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An electronic health record for all? Deaf and hard-of-hearing adults' perspectives on accessibility, trust and self-determination in Germany's ePA – a qualitative study

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Abstract

Background

Deaf and hard-of-hearing (DHH) people experience persistent communication barriers in healthcare, while often using digital communication tools intensively and competently. Germany's electronic patient record (elektronische Patientenakte, ePA) is being introduced as a nationwide opt-out infrastructure intended to improve access to health information and support care coordination. However, little is known about how DHH people perceive this infrastructure and what conditions are required for accessible and self-determined use. This study explored DHH adults' experiences of healthcare communication, their knowledge and expectations of the ePA, and their requirements for an accessible electronic patient record.

Methods

We conducted an exploratory qualitative interview study with ten deaf and hard-of-hearing adults in Germany. Participants were recruited through professional and community networks using purposive sampling to achieve heterogeneity in age, gender and place of residence. Semi-structured interviews were conducted via video telephony between January and March 2026, supported by qualified sign-language interpreters. Data were analysed using structured qualitative content analysis following an iterative deductive-inductive approach.

Results

Participants described healthcare access as strongly dependent on successful communication, particularly the availability and quality of sign-language interpreting. Knowledge of the ePA was low and fragmented, reflecting limited accessible information rather than limited digital competence. Participants saw considerable potential in the ePA: it could reduce repeated anamnesis, provide a "common thread" across treatments, make hearing status and communication needs visible, and strengthen autonomy. At the same time, they anticipated linguistic, technical and data-protection barriers. Trust depended on understandable information, granular control over access rights and support that is itself accessible. Participants did not call for a single accessibility feature, but for a modular concept including sign-language videos, subtitles, plain language, explanations of medical terminology, visual customization and sign-language-competent support.

Conclusions

For DHH users, the ePA represents a double promise: it could reduce communicative burden, or it could become another inaccessible digital infrastructure. Acceptance and use depend on communicative self-determination: the ability to understand, control and use health information on one's own terms. Accessibility should therefore be embedded in the design, governance and implementation of the ePA from the outset.

Background

Communication access is a fundamental prerequisite for safe, coordinated and patient-centred healthcare. For deaf and hard-of-hearing (DHH) people, communication barriers can substantially affect access to care, quality of

treatment and participation in medical decision-making. Previous research has shown that DHH patients often face difficulties in describing symptoms, understanding medical information, asking questions and taking part in decisions, with consequences ranging from dissatisfaction and misunderstanding to risks for patient safety [1–4].

These barriers are not merely individual communication problems, but reflect structural conditions within healthcare systems. Access to qualified sign-language interpreting, healthcare professionals' communicative competence and the availability of accessible health information shape whether DHH people can use healthcare on an equal basis [5, 6]. Evidence from Germany points to persistent deficits: a nationwide online survey conducted in German Sign Language found that DHH patients were frequently dissatisfied with medical care and sometimes avoided healthcare visits, mainly due to communication problems, fear of misunderstanding and negative previous experiences [7].

Communication barriers also extend beyond direct encounters with physicians and other healthcare professionals. They affect access to health information more broadly, as communication and language barriers can isolate Deaf sign-language users from mass media, healthcare messages and healthcare communication [8]. Health information is often provided in written, technical and linguistically complex formats, whereas accessible alternatives such as sign-language videos, plain-language explanations or culturally adapted materials remain limited [9, 10]. For many signing DHH people, the national sign language is their first language, while the surrounding written language may function as a second language; written-language competence and health-related vocabulary can therefore shape access to health information [11, 12]. Medical terminology, long written documents and complex digital interfaces may consequently create substantial access barriers, contributing to lower health literacy and health knowledge among DHH populations [13, 14].

This perspective is particularly relevant for digital health infrastructures such as electronic health records and patient portals. Personal health records and patient portals are commonly introduced with the promise of improving patients' access to health information, facilitating communication with healthcare providers, supporting self-management and strengthening patient engagement and autonomy [15, 16]. At the same time, the international literature shows that patient-facing digital health services do not benefit all groups equally. Portal registration and use are often socially patterned, with lower uptake among older adults, people with lower income, limited English proficiency or other forms of social disadvantage [16–19]. Health literacy, digital access, usability and available support are recurring determinants of whether patients can meaningfully use such portals [20, 21]. Without attention to accessibility and implementation conditions, digital health infrastructures may therefore reproduce or amplify existing inequalities rather than reduce them [22]. For DHH people, the key question is therefore not only whether a digital record is available, but whether it is designed in a way that enables communicative, linguistic and organisational access.

