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Healthcare providers intentions to use an electronic personal health record for undocumented migrants: A qualitative exploration study in The Netherlands

Paulien Tensen ^{a,b}, Simone van Dormolen ^b, Steven J. M. van de Vijver ^{a,b,c}, Myrthe L. van de Pavert ^d and Charles O. Agyemang ^{a,e}

^aDepartment of Public and Occupational Health, Amsterdam Public Health, Amsterdam UMC location University of Amsterdam, Amsterdam, The Netherlands; ^bAmsterdam Health & Technology Institute, Amsterdam, The Netherlands; ^cDepartment of General Practice, OLVG hospital, Amsterdam, The Netherlands; ^dCentre of Expertise Palliative Care, Leiden University medical Centre, Leiden, The Netherlands; ^eDivision of Endocrinology, Diabetes, and Metabolism, Department of Medicine, Johns Hopkins University School of Medicine, Baltimore, MD, USA

ABSTRACT

Electronic Personal Health Records (EPHRs) are potentially effective tools for improving the continuity and quality of care for migrants and refugees, and specifically for undocumented migrants (UDMs). However, little is known about the intention and preconditions of healthcare providers (HCPs) to use an EPHR for UDM in the Netherlands. Between April 2023 and June 2023, thirteen interviews, using a semi-structured topic guide, were conducted with Dutch HCPs. Open coding and axial coding were used for data coding, organised using the Technology Acceptance Model (TAM). HCPs reported a positive user intention towards using an EPHR for UDMs, coupled with a cautious optimism regarding UDMs' willingness to use an EPHR. Actual usage was dependent on several preconditions: establishing trust among HCPs and UDMs in the EPHR, implementing a highly secure system to protect UDM's sensitive data, giving UDMs control over their EPHR, and using approaches to minimise dual record keeping and developing a user-friendly system. An EPHR shows promise to enhance continuity of care and quality for UDMs in the Netherlands. However, an EPHR should not be a prerequisite for receiving medical care but rather a supportive element in the provision of care.

Abbreviations: Ahti: Amsterdam health & technology institute; EPHR: Electronic Personal Health Record; GZA: Gezondheidszorg Asielzoekers; HCP: Healthcare provider; PHR: Personal health record; NGO: Non-Governmental Organisation; TAM: Technology Acceptance Model; UDM: Undocumented Migrant

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Introduction

Digital tools in healthcare provide many opportunities to improve access and quality of care. However, there are considerable differences in digital readiness across health systems in EU countries

CONTACT Paulien Tensen  p.tensen@amsterdamumc.nl  Amsterdam UMC, location AMC, Meibergdreef 9, 1105 AZ Amsterdam

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(Fonda et al., 2023; Majcherek et al., 2024), and not all individuals – especially those living in vulnerable circumstances, such as refugees and migrants – equally benefit from these innovations. The need to include people living in vulnerable circumstances in digital health initiatives is emphasised globally in the WHO Global Digital Health Strategy 2020–2025 (WHO, 2021). To overcome health inequalities and improve access to healthcare for vulnerable groups, it is important to ensure ‘digital health for all’ (van de Vijver et al., 2023).

One way to contribute to ‘digital health for all’ is via Electronic Personal Health Records (EPHRs), which are believed to be potentially effective tools for improving the health of refugees and migrants (Chiesa et al., 2019). An EPHR is an electronic version of a Personal Health Record (PHR). A PHR is designed to be managed and accessed by patients, and it contains (I) all personal health information belonging to an individual, (II) information entered and accessed by healthcare workers and (III) information that extends beyond acute inpatient situations, including all ambulatory care settings in which the patient receives care (Chiesa et al., 2019; WHO, 2006).

Access to one’s own medical data is believed to induce patient empowerment and knowledge of one’s medical history is pivotal to ensuring access to good quality healthcare (Essén et al., 2017). This is especially the case when language barriers exist between healthcare providers (HCPs) and patients (Jahn et al., 2018). Additionally, from the perspective of HCPs, EPHRs are believed to be an effective tool for coordinating healthcare delivery among various HCPs for refugees (Jahn et al., 2018; Pavli & Maltezou, 2017). Furthermore, increased accuracy of medical information is instrumental for HCPs to improve diagnostic practices (Chiesa et al., 2019; Dziedzic et al., 2022).

Several EPHRs for refugees and migrants already exist, such as the IOM’s Re-Health2 and the CARE project (Ashworth et al., 2022; Chiesa et al., 2019). However, the current body of literature suggests that there is still insufficient evidence regarding the opportunities, challenges of implementing an EPHR, including their acceptance among migrants, refugees, and healthcare professionals (Chiesa et al., 2019). Moreover, current (E)PHRs are developed for specific countries, merely for specific conditions or foremost focused on HCPs rather than patients.

