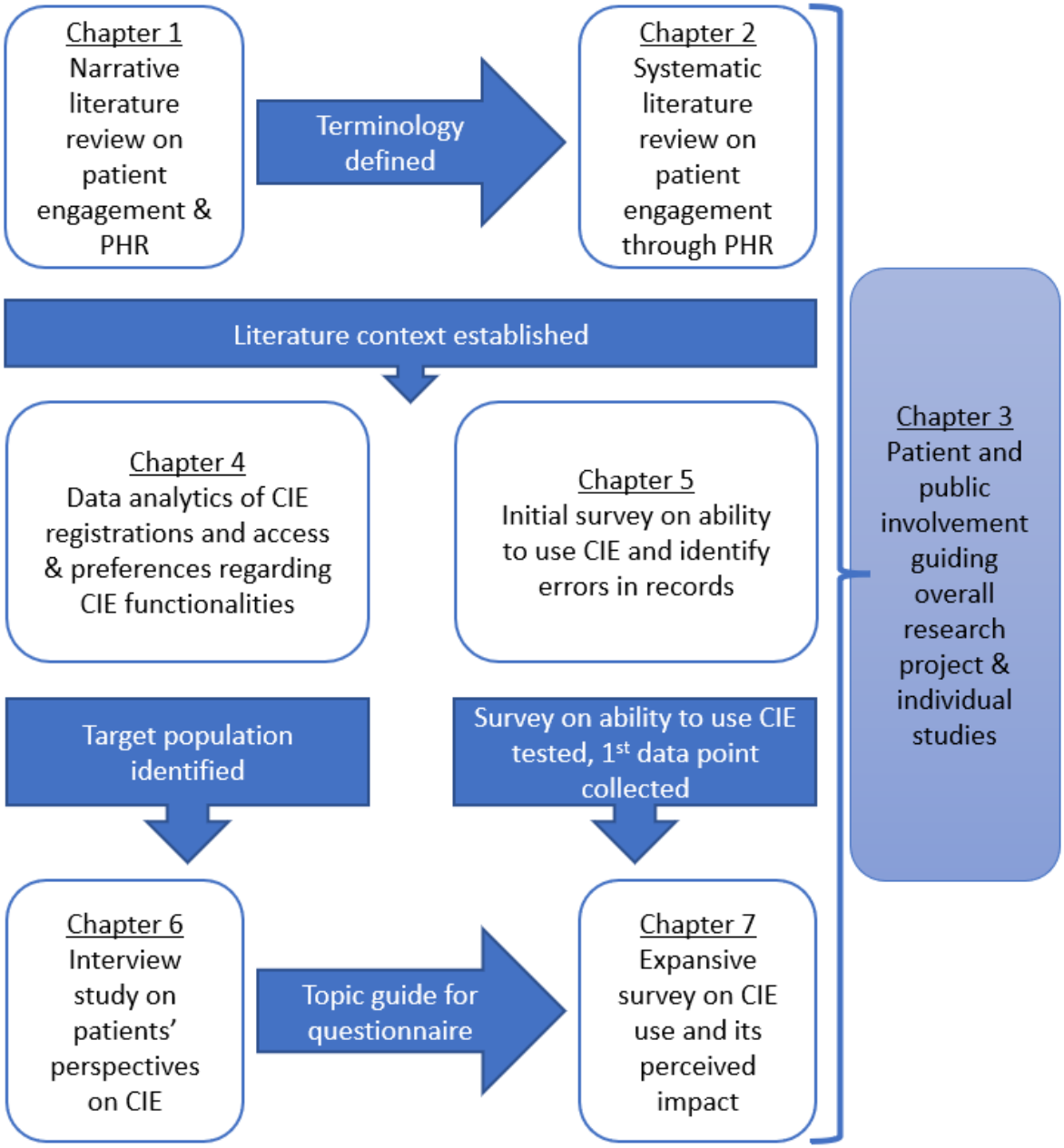


Figure 25. Research project flow showing methodological connections between the individual studies. Note. Personal health record (PHR), Care Information Exchange (CIE).

However, unfortunately, not all studies could be run consecutively due to time constraints. Consistent with pragmatism decisions were made to achieve the most robust and relevant

research studies within the existing limitations. For instance, the survey questionnaire for *Chapter 7* was based on the preliminary thematic map. Optimally, the final thematic map should have been the basis for the survey questionnaire but due to timing constraints this was not possible. The preliminary thematic map resulted from the codes by the researcher and PPG but had not yet been discussed and finalised in a meeting with all coders as the scheduling and re-scheduling proved challenging. Hence, while not the perfect solution, the preliminary thematic map was an adequate base for the survey questionnaire.

The project as well as its individual studies were carefully planned to maximise the impact and minimise problems and concerns. As the research was highly focused on patients, the patient perspective was vital. Hence, in line with recommendations (National Institute for Health and Care Excellence, 2013; National Institute for Health Research, 2014, 2015), the research approach was strengthened by patient and public involvement.

Patient and public involvement

The involvement of patients and the public continued throughout the project. The researcher regularly reflected on its impact and recorded feedback from lay partners whenever possible. Involvement of patients and the public in research brings both benefits and challenges (Pratte et al., 2023). While more coproduction and involvement are always theoretically beneficial and useful, limitations based on resources such as funding, project schedule, availability of patients and members of the public, time, meeting planning and preparation, and organisational needs exist. The identified limitations match those identified in the literature (Brett et al., 2022; Gonzalez et al., 2023). To keep the level of patient and public involvement manageable for the PPG and avoid overburdening the group (Gonzalez et al., 2023), the PPG was in charge on how they wanted to be involved throughout the research

project. Coproducing more than the interview study together with the PPG as co-researchers would have strengthened the research project. Unfortunately, mainly due to the project timeline in combination with the PPG members' schedules, additional coproduction was not feasible.

Implications of research project's findings for transforming contemporary healthcare delivery

In essence the results of this piece of work indicate that patient engagement in their health and care through access to PHR is beneficial. Furthermore, it has been demonstrated beyond this work that patient engagement via PHR can benefit the quality of and satisfaction with care (Gerard et al., 2018; Neves et al., 2020; Reed et al., 2019; Walker et al., 2019). Therefore, measures should be taken to facilitate this mode of patient engagement through PHR access. Both policy and practice should aim to lever PHR access for the benefit of patient health and care as patient engagement in their health and care is an important part of healthcare delivery. Yet, to ensure healthcare equity, factors of digital inclusion need to be considered. Unless barriers experienced by socially disadvantaged groups, such as low digital health literacy, are addressed, a digital divide will exist (Cheng et al., 2020). Attention should be given to how PHR systems can be further developed and rolled out without exacerbating the digital divide. Any policy aiming at greater engagement of patients in their health and care through patient PHR access, needs to consider health equality aspects. The same is true when healthcare practitioners implement PHR access for their patients.

This research project and previous studies have shown that patients can support the safety of their care by identifying errors and, consequently, increasing the accuracy of their

healthcare records (Bell et al., 2020; Bell, Gerard, et al., 2017; Hägglund et al., 2022; Johansen et al., 2019; Lam et al., 2021; Ross & Lin, 2003). However, mechanisms for patient error reporting and correcting are currently not well established (Lam et al., 2021) and need to be further explored.

Recommendations for future work

As patients' motivation to use PHR depends on their perceived need for it and legitimisation of their PHR access from a healthcare professional, these aspects should be further investigated in future. Since this research project strongly relied on subjective patient perceptions, it would be beneficial to assess patients' ability to understand and use a PHR with the related barriers and facilitators more objectively. One option might be to run a simulation study to capture and analyse patients' use and navigation of a PHR, including flagging of any errors that patients may identify. To investigate error identification further it would be important to compare errors identified by patients with those perceived by healthcare professionals. Strategies to better support patients in using PHR effectively should then be developed. A validated measure of patient engagement which can be applied across engagement opportunities, such as PHR use or health related decision making, would be very useful but difficult to achieve. In any case, patient engagement should only be investigated with patient and public involvement since patients are the main focus of patient engagement and related interventions.

Final conclusion

Patient engagement in their health and care via PHR access is certainly worthwhile as it comes with improvements in care quality and satisfaction with care. However, steps need to be taken to maximise these benefits and ensure no one is excluded from them. Both existing barriers and facilitators have to be considered in the design of PHR systems to enhance PHR adoption and continued use. Furthermore, consideration should be given to how to improve digital health literacy to support PHR access among digitally disempowered groups. PHR offer the possibility to improve patient safety through error identification by patients. Hence, the opportunity to partner with patients to improve the accuracy of their health records should be further explored.

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Appendix A

Chapter 2: A systematic review of the literature on the impact of patients' access to health records on patient engagement

PRISMA 2020 checklist

The PRISMA checklist includes items on quantitative synthesis and meta-analyses which would require defined, measurable outcomes. Given the research question and types of outcomes a narrative synthesis was performed in the given systematic review. Hence, not all checklist items are applicable (see *Table 38-Table 41*).

Table 38. PRISMA 2020 checklist adapted from: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. MetaArXiv. 2020, September 14. DOI: 10.31222/osf.io/v7gm2. For more information, visit: www.prisma-statement.org. All item locations are situated in Chapter 2; part 1 of 4.

Topic	No.	Item	Location of item report
Title	1	Identify the report as a systematic review.	*Chpt 2 title*
Abstract	2	See the PRISMA 2020 for Abstracts checklist	n/a
		INTRODUCTION	
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	*Introduction*
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	*Aims and objectives*
		METHODS	
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	*Study selection criteria*
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	*Search strategy*
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	*Table 1*

Table 39. PRISMA 2020 checklist adapted from: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. MetaArXiv. 2020, September 14. DOI: 10.31222/osf.io/v7gm2. For more information, visit: www.prisma-statement.org. All item locations are situated in Chapter 2; part 2 of 4.

Topic	No.	Item	Location of item report
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	*Screening*
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	*Data extraction*
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g., for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	*Data extraction*
	10b	List and define all other variables for which data were sought (e.g., participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	*Data extraction*
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	*Quality appraisal with risk of bias assessment*
Effect measures	12	Specify for each outcome the effect measure(s) (e.g., risk ratio, mean difference) used in the synthesis or presentation of results.	*Results*
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g., tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item 5)).	n/a
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	n/a
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	*Data synthesis*
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	*Data synthesis*

Table 40. PRISMA 2020 checklist adapted from: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. MetaArXiv. 2020, September 14. DOI: 10.31222/osf.io/v7gm2. For more information, visit: www.prisma-statement.org. All item locations are situated in Chapter 2; part 3 of 4.

Topic	No.	Item	Location of item report
Synthesis methods	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g., subgroup analysis, meta-regression).	n/a
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	n/a
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	n/a
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	n/a
		RESULTS	
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	*Figure 6*
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	*Results*
Study characteristics	17	Cite each included study and present its characteristics.	*Table 3, Table 4, Table 5*
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	*Table 6*
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	*Table 7, Table 8*
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	*Quality appraisal with risk of bias assessment*
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g., confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	n/a
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	n/a
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	n/a
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	n/a
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	n/a

Table 41. PRISMA 2020 checklist adapted from: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. MetaArXiv. 2020, September 14. DOI: 10.31222/osf.io/v7gm2. For more information, visit: www.prisma-statement.org. All item locations are situated in Chapter 2; part 4 of 4.