In Germany, this question has gained particular relevance with the introduction of the electronic patient record, the elektronische Patientenakte (ePA). Under the Digital Act, the ePA has been introduced as a nationwide, patient-facing infrastructure based on an opt-out model; since 15 January 2025, statutory health insurance funds have been required to provide an ePA to insured persons unless they object [23]. Since 1 October 2025, healthcare providers have been required to use and populate the ePA with legally defined treatment data, including findings and medical letters [24]. The ePA is intended to make health information centrally available, support treatment processes, improve medication safety and facilitate information exchange between healthcare providers [23, 25].

The ePA therefore differs from voluntary or locally implemented patient portals. It is designed as a national, patient-facing infrastructure and potentially concerns almost all people covered by statutory health insurance in Germany [23]. Its accessibility is therefore not a marginal design issue, but a matter of equitable participation in a core component of healthcare. Existing studies on the ePA suggest that awareness, trust, perceived usefulness, usability and data control are central prerequisites for acceptance and use [26–28]. For DHH people, general barriers may be compounded by additional linguistic, communicative and informational barriers [5–7.]

To date, little is known about how DHH people perceive the ePA, what information they have received about it, which barriers they expect or experience when using it, and what requirements they formulate for accessible and self-determined use. Existing research has addressed either communication barriers in healthcare for DHH people or general questions of acceptance and use of patient portals and electronic health records. The intersection of these two fields, namely DHH users' perspectives on a national, patient-controlled electronic health record, remains largely unexplored.

Against this background, the present qualitative study explores how DHH adults experience access to healthcare, how well informed they are about the ePA, what opportunities and risks they associate with it, and what concrete requirements they formulate for an accessible and user-friendly electronic patient record. The aim is to identify, from the perspective of DHH users, the conditions under which the ePA can become not only technically available, but also practically usable in ways that support communicative self-determination, access to health information and more equitable healthcare. Entering this gap this study asks the following research questions:

- How do people with hearing impairments experience access to and use of the healthcare system?
- How well informed are they about the ePA, and how accessible is that information?
- What barriers and support needs arise in dealing with the ePA?
- What opportunities and risks do they perceive in using it?
- What concrete requirements do they formulate for an accessible and user-friendly ePA?

Methods

Study design

This study was designed as an exploratory qualitative interview study and is part of the larger ePA4all project, which investigates facilitators and barriers to the adoption and use of Germany's electronic patient record (ePA). Semi-structured interviews were conducted with deaf and hard-of-hearing adults to explore their experiences with healthcare communication and their expectations, concerns and accessibility needs regarding the ePA. Reporting follows the Consolidated Criteria for Reporting Qualitative Research (COREQ) [29] (please see Supplementary Material 1).

Participants and recruitment

Participants were eligible if they were deaf or hard of hearing, aged 18 years or older, living in Germany, and able to communicate in German Sign Language (Deutsche Gebärdensprache, DGS). Participants were recruited through professional and community networks. Purposive sampling was used to achieve heterogeneity with regard to age, gender and size of place of residence [30, 31]. The final sample included ten deaf and hard-of-

hearing adults aged 35 to 76 years, including three women, six men and one non-binary person. Participants lived in communities ranging from small towns to major cities.

Data collection

Data were collected between January and March 2026. Semi-structured interviews were conducted via video telephony. Interviews were supported by qualified sign-language interpreters; the interviewer also had competence in DGS. A semi-structured interview guide was developed by a multiprofessional research team. The guide covered experiences with healthcare communication, knowledge and perceptions of the ePA, expected barriers and facilitators of use, data protection and trust, and requirements for accessible ePA design (supplementary material 2). Sociodemographic data were collected alongside the interviews. The first three interviews were treated as pilot interviews to assess clarity, relevance and feasibility of the interview guide. As no substantive changes to the guide were necessary, these interviews were included in the final analysis. All interviews were audio-recorded, transcribed into written German using locally installed transcription software and anonymized before analysis.