Therefore, the Amsterdam health & technology institute (Ahti) is exploring the development of HealthEmove, a potential EPHR for ‘people on the move’ in Europe. ‘People on the move’ in this study refers to migrants and refugees who are frequently changing geographical locations and, consequently, change HCPs. Although this EPHR was initially aimed at migrants and refugees, it does not exclude other people on the move, such as displaced persons, migrants living in asylum centres, labour migrants or people travelling back to home countries to seek medical care.

One specific group that could potentially benefit from an EPHR are Undocumented Migrants (UDMs). UDMs often changes locations and, consequently, HCPs. In Europe, the number of UDMs is estimated to be between 3.9 and 4.8 million, of whom between 23,000 and 58,000 resided in the Netherlands in 2018 (Rijksoverheid, 2020). A person is considered ‘undocumented’ when he or she resides in the Netherlands for three months or more without any valid residence papers. This often comprises people whose residence status has expired, whose asylum application was declined or who are working in the Netherlands without a valid visa (Pharos, 2022).

Despite an individual’s right to health, as stated in the United Nations International Covenant on Economic, Social and Cultural Rights (Hintjens et al., 2020), UDMs face many barriers in accessing healthcare (Hacker et al., 2015), including in the Netherlands. Barriers include, among others, financial barriers, fear of UDMs being reported to the police or immigration authorities and unwillingness of some HCPs to treat UDMs (Hacker et al., 2015; Hintjens et al., 2020; Vollebregt et al., 2023). Additionally, due to the absence of a social security number, UDMs cannot make use of Digital Health tools, linked to the Dutch healthcare system. Moreover, UDMs have an increased risk of infectious diseases (e.g. hepatitis B and tuberculosis), poor dental health, mental health problems (e.g. due to stress and poor living conditions), and chronic diseases and pregnancy-related illnesses (i.e. in the form of both complications and unwanted pregnancies) (Bloemen, 2019).

HCPs also encounter obstacles in delivering care to UDMs, even in countries like the Netherlands, where the law grants UDMs access to ‘medically necessary care’ (Hacker et al., 2015). One of

the barriers HCPs face in providing care to UDMs is a lack of access to prior medical records (Hacker et al., 2015). The lack of access to medical records refers to the unavailability of one's medical history from the country of origin as well as to medical data received in the Netherlands or enroute in Europe (Chiarenza et al., 2019; Chiesa et al., 2019; Feeney et al., 2020; Jahn et al., 2018). This leads to poorly informed HCPs and may result in the duplication of medical tests and healthcare delays, which present a significant barrier in both accessing and delivering high-quality healthcare (Chiarenza et al., 2019; DVDW, 2023). This lack of medical history thus further enhances the inefficiency of accessing and delivering healthcare (Chiesa et al., 2019; Feeney et al., 2020).

Despite the potential added value of an EPHR for UDMs, no research has been done to explore the perspective of HCPs working with UDMs about their intention to use an EPHR. Analysing the perspective of healthcare providers is considered a pivotal first step, as it is hypothesised that the user intention among gatekeepers in healthcare will be inextricably linked with the (un)successful development of an EPHR approach for people on the move, in our study, specifically for UDMs. Moreover, the Netherlands is a suitable location to explore the interest in an EPHR for UDMs, given the 'readiness' for digital solutions to improve access to healthcare (Majcherek et al., 2024), the widespread use of digital health tools and the traditionally willing and inclusive healthcare system for vulnerable groups such as refugees and UDMs, despite current pressures. Therefore, the aim of this study was to explore the intention of Dutch HCPs to use an EPHR for UDMs by investigating the opportunities, challenges and preconditions.

Materials and methods

Given the complexity of healthcare delivery to UDMs, which depends on policy, regulations, and the personal involvement of HCPs, this study used a qualitative approach with an interpretivist research perspective.

Data collection

In this exploratory qualitative research, 13 HCPs who have experience working with UDMs or people in asylum procedure, were interviewed using a semi-structured topic guide. The topic guide was tested before the first interview with the research team and with an external researcher. Interviews were conducted by the second author. This author had no personal relationship with the participants. Participants were invited via email based on purposive sampling and were recruited from relevant organisations working in the field of care for UDMs or for people in the asylum process, as well as from the researchers' social-professional networks. The sole inclusion criterion for the HCPs was that the individual provides medical care to UDMs in the Netherlands, such as general practitioners (GPs) or Non-Governmental Organisation (NGO) employees working with UDMs in healthcare settings in the Netherlands. Additionally, HCPs working in crisis emergency centres or at 'Gezondheidszorg Asielzoekers' (GZA), who provide medical care to migrants within the Dutch asylum procedure, were included. These latter HCPs frequently interact with newly arrived refugees or migrants who may lack access to medical records, as well as UDMs who were previously undocumented and are now applying for asylum. Written informed consent was obtained before the interview took place, and verbal confirmation was requested again before the interview began. All interviews were conducted between April 2023 and June 2023. Data saturation was reached after 11 interviews, as no new information or insights emerged from the two additional interviews. The COREQ-checklist was used as a guide to report this study (see Appendix 1) (Tong et al., 2007).