Topic	No.	Item	Location of item report
		DISCUSSION	
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	*Results in context*
	23b	Discuss any limitations of the evidence included in the review.	*Strengths and limitations*
	23c	Discuss any limitations of the review processes used.	*Strengths and limitations*
	23d	Discuss implications of the results for practice, policy, and future research.	*Future work*
		OTHER INFORMATION	
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	*Methods*
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	*Methods*
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	n/a
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	n/a
Competing interests	26	Declare any competing interests of review authors.	n/a
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	*Results*

SWiM reporting guideline

Table 42. SWiM reporting guideline adherence as adapted from Campbell, M., McKenzie, J. E., Sowden, A., Katikireddi, S. V., Brennan, S. E., Ellis, S., Hartmann-Boyce, J., Ryan, R., Shepperd, S., Thomas, J., Welch, V., & Thomson, H. (2020). Synthesis without meta-analysis (SWiM) in systematic reviews: Reporting guideline. The BMJ, 368. https://doi.org/10.1136/bmj.l6890.

	SWiM reporting item	Item description	Location of item report
Methods	1 Grouping of studies for synthesis	Description of and rationale for groups used in synthesis	*Data synthesis*
		Detail and justify changes made to groups from protocol to synthesis	*n/a*
	2 Describe standardised metric & transformation methods used	Describe and justify standardised metric and, if applicable, transformation methods for each outcome	*Measurements of patients' engagement in their health and care*
	3 Describe synthesis methods	Describe and justify the methods used to synthesise the effects for each outcome (not meta-analysed)	*Results measuring patient engagement in personal care*
	4 Criteria to prioritise results for summary/synthesis	Where applicable, provide criteria used, with supporting justification, to select particular studies, for the main synthesis or to draw conclusions from the synthesis	*n/a*
	5 Investigation of heterogeneity in reported effects	State the method(s) used to examine heterogeneity in reported effects when it was not possible to undertake a meta-analysis of effect estimates and its extensions to investigate heterogeneity	*Data synthesis*
	6 Certainty of evidence	Describe the methods used to assess the certainty of the synthesis findings	*Quality appraisal with risk of bias assessment*
	7 Data presentation	Describe the graphical and tabular methods used to present the effects	*Data extraction*
		Specify key study characteristics used to order the studies in text/tables/graphs, clearly referencing the studies included	*Data extraction*
Results	8 Reporting results	For each comparison and outcome, describe synthesised findings and their certainty. Describe result in language consistent with the question the synthesis addresses	*Results*
Discussion	9 Limitations of the synthesis	Report limitations of the synthesis methods used and/or groupings used in the synthesis and how these affect the conclusions that can be drawn in relation to the original review question	*Discussion*

Chapter 3: Patient and public involvement

Project partner group recruitment advertisement

Imperial College London

NHS National Institute for Health Research

Three patient and public representatives for the research project: 'Engaging patients and the public in their care through electronic patient record access'

Role description

Three patients or members of the public are sought who are interested in partnering with the researchers to enhance the project through taking part in critical discussions of contents and design of the studies as well as their implementation and the interpretation of results.

Summary

This project will evaluate the role patients and the public have in their own care and the impact of patients engaging with their personal health, through electronic health records.

Background

When patients are engaged with their health and care it has benefits for them such as improved health outcomes, such as fewer Accident and Emergency admissions, and more positive experiences with the healthcare system. Previous research shows that supporting interactions between patients and healthcare professionals using digital tools is more effective than replacing face-to-face meetings. This project will investigate how digital tools can be used to enhance engagement and interactions between healthcare professionals and patients.

Roles and responsibilities of patient and public representatives (appropriate training will be provided)

Duties:

- Contribute to discussion of design and results of the project in occasional face-to-face meetings with researchers in London for one to three hours to discuss project details
- Become involved closely in one or more stages of the project e.g. being trained to analyse data

Areas where patient and public representatives may get involved:

- Design of various studies within the project
- Ethics applications
- Data analysis and interpretation
- Result interpretation

Essential criteria for applying:

- Interest in being involved in a research project from start to end (approx. 2 year period)
- Confidence in giving opinions on matters and listening to others
- Able to attend some meetings face-to-face close to Paddington, London

Payment

Participation will be paid an hourly rate based on the Imperial recognition and remuneration policy. **Travel expenses (up to £10 per meeting) will be repaid**, as well.

Support

Patient and public representatives will be:

- Buddied with the lead researcher for this project, as their main contact (below).
- Appropriately trained about the project and supported to deliver the tasks at hand
- Given the contact details for the patient involvement manager at the research centre for any other queries.

Further information

For further details about this project please contact Lisa Freise at l.freise16@imperial.ac.uk. The application deadline is **5th January 2018.**

Figure 26. Project partner recruitment advertisement

Project partner group application form

Imperial College London

NHS National Institute for Health Research

Application form

Patient and public representatives for the research project: 'Engaging patients and the public in their care through electronic patient record access'

Thank you for your interest in joining the project partner group. There are three places available in total. If you would like to apply to join please fill out this application form and return it by email to Lisa Freise (l.freise16@imperial.ac.uk) by **5th January 2018**.

You must be above 18 years of age and able to attend face-to-face meetings in London to be eligible to apply.

About you

Please complete the information below by typing your answers in the boxes. If you need any help please contact Lisa Freise (email: l.freise16@imperial.ac.uk). The information you provide will be kept securely by the project team and not shared with any third parties.

Are you eligible to work in the UK? ☐ YES ☐ NO (tick one)

Are you over 18 years of age? ☐ YES ☐ NO (tick one)

Are there any dates that you are not available in the second and third week of January 2018 for a 2-3 hour meeting in London?

Click here to enter text.

Full name:	Click here to enter text.	**Email:**	Click here to enter text.
		Contact number:	Click here to enter number.
Gender: (optional)	Click here to enter text.	**Ethnicity: (optional)**	Click here to enter text.
Would you like to share anything about your health or your experience in using health services (optional): Click here to enter text.			
We are only asking you about this information so that we can be mindful about the diversity of the people applying to the group.			

Figure 27. Project partner group application form, page 1 of 3.

Imperial College London

NIHR National Institute for Health Research

Please tell us about why you would like to become a member of the project partner group.

Click here to enter text.

Please tell us about any experience that you have of being involved in health research or health services. This includes sitting on study steering groups or funding panels or patient participation groups at GP surgeries. If not, what experience do you have in non-health settings that might be relevant?

Click here to enter text.

What skills do you have that might be relevant to join the patient partner group?

Click here to enter text.

Is there anything else that you would like to tell us?

Click here to enter text.

The work involved in this project may include some of the following activities. Please let us know whether you feel comfortable with these and whether you are likely to want some training or support from the team. Please tick one box per item and row.

	No problem	I may need some help	I do not feel able to do this
Communicating by email, including using attachments and commenting by track changes on Word documents.	☐	☐	☐
Working with complex documents. Due to the content of the project such documents will sometimes be conceptual in nature.	☐	☐	☐
Travelling independently to meetings.	☐	☐	☐
Analysing data with prior training.	☐	☐	☐
Considering the meaning of study results in connection to your experiences.	☐	☐	☐

Figure 28. Project partner group application form, page 2 of 3.

Imperial College London

NHS National Institute for Health Research

Voicing your views and listening to others in a group meeting.	☐	☐	☐
Getting involved in communication activities to talk about research results (e.g. writing blogs, doing presentations etc.).	☐	☐	☐

Would you like to join the Patient Safety Translational Research Centre secure mailing list, and keep informed about other opportunities?

☐ YES ☐ NO (tick one)

Next steps

Thank you for your application. Lisa will be in touch to let you know if you have been offered a place on the group by 9th January 2018.

Figure 29. Project partner group application form, page 3 of 3.

GRIPP2 long form

The GRIPP2 long version is directed at individual studies, not research projects. Furthermore, as the lay partners were members of the research team especially for the interview study, a clear separation between research, researcher, and PPI is difficult. *Table 43*-*Table 45* provide the filled in GRIPP2 checklist with items marked as not applicable (n/a) as required.

Table 43. GRIPP2 long version from: Staniszewska, S., Brett, J., Simera, I., Seers, K., Mockford, C., Goodlad, S., Altman, D. G., Moher, D., Barber, R., Denegri, S., Entwistle, A., Littlejohns, P., Morris, C., Suleman, R., Thomas, V., Tysall, C. (2017). GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. BMJ, 358. https://doi.org/10.1136/BMJ.J3453; part 1 of 3.

Section & topic	Item	Location reported
Section 1: Abstract		n/a
Section 2: Background		
a: Definition	Report the definition of PPI used in the study and how it links to comparable studies	*Chapter 3: Patient and public involvement*
b: Theoretical underpinnings	Report the theoretical rationale and any theoretical influences relating to PPI in the study	*Chapter 3: Patient and public involvement*
c: Concepts & theory development	Report any conceptual models or influences used in the study	*Chapter 3: Patient and public involvement*
Section 3: Aims		
3: Aim	Report the aim of the study	*Rationale for patient and public involvement in the project*
Section 4: Methods		
a: Design	Provide a clear description of methods by which patients and the public were involved	*Figure 7*
b: People involved	Provide a description of patients, carers, and the public involved with the PPI activity in the study	*Research Partners Group (RPG), Group members*
c: Stages of involvement	Report on how PPI is used at different stages of the study	*Figure 7, Table 11*
d: Level or nature of involvement	Report the level or nature of PPI used at various stages of the study	
Section 5: Capture or measurement of PPI impact		
a: Qualitative evidence of impact	If applicable, report the methods used to qualitatively explore the impact of PPI in the study	*Table 11*

Table 44. GRIPP2 long version from: Staniszewska, S., Brett, J., Simera, I., Seers, K., Mockford, C., Goodlad, S., Altman, D. G., Moher, D., Barber, R., Denegri, S., Entwistle, A., Littlejohns, P., Morris, C., Suleman, R., Thomas, V., Tysall, C. (2017). GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. BMJ, 358. https://doi.org/10.1136/BMJ.J3453; part 2 of 3.

Section & topic	Item	Location reported
b: Quantitative evidence of impact	If applicable, report the methods used to quantitatively measure or assess the impact of PPI	n/a
c: Robustness of measure	If applicable, report the rigour of the method used to capture or measure the impact of PPI	n/a
Section 6: Economic assessment		n/a
Section 7: Study results		
a: Outcomes of PPI	Report the results of PPI in the study, including both positive and negative outcomes	*Reflection on patient and public involvement, Reflection on impact of Research Partners Group's contribution, Reflection on data analysis training and expectations of the day, Reflection on data analysis, Reflection on the interview study co-research process*
b: Impacts of PPI	Report the positive and negative impacts that PPI has had on the research, the individuals involved (including patients and researchers), and wider impacts	
c: Context of PPI	Report the influence of any contextual factors that enabled or hindered the process or impact of PPI	
d: Process of PPI	Report the influence of any process factors, that enabled or hindered the impact of PPI	
ei: Theory development	Report any conceptual or theoretical development in PPI that have emerged	n/a
eii:	Report evaluation of theoretical models, if any	n/a
f: Measurement	If applicable, report all aspects of instrument development and testing (eg, validity, reliability, feasibility, acceptability, responsiveness, interpretability, appropriateness, precision)	n/a
g: Economic assessment	Report any information on the costs or benefit of PPI	n/a
Section 8: Discussion and conclusions		
a: Outcomes	Comment on how PPI influenced the study overall. Describe positive and negative effects	*Table 11, Reflection on patient and public involvement*
b: Impacts	Comment on the different impacts of PPI identified in this study and how they contribute to new knowledge	
c: Definition	Comment on the definition of PPI used (reported in the Background section) and whether or not you would suggest any changes	n/a
d: Theoretical underpinnings	Comment on any way your study adds to the theoretical development of PPI	n/a
e: Context	Comment on how context factors influenced PPI in the study	*Patient and public involvement throughout the project*
f: Process	Comment on how process factors influenced PPI in the study	

Table 45. GRIPP2 long version from: Staniszewska, S., Brett, J., Simera, I., Seers, K., Mockford, C., Goodlad, S., Altman, D. G., Moher, D., Barber, R., Denegri, S., Entwistle, A., Littlejohns, P., Morris, C., Suleman, R., Thomas, V., Tysall, C. (2017). GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. BMJ, 358. https://doi.org/10.1136/BMJ.J3453; part 3 of 3.