Data analysis

The interview material was analyzed using Kuckartz's structured qualitative content analysis [32]. Analysis followed an iterative deductive-inductive approach. Initial deductive categories were informed by the research questions and interview guide, while additional categories and subcategories were developed inductively from the material. Two researchers were involved in coding. Coding decisions, category definitions and emerging interpretations were discussed regularly within the research team until consensus was reached. Data were managed and analyzed using MAXQDA (VERBI Software). Data collection and analysis proceeded iteratively. Following Hennink et al.'s distinction between code saturation and meaning saturation, we used meaning saturation as the relevant criterion for this study [33]. After approximately eight interviews, no substantially new themes emerged, and the final interviews were used to examine whether the existing themes were sufficiently developed in terms of depth, nuance, variation and contrasting cases. As these additional interviews further elaborated but did not substantially alter the thematic interpretation, we considered meaning saturation to have been reached.

Ethical considerations

The ePA4all study was approved by the Ethics Committee of Charité – Universitätsmedizin Berlin (Reference ID: EA1/333/24). All participants received information about the study purpose, procedures, voluntary participation, data protection and their right to withdraw at any time. Informed consent was obtained prior to participation. Data were pseudonymized and stored securely. Participants received an expense allowance of €50.

Results

Participant characteristics

A total of ten deaf and hard-of-hearing adults participated in the study. Participants were between 35 and 76 years old and included three women, six men and one non-binary person. They lived in different residential

contexts, ranging from small towns to large urban areas, and differed with regard to occupational status and reported chronic conditions (please see Table 1).

Table 1
Sociodemographic characteristics of participants. Municipality size was categorized as rural municipality (< 5,000 residents), small town (5,000–<20,000), medium-sized town (20,000–<100,000), or large city (≥ 100,000).

ID	Age	Gender	Occupation	Municipality size	Chronic conditions	Interview Duration
IP01	47	female	office clerk	rural municipality	none	36 min
IP02	39	male	special needs care worker	small town	none	39 min
IP03	64	male	unemployed	small town	yes	38 min
IP04	76	male	retired	small town	yes	26 min
IP05	53	male	service employee	large city	yes	70 min
IP06	52	female	sign language instructor	small town	yes	54 min
IP07	35	non-binary	job seeking	large city	yes	43 min
IP08	65	male	disability pension	rural municipality	none	56 min
IP09	59	male	managing director	large city	none	45 min
IP10	44	female	unemployed	small town	yes	90 min

The findings are presented in five thematic sections. First, we describe participants' experiences of communication in healthcare as the central condition for access to care. We then present their level of information about the ePA and related information needs, followed by anticipated barriers to ePA use and support needs. The fourth theme addresses perceived opportunities and risks of the ePA, particularly in relation to autonomy, data protection and trust. Finally, we outline participants' requirements for an accessible and user-friendly ePA. The detailed category systems can be found in the supplementary material 3.

Access to and use of the healthcare system

Participants' experiences with the healthcare system were largely shaped by whether communication could be established in medical encounters. Sign language interpreters were described as a central prerequisite for appropriate care, particularly for complex, important, or emotionally stressful concerns. Interpreting appeared not only as a supportive resource, but also as an expression of structural dependence: whether a medical consultation could be understood, questions could be asked, and decisions could be followed often depended on the availability and quality of professional mediation.

"With an interpreter, it works well. They explain everything to me. Sometimes, however, it is tedious with interpreters. As a deaf person, I depend on an interpreter, but depending on the interpreter, it sometimes works better and sometimes less well." (IP01_47_female_Pos. 18)

This dependence became particularly visible when participants distinguished between simple contacts and more in-depth medical conversations. While short or routine concerns could sometimes be managed without an interpreter, this did not apply to more complex consultations. Interpreting thus became a condition of patient safety, because medical information could not be reliably understood without appropriate linguistic mediation.

"When it goes deeper, I try to get an interpreter for the appointment. If I want to discuss something important, I also get the interpreter." (IP02_39_male_Pos. 13)

When no interpreters were present, participants developed pragmatic communication strategies. These included writing on paper or on a smartphone, prepared notes, lip-reading, email communication, apps, or combinations of these forms. These strategies enabled healthcare encounters, but remained fragile. Their success depended on individual written-language skills, residual hearing, the mouth movements of physicians, time resources, and the willingness of medical staff to engage with alternative communication channels.