The topic guide consisted of two parts (see Appendix 2). First, experiences and obstacles in providing care to UDMs in the Dutch context were discussed. Second, the HCPs were asked to reflect on a potential EPHR as a tool for UDMs to carry their own medical records and share their records with new HCPs. Twelve interviews were conducted in Dutch and one in English; the interviews

lasted approximately 30–45 min and participants chose whether the interview took place either online (via Zoom (<https://zoom.us/>)) or at the participant's place of employment. This research was approved by the VU Amsterdam Science Faculty's Research Ethics Review Committee under review number 23-005, on April 21, 2023.

Data processing and analysis

All participants gave their informed consent for audio recording the interview. Informed consents and audio recordings were stored on a secured cloud that can only be accessed with a password and an organisational email address. Interviews were audio recorded using an iPhone (iOS) and transcribed using Sonix.ai (<https://sonix.ai/>). Thereafter, the transcribed data were thoughtfully checked for inconsistencies, and all data were anonymised, removing names and personal identifiers that can be traced back to the identity of the participant. Audio recordings were removed directly after transcription. The interviews were analysed using ATLAS.ti (<https://atlasti.com/>) coding software. The coding process consisted of two steps. First, through open coding, codes emerged from the dataset directly. Second, via axial coding, the data were organised and regrouped (Gray, 2004) using the Technology Acceptance Model (TAM) and adding re-emerging codes. Initial coding was performed by the second author. To enhance credibility, the first and second author discussed the coding and added codes after thoughtful consideration. Both researchers read all interviews multiple times to become familiar with the data. The TAM was developed in 1985 by Fred Davis and predicts the use of technology by examining people's intention to use it, referred to as 'technology acceptance'. This intention is influenced by two primary variables: perceived usefulness and perceived ease of use (Ammenwerth, 2019). Both variables have a positive relationship with usage intention: higher levels of perceived usefulness and perceived ease of use promote technology acceptance (Davis, 1989). Usage intention refers to 'technology acceptance', reflected by one's intention to use the eHealth tool. Perceived usefulness pertains to the expected improvement in healthcare access and quality. Perceived ease of use involves the expected ease of usage of the eHealth tool (Kamal et al., 2020).

Results

A total of 13 participants contributed to this study. 10 participants were medical doctors, one worked as a general practice assistant, one as a nurse and one participant, working at an NGO, served as the first point of contact for UDMs to guide them into healthcare. Most of the participants were between 30 and 60 years old, one participant was between 25 and 30 years old, and two participants were 65 years or older. Most of the participants ($n = 11$) had experience working with UDMs, and all except one had experience working with migrants in the asylum procedure or directly after the approval of the asylum. Most participants were employed in cities ($n = 11$). Table 1 provides a complete description of the sample and the variation in the characteristics of the participants.

The *attitudes* of HCPs towards using an EPHR are described below, subdivided into *opportunities* and *barriers* for HCPs using an EPHR and opportunities and barriers for UDMs according to HCPs; see Table 2. Finally, multiple *preconditions* for using an EPHR are described.

Attitude towards using an EPHR

All HCPs recognised the lack of medical records as a barrier to the continuity and quality of care delivery to UDMs in the Netherlands. Almost all participants expressed an intention to use an EPHR to facilitate medical record exchange for UDMs. Nonetheless, while expressing a positive intention to use an EPHR, some HCPs shared concerns about the feasibility of implementing it.

Table 1. Characteristics of HCPs.

	Provision	Age group	Experience with working with UDMs	Experience working with migrants in asylum procedure or directly after approval of asylum	Currently employed – Rural and city
HCP1	Medical doctor	30–65	Yes	Yes	City
HCP2	Medical doctor	30–65	No	Yes	Rural
HCP3	Medical doctor	65+	Yes	Yes	City
HCP4	Medical doctor	65+	No	Yes	City
HCP5	General Practice assistant	30–65	Yes	Yes	City
HCP6	Medical doctor	30–65	Yes	Yes	Rural
HCP7	Medical doctor	30–65	Yes	Yes	City
HCP8	Nurse	30–65	Yes	Yes	City
HCP9	NGO employee	25–30	Yes	No	City
HCP10	Medical doctor	30–65	Yes	Yes	City
HCP11	Medical doctor and public health services	30–65	Yes	Yes	City
HCP12	Medical doctor	30–65	Yes	Yes	City
HCP13	Medical doctor	30–65	Yes	Yes	City

I definitely think that having such a file on the go, if you think about it in an ideal scenario, would be amazing. But I just find it very complicated to figure out how to get there – HCP13.