Section & topic	Item	Location reported
g: Measurement & capture of PPI impact	If applicable, comment on how well PPI impact was evaluated or measured in the study	*Table 11, Reflection on patient and public involvement*
h: Economic assessment	If applicable, discuss any aspects of the economic cost or benefit of PPI, particularly any suggestions for future economic modelling.	*Reflection on patient and public involvement*
i: Reflections/ critical perspective	Comment critically on the study, reflecting on the things that went well and those that did not, so that others can learn from this study	

Chapter 4: Analysing patient registrations and access to a personal health record: Care Information Exchange case study

CHERRIES checklist

Table 46. CHERRIES checklist for Chapter 4 adapted from Eysenbach, G. (2004). Improving the Quality of Web Surveys: The Checklist for Reporting Results of Internet E-Surveys (CHERRIES). Journal of Medical Internet Research, 6(3), e34. https://doi.org/10.2196/jmir.6.3.e34; part 1 of 2.

Domain/ Item	Abbreviated description	Location reported
Design		
Describe survey design	Describe target population, sample frame. Is the sample a convenience sample?	pp. 133-134
Institutional review board (IRB) approval & informed consent process		
IRB approval	Mention whether the study has been approved by an IRB.	pp. 133-134
Informed consent	Describe the informed consent process.	pp. 133-134
Data protection	If any personal information was collected or stored, describe what mechanisms were used to protect unauthorized access.	n/a
Development & pre-testing		
Development & testing	State how the survey was developed and tested before fielding it.	pp. 133-134
Recruitment process & description of sample having access to survey		
Open survey vs. closed survey	An “open survey” is open for each site visitor, while a closed survey is only open to a sample which the investigator knows.	
Contact mode	Was the initial contact with potential participants made on the Internet?	pp. 133-134
Advertising the survey	How/where was the survey announced or advertised? Is the survey announcement published as an appendix?	
Survey administration		
Web/E-mail	State the type of e-survey.	
Context	Describe the Web site (for mailing list/newsgroup) in which the survey was posted. Could choice pre-select the sample or influence the results?	pp. 133-134
Mandatory/ voluntary	Was it a mandatory survey to be filled in by every visitor who wanted to enter the Web site, or was it voluntary?	
Incentives	Were any incentives offered?	
Time/date	In what timeframe were the data collected?	
Randomisation of items or surveys	To prevent biases items can be randomized or alternated.	n/a
Adaptive questioning	Use adaptive questioning to reduce number/complexity of questions.	n/a
Number of items	What was the number of survey items per page?	n/a
Number of screens (pages)	Over how many pages was the survey distributed?	n/a
Completeness check	Were consistency or completeness checks done before survey submission? If “yes”, how? Was a check for completeness done after the survey had been submitted?	n/a
Review step	State whether respondents were able to review and change their answers.	pp. 133-134

Table 47. CHERRIES checklist for Chapter 4 adapted from Eysenbach, G. (2004). Improving the Quality of Web Surveys: The Checklist for Reporting Results of Internet E-Surveys (CHERRIES). Journal of Medical Internet Research, 6(3), e34. https://doi.org/10.2196/jmir.6.3.e34; part 2 of 2.

Domain/ Item	**Abbreviated description**	**Location reported**
Response rates		
Unique site visitor	If you provide view rates or participation rates, define how you determined a unique visitor.	n/a
View rate	Requires counting unique visitors to the first page of the survey, divided by the number of unique site visitors.	n/a
Participation rate	Count the unique number of people who filled in the 1st survey page (or agreed to participate, for example by checking a checkbox), divided by visitors who visit the 1st page of the survey (or informed consents page, if present).	n/a
Completion rate	The number of people submitting the last survey page, divided by the number of people agreeing to participate (or submitted the 1st survey page); only relevant if there is a separate "informed consent" page or if the survey goes over several pages. This is a measure for attrition.	n/a
Preventing multiple entries from the same individual		
Cookies used	Were cookies used to assign a unique user identifier to each client computer? Were duplicate entries avoided by preventing users access to the survey twice; or were duplicate database entries having the same user ID eliminated before analysis? In the latter case, which entries were kept for analysis?	
IP check	Was the IP address of the client computer used to identify potential duplicate entries from the same user?	pp. 133-134
Log file analysis	Indicate whether other techniques to analyse the log file for identification of multiple entries were used. If so, please describe.	
Registration	In "closed" surveys, users need to login first and it is easier to prevent duplicate entries from the same user. Describe how this was done.	
Analysis		
Handling of incomplete surveys	Were only completed surveys analysed? Were surveys which terminated early also analysed?	
Surveys submitted with atypical timestamp	Some investigators may measure the time people needed to fill in a survey and exclude surveys that were submitted too soon.	pp. 133-134
Statistical correction	Were any methods (*e.g.*, weighting of items, propensity scores) used to adjust for non-representative sample?	

Chapter 5: A cross-sectional survey on patients' perceived ability to understand PHR information and identify potential errors

CHERRIES checklist

Table 48. CHERRIES checklist for Chapter 5 adapted from Eysenbach, G. (2004). Improving the Quality of Web Surveys: The Checklist for Reporting Results of Internet E-Surveys (CHERRIES). Journal of Medical Internet Research, 6(3), e34. https://doi.org/10.2196/jmir.6.3.e34; part 1 of 2.

Domain/ Item	Abbreviated description	Location reported
Design		
Describe survey design	Describe target population, sample frame. Is the sample a convenience sample?	p. 155
Institutional review board (IRB) approval & informed consent process		
IRB approval	Mention whether the study has been approved by an IRB.	p. 155
Informed consent	Describe the informed consent process.	p. 155
Data protection	If any personal information was collected or stored, describe what mechanisms were used to protect unauthorized access.	pp. 155-156
Development & pre-testing		
Development & testing	State how the survey was developed and tested before fielding it.	p. 155
Recruitment process & description of sample having access to survey		
Open survey vs. closed survey	An "open survey" is open for each site visitor, while a closed survey is only open to a sample which the investigator knows.	p. 155
Contact mode	Was the initial contact with potential participants made on the Internet?	p. 155
Advertising the survey	How/where was the survey announced or advertised? Is the survey announcement published as an appendix?	p. 155
Survey administration		
Web/E-mail	State the type of e-survey.	p. 155
Context	Describe the Web site (for mailing list/newsgroup) in which the survey was posted. Could choice pre-select the sample or influence the results?	p. 155
Mandatory/ voluntary	Was it a mandatory survey to be filled in by every visitor who wanted to enter the Web site, or was it voluntary?	p. 155
Incentives	Were any incentives offered?	p. 155
Time/date	In what timeframe were the data collected?	p. 155
Randomisation of items or surveys	To prevent biases items can be randomized or alternated.	n/a
Adaptive questioning	Use adaptive questioning to reduce number/complexity of questions.	n/a
Number of items	What was the number of survey items per page?	n/a
Number of screens (pages)	Over how many pages was the survey distributed?	n/a
Completeness check	Were consistency or completeness checks done before survey submission? If "yes", how? Was a check for completeness done after the survey had been submitted?	n/a
Review step	State whether respondents were able to review and change their answers.	p. 156

Table 49. CHERRIES checklist for Chapter 5 adapted from Eysenbach, G. (2004). Improving the Quality of Web Surveys: The Checklist for Reporting Results of Internet E-Surveys (CHERRIES). Journal of Medical Internet Research, 6(3), e34. https://doi.org/10.2196/jmir.6.3.e34; part 2 of 2.

Domain/ Item	**Abbreviated description**	**Location reported**
Response rates		
Unique site visitor	If you provide view rates or participation rates, define how you determined a unique visitor.	p. 155
View rate	Requires counting unique visitors to the first page of the survey, divided by the number of unique site visitors.	n/a
Participation rate	Count the unique number of people who filled in the 1st survey page (or agreed to participate, for example by checking a checkbox), divided by visitors who visit the 1st page of the survey (or informed consents page, if present).	p. 157
Completion rate	The number of people submitting the last survey page, divided by the number of people agreeing to participate (or submitted the 1st survey page); only relevant if there is a separate "informed consent" page or if the survey goes over several pages. This is a measure for attrition.	n/a
Preventing multiple entries from the same individual		
Cookies used	Were cookies used to assign a unique user identifier to each client computer? Were duplicate entries avoided by preventing users access to the survey twice; or were duplicate database entries having the same user ID eliminated before analysis? In the latter case, which entries were kept for analysis?	
IP check	Was the IP address of the client computer used to identify potential duplicate entries from the same user?	p. 155-156
Log file analysis	Indicate whether other techniques to analyse the log file for identification of multiple entries were used. If so, please describe.	
Registration	In "closed" surveys, users need to login first and it is easier to prevent duplicate entries from the same user. Describe how this was done.	
Analysis		
Handling of incomplete surveys	Were only completed surveys analysed? Were surveys which terminated early also analysed?	
Surveys submitted with atypical timestamp	Some investigators may measure the time people needed to fill in a survey and exclude surveys that were submitted too soon.	p. 155-156
Statistical correction	Were any methods (*e.g.*, weighting of items, propensity scores) used to adjust for non-representative sample?	

COREQ checklist

Table 50. COREQ checklist for Chapter 5 adapted from: Tong, A., Sainsbury, P., Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. International Journal for Quality in Healthcare. 19(6), 349-357. https://doi.org/10.1093/intqhc/mzm042; part 1 of 2.