"I write it down on my phone beforehand and show it to the doctor. He then reads it and answers me. Sometimes I understand what he says, sometimes I do not." (IP02_39_male_Pos. 11)

In addition to the availability of interpreting, physicians' communication behavior was a quality factor in its own right. Physicians were described positively when they spoke slowly, maintained eye contact, provided written support for difficult terms, and were aware of communication needs. Situations were problematic when patients were not addressed directly or when communication primarily took place via the interpreting person. In such moments, not only comprehensibility was affected, but also the participants' position as autonomous patients.

"The doctor should please look at me and not always at the interpreters. [...] And then I think to myself, yes, but I am the patient." (IP07_35_non-binary_Pos. 25)

Interpreting by relatives represented a particular problem. Individual participants reported that family members translated in medical situations. Although this practice became visible as a pragmatic solution in gaps in care, it was also evaluated as ethically and emotionally problematic, especially in the case of sensitive diagnoses or distressing information. Professionally secured, direct, and confidential communication therefore appeared as a fundamental prerequisite for accessible care. The analytical main categories relating to access to and use of the healthcare system are shown in Fig. 1.

Information about the ePA and information needs

Overall, the level of information about the ePA was low and heterogeneous. Some participants had received little or no information about the ePA before the interview; others knew the term but could not confidently classify its functions, access routes, or possible uses. As a result, the ePA appeared less as a familiar instrument of care and more as an abstract digitalization project whose practical significance remained unclear.

"Simply because I had never heard of it; nobody told me. I only found out about it through your email." (IP01_47_female_Pos. 73)

"Heard of it, yes, but I do not have much information about it." (IP09_59_male_Pos. 24)

The information deficit should not be understood merely as individual lack of knowledge. Rather, it became apparent that existing information channels evidently did not reliably reach the target group. Where information

was available, it was often obtained through informal or self-initiated routes, such as internet searches, news, acquaintances, family, self-help contexts, or digital tools. By contrast, institutional communication by health insurance funds, medical practices, or public bodies emerged less clearly as a reliable information channel.

At the same time, it became clear that access to information itself was marked by barriers. Purely text-based information, complex written language, and medical terminology were described as central obstacles. For sign language users, accessibility therefore meant not only that information is available in principle, but that it is provided in a comprehensible and linguistically accessible form.

"Most of the time it is just text to read. Sign language videos would of course be great. That would be accessible for me. Plain language is unfortunately not yet widely available." (IP02_39_male_Pos. 35)

"But it was not in plain language. I can read it, but I have to read it three or four times to understand it, or ask someone." (IP04_76_male_Pos. 39)

Accordingly, participants formulated clear ideas for accessible information formats. In addition to sign language videos and short explanatory videos, they mentioned in-person presentations in deaf associations, exchange formats, and peer multipliers. Such formats were valued not only because of their linguistic accessibility, but also because they allow questions, repetition, and shared understanding.

"Ideally, my wish would be for the deaf association to hold a presentation about the ePA without time pressure, so that we can ask questions, have it explained, internalize it, and understand it." (IP04_76_male_Pos. 81)

Anticipated barriers to use and support needs

Because the ePA was hardly being actively used by participants at the time of data collection, many statements referred to anticipated usage situations and to experiences with comparable digital health information. The expected barriers were linguistic, technical, and informational. Concerns about not sufficiently understanding medical terminology, findings, or system notifications were particularly prominent. Participants wanted the ePA not only to display technical language, but to explain it in an understandable way.

"I myself do not want to look up the technical terms; it would be nice if they were explained directly. A text that is easy to understand would also be nice." (IP01_47_female_Pos. 85)

Noteworthy in this context was the pragmatic use of digital tools to ensure understanding. Individual participants reported converting medical texts into more understandable language with the help of search engines or AI applications. Such strategies were experienced as helpful, but at the same time point to a gap in institutional health communication: comprehensibility was partly shifted onto users themselves.

"Sometimes when I do not understand it, I copy the text and paste it into ChatGPT, and it writes it out for me in an easy-to-understand way. Then I understand it." (IP02_39_male_Pos. 47)

Technical and informational uncertainties mainly concerned access to the ePA, login credentials, activation, permission management, and specific steps of use. These uncertainties could not be reduced to a lack of affinity for technology. Even digitally experienced participants needed information about what exactly the ePA is, how it is used, and what control users have over content and access.