Opportunities and challenges for HCPs using an EPHR

Enhancing efficiency of care by reducing duplication and improving communication. HCPs often discussed the frequent relocation of UDMs, both in the Dutch and European context, which necessitated them to repeat medical procedures, as they often do not have access to prior medical records of UDMs. Many HCPs argued that implementing an EPHR for UDMs would reduce the duplication of medical procedures since HCPs would gain access via an EPHR to a patient's medical history.

Because very often you get people who have already had everything done in Italy or elsewhere, and then you become very unhappy because then I also think about the societal importance. Then, you just see everything being redone because someone would rather be here [in the Netherlands] – HCP11.

Moreover, many HCPs reasoned that an EPHR for UDMs would facilitate communication with new HCPs, resulting in less time needed for a consultation because of available medical information.

For me as a doctor, it works when a patient can show me things, black on white. This, I've used this before. So that I don't have to do all that work again because that often takes a lot of time in such a consultation, asking questions, arranging an interpreter [...] – HCP12.

HCPs acknowledged that the lack of medical record sharing for UDMs is maintained within the current system, perpetuated by the wide variety of record keeping systems. Additionally, an HCP

Table 2. Opportunities and challenges of an EPHR for UDMs.

Opportunities of an EPHR for UDMs		Challenges of an EPHR for UDMs	
For HCPs	For UDMs (reflection HCPs)	For HCPs	For UDMs (reflection HCPs)
Reduce duplications in medical procedures	Increase feeling of being better assisted	Ensure accuracy of medical data in an EPHR	Low priority given to health
Improve communication	Improve self-management and ownership	Lack of time of HCPs	Responsibility over own information
Improve efficiency of care	Improve continuity of care for those with a chronic illness or without regular GP	Dependence on UDMs for medical information	Digital practicalities: skills and devices
Protect human rights			Trust in system

argued that they often do not share medical records of UDMs with new HCPs, nor do UDMs receive a copy of their medical records.

They are bouncing between different providers within Holland, so different organisations or different care providers, there's no sharing of that record keeping. So then, we do not know what other people have prescribed, what they were given or what advice. So yeah, patients never carry their own records with them, at least in the group that we see. [...]. It is all obviously maintained within our own system – HCP8.

HCPs argued that both the reduction in duplication of medical procedures and the improved communication between HCPs by means of an EPHR are believed to increase the efficiency of care delivery for UDMs and thereby improve the continuity of care.

Protecting human rights. In addition to improving the efficiency of healthcare delivery, several HCPs considered access to medical information a human right for UDMs, which outweighed potential barriers according to some HCPs.

I also think it is somewhat of a human right to have your medical data with you wherever you go and that you have it readily available, wherever you need to register or travel through – HCP9.

Ensuring the accuracy of medical information in the EPHR. The accuracy of medical information in the EPHR was considered a challenge according to the HCPs. There was no consensus reached among HCPs regarding who should be able to add information to the EPHR: HCPs or UDMs. Some HCPs stressed the necessity for exclusively granting HCPs access to the EPHR to put information in the record, citing the importance of trustworthiness and verification. One HCP illustrated this concern: *'garbage in is garbage out'* – HCP11.

Conversely, other HCPs advocated for patient involvement in adding information to the EPHR, if there is traceability regarding who added each piece of information. These HCPs advocated for a system where various HCPs and UDMs can contribute to adding medical information to an EPHR.

I think it would be nicer if many different people could write in it. That it is not closed off again, but rather as open as possible. However, perhaps you could show it in a way that this is entered by the patient themselves, this by healthcare provider X from place X – HCP13.

Moreover, the accuracy of the EPHR relies on the interaction between previous HCPs and the patient. One HCP emphasised the importance of earning the client's trust, addressing uncertainties surrounding the completeness of medical information provided in the EPHR, as an HCP cannot be sure that the previous HCP earned the trust of a UDM.

It is about gaining the client's trust, so that they're willing to share everything with you. In addition, which pertains to numerous aspects. Every time someone else adds something to the file, you have to assume that the interaction went well. In addition, you no longer have control over that once you have created the file – HCP7.

Moreover, a challenge highlighted by HCPs is their reliance on UDMs to share their medical history by means of an EPHR. A minority of UDMs may intentionally avoid using an EPHR because they are trying to access specific medications or treatments and do not want to share that their request was rejected by other HCPs.

If they want a certain blood test or they want a certain medication and they're not getting it at one and they will try another. [...] Again, we're talking about a minority, but these are definitely cases that I deal with – HCP8.

Lack of time of HCPs. A frequently mentioned challenge among HCPs is the scarcity of time to perform additional tasks. While HCPs recognised the need for reliable and prioritised information in the EPHR, HCPs emphasised that it should not impose an additional burden on them.

Not burdening healthcare providers additionally by giving them an extra task, [...] you actually do not want to make them do the work, so finding a solution for that is crucial – HCP1.