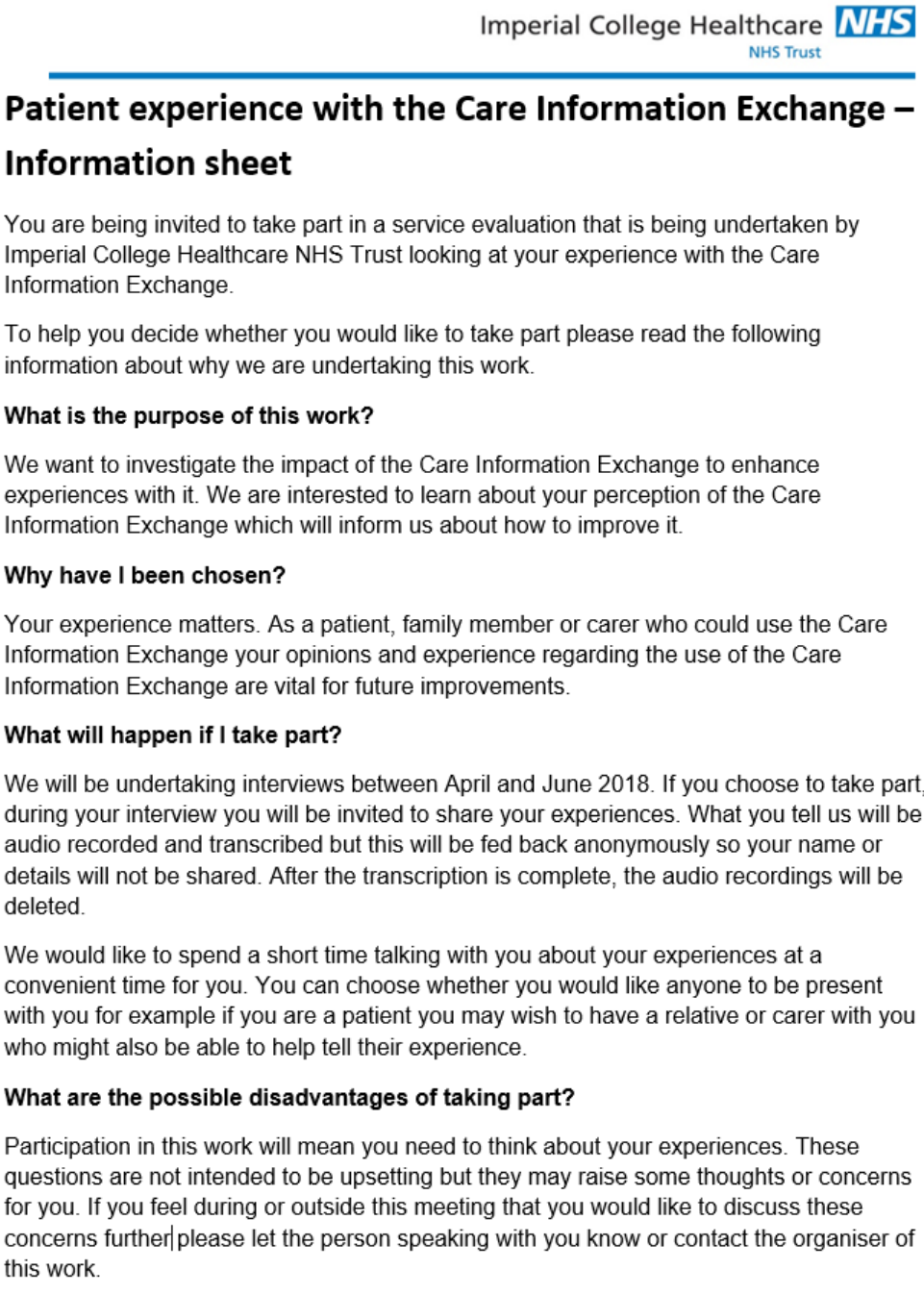
Domain	No.	Item	Description	Location reported
Research team & reflexivity	1	Interviewer/ facilitator	Which author/s conducted the interview or focus group?	n/a
	2	Credentials	What were the researcher's credentials?	*Data analysis*
	3	Occupation	What was their occupation at the time of the study?	*Data analysis*
	4	Gender	Was the researcher male or female?	*Data analysis*
	5	Experience & training	What experience or training did the researcher have?	*Strengths and limitations*
	6	Relationship established	Was a relationship established prior to study commencement?	n/a
	7	Participant knowledge of interviewer	What did the participants know about the researcher?	n/a
	8	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator?	*Strengths and limitations*
Study design	9	Methodological orientation & Theory	What methodological orientation was stated to underpin the study?	*Data analysis*
	10	Sampling	How were participants selected?	*Participants and sampling*
	11	Method of approach	How were participants approached?	*Data collection*
	12	Sample size	How many participants were in the study?	*Participant characteristics*
	13	Non-participation	How many people refused to participate or dropped out? Reasons?	n/a
	14	Setting of data collection	Where was the data collected?	*Data collection*
	15	Presence of non-participants	Was anyone else present besides the participants and researchers?	*Participants and sampling*
	16	Description of sample	What are the important characteristics of the sample?	*Participant characteristics*
	17	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	*Data collection*
	18	Repeat interviews	Were repeat interviews carried out? If yes, how many?	*Data analysis*

Table 51. COREQ checklist for Chapter 5 adapted from: Tong, A., Sainsbury, P., Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. International Journal for Quality in Healthcare. 19(6), 349-357. https://doi.org/10.1093/intqhc/mzm042; part 2 of 2.

Domain	No.	Item	Description	Location reported
Study design	19	Audio/visual recording	Did the research use audio or visual recording to collect the data?	n/a
	20	Field notes	Were field notes made during and/or after the interview or focus group?	n/a
	21	Duration	What was the duration of the interviews or focus group?	n/a
	22	Data saturation	Was data saturation discussed?	*Data analysis*
	23	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	*Data analysis*
Analysis & findings	24	Number of data coders	How many data coders coded the data?	*Data analysis*
	25	Description of the coding tree	Did authors provide a description of the coding tree?	*Results*
	26	Derivation of themes	Were themes identified in advance or derived from the data?	*Data analysis*
	27	Software	What software, if applicable, was used to manage the data?	*Data analysis*
	28	Participant checking	Did participants provide feedback on the findings?	*Data analysis*
	29	Quotations presented	Were participant quotations presented to illustrate the themes/ findings? Was each quotation identified?	*Results*
	30	Data & findings consistent	Was there consistency between the data presented and the findings?	*Results*
	31	Clarity of major themes	Were major themes clearly presented in the findings?	*Results*
	32	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	*Results*

Chapter 6: A semi-structured interview study on patient expectations of the Care Information Exchange, its functionalities, and their usefulness

Participant information and consent forms



Imperial College Healthcare NHS Trust

Patient experience with the Care Information Exchange – Information sheet

You are being invited to take part in a service evaluation that is being undertaken by Imperial College Healthcare NHS Trust looking at your experience with the Care Information Exchange.

To help you decide whether you would like to take part please read the following information about why we are undertaking this work.

What is the purpose of this work?

We want to investigate the impact of the Care Information Exchange to enhance experiences with it. We are interested to learn about your perception of the Care Information Exchange which will inform us about how to improve it.

Why have I been chosen?

Your experience matters. As a patient, family member or carer who could use the Care Information Exchange your opinions and experience regarding the use of the Care Information Exchange are vital for future improvements.

What will happen if I take part?

We will be undertaking interviews between April and June 2018. If you choose to take part, during your interview you will be invited to share your experiences. What you tell us will be audio recorded and transcribed but this will be fed back anonymously so your name or details will not be shared. After the transcription is complete, the audio recordings will be deleted.

We would like to spend a short time talking with you about your experiences at a convenient time for you. You can choose whether you would like anyone to be present with you for example if you are a patient you may wish to have a relative or carer with you who might also be able to help tell their experience.

What are the possible disadvantages of taking part?

Participation in this work will mean you need to think about your experiences. These questions are not intended to be upsetting but they may raise some thoughts or concerns for you. If you feel during or outside this meeting that you would like to discuss these concerns further please let the person speaking with you know or contact the organiser of this work.

Figure 30. Chapter 6 participant information sheet for interviews, page 1 of 2.

What are the possible benefits of taking part?

We expect the findings of this work to help improve experiences with the Care Information Exchange. Although this may not benefit you personally, information you give may help influence and shape the Care Information Exchange in the future.

What information will be held and shared?

The information you tell us about your experience with the Care Information Exchange will be collected and shared anonymously with people involved in this project. We may publicise summarised findings more widely. We will not assign your name or any personal details to what you have told us so you will not be identified.

Who is the organiser/lead for this work?

The work is being undertaken by a team led by Lisa Freise (Imperial College London) and sponsored by Mr Erik Mayer (Imperial College Healthcare NHS Trust). If you have any questions or would like to discuss anything further, such as concerns about what you have told us or the process undertaken, please contact: l.freise16@imperial.ac.uk.

Figure 31. Chapter 6 participant information sheet for interviews, page 2 of 2.

Imperial College Healthcare NHS
NHS Trust

Patient experience with the Care Information Exchange – Consent form

_____

INTERVIEWER (NAMED INDIVIDUAL CONDUCTING THE INTERVIEW)

		PLEASE INITIAL
1	I confirm that I have read and understood the information sheet for the above project and have had the opportunity to ask questions.	☐
2	I understand that my participation is voluntary and I am free to withdraw at any time.	☐
3	I understand that I can ask for any comments I have made to be removed.	☐
4	I understand that my comments (or part of them) may be used in different formats to share with others possible ways to improve the Care Information Exchange experience.	☐
5	I understand that any of my comments used will appear anonymously.	☐
6	I agree that the interview may be audio recorded.	☐
7	I agree to take part.	☐

NAME OF PARTICIPANT	*DATE*	*SIGNATURE*
_____	_____	_____
NAME OF INTERVIEWER	*DATE*	*SIGNATURE*
_____	_____	_____

Figure 32. Chapter 6 consent form for interviews.

GRIPP2 short form

Table 52. GRIPP2 short form for Chapter 6 from: Staniszewska, S., Brett, J., Simera, I., Seers, K., Mockford, C., Goodlad, S., Altman, D. G., Moher, D., Barber, R., Denegri, S., Entwistle, A., Littlejohns, P., Morris, C., Suleman, R., Thomas, V., Tysall, C. (2017). GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. BMJ, 358. https://doi.org/10.1136/BMJ.J3453.

Section and topic	Item	Location reported
Aim	Report the aim of PPI in the study	*Patient and public involvement*
Methods	Provide a clear description of the methods used for PPI in the study	*Patient and public involvement, Data analysis*
Study results	Outcomes – Report the results of PPI in the study, including both positive and negative outcomes	*Changes to initial thematic map based on PPG coding and discussion*
Discussion & conclusions	Outcomes – Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects	*Discussion, Strengths and limitations*
Reflections/ critical appraisal	Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience	*Strengths and limitations*

COREQ checklist

Table 53. COREQ checklist for Chapter 6 adapted from: Tong, A., Sainsbury, P., Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. International Journal for Quality in Healthcare. 19(6), 349-357. https://doi.org/10.1093/intqhc/mzm042; part 1 of 3.

Domain	No.	Item	Description	Location reported
Research team & reflexivity	1	Interviewer/ facilitator	Which author/s conducted the interview or focus group?	*Data collection*
	2	Credentials	What were the researcher's credentials?	*Data analysis*
	3	Occupation	What was their occupation at the time of the study?	*Data analysis*
	4	Gender	Was the researcher male or female?	*Data collection, Data analysis*
	5	Experience & training	What experience or training did the researcher have?	*Patient and public involvement, Data analysis*
	6	Relationship established	Was a relationship established prior to study commencement?	*Participants and sampling*

Table 54. COREQ checklist for Chapter 6 adapted from: Tong, A., Sainsbury, P., Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. International Journal for Quality in Healthcare. 19(6), 349-357. https://doi.org/10.1093/intqhc/mzm042; part 2 of 3.

Domain	No.	Item	Description	Location reported
Research team & reflexivity	7	Participant knowledge of interviewer	What did the participants know about the researcher?	*Data collection*
	8	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator?	*Data collection, Data analysis*
Study design	9	Methodological orientation & Theory	What methodological orientation was stated to underpin the study?	*Methods*
	10	Sampling	How were participants selected?	*Participants and sampling*
	11	Method of approach	How were participants approached?	*Participants and sampling*
	12	Sample size	How many participants were in the study?	*Participants*
	13	Non-participation	How many people refused to participate or dropped out? Reasons?	n/a
	14	Setting of data collection	Where was the data collected?	*Data collection*
	15	Presence of non-participants	Was anyone else present besides the participants and researchers?	*Data collection*
	16	Description of sample	What are the important characteristics of the sample?	*Participants*
	17	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	*Data collection*
	18	Repeat interviews	Were repeat interviews carried out? If yes, how many?	*Data collection*
	19	Audio/visual recording	Did the research use audio or visual recording to collect the data?	*Data collection*
	20	Field notes	Were field notes made during and/or after the interview or focus group?	*Data collection*
	21	Duration	What was the duration of the interviews or focus group?	*Interviews*
	22	Data saturation	Was data saturation discussed?	*Data analysis*
	23	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	*Data collection*
Analysis & findings	24	Number of data coders	How many data coders coded the data?	*Data analysis*
	25	Description of the coding tree	Did authors provide a description of the coding tree?	*Results*
	26	Derivation of themes	Were themes identified in advance or derived from the data?	*Data analysis*

Table 55. COREQ checklist for Chapter 6 adapted from: Tong, A., Sainsbury, P., Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. International Journal for Quality in Healthcare. 19(6), 349-357. https://doi.org/10.1093/intqhc/mzm042; part 3 of 3.