"Well, I have the insurance card, but what do I do with it now, or is that already the ePA, or how do I get digital access to it? Um, I do not know any of that. How would I?" (IP09_59_male_Pos. 46)

The need for support was therefore not understood merely as technical support. Participants wanted knowledgeable, multi-channel support with sign language competence that answers questions about the ePA in an understandable way and enables direct communication. Direct communication in sign language was also described as a matter of privacy, because ePA-related concerns involve sensitive health information and should not always have to be mediated through third parties.

"My wish would be for support to be able to sign." (IP02_39_male_Pos. 141)

"Yes, exactly, because these are my private matters and the interpreter does not need to know everything. Then you have to explain everything and explain it again - direct communication would be good." (IP01_47_female_Pos. 95–99)

Figure 2. Analytical main categories linking information about the ePA and related information needs with anticipated barriers to use and support needs (Coding tree).

Opportunities and risks of the ePA

The ePA was not rejected in principle. Rather, a conditional willingness to use it became apparent: participants saw concrete opportunities, but linked meaningful use to prerequisites such as comprehensibility, control, data protection, and accessible support. The potential to relieve communication in healthcare emerged as a central opportunity. If physicians could already view relevant information, patients would not have to repeatedly explain their medical history. For people with hearing impairments, this potential carried particular weight because each new anamnesis can create additional communicative effort.

"Sometimes it is exhausting to tell other doctors exactly the same thing. For the doctors, everything important is then written there." (IP03_64_male_Pos. 65)

"The advantage would of course be that the doctor can read it himself and that the doctors can send it to each other. Then you do not have to tell everything all over again." (IP01_47_female_Pos. 113)

In addition, the ePA was understood as a way to gain an overview of diagnoses, medications, previous treatments, and medical events. From the participants' perspective, this "common thread" could strengthen their own orientation and help them understand information or detect errors. A specific opportunity also consisted in making hearing status and communication needs visible. If medical staff knew before or at the beginning of an encounter that a person is deaf or hearing-impaired and which form of communication is needed, misunderstandings and discussions could be reduced.

"If the doctor can read that the person is deaf and needs an interpreter, that could save some discussions." (IP02_39_male_Pos. 139)

The opportunities were accompanied by pronounced concerns. Data protection, access rights, and the unwanted visibility of sensitive health information were at the forefront. Participants distinguished between understandable access by treating physicians and problematic access by other actors, such as health insurance funds or

specialist disciplines not involved in their care. Data protection was thus not formulated as a blanket rejection of digital records, but as a condition for trust.

"The doctors are okay, but the health insurance fund is not. I do not know what their goal is." (IP01_47_female_Pos. 122)

"What I wish for is that I am allowed to decide who can see my things and who cannot. I want to decide that. That is my self-determination." (IP09_59_male_Pos. 64)

Individual findings deepened these data-related concerns qualitatively. It was pointed out that health data can also be historically burdened for deaf people, for example against the background of persecution and forced sterilization under National Socialism. Here, fear of data did not appear only as a technical data protection concern, but as a historically and collectively framed concern about control, categorization, and discrimination.

"The transparency, and for deaf people in the Nazi era [...] data, such survey data, also led to deaf people being persecuted." (IP0959_male_Pos. 72)

Further risks concerned the possible influence on independent second opinions as well as incorrect or undiscussed entries in the record. The ePA could make such entries visible and thus enable correction, but at the same time it could also lead to problematic attributions being passed on more easily. This ambivalence was particularly relevant against the background of reported experiences with diagnostic misattributions and findings that had not been sufficiently explained.

Requirements for an accessible and user-friendly ePA

From the barriers and potentials described above, the central requirement that emerged was not a single additional service, but a modular accessibility concept. Participants wanted sign language videos, subtitles, simple or plain language, explanations of technical terms, visual customization options, documentable communication needs, and support with sign language competence. Individualizability was crucial: in the material, people with hearing impairments did not appear as a homogeneous user group, but differed in terms of language biography, sign language preferences, written-language skills, affinity for technology, and support needs.

"It would be important to see the subtitles and the sign language videos at the same time, because sometimes you do not understand the sign and then look at the subtitles." (IP01_47_female_Pos. 132)

"I believe we cannot get around sign language videos." (IP06_52_female_Pos. 50)

Subtitles and understandable written language were described not as substitutes for sign language, but as complementary forms of access. Conversely, sign language videos were not equally central for all participants. It was precisely this heterogeneity that led to the demand for options. Users should be able to decide for themselves whether they use information in standard language, plain language, with explanations of technical terms, subtitles, sign language videos, or in a combination of these formats.