Opportunities and challenges for UDMs as perceived by HCPs

Most HCPs who reflected on the intention of UDMs to make use of an EPHR shared cautious optimism regarding a positive attitude of UDMs towards its usage.

Continuity of care for those with a chronic illness or without regular GPs. HCPs identify two groups of UDMs who might have the most interest in an EPHR: those without a regular general practitioner in the Netherlands and UDMs who frequently require healthcare, such as individuals with chronic illnesses. An EPHR was believed to be most beneficial if a UDM needs healthcare.

People who do not have that much need might think oh, medical records, I will deal with it later. However, for those who know they have diabetes or any other chronic illness, they might quickly latch onto such an idea. In addition, I think it can truly alleviate a lot of hassle and uncertainty for them – HCP9.

The primary reason, according to HCPs for UDMs to make use of an EPHR, was the belief that an EPHR could enhance communication between the UDM and its HCP, assisting the UDM in explaining their history. This was believed an opportunity to result in a sense of being better assisted by the HCP and improving the continuity of care.

I cannot speak for refugees, of course, but I do have the impression that everyone seeking care wants to be well assisted. And then it just helps to be able to show a doctor properly: Listen, this is my medical history– HCP12.

Self-management and ownership. Several HCPs emphasised the opportunity for UDMs to provide a HCP with one's medical history and information on medications, suggesting that people have a fundamental need for a level of control and self-management in their healthcare.

My idea is that people have a need for that [ability to show medical records] and to be able to have that control themselves, to manage it themselves – HCP12.

Responsibility over own medical record can impose a burden. Regardless of the need of UDMs for a level of control in healthcare, multiple HCPs highlighted the challenge that healthcare is not always the foremost priority of UDMs. Legal status often takes precedence over health concerns. This was considered to be a challenge for the adoption of an EPHR among UDMs.

While the importance of control for the patient was often stressed, another HCP noted that while some UDMs may appreciate the control afforded by managing their own information, others may prefer their medical information to be entrusted to HCPs. Taking charge of your own medical records was believed to also pose a burden on people.

I can imagine that people might find this [an EPHR] comforting because they are not stored in a system controlled by an institution or even a healthcare provider. [...] But it also imposes a burden on people. Pressure. Sometimes, people actually find it comforting when they say: 'but doctor, you know everything about me, just look in the computer– HCP13.

Moreover, not all UDMs might have the digital skills and digital devices to use an EPHR. Several HCPs mentioned that there is a small group consisting of UDMs who were less self-reliant, already demanding more time and effort for treatment, and often lacking insight into their medical history, who might encounter difficulties with using an EPHR and taking responsibility. This latter group was argued to include individuals with low literacy, limited digital skills, or lower educational attainment.

Trust in the ‘system’. Multiple HCPs mentioned that gaining trust in some groups of UDMs to share medical information in an EPHR might pose a challenge. HCPs acknowledged that trust levels vary among individuals. Some HCPs explained that UDMs who lack trust in government systems might not trust adding their personal information to an EPHR. The reasons for mistrust in an EPHR were multifaceted according to the HCPs. First, some UDMs were believed to be hesitant to share personal information, such as email addresses and phone numbers, due to fear of being caught by the Dutch immigration authorities (IND). Second, some UDMs do not trust the government of their home country and therefore might have less trust in an EPHR.

And the trust, you see, these are people coming from countries where institutions are not trusted at all. [...] who do not find it a comfortable feeling, who do not like the idea, who cannot emotionally grasp or comprehend that it might be safe – HCP11.

Preconditions

The user intention of HCPs and of UDMs from the perspective of UDMs was heavily reliant on various preconditions: the establishment of trust in an EPHR from both HCPs and UDMs, the development of a high-secure system, the use of a patient-centred design, and the development of a user-friendly system.

Building trust in an EPHR

A key precondition, as identified by HCPs, is gaining trust from UDMs in an EPHR to ensure willingness and comfort to share their medical information in an EPHR. HCPs suggested several ways to increase trust in an EPHR among UDMs. Some HCPs noted that trust in an EPHR can be strengthened by explanations about an EPHR from trusted healthcare professionals. For instance, an HCP illustrated that individuals accustomed to receiving care from trusted *straatdokters* (medical volunteers providing care for the homeless in the Netherlands) may trust an EPHR if recommended by this HCP.

Other ways mentioned to increase trust were emphasising patient ownership of the EPHR, sharing the EPHR among UDMs at entry points in Europe, using high standards of security, and finally, it is believed that building trust takes time.

If at some point the story circulates that no one has experienced anything negative with this, then it will eventually come, but yeah, that takes a few years – HCP10.