Domain	No.	Item	Description	Location reported
	27	Software	What software, if applicable, was used to manage the data?	n/a
	28	Participant checking	Did participants provide feedback on the findings?	*Data collection*
	29	Quotations presented	Were participant quotations presented to illustrate the themes/ findings? Was each quotation identified?	*Results*
Analysis & findings	30	Data & findings consistent	Was there consistency between the data presented and the findings?	*Results*
	31	Clarity of major themes	Were major themes clearly presented in the findings?	*Results*
	32	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	*Results*

Chapter 7: A cross-sectional survey outlining patients' motivation and abilities for using a PHR and the patient perceived impact of PHR access on care quality

Questionnaire – Personal health records and care quality and safety

Survey Flow

Block: Personal health records and care quality and safety
Standard: PART 1. Usage
Standard: PART 2. Experience
Standard: PART 3. Impact on perceptions about health and health care
Standard: PART 4. The way forward
Standard: IF NO
Standard: PART 2. Experience - if no
Standard: PART 5. Characterisation

Start of Block: Personal health records and care quality and safety

Q1 The Care Information Exchange (CIE) provides online access to health records for you and the health and care professionals involved in your care. We, the CIE implementation and evaluation team, are interested in understanding your experience using the CIE. Our research team will analyse your responses to evaluate whether this system improves the way you feel about managing your own health, and about the quality of care that you receive.

All responses are anonymous and the information you provide will only be used to help make improvements to the CIE system. No information will be shared with third parties.

Thank you for your time and support participating in this survey.

End of Block: Personal health records and care quality and safety

Start of Block: PART 1. USAGE

How you use CIE

Q4 Have you ever used the CIE?

- ○ Yes
- ○ No

Skip To: End of Block If Have you ever used the CIE? = No

Q5 If yes, for how many months have you used CIE? _____

Q6 How often do you use CIE?

- ○ Less than once a month
- ○ Once a month
- ○ Once a week
- ○ Twice a week or more

Q7 What is the main reason you use CIE? _____

Q9 In general, how useful do you find CIE?

- ○ Not useful at all
- ○ Slightly useful
- ○ Moderately useful
- ○ Very useful
- ○ Not sure

Q10 How useful did you find the following features of CIE?

	Not at all useful	Slight-ly useful	Mode-rately useful	Very useful	Ex-tremely useful	Not applic-able
Appointments – being able to see outpatient clinic appointments and add others yourself	○	○	○	○	○	○
Test results – being able to check your blood test results	○	○	○	○	○	○
Radiology reports – being able to view your radiology reports	○	○	○	○	○	○
Clinic and discharge letters – being able to see your clinic and discharge letters	○	○	○	○	○	○
Diagnoses – being able to keep a record of your diagnoses	○	○	○	○	○	○
Allergies – being able to keep a record of your allergies	○	○	○	○	○	○
Symptoms – being able to keep a record of your symptoms	○	○	○	○	○	○
Measurements – being able to record your measurements such as pulse and blood pressure	○	○	○	○	○	○
Care plans – being able to view your care plan with a record of your treatment	○	○	○	○	○	○
Medicines – being able to record the medicines you are taking	○	○	○	○	○	○
Library – being able to access information materials provided by your healthcare professionals	○	○	○	○	○	○
Journal – being able to note your thoughts and observations about your health	○	○	○	○	○	○
Being able to contact your clinical team	○	○	○	○	○	○
Being able to upload information to CIE from other healthcare devices or apps	○	○	○	○	○	○

Q11 Would you like to see any other features in the CIE?

- ○ If yes, please specify _____
- ○ No

Q12 The CIE allows you to share your healthcare record with other people. Who have you invited to share your record? (Tick all that apply)

- ○ Carers
- ○ Family
- ○ Friends
- ○ My GP
- ○ Other healthcare professionals
- ○ I have not shared my record
- ○ I did not know this was possible

End of Block: PART 1. USAGE

Start of Block: PART 2. EXPERIENCE

Display This Question:
If Have you ever used the CIE? = Yes

Your experience of using CIE

Display This Question:
If Have you ever used the CIE? = Yes

Q15 How was your experience of navigating your CIE record?

- ○ Very difficult, please specify _____
- ○ Difficult, please specify _____
- ○ Easy
- ○ Very easy
- ○ Not applicable

Display This Question:
If Have you ever used the CIE? = Yes

Q16 Did you understand the information that you saw on the CIE?

- ○ Yes, definitely
- ○ Yes, to some extent
- ○ No, please specify _____
- ○ Not sure, please specify _____

Display This Question:
If Have you ever used the CIE? = Yes

Q17 CIE provides email notifications to users when their record has been changed. Did these emails help you keep track of changes in your record?

- ○ Never
- ○ Rarely
- ○ Sometimes
- ○ Always
- ○ I did not receive any email notifications

Display This Question:
If Have you ever used the CIE? = Yes

Q18 When using the CIE, did you notice any errors in your record?

- ○ No, I did not notice any errors
- ○ Yes, I did notice errors. Please specify _____

Display This Question:
If When using the CIE, did you notice any errors in your record? = Yes, I did notice errors. Please specify

Q20 If you have noticed errors in your record and have not already reported them, then it is important to contact your clinical team.

Display This Question:
If Have you ever used the CIE? = Yes

Q19 If you were to see an error in your medical records, what would you like to be able to do?

- ○ Nothing
- ○ Flag it up to my healthcare professional for correction
- ○ Correct it myself
- ○ Unsure

Display This Question:
If If you were to see an error in your medical records, what would you like to be able to do? = Correct it myself

Q21 Which type of errors would you personally feel comfortable correcting? Tick all that apply.

- ○ Personal information
- ○ Medication names
- ○ Medication doses
- ○ Doctor's notes
- ○ Dates of appointments
- ○ Diagnosis
- ○ Other, please specify _____

Display This Question:
If Have you ever used the CIE? = Yes

Q22 Did you have any of the following problems or concerns when using CIE? Tick all that apply.

- ○ Finding information
- ○ Understanding information
- ○ Problems using PC or tablet
- ○ Problems with internet connection
- ○ Concerns about confidentiality
- ○ Concerns about data security
- ○ Worry about information read on CIE
- ○ Risk of overestimating my own knowledge
- ○ Other, please specify _____

End of Block: PART 2. EXPERIENCE

Start of Block: PART 3. IMPACT ON PERCEPTIONS ABOUT HEALTH AND HEALTH CARE

Display This Question:
If Have you ever used the CIE? = Yes

How CIE has affected your health and care

Display This Question:
If Have you ever used the CIE? = Yes

Q25 Has CIE changed how you feel about self-managing your health?

- ○ Yes, for better
- ○ Yes, for worse
- ○ No

Display This Question:
If Have you ever used the CIE? = Yes

Q26 Has CIE changed how much you know about your health?

- ○ Yes, I know more
- ○ No, I have not learned anything new
- ○ No, I feel like I know less

Display This Question:
If Have you ever used the CIE? = Yes

Q27 Has CIE changed your role when making decisions about your health care?

- ○ Yes, I feel I have more of a role
- ○ Yes, I feel I have less of a role
- ○ No

Display This Question:
If Have you ever used the CIE? = Yes

Q28 Has CIE changed how much you feel in control about your health care?

- ○ Yes, I feel I have more control
- ○ Yes, I feel I have less control
- ○ No

Display This Question:
If Have you ever used the CIE? = Yes

Q30 Has CIE changed the number of questions you have about your health?

- ○ Yes, I have more questions about my health
- ○ Yes, I have less questions about my health
- ○ No

Display This Question:
If Have you ever used the CIE? = Yes

Q31 Has CIE changed any of the following for you?

	Much worse	Some-what worse	About the same	Some-what better	Much better
Overall quality of care received	○	○	○	○	○
Satisfaction with care received	○	○	○	○	○
Accessibility of my personal health history	○	○	○	○	○
Healthcare professionals being informed about my health history	○	○	○	○	○
Communication with healthcare professionals	○	○	○	○	○
Workload for healthcare professionals involved in my care	○	○	○	○	○
My own workload relating to my health and care	○	○	○	○	○
Health conditions	○	○	○	○	○
Safety of care	○	○	○	○	○
Accuracy of your health information	○	○	○	○	○
Detection of errors in your health records	○	○	○	○	○
Quickness of my appointments, diagnosis and/or treatment	○	○	○	○	○
Other, please specify	○	○	○	○	○

Display This Question:
If Have you ever used the CIE? = Yes

Q32 Has using CIE:

- ○ Increased your number of appointments
- ○ Decreased your number of appointments
- ○ Increased your number of telephone calls with your healthcare professionals
- ○ Decreased your number of telephone calls with your healthcare professionals

Display This Question:
If Has using CIE: = Increased your number of appointments

Q58 In which care settings were the appointments?

- Hospital
- GP
- Other, please specify _____

Display This Question:
If Has using CIE: = Increased your number of appointments

Q59 Was it the first appointment with the healthcare provider or professional?

- Yes
- No

Display This Question:
If Has using CIE: = Increased your number of appointments

Q60 Please describe a situation where you needed an appointment due to viewing CIE. _____

Display This Question:
If Has using CIE: = Increased your number of appointments

Q61 How many times did you need to schedule appointments due to using CIE?

- 1
- 2
- 3
- 4
- 5 or more

Display This Question:
If Has using CIE: = Decreased your number of appointments

Q62 In which care settings would the appointments have been?

- Hospital
- GP
- Other, please specify _____

Display This Question:
If Has using CIE: = Decreased your number of appointments

Q63 Would it have been the first appointment with the healthcare provider or professional?

- Yes
- No

Display This Question:
If Has using CIE: = Decreased your number of appointments

Q64 Please describe a situation where you did not need an appointment due to viewing CIE. _____

Display This Question:
If Has using CIE: = Decreased your number of appointments

Q65 How many times did you not need an appointment due to using CIE?

- 1
- 2
- 3
- 4
- 5 or more

Display This Question:
If Has using CIE: = Increased your number of telephone calls with your healthcare professionals

Q66 Which care settings did you call?

- Hospital
- GP
- Other, please specify _____

Display This Question:
If Has using CIE: = Increased your number of telephone calls with your healthcare professionals

Q67 Please describe a situation where you needed to call your healthcare provider or professional due to viewing CIE. _____

Display This Question:
If Has using CIE: = Increased your number of telephone calls with your healthcare professionals

Q69 How many times did you need to call?

- 1
- 2
- 3
- 4
- 5 or more

Display This Question:
If Has using CIE: = Decreased your number of telephone calls with your healthcare professionals

Q70 Which care setting did you not need to call?

- Hospital
- GP
- Other, please specify _____

Display This Question:
If Has using CIE: = Decreased your number of telephone calls with your healthcare professionals

Q71 Please describe a situation where you did not need to call your healthcare provider or professional due to viewing CIE. _____

Display This Question:
If Has using CIE: = Decreased your number of telephone calls with your healthcare professionals

Q72 How many times did you not need to call?

- 1
- 2
- 3
- 4
- 5 or more

Display This Question:
If Have you ever used the CIE? = Yes

Q33 Please give any examples of things you have done differently as a result of using the CIE.
_____

End of Block: PART 3. IMPACT ON PERCEPTIONS ABOUT HEALTH AND HEALTH CARE

Start of Block: PART 4. THE WAY FORWARD

Display This Question:
If Have you ever used the CIE? = Yes

Improving your experience of CIE

Display This Question:
If Have you ever used the CIE? = Yes

Q35 There is a general tendency of moving from paper-based medical record to electronic medical records. How comfortable do you feel about your information being stored as electronic medical records?

- Extremely uncomfortable
- Somewhat uncomfortable
- Neither comfortable nor uncomfortable
- Somewhat comfortable
- Extremely comfortable

Display This Question:
If Have you ever used the CIE? = Yes

Q36 How likely is it that you would recommend the CIE to a friend or colleague?