"I would most like to be able to choose whether I want the text in plain language or an explanation of the technical terms." (IP01_47_female_Pos. 87)

"If it could run in parallel, so I have the written text and I have a video and I can then decide whether I choose this or that, that would be cool. Because deaf people are different." (IP10_44_female_Pos. 119)

The documentation of hearing status and communication needs was understood both as a function of the ePA and as a prerequisite for better care. Such information could prepare medical staff, reduce communication breakdowns, and at the same time support a personalized presentation of the ePA. The requirement for the ePA is thus directly linked to the communication barriers reported in healthcare.

"I would wish for the record to state that one is deaf." (IP02_39_male_Pos. 139)

For support, participants called for a permanent, quality-assured structure. Sign language competence should not be available only selectively or by chance, but should be reliably integrated into support services. At the same time, participants pointed to the need for linguistic quality assurance, because sign language varies regionally and individually and not every translation is automatically understandable.

"My wish would be for support to be able to sign. For the companies to teach their employees this and to do so repeatedly, not just once." (IP02_39_male_Pos. 141)

Figure 3. Analytical main categories describing perceived opportunities and risks of the ePA and requirements for its accessible and user-friendly implementation (Coding tree).

Discussion

This study is, to our knowledge, the first to examine how deaf and hard-of-hearing sign language users experience, interpret and formulate requirements for a national patient-facing electronic health record infrastructure. Its central finding is that the ePA represents a double promise: it may reduce communicative burdens and strengthen patient autonomy, but it may also reproduce or amplify existing linguistic, informational and data-related barriers. Which side of this promise is realised depends less on individual digital capability than on the accessibility, governance and communicative design of the infrastructure.

Our findings on communication barriers align with and extend evidence showing that sign language interpreting is essential for safe care, while also creating structural dependence when understanding relies on third-party mediation. Substitute strategies such as writing, lip-reading or digital tools can enable care encounters, but remain fragile and context-dependent, and family interpreting is an ethically ambivalent stop-gap, especially in sensitive situations [1–3]. Our contribution is to locate these barriers in institutional and policy structures rather than individual communicative limitations [6, 34, 35], and to show that interpreting is not simply available or unavailable: its quality, mode and appropriateness vary by situation. Participants preferred on-site interpreting for complex or emotionally charged encounters, while remote or written strategies could be acceptable for routine contacts, reflecting documented situational preferences and the partial substitutability of video remote interpreting [36–38]. The discomfort of being addressed through the interpreter rather than directly as the patient illustrates the interactional consequences of structural dependence. Against this baseline of mediated and unevenly accessible communication, participants evaluated the ePA as an infrastructure that might reduce communicative burden, but could also reproduce it if not designed accessibly. Evidence from Germany that DHH patients avoid healthcare encounters underscores the urgency of this issue [7].

Participants saw genuine potential for the ePA to reduce communicative burden by avoiding repeated anamnesis, providing a “common thread” across diagnoses, medications and treatment history, and making hearing status and communication needs visible before a care encounter. At the same time, they perceived the risk that the ePA itself could become a new barrier if information about it does not reach DHH users or if its contents remain text-heavy and jargon-laden. This finding cautions against a deficit interpretation of low engagement: participants’ limited knowledge of the ePA did not reflect a general lack of digital capability, as DHH people are often competent and early users of digital communication technologies [39, 40]. This creates an early-adopter paradox: a group that may be highly experienced in using digital tools to overcome communication barriers can nevertheless be excluded from a digital health infrastructure when that infrastructure is not designed around their linguistic and informational needs. This aligns with the patient portal equity literature, which shows that digital health tools can reproduce existing social gradients in uptake and use [16, 18]. Veinot et al.’s concept of intervention-generated inequalities helps explain why even well-intentioned informatics interventions may benefit already advantaged groups unless they are deliberately designed for equity [22, 41]. In this sense, the ePA’s opt-out model may reduce enrolment barriers, but it does not automatically close the use gap. For DHH users, the decisive question is therefore whether the national record is designed merely to be available, or whether it is designed to be understandable, usable and actionable.