Another precondition, which was considered essential according to HCPs and in line with building trust, was to develop a highly secure system to protect UDMs against themselves sharing medical information and from others misusing medical information in the EPHR. An HCP argued that people are not always aware of the value of their medical information and should be protected against the ability to share their information with unauthorised individuals. Several HCPs mentioned that UDMs must be protected from misuse of the tool (e.g. by immigration authorities) because ‘*anything can be used against this group*’ (HCP13). One HCP explained that mobile phones were often confiscated by police forces or broken, and therefore stressed the importance that only UDMs themselves should be able to log in with a password:

If someone like that gets arrested by the border police and there’s a whole asylum story in there, that could be used against you. Also, by the IND, for example. So, you really have to be very careful that it is securely protected and not just anyone can access it – HCP12.

Ensuring medical information accuracy and verification was deemed crucial for building trust among HCPs and was considered a precondition for using the EPHR. Regardless of whether HCPs or UDMs add data to the record, it is imperative that the information in the EPHR can be verified to maintain accuracy and prevent misinformation for HCPs to trust the EPHR.

It [EPHR] must also be thoroughly verified. So that what is stated there aligns with reality and people do not insert things themselves that turn out to be untrue, because then it becomes difficult again – HCP12.

Giving UDMs control over their record

A patient-centred design was additionally considered a precondition according to most HCPs. Several HCPs stated that an EPHR could empower patients, providing ownership and autonomy in accessing healthcare. Providing UDMs control over their EPHR was thereby considered key by HCPs.

Simply build something that works well for the patient themselves, allowing them to have control and overview. It should contain information about who they are and their medical history – HCP12.

Moreover, it was considered important by HCPs to give UDMs autonomy over with whom they share their EPHR.

That the patient can somewhat control who has access, that they can easily share it as well, so there's no additional hassle with it not being easily shareable – HCP13.

Avoiding dual record-keeping for HCPs and not creating a parallel system were considered important preconditions for HCPs. Several HCPs proposed connecting the EPHR to existing patient registration systems to mitigate the burden of duplicative record-keeping and to not impose an additional workload on HCPs. In particular, an EPHR should not replace existing records according to many HCPs.

When someone comes to us, you're going to create an electronic patient record on the local computer anyway. You're not going to enter that into their thing. There's just no time – HCP7.

However, some HCPs expressed concerns regarding the feasibility of connecting the EPHR to existing systems due to compatibility issues and outdated software. In response, alternative approaches were proposed to minimise dual record-keeping. These included capturing screenshots of existing patient records, utilising QR codes for record sharing, allowing patients to take pictures of the computer screen of an HCP, or allowing patients to upload PDF files received from their HCPs directly into their EPHR.

Cannot you just do something with screenshots and such? You know, that could also be a good option, that you take screenshots of different types of EHRs, just after you as a doctor have typed your notes: *boom*, one photo of it and that is it, the easiest way – HCP13.

Building a user-friendly system for HCPs and UDMs

A simple, user-friendly EPHR was considered a precondition for using the EPHR for both HCPs and UDMs. A user-friendly system should not require many steps before being able to add information to the record.

Moreover, compactness and clarity of the information were frequently mentioned as crucial for a user-friendly system. It was considered important by HCPs that an EPHR only provides essential information relevant for further treatment.

They just want to show the most important things, so to speak. But they do not need to show all the past colds, bronchitis, and pneumonia cases – HCP4.

Furthermore, it was considered essential by an HCP that the EPHR can be accessed when a UDM has a new phone, as UDMs often switch phones.

You also do not want to burden people with an app that is too complex. The app should keep working. And if they get a new phone, it should immediately work on that new one too – HCP7.

Finally, a user-friendly system should, according to HCPs, not burden HCPs with additional tasks.

Discussion

This study explored the intention of Dutch HCPs to use an EPHR for UDMs in the Netherlands. Our results reveal a positive user intention among HCPs towards adopting an EPHR for UDMs. Reasons for the positive user intention included the potential of an EPHR to improve care efficiency by reducing duplicate medical procedures and enhancing communication between UDMs and HCPs. In theory, this could lead to reduced healthcare costs, especially as UDMs are entitled to access medically necessary care in the Netherlands. This positive user intention is coupled with cautious optimism regarding UDMs' willingness to use an EPHR. UDMs who have chronic diseases or who lack a regular GP are most likely, according to HCPs, to be interested in using an EPHR. The potential of an EPHR for UDMs to enhance healthcare continuity and quality is acknowledged in the literature (Ashworth et al., 2022; Chiesa et al., 2019, 2020; Feeney et al., 2020; Jahn et al., 2018; van de Vijver et al., 2023). Several preconditions for using an EPHR were described based on the opportunities and barriers discussed in this article: establishing trust from UDMs and HCPs in the EPHR, implementing a highly secure system to protect the UDM's information, giving the UDM control over their EPHR, avoiding duplicative record keeping, and developing an user-friendly system.