- Extremely unlikely
- Somewhat unlikely
- Neither likely nor unlikely
- Somewhat likely
- Extremely likely

Display This Question:
If Have you ever used the CIE? = Yes

Q37 Please give us any other comments you have about the CIE so that we can improve the system. _____

End of Block: PART 4. THE WAY FORWARD

Start of Block: IF NO

Display This Question:
If Have you ever used the CIE? = No

Q50 Why have you not used CIE? _____

Display This Question:
If Have you ever used the CIE? = No

Q51 Would you like to register for CIE?

- Yes
- No
- I do not know
- I prefer not to say

Display This Question:
If Have you ever used the CIE? = No

Q52 If you got access to CIE, how much do you think you would use it?

- Less than once a month
- Once a month
- Once a week
- Twice a week or more

Display This Question:
If Have you ever used the CIE? = No

Q55 How useful would you find the following features of CIE?

	Not at all useful	Slightly useful	Moderately useful	Very useful	Extremely useful	Not applicable
Appointments – being able to see outpatient clinic appointments and add others yourself	○	○	○	○	○	○
Test results – being able to check your blood test results	○	○	○	○	○	○
Radiology reports – being able to view your radiology reports	○	○	○	○	○	○
Clinic and discharge letters – being able to see your clinic and discharge letters	○	○	○	○	○	○
Diagnoses – being able to keep a record of your diagnoses	○	○	○	○	○	○
Allergies – being able to keep a record of your allergies	○	○	○	○	○	○
Symptoms – being able to keep a record of your symptoms	○	○	○	○	○	○
Measurements – being able to record your measurements such as pulse and blood pressure	○	○	○	○	○	○
Care plans – being able to view your care plan with a record of your treatment	○	○	○	○	○	○
Medicines – being able to record the medicines you are taking	○	○	○	○	○	○
Library – being able to access information materials provided by your healthcare professionals	○	○	○	○	○	○
Journal – being able to note your thoughts and observations about your health	○	○	○	○	○	○
Being able to contact your clinical team	○	○	○	○	○	○
Being able to upload information to CIE from other healthcare devices or apps	○	○	○	○	○	○

Display This Question:
If Have you ever used the CIE? = No

Q55 Would you like to see any other features in the CIE?

- ○ Yes, please specify _____
- ○ No

Display This Question:
If Have you ever used the CIE? = No

Q56 The CIE allows you to share your record with others. Would you invite any of the following to share your record? Tick all that apply.

- ○ Carers
- ○ Family
- ○ Friends
- ○ My GP
- ○ Other healthcare professionals
- ○ I would not want to share my records with any of these

End of Block: IF NO

Start of Block: PART 2. EXPERIENCE - IF NO

Display This Question:
If Have you ever used the CIE? = No

We would like to understand more about why you have not used the Care Information Exchange and explore any anticipated difficulties or concerns about Care Information Exchange.

Display This Question:
If Have you ever used the CIE? = No

Q60 Do you have any problems in regards to the CIE? Select all that apply.

- ○ I do not think I would be able to find information
- ○ I do not think I would be able to understand information
- ○ I think I would have problems using PC or tablet
- ○ I think I would have problems with internet connection
- ○ I have concerns about confidentiality
- ○ I have concerns about data security
- ○ I think I would worry about information read on CIE
- ○ I think I would overestimate my own knowledge
- ○ If other, please specify _____

Display This Question:
If Have you ever used the CIE? = No

Q61 There is a general tendency of moving from paper-based medical record to electronic medical records. How comfortable do you feel about your information being stored as electronic medical records?

- ○ Extremely uncomfortable
- ○ Somewhat uncomfortable
- ○ Neither comfortable nor uncomfortable
- ○ Somewhat comfortable
- ○ Extremely comfortable

End of Block: PART 2. EXPERIENCE - IF NO

Start of Block: PART 5. CHARACTERISATION

Personal details

Finally, we need to make sure that CIE has a positive impact for all patients. By providing some information on these characteristics, you will help us to identify underserved groups, and design specific solutions to improve their experience.

Q39 Age (in years) _____

Q40 Gender

- ○ Male
- ○ Female
- ○ Other _____
- ○ Prefer not to answer

Q41 Ethnicity

- ○ White
- ○ Asian/British Asian
- ○ Black/African/Caribbean/Black British
- ○ Mixed/multiple ethnic groups
- ○ Other _____
- ○ Prefer not to answer

Q42 Is English your native language?

- ○ Yes
- ○ No, please specify your native language _____

Q44 What is your highest level of education?

- ○ GCSE/NVQ/apprenticeship
- ○ AS-levels/A-levels/equivalent
- ○ Undergraduate degree
- ○ Postgraduate degree
- ○ Professional degree
- ○ Doctorate
- ○ Prefer not to answer

Q45 How good do you think your health is?

- ○ Very poor
- ○ Somewhat poor
- ○ Neither good nor poor
- ○ Somewhat good
- ○ Very good

Q46 In general, how motivated to be involved in your healthcare are you?

- ○ Very much
- ○ A lot
- ○ A moderate amount
- ○ A little
- ○ Not at all

Q47 We would like to know how comfortable you are using digital technologies.

	Strongly disagree	Some-what disagree	Neither agree nor disagree	Some-what agree	Strongly agree
I know what health resources are available on the internet	○	○	○	○	○
I know where to find helpful health resources on the internet	○	○	○	○	○
I know how to find helpful health resources on the internet	○	○	○	○	○
I know how to use the internet to answer my questions about health	○	○	○	○	○
I know how to use the health information I find on the internet to help me	○	○	○	○	○
I have the skills I need to evaluate the health resources on the internet	○	○	○	○	○
I can tell high quality health resources from low quality health resources on the internet	○	○	○	○	○
I feel confident in using information from the internet to make health decisions	○	○	○	○	○

Q48 Please enter the first part of the postcode where you live (for instance B28 or SE16):

_____

Thank you for completing this survey. Your views will help us to keep improving the Care Information Exchange, in order to better its users' needs and expectations. If you would like to receive information on the results of this evaluation, please contact us at imperial.cie.project@nhs.net. _____

End of Block: PART 5. CHARACTERISATION

CHERRIES checklist

Table 56. CHERRIES checklist for Chapter 7 adapted from Eysenbach, G. (2004). Improving the Quality of Web Surveys: The Checklist for Reporting Results of Internet E-Surveys (CHERRIES). Journal of Medical Internet Research, 6(3), e34. https://doi.org/10.2196/jmir.6.3.e34; part 1 of 2.

Domain/ Item	**Abbreviated description**	**Location reported**
Design		
Describe survey design	Describe target population, sample frame. Is the sample a convenience sample?	p. 217
Institutional review board (IRB) approval & informed consent process		
IRB approval	Mention whether the study has been approved by an IRB.	p. 216
Informed consent	Describe the informed consent process.	p. 217, p. 365
Data protection	If any personal information was collected or stored, describe what mechanisms were used to protect unauthorized access.	p. 216
Development & pre-testing		
Development & testing	State how the survey was developed and tested before fielding it.	pp. 217-220
Recruitment process & description of sample having access to survey		
Open survey vs. closed survey	An “open survey” is open for each site visitor, while a closed survey is only open to a sample which the investigator knows.	
Contact mode	Was the initial contact with potential participants made on the Internet?	p. 217
Advertising the survey	How/where was the survey announced or advertised? Is the survey announcement published as an appendix?	
Survey administration		
Web/E-mail	State the type of e-survey.	
Context	Describe the Web site (for mailing list/newsgroup) in which the survey was posted. Could choice pre-select the sample or influence the results?	p. 217
Mandatory/ voluntary	Was it a mandatory survey to be filled in by every visitor who wanted to enter the Web site, or was it voluntary?	
Incentives	Were any incentives offered?	
Time/date	In what timeframe were the data collected?	
Randomisation of items or surveys	To prevent biases items can be randomized or alternated.	
Adaptive questioning	Use adaptive questioning to reduce number/complexity of questions.	pp. 217-220, pp. 365-379
Number of items	What was the number of survey items per page?	
Number of screens (pages)	Over how many pages was the survey distributed?	
Completeness check	Were consistency or completeness checks done before survey submission? If “yes”, how? Was a check for completeness done after the survey had been submitted?	pp. 217-220
Review step	State whether respondents were able to review and change their answers.	n/a

Table 57. CHERRIES checklist for Chapter 7 adapted from Eysenbach, G. (2004). Improving the Quality of Web Surveys: The Checklist for Reporting Results of Internet E-Surveys (CHERRIES). Journal of Medical Internet Research, 6(3), e34. https://doi.org/10.2196/jmir.6.3.e34; part 2 of 2.

Domain/ Item	**Abbreviated description**	**Location reported**
Response rates		
Unique site visitor	If you provide view rates or participation rates, define how you determined a unique visitor.	p. 228
View rate	Requires counting unique visitors to the first page of the survey, divided by the number of unique site visitors.	n/a
Participation rate	Count the unique number of people who filled in the 1st survey page (or agreed to participate, for example by checking a checkbox), divided by visitors who visit the 1st page of the survey (or informed consents page, if present).	p. 228
Completion rate	The number of people submitting the last survey page, divided by the number of people agreeing to participate (or submitted the 1st survey page); only relevant if there is a separate "informed consent" page or if the survey goes over several pages. This is a measure for attrition.	n/a
Preventing multiple entries from the same individual		
Cookies used	Were cookies used to assign a unique user identifier to each client computer? Were duplicate entries avoided by preventing users access to the survey twice; or were duplicate database entries having the same user ID eliminated before analysis? In the latter case, which entries were kept for analysis?	n/a
IP check	Was the IP address of the client computer used to identify potential duplicate entries from the same user?	n/a
Log file analysis	Indicate whether other techniques to analyse the log file for identification of multiple entries were used. If so, please describe.	n/a
Registration	In "closed" surveys, users need to login first and it is easier to prevent duplicate entries from the same user. Describe how this was done.	n/a
Analysis		
Handling of incomplete surveys	Were only completed surveys analysed? Were surveys which terminated early also analysed?	p. 222, pp. 225-228
Surveys submitted with atypical timestamp	Some investigators may measure the time people needed to fill in a survey and exclude surveys that were submitted too soon.	n/a
Statistical correction	Were any methods (*e.g.*, weighting of items, propensity scores) used to adjust for non-representative sample?	pp. 220-228

Additional data and analyses

Objective 2: ability and needs for using a PHR

Table 58. Objective 2: Cross-tabulation of patients' sociodemographic characteristics and their understanding of information in CIE.