The requirement participants formulated was not a single feature but a menu of sign-language video, subtitles, simple/easy language and jargon explanation, with genuine choice, and is often read as a matter of preference. Our second- and third-theme findings show it is a matter of mechanism. Because much health knowledge is acquired incidentally through spoken channels that are closed to signing deaf people, and because written language is frequently a second language layered over a signed first language, dense clinical text imposes a real comprehension load rather than a stylistic inconvenience [13, 42]. A record that only displays findings and terminology thus reproduces the very information-environment deprivation that produces measured health-knowledge gap. A record that explains jargon and offers signed and easy-language renderings intervenes on it. That one participant already routes ePA-style text through a general-purpose language model to make it comprehensible is a telling piece of evidence: the demand for explanation is not hypothetical, and users are improvising the function the record fails to provide.

The heterogeneity participants described, differing across language biography, sign-language preference, written-language competence and technical affinity, is why a single “deaf-friendly” feature cannot suffice, and why individualisability, not a fixed accommodation, is the operative requirement. This aligns with the formats catalogued for digital health communication with deaf people [43] and with a universal-design logic in which subtitles and comprehensible text complement rather than replace sign language. The burden-of-treatment framework sharpens what is at stake: patients already carry substantial work to manage health and navigate systems, and interventions that add workload erode adherence and outcomes through cumulative complexity [44, 45]. The ePA’s central appeal to participants, not having to reconstruct their history at every contact, is precisely a reduction of this burden; an inaccessible ePA inverts the promise, adding the work of decoding text, chasing support and managing access on top of the communicative labour DHH patients already perform. Two elements distinguish the requirement from a generic accessibility checklist: sign-language-competent, multichannel support as part of the design, and as a privacy matter that should not always be routed through third parties; and documentation of hearing status and communication need as a record function that feeds back into the Theme-1 barriers. Deriving these requirements from users rather than for them reflects the participatory-design principle that has become standard in disability research [46], and yields a user-grounded specification for a national EHR

that the prior literature, concerned with clinicians documenting hearing status [47] or with adjacent digital objects [9, 48], does not provide.

Participants did not reject digital records wholesale; they made trust a condition, and, crucially, a differentiated one, distinguishing legitimate access by treating clinicians from problematic access by insurers or uninvolved parties. This is not idiosyncratic. German patients want granular control over who sees their record: a majority endorse being able to selectively withhold ePA data even from treating physicians, and this need for data sovereignty is more pronounced among those who know the ePA better [26]. Evidence that a differentiated, recipient-sensitive stance towards data access is a general feature of the population, not a peculiarity of our sample. Typologies of EHR adopters likewise organise around privacy posture rather than a simple accept/reject axis [49]. For DHH people a further layer deepens the concern beyond the technical. Health data on deaf people are historically implicated in persecution: the “Law for the Prevention of Hereditarily Diseased Offspring” (14 July 1933) underpinned the forced sterilisation of disabled people, deaf people among them, and the eugenic targeting of the deaf community is documented in the historical scholarship [50]. That patient records were themselves instruments of this ideology is not incidental to a discussion of digital records [51], and the concern is not merely historical: wariness about genetic categorisation and discrimination persists in the deaf community [52, 53], where even health-education materials must be built bilingually and with community involvement to be trusted and understood [54]. Data-protection design is thus not a generic requirement here but one charged with a collective memory that a national record must take seriously to earn trust. We keep this strand proportionate: it qualifies the trust condition rather than displacing the access-and-self-determination core.

The preceding points converge on a single reading: acceptance of the ePA turns on communicative self-determination. Opportunities, risks and design requirements are all expressions of the same demand: that DHH users be enabled to understand health information, control who sees it, and deploy it on their own terms. Technology-acceptance research would predict adoption from perceived usefulness and ease of use [55, 56]; our findings suggest that for this group both hinge on accessibility, so that the standard acceptance predictors are themselves downstream of whether the record is designed for signed and plain-language access. Self-determination is the category under which opportunities, risks and requirements cohere, and from which the implications follow.

Implications for practice and policy

The findings translate into implications at three levels: the design of the record itself, the governance that must mandate that design, and the research still needed. Because the study is formative and the sample small, we frame these as directions warranting action and evaluation rather than validated solutions; their strength is that each is anchored in a specific finding and, at the policy level, in an existing obligation.