Trust emerged as a reoccurring theme among HCPs when it comes to their intention to use an EPHR, and establishing trust was considered a precondition for using it. Montague et al. (2009) describe trust as 'a feeling of certainty that a person or thing will not fail and is often based on inconclusive evidence'. Previous research revealed that trust significantly impacts eHealth usage intention and could greatly affect the how the tool is being received and its adoption (Arfi et al., 2021; Zhao et al., 2018). According to HCPs, establishing trust for UDMs in an EPHR was considered crucial for UDMs to be willing to add medical information in an EPHR due to fear of misuse of their information by the Dutch Immigration Authorities (IND). Janssens et al. (2006) recognise that mistrust and suspicion are common among UDMs. Moreover, UDMs seem to lack trust in healthcare and wider governance systems, often because of poor experiences with stories from friends (Deal et al., 2021). Addressing these concerns is vital, as highlighted by Feeney et al. (2020), who warned that UDMs might avoid seeking medical assistance if uncomfortable with their information being stored digitally. Given that UDMs might not (yet) trust an EPHR with their medical information and that building trust will take time, it is important that an EPHR should not be perceived as a prerequisite for receiving medical care but rather function as a supportive element in the provision of care.

A highly secure EPHR to protect UDMs against misuse of medical information was also considered a precondition for using an EPHR. The need for an extremely high standard of data security for migrants is recognised by Feeney et al. (2020), who argue that the fate of migrants might be dependent on who has access to their information. Additionally, Feeney et al. (2018) described that an EPHR must be set up to avoid any form of injustice, such as discrimination, including in terms of which information is included, access and use of information in the EPHR. While the practice of confiscating mobile phones and extracting information without an individual's permission breaches human rights, the HCPs in this study revealed that this does occur. This is also recognised by several European media sources (Bulman, 2017; Taylor, 2022). Moreover, in the Netherlands, 'reading out people's phones' is proposed as a measure to limit the influx of asylum seekers (Hoofdlijnenakkoord, 2024). To protect people's medical information, creating a highly secure EPHR that cannot be accessed by government agencies or police forces is important, and will most likely increase trust among UDMs in the EPHR.

For HCPs, trust mainly resolves around the credibility of the content of the EPHR. There was no consensus on who should be authorised to add information to the EPHR – UDMs or HCPs – but there was a strong agreement on the importance of ensuring accurate and verifiable information in the EPHR. In our study, multiple HCPs preferred to enter information into the EPHR themselves to ensure credibility; however, they also expressed concerns regarding the time constraints and

logistical challenges associated with this responsibility. This underscores a challenge in the feasibility of integrating EPHRs into current healthcare practices. A scoping review by Damen et al. (2022), on the other hand, recognised initial concerns about the validity and applicability of medical information entered by patients, showed that these concerns were unfounded. Patients in multiple studies, who had legal documents, accurately reported medical information to their records, making their records more concrete.

Allowing patients to add information to the record is in line with the precondition of patient ownership of the record. A patient-centred design, in our study, meant that the patient is in control over their record and the record is built around the needs of the patients. Evidence shows that patients who managed their medical information felt more informed, had greater control over their own health care, and adhered better to their treatment than those who did not manage their own information (Damen et al., 2022). Patients inserting their own medical information in an EPHR, moves beyond the definition of a PHR used by Chiesa et al. (2019), in which HCPs enter and access an EPHR (Chiesa et al., 2019). The importance of improving the autonomy of UDMs within their own healthcare and having greater control over their own health records has been recognised (Feeney et al., 2020). Our study, however, illustrates that managing one's health record can also pose a burden on individuals. This finding is in line with findings in the literature indicating that patients tend to prefer a passive rather than an active role when it comes to managing their health information (Damen et al., 2022). More research is needed to understand the perspectives of UDMs on holding this responsibility.

Avoiding duplicative recordkeeping was another precondition for HCPs. Allowing patients to take pictures of the screen of a doctor with their information after consultations, using QR codes to transfer information, or providing mechanisms for uploading PDF files directly into the EPHR were approaches mentioned to prevent duplicative recordkeeping. By facilitating these approaches, HCPs can leverage patient involvement to enhance the completeness and accuracy of EPHRs while mitigating the burden on HCPs. To the best of our knowledge, no EPHR for refugees or UDMs has focused on the potential of users taking pictures of medical information provided by HCPs. Nonetheless, taking pictures of printed medical records is not entirely new. A study in China explored the use of character recognition techniques to add information from pictures of paper medical records to an EPHR (Li et al., 2015). This technique still faces barriers due to the low quality of pictures and the different medical record systems used. These barriers should also be considered when integrating innovative techniques, such as photographs, to add medical information to the EPHR.