Did you understand the information you saw on CIE?	No	Not sure	Yes, to some extent	Yes, definitely		
	n (%)	*n* (%)	*n* (%)	*n* (%)	χ^2	*P*
Gender					22.17	.001
Female	16 (5.8)	8 (2.9)	128 (46.4)	124 (44.9)		
Male	15 (9.0)	4 (2.4)	91 (54.5)	57 (34.1)		
Other	0 (0.0)	1 (50.0)	1 (50.0)	0 (0.0)		
Age					9.84	.63
≤30	3 (13.6)	0 (0.0)	9 (40.9)	10 (45.5)		
31-40	4 (8.3)	3 (6.3)	19 (39.6)	22 (45.8)		
41-50	3 (4.8)	2 (3.2)	36 (58.1)	21 (33.9)		
51-64	9 (4.8)	4 (3.2)	80 (58.1)	73 (33.9)		
≥65	12 (8.2)	4 (2.7)	76 (51.7)	55 (37.4)		
Ethnicity					4.08	.25
Ethnic minority	3 (3.1)	3 (3.1)	46 (47.4)	45 (46.4)		
White	28 (8.2)	10 (2.9)	173 (50.4)	132 (38.5)		
Education					11.53	.07
Secondary school or below	5 (8.1)	0 (0.0)	69 (58.5)	44 (37.3)		
Undergraduate/ professional degree	13 (7.2)	7 (3.9)	85 (47.2)	75 (41.7)		
Postgraduate or higher	10 (8.9)	5 (4.5)	46 (41.1)	51 (45.5)		
Language					1.91	.59
Non-english	2 (3.4)	1 (1.7)	31 (53.4)	24 (41.4)		
English	29 (7.7)	12 (3.2)	182 (48.0)	156 (41.2)		
Digital Literacy					40.99	<.001
High digital literacy	17 (5.2)	6 (1.8)	142 (43.0)	165 (50.0)		
Low digital literacy	11 (11.6)	4 (4.2)	67 (70.5)	13 (13.7)		
Health status					12.21	.06
Good	16 (9.0)	3 (1.7)	78 (44.1)	80 (45.2)		
Neutral	8 (7.5)	5 (4.7)	62 (58.5)	31 (29.2)		
Poor	7 (4.3)	5 (3.1)	80 (49.4)	70 (43.2)		
Motivation to be involved in own care					20.47	.02
Very much	13 (4.7)	8 (2.9)	126 (45.3)	131 (47.1)		
A lot	13 (11.2)	4 (3.4)	59 (50.9)	40 (34.5)		
A moderate amount	5 (11.6)	1 (2.3)	29 (67.4)	8 (18.6)		
Not very much	0 (0.0)	0 (0.0)	4 (66.7)	2 (33.3)		

Table 59. Objective 2: Cross-tabulation of patients' sociodemographic characteristics and their preferences for responding to errors in their records.

If you were to see an error in your medical records, what would you like to be able to do?	Do nothing *n* (%)	Unsure *n* (%)	Flag it up to health professional *n* (%)	Correct it myself *n* (%)	χ^2	*P*
Gender					13.55	.04
Female	8 (3.0)	36 (13.3)	167 (61.6)	60 (22.1)		
Male	7 (4.3)	21 (12.9)	104 (63.8)	31 (19.0)		
Other	1 (50.0)	0 (0.0)	1 (50.0)	0 (0.0)		
Age					13.24	.35
≤30	2 (9.5)	3 (14.3)	7 (33.3)	9 (42.9)		
31-40	3 (6.3)	6 (12.5)	30 (62.5)	9 (18.8)		
41-50	2 (3.3)	8 (13.3)	40 (66.7)	10 (16.7)		
51-64	5 (3.0)	18 (11.0)	107 (65.2)	34 (20.7)		
≥65	4 (2.8)	22 (15.4)	88 (61.5)	29 (20.3)		
Ethnicity					1.73	.63
Ethnic minority	5 (5.3)	13 (13.8)	57 (60.6)	19 (20.2)		
White	9 (2.7)	44 (13.1)	212 (62.9)	91 (21.4)		
Education					1.56	.96
Secondary school or below	5 (4.3)	13 (11.1)	74 (63.2)	25 (21.4)		
Undergraduate/ professional degree	5 (2.9)	20 (11.4)	116 (66.3)	34 (19.4)		
Postgraduate or higher	3 (2.7)	12 (10.8)	69 (62.2)	27 (24.3)		
Language					4.96	.18
Non-english	5 (8.8)	8 (14.0)	34 (59.6)	10 (17.5)		
English	11 (3.0)	47 (12.7)	234 (63.1)	79 (21.3)		
Digital Literacy					5.11	.16
High digital literacy	11 (3.4)	36 (11.1)	204 (63.2)	72 (22.3)		
Low digital literacy	3 (3.2)	18 (19.4)	57 (61.3)	12 (16.1)		
Health status					17.03	.009
Good	4 (2.3)	20 (11.4)	113 (64.2)	39 (22.2)		
Neutral	6 (5.8)	22 (21.2)	65 (62.5)	11 (10.6)		
Poor	6 (3.8)	15 (9.6)	94 (60.3)	41 (26.3)		
Motivation to be involved in own care					13.23	.15
Very much	8 (2.9)	36 (13.2)	169 (61.9)	60 (22.0)		
A lot	5 (4.5)	10 (8.9)	75 (67.0)	22 (19.6)		
A moderate amount	3 (7.0)	8 (18.6)	24 (55.8)	8 (18.6)		
Not very much	0 (0.0)	3 (50.0)	3 (50.0)	0 (0.0)		

Table 60. Objective 2: Sociodemographic characteristics of patients in the missing data sample and in the analysis sample.

	Missing data sample[a] (*n*=78)	**Analysis sample (*n*=445)**
Gender	n (%)	n (%)
Male	0 (0.0)	167 (37.5)
Female	7 (9.0)	276 (62.0)
Other	0 (0.0)	2 (0.4)
No response	71 (91.0)	0 (0.0)
Age Group		
<30	0 (0.0)	22 (4.9)
31-40	0 (0.0)	48 (10.8)
41-50	0 (0.0)	62 (13.9)
51-64	0 (0.0)	166 (37.3)
>65	2 (2.6)	147 (33.0)
No response	76 (97.4)	0 (0.0)
Ethnicity		
Ethnic minority	5 (6.4)	97 (21.8)
White	5 (6.4)	343 (77.1)
No response	68 (87.2)	5 (1.1)
Language		
English	12 (15.4)	379 (85.2)
Non-English	2 (2.6)	58 (13.0)
No response	64 (82.1)	8 (1.8)
Geographic location		
London	7 (9.0)	284 (63.8)
Other location in England	2 (2.6)	145 (32.6)
No response	69 (88.5)	16 (3.6)
Education		
Secondary school or below	3 (3.8)	118 (26.5)
Undergraduate/professional degree	4 (5.1)	180 (40.4)
Postgraduate or higher	5 (6.4)	112 (25.2)
No response	66 (84.6)	35 (7.9)
eHealth Literacy (eHEALS score)		
Higher eHealth literacy ≥30	8 (10.3)	329 (73.9)
Lower eHealth literacy ≤29	5 (6.4)	97 (21.8)
No response	65 (83.3)	19 (4.3)
Overall Health Status		
Good or very good	9 (11.5)	177 (39.8)
Neither good nor poor	2 (2.6)	106 (23.8)
Poor or very poor	4 (5.1)	162 (36.4)
No response	63 (80.8)	0 (0)
Motivation to be involved in own care		
Very much/a lot	11 (14.1)	394 (88.5)
Not very much/a moderate amount	4 (5.1)	49 (11.0)
No response	63 (80.8)	2 (0.4)

Note. [a]Respondents who did not report age and/or gender were excluded from the analysis.

Table 61. Objective 2: Missing data analysis for structured questionnaire items.

	Missing data[a] sample	Analysis sample		
	n (%)	*n* (%)	χ^2	*P*
Did you understand the information you saw on CIE?			.94	.82
No	6 (7.7)	31 (7.0)		
Not sure	1 (1.3)	13 (2.9)		
Yes, to some extent	41 (52.6)	219 (49.3)		
Yes, definitely	30 (38.5)	181 (40.8)		
No response	0	1		
When using CIE, did you notice any errors in your record?			1.84	.18
No, I did not	68 (88.3)	360 (82.0)		
Yes, I did notice errors	9 (11.7)	79 (18.0)		
No response	1	6		
If you were to see an error in your medical record, what would you like to be able to do?			5.13	.16
Correct it myself	8 (10.5)	91 (20.9)		
Flag it up to my healthcare professionals	55 (72.4)	271 (62.3)		
Unsure	9 (11.8)	57 (13.1)		
Nothing	4 (5.3)	16 (3.7)		
No response	2	10		

Note. [a]Respondents who did not report age and/or gender were excluded from the analysis.

Objective 3: impact of patient PHR use

Table 62. Objective 3: Cross-tabulation of patients' sociodemographic characteristics and their perceptions of the impact of CIE on overall quality of care.

Survey item: Has CIE changed overall quality of care received?	Much worse *n* (%)	Somewhat worse *n* (%)	About the same *n* (%)	Somewhat better *n* (%)	Much better *n* (%)	χ^2	*p*
Gender						3.62	.46
Male	2 (1.2)	1 (0.6)	89 (54.3)	37 (22.6)	35 (21.3)		
Female	5 (1.9)	6 (2.3)	154 (58.3)	55 (20.8)	44 (16.7)		
Age						12.32	.72
≤30	1 (4.5)	0 (0.0)	9 (40.9)	7 (31.8)	5 (22.7)		
31-40	1 (2.1)	2 (4.2)	24 (50.0)	13 (27.1)	8 (16.7)		
41-50	1 (1.7)	2 (3.4)	32 (55.2)	9 (15.5)	14 (24.1)		
51-64	2 (1.2)	1 (0.6)	93 (57.8)	35 (21.7)	30 (18.6)		
≥65	2 (1.4)	2 (1.4)	85 (60.7)	29 (20.7)	22 (15.7)		
Ethnicity						15.17	.004
Ethnic minority	0 (0.0)	3 (3.8)	32 (40.5)	21 (26.6)	23 (29.1)		
White	6 (1.8)	4 (1.2)	200 (60.4)	67 (20.2)	54 (16.3)		
Education						6.01	.65
Secondary school or below	1 (0.9)	0 (0.0)	65 (55.6)	30 (25.6)	21 (17.9)		
Undergraduate/ professional degree	4 (2.3)	3 (1.7)	99 (57.6)	38 (22.1)	28 (16.3)		
Postgraduate or higher	2 (1.9)	2 (1.9)	65 (61.3)	17 (16.0)	20 (18.9)		
Language						5.62	.23
Non-english	1 (1.7)	2 (3.4)	25 (43.1)	17 (29.3)	13 (22.4)		
English	5 (1.4)	5 (1.4)	213 (58.5)	76 (20.9)	65 (17.9)		
Digital Literacy						13.15	.01
High digital literacy	3 (0.9)	6 (1.9)	165 (52.1)	77 (24.3)	66 (20.8)		
Low digital literacy	2 (2.1)	1 (1.1)	67 (71.3)	15 (16.0)	9 (9.6)		
Health status						8.63	.37
Good	2 (1.2)	2 (1.2)	95 (56.5)	33 (19.6)	36 (21.4)		
Neutral	4 (3.8)	1 (1.0)	62 (59.6)	23 (22.1)	14 (13.5)		
Poor	1 (0.6)	4 (2.5)	86 (54.8)	37 (23.6)	29 (18.5)		
Motivation to be involved in own care						11.07	.52
Very much	4 (1.5)	6 (2.3)	137 (51.5)	60 (22.6)	59 (22.2)		
A lot	2 (1.7)	1 (0.9)	73 (63.5)	25 (21.7)	14 (12.2)		
A moderate amount	1 (2.4)	0 (0.0)	28 (68.3)	7 (17.1)	5 (12.2)		
Not very much	0 (0.0)	0 (0.0)	3 (60.0)	1 (20.0)	1 (20.0)		

Table 63. Objective 3: Cross-tabulation of patients' sociodemographic characteristics and their perceptions of the impact of CIE on satisfaction with care.