At the point of use, the findings specify what an accessible ePA must contain rather than merely suggest that it should be “deaf-friendly.” First, a choice of information formats bound to the content it explains: sign-language video for key documents and findings, subtitling for any video, plain and easy-language renderings of clinical text, and jargon explanation available on demand rather than assumed. That participants already improvise this function with general-purpose language models shows both the demand and a design pattern: an integrated “explain this” affordance is a concrete, buildable feature, not an aspiration. Second, a structured, patient-controlled field for hearing status and communication need, which interpreting mode, whether an interpreter must be booked, so that the record actively reduces the barrier by signalling the need before a contact rather than

leaving the patient to renegotiate it each time. Third, support that is itself accessible: sign-language-competent, multichannel and reachable without routing sensitive health matters through a third party, since the support channel is otherwise a new privacy barrier in place of the old communication one. Because the group is heterogeneous, these are user-selectable options, not a fixed default; individualisability is the design principle, not an add-on to it.

The barriers documented in this study are unlikely to be resolved through voluntary good practice at the level of individual applications alone. Rather, the requirements formulated by participants indicate that accessibility must be structurally embedded in the governance, technical specification and implementation of the ePA. For the gematik and other actors responsible for ePA specifications, this means that minimum standards for accessible information, navigation, authentication, consent management and access control should be centrally defined and integrated into approval, testing and certification processes. Otherwise, accessibility may become fragmented across different insurer applications, leaving users without a reliable standard. Statutory health insurance funds and app providers should translate these standards into accessible front-end services, including information in German Sign Language, subtitles, plain language, jargon-free explanations of medical and technical terms and accessible support structures. Healthcare providers, too, cannot assume that the ePA is self-explanatory; they should address patients' information needs, communication preferences and concerns about data control where the ePA becomes relevant in care. For policymakers and regulators, the findings imply that accessibility should be operationalised through clear requirements, user testing with DHH people, transparent complaint pathways and continuous monitoring. Sustained involvement of DHH users and their organisations in specification, testing and evaluation is essential to ensure that accessibility is not only formally provided but practically usable in everyday care.

Three gaps follow directly from the study's formative design. First, the present findings concern anticipated use; once the ePA is in real use, the same questions should be put to actual use behaviour and to usability testing of signed and plain-language renderings with DHH users. Second, the requirements identified here are candidates for co-design and evaluation. Building the format-choice and communication-need features with deaf users and testing whether they measurably narrow the knowledge and access gaps, rather than assuming they will. Third, the equity mechanism should be monitored directly: because a national record can generate intervention-generated inequalities [22] uptake and use among DHH users should be tracked as an explicit equity indicator of the rollout, not inferred from aggregate adoption figures that average the disadvantage away.

Strengths and limitations

The study's strengths are its timing, capturing expectations at the moment of the opt-out rollout before use is entrenched, and a deliberately heterogeneous sample that surfaces the very diversity that grounds the modularity requirement. Several limitations bound the claims. The sample is small (N = 10) and self-selected, and participants who engage with a study on the ePA may not represent those hardest to reach. The sample size must, however, be read against the considerable effort each case required: interviews with deaf participants were conducted with professional sign language interpretation, and all interviews were transcribed verbatim, with interpreted passages rendered into written German for analysis. Each individual account therefore entailed a substantial investment of resources. Because the ePA was scarcely in active use, much of the evidence concerns anticipated rather than realised use; this is appropriate for a formative study but should be revisited once use is

established. Findings are specific to the German-speaking context and its legal frame and are not straightforwardly transferable to other systems.

Conclusion

For deaf and hard-of-hearing people, the ePA could relieve precisely the communicative burdens that make healthcare effortful and dependent on others, or it could add another barrier of language, technology and data protection. Which of these it becomes is not determined by users' capabilities: a group that adopts accessible digital tools early will use an accessible record, and will not use an inaccessible one. The determinant is whether the record is designed and governed to support communicative self-determination: comprehensible information, controllable access, and a genuine choice of formats. An accessible ePA would therefore not merely be reachable; it would actively enable its users to understand, control and deploy their health information on their own terms.

Declarations

Ethics approval and consent to participate

This study was conducted in accordance with the principles of the Declaration of Helsinki. It involved human participants and was approved by the Ethics Committee of Charité – Universitätsmedizin Berlin (Reference ID: EA1/333/24). All participants received written and/or accessible information about the study purpose, procedures, voluntary participation, data protection and their right to withdraw at any time. Informed consent was obtained from all participants prior to participation.

Consent for publication

Not applicable. The manuscript does not contain any