The last precondition mentioned by HCPs revolved around a user-friendly system in which an easy-to-use EPHR was considered key. One HCP expressed the importance that records should be accessed via a new phone. For this latter requirement, it is important to explore the best way to store medical records on a highly secure cloud or blockchain and not on the phone itself. HCPs stress the need for an easy-to-use system due to time constraints. Additionally, in the literature, the barrier of additional time required by HCPs to fill out a personal-held health record was mentioned as a barrier (Chiesa et al., 2019, 2020; Schoevers et al., 2011). However, the HCPs in our study shared that having access to the medical history of a patient during consultation potentially improved their work efficiency. Therefore, it is important to explore the time benefit of HCPs having access to the medical background of a UDM compared to the time it takes for HCPs to fill out an EPHR or to help the patient add information to the EPHR. For UDMs, as indicated by HCPs, the necessity of an easy-to-use system is due to the possible lack of digital skills and devices to make use of an EPHR, which is also described as a barrier for UDMs in our study. As the challenge of low digital literacy among migrants and refugees is recognised in literature (Kaihlainen et al., 2022; Liem et al., 2020), it is crucial that an EPHR should accommodate diverse levels of digital literacy (Talhok, 2016). Regarding people's access to mobile phones, research by UNHCR (2016) showed that in 2016, 68% of all refugees worldwide living in urban settings had access to a phone that was capable of using the internet, compared to 22% in rural refugee populations. However, we hypothesise that

this number has grown rapidly, as mobile phones are considered ‘even more important than food’ (Benton & Glennie, 2016). However, empirical evidence is lacking. Device affordability and low literacy are the foremost reasons for not having access to the internet. Given the potential of an EPHR to improve the health of migrants and refugees (Chiesa et al., 2019; van de Vijver et al., 2023) and the commitment of the United Nations 2030 Agenda on Sustainable Development to ensure ‘leave no one behind’, ensuring mobile device access and educating people in using digital devices has become a collective imperative. This aligns with the UNHCR’s emphasis on the crucial role of reliable mobile and internet connectivity in leveraging the benefits of the digital revolution (Grandi, n.d.).

Strengths and limitations

This study represents the first exploration of HCP’ perspectives regarding the implementation of an EPHR for UDMs in the Netherlands. This study fills a significant gap in the literature and lays the foundation for EPHR development in this area. While further exploration is warranted, this initial understanding is essential for informing future research and development efforts.

Some limitations need to be considered. We recognise that HCPs included in this study already have experience with UDMs or migrants in the asylum procedure, or directly after approval of asylum; therefore, the sample may not fully represent the perspectives of all HCPs, particularly those who are less familiar with treating UDMs. Moreover, conducting interviews online might have introduced bias related to communication dynamics and the inability to fully capture nonverbal cues. Additionally, HCPs reflected on the intention of UDMs to make use of an EPHR; however, it is important to explore the perspective of a wide range of UDMs themselves. Special emphasis should be placed on exploring trust-building with UDMs regarding the sharing of medical information in an EPHR, including their views on the use of their anonymised data for public health surveillance and monitoring. One potential bias in this study is the possibility that HCPs may have been influenced in their initial responses by the knowledge that the discussion would focus on the implementation of an EPHR for UDMs. This awareness might have led them to prioritise or emphasise barriers related to EPHRs over other challenges they encounter when providing care to UDMs. However, efforts were made to mitigate this bias by encouraging HCPs to reflect on a wide range of barriers encountered in caring for UDMs. By explicitly prompting participants to consider various challenges beyond the scope of EPHRs, this study aimed to provide a comprehensive understanding of the issues faced by HCPs in this context.

Conclusion

The EPHR shows promise to enhance continuity of care for UDMs in the Netherlands, especially for UDMs patients with chronic diseases or who do not have access to a regular GP, providing efficient healthcare and facilitating communication between the UDM and the HCP. Using an EPHR for UDMs should not be perceived as a prerequisite for receiving medical care but rather as a supportive element in the provision of care. The key preconditions for the EPHR are establishing trust among UDMs and HCPs in an EPHR, including developing a highly secure system, avoiding duplicative recordkeeping and a user-friendly system. A challenge remains the integration of an EPHR into existing health practices, particularly concerning the practicalities of maintaining an accurate and complete EPHR for UDMs and reducing additional workload of HCPs. Exploring innovative approaches, such as empowering UDMs to take responsibility for their EPHR by incorporating images of doctors’ notes, adding PDF-files or taking pictures of the computer screen of the doctor, could potentially alleviate the workload of HCPs and reduce duplicative record keeping while enhancing patient autonomy. As a next step we propose exploring the perspective of UDMs themselves around their intention to use an EPHR.

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Ethical considerations

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ORCID

Paulien Tensen  <http://orcid.org/0009-0008-6090-9685>
 Simone van Dormolen  <http://orcid.org/0009-0002-3158-3790>
 Steven J. M. van de Vijver  <http://orcid.org/0000-0002-9174-7737>
 Myrthe L. van de Pavert  <http://orcid.org/0009-0006-0489-0217>
 Charles O. Agyemang  <http://orcid.org/0000-0002-3882-7295>

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