Survey item: Has CIE changed satisfaction with care received?	Much worse *n* (%)	Somewhat worse *n* (%)	About the same *n* (%)	Somewhat better *n* (%)	Much better *n* (%)	χ^2	*p*
Gender						2.53	.64
Male	2 (1.2)	4 (2.5)	75 (46.3)	42 (25.9)	39 (24.1)		
Female	5 (1.9)	8 (3.1)	137 (52.3)	54 (20.6)	58 (22.1)		
Age						12.90	.68
≤30	1 (4.8)	0 (0.0)	6 (28.6)	8 (38.1)	6 (28.6)		
31-40	1 (2.1)	2 (4.2)	22 (45.8)	14 (29.2)	9 (18.8)		
41-50	0 (0.0)	2 (3.4)	27 (45.8)	16 (27.1)	14 (23.7)		
51-64	2 (1.3)	3 (1.9)	86 (54.1)	30 (18.9)	38 (23.9)		
≥65	3 (2.2)	5 (3.6)	71 (51.4)	29 (21.0)	30 (21.7)		
Ethnicity						12.63	.01
Ethnic minority	0 (0.0)	3 (3.8)	27 (34.2)	22 (27.8)	27 (34.2)		
White	6 (1.8)	9 (2.8)	175 (53.5)	69 (21.1)	68 (20.8)		
Education						9.42	.31
Secondary school or below	1 (0.9)	0 (0.0)	63 (55.3)	20 (17.5)	30 (26.3)		
Undergraduate/ professional degree	4 (2.3)	7 (4.1)	85 (49.7)	43 (25.1)	32 (18.7)		
Postgraduate or higher	2 (1.9)	3 (2.8)	53 (50.0)	24 (22.6)	24 (22.6)		
Language						3.67	.45
Non-english	1 (1.7)	2 (3.4)	23 (39.7)	18 (31.0)	14 (24.1)		
English	5 (1.4)	9 (2.5)	187 (51.8)	78 (21.6)	82 (22.7)		
Digital Literacy						12.92	.01
High digital literacy	4 (1.3)	8 (2.5)	149 (47.3)	68 (21.6)	86 (27.3)		
Low digital literacy	1 (1.1)	3 (3.2)	55 (58.2)	26 (27.7)	9 (9.6)		
Health status						16.16	.04
Good	3 (1.8)	5 (3.0)	85 (51.2)	29 (17.5)	44 (26.5)		
Neutral	4 (3.8)	1 (1.0)	55 (52.9)	29 (27.9)	15 (14.4)		
Poor	0 (0.0)	6 (3.9)	72 (46.5)	39 (25.2)	38 (24.5)		
Motivation to be involved in own care						20.01	.07
Very much	3 (1.1)	8 (3.0)	120 (45.6)	57 (21.7)	75 (28.5)		
A lot	3 (2.6)	4 (3.5)	60 (52.6)	32 (28.1)	15 (13.2)		
A moderate amount	1 (2.4)	0 (0.0)	28 (68.3)	7 (17.1)	5 (12.2)		
Not very much	0 (0.0)	0 (0.0)	2 (40.0)	1 (20.0)	2 (20.0)		

Appendix B

Poster presentations

Chapter 3: Patient and public involvement

Figure 33. Poster presentation: ***Freise, L.****, Lawrence-Jones, A., Neves, A. L., Flott, K., Darzi, A., & Mayer, E. K. Patient and public involvement in a PhD project: Co-production of research on partnering with patients in their healthcare. Graduate School PhD Summer Showcase 2019, 12th July 2019, London.*

Chapter 4: Analysing patient registrations and access to a personal health record: Care Information Exchange case study

Imperial College London

Patient-controlled electronic health records: Patient registrations and access to the Care Information Exchange

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Sowerby eHealth Forum, Imperial College London

BACKGROUND

Electronic health records (EHR) have the potential to improve quality of care by enhancing patient-centeredness, safety, and effectiveness, particularly when EHR information is shared directly with, and can be edited by, patients. Low patient adoption rates, however, may hinder the potential of this technology and limit its impact. Better understanding patient adoption of patient-controlled EHR is needed as a first step to facilitate current and future system improvement.

AIMS AND OBJECTIVES

Evaluate the implementation of an EHR, the Care Information Exchange (CIE) in North-West London and, specifically, to assess patient registrations and access.

METHODS

Patient adoption of an EHR was assessed using CIE website registrations (n=1566) and analysed descriptively; it was evaluated January 2016 – January 2018. For each clinical service, we specifically evaluated:

a) Numbers of patients completing the CIE registration rates

b) Numbers of patients accessing CIE compared with completed registrations

Total Spearman correlations were used to investigate the association between registrations and access. Analysis was performed in SPSS v.12; p=0.05 was the threshold for statistical significance.

RESULTS

The proportion of patients who, having been invited to register for CIE, went on to complete registration, varied markedly across clinical services (see Table 1). The lowest was seen for Multiple Sclerosis (36.6%) and the highest Interstitial Lung Disease (76.9%).

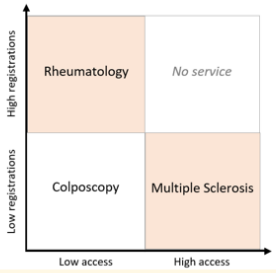
Access rates (percentage of registered patients accessing the EHR at least once in the 4 weeks preceding 29.01.18, or at least twice in case of higher access) also varied considerably across the clinical services. The lowest was seen for Colposcopy (26.4%) and the highest Neuro-oncology (72.3%).

There was no association seen between levels of registrations and access (R2 = 0.181; p=0.618).

Clinical Service	Invited	Registered	Conversion Rate	Access Rate	Higher Access Rate
Interstitial Lung Disease	26	20	76.9%	60.0%	50.0%
Renal Transplant	723	530	73.3%	66.0%	54.0%
Rheumatology	245	177	72.2%	41.2%	28.2%
Oncology	307	197	64.2%	59.4%	44.7%
HIV	100	60	60.0%	53.3%	40.0%
Renal Dialysis A	30	17	56.7%	70.6%	64.7%
Neuro-oncology	84	47	56.0%	72.3%	53.2%
Renal Dialysis B	36	15	41.7%	53.3%	53.3%
Colposcopy	1192	451	37.8%	26.4%	16.0%
Multiple Sclerosis	142	52	36.6%	69.2%	57.7%

TABLE 1. Clinical services sorted from highest to lowest conversion rate from invited to registered patients. Green marks the two highest percentages and blue the two lowest ones per column. Access rate refers to percentage of registered patients accessing the EHR at least once in the 4 weeks preceding 29.01.18 (or at least twice in case of higher access).
Note: If the third highest or lowest values differed from the second ones by less than 1.5% it was marked as well.

FIGURE 1.
Congruence and incongruity between high and low registration and access rates of the Care Information Exchange based on conversion rates from invited to registered patients and percentage of CIE accessing users out of registered ones (see *Table 1*). Below incongruent fields are marked in red.



DISCUSSION

Large variations exist between registration and access rates both within and across services. The given results provide initial information on patient registration and access patterns which can be used to guide the future investigation of specific barriers hindering registrations and access.

Reflecting on the observed variations between the registration and access rates between the services, strategies can be developed to maximise the safety impact and patient benefit of EHR-based approaches.

ACKNOWLEDGEMENTS

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Figure 34. Poster presentation: ***Freise, L.****, Neves, A. L., Flott, K., Darzi, A., & Mayer, E. K. Patient-controlled electronic health records: Patient registrations and access to the Care Information Exchange. Divisional Research Afternoon 2018, 13th December 2018, London.*

Chapter 5: A cross-sectional survey on patients' perceived ability to understand PHR information and identify potential errors

Imperial College London

Patient-controlled electronic health record: Patients' ability to understand health information and identify potential errors

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Sowerby eHealth Forum, Imperial College London

BACKGROUND

Electronic health records (EHR) can share their medical record information directly with patients. Several proposed benefits of EHR implementation and patient-facing information sharing include the potential for patients to identify errors in their medical records, improving patient safety.

This patient-driven opportunity for error identification, and subsequent correction, however relies on patients being able to understand all the information contained and presented in their EHR to have the skills necessary to identify potential errors.

AIMS AND OBJECTIVES

This study aimed to assess:

a) Patients' perceived **ability to understand** EHR information,
b) **Barriers preventing this understanding.**
c) Patients' **ability to identify errors** in EHRs,
d) The **type of errors identifiable** by patients.

METHODS

Patients using the Care Information Exchange (CIE), a patient-controlled EHR initiative in North-West London, responded to an online survey regarding their current CIE usage during March 2017 – April 2018. The survey allowed responses to individual questions voluntary. Qualitative free text data was analysed thematically according to the framework analysis methodology. Quantitative multiple-choice data was analysed descriptively.

RESULTS

A total of 211 patients completed the survey. Most respondents (68.7%) did not report problems in understanding EHR information (*n*=179 for the specific question).

Barriers to understanding were identified as relating to information issues (i.e. medical terminology and knowledge, interpretation of test results in terms of their meaning and significance) and technology issues (i.e. user-friendliness, website layout, content, result presentation) (see *Figure 1*).

Almost 14% (*n*=187 for the specific question) of the participants identified errors in their records during their current use of the CIE. Errors identified are shown in *Figure 2*.

FIGURE 1.

Thematic map of barriers to patients' understanding of EHR information

FIGURE 2.

Thematic map of kinds of errors patients identified in EHR information

DISCUSSION

While the majority of patients did not report difficulties in understanding EHR information, **information and technology-based barriers still persist**.

To enhance the impact of patient access to EHRs on error correction, these barriers need to be addressed through better EHR design and improved content presentation in order to develop patient-centred information platforms.

ACKNOWLEDGEMENTS

The given work was supported by the NIHR Imperial Patient Safety Translational Research Centre, Imperial College London, and the Sowerby eHealth Forum, Imperial College London.

Figure 35. Poster presentation: ***Freise, L.****, Neves, A. L., Flott, K., Darzi, A., & Mayer, E. K. Patient-controlled electronic health record: Patients' ability to understand health information and identify potential errors. 6th Annual NIHR Imperial PSTRC Symposium, 29th November 2018, London.*

Chapter 6: A semi-structured interview study on patient expectations of the Care Information Exchange, its functionalities, and their usefulness

Imperial College London

Patient-controlled electronic health record: patients' preferences & expectations – preliminary results of an interview study

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Sowerby eHealth Forum, Imperial College London

BACKGROUND

Electronic health records (EHR) can share medical record information directly with patients. EHR have the potential to improve quality of care, and in particular to enhance patient-centeredness, safety, and effectiveness. However, low adoption rates and patient perceived usefulness of the system may hinder the potential and impact of this technology.

AIMS AND OBJECTIVES

The aim of this study was to evaluate the implementation of an EHR, the Care Information Exchange (CIE) in North-West London and, specifically, to assess patients' preferences and expectations regarding its use.

METHODS

Patients from two services (Colposcopy and Rheumatology) that actively enrolled patients to the CIE participated in semi-structured interviews. The interviews were audio recorded with explicit permission from the participants and transcribed verbatim by LF. The transcripts were analysed thematically by a researcher and three trained patient representatives. Each interview was coded by at least LF and one of the patient representatives. Preliminary themes were identified by reviewing the codes from all coders.

RESULTS

The interviewees (n=31, 84% female) had prior experience of using the CIE in 29% of the interviews. The themes identified in the analysis revolved around

a) patients' motivation to use the CIE,
b) their ability to do so including barriers and enablers for it,
c) their concerns and potential weaknesses of the CIE, and
d) preferences for and perceived strengths of the CIE.

DISCUSSION

The interviews gave valuable insights into patients' preferences and concerns regarding CIE use and emphasised the need for understandable presentation of information. To enhance the impact of patient access to EHRs on quality of care, the perceived barriers and problems of the system need to be addressed through a review of the CIE design in order to further develop the usefulness of the patient-centred information platform to patients.

Patient and public involvement

Three patient and public representatives were involved throughout the study. They contributed e.g. to the interview guide, information and consent forms as well as the analysis and interpretation of the results. Training for the data analysis was provided and the researchers were available to respond to any questions.

FIGURE 1.

Thematic map of patient views and experiences of the CIE.

ACKNOWLEDGEMENTS

The given work was supported by the NIHR Imperial Patient Safety Translational Research Centre, Imperial College London, and the Sowerby eHealth Forum, Imperial College London.

Figure 36. Poster presentation: ***Freise, L.****, Neves, A. L., Flott, K., Darzi, A., & Mayer, E. K. Patient-controlled electronic health record: patients' ability, preferences & expectations – preliminary results of an interview study. PSTRC PhD Network Forum 2019, 5th February 2019, Leeds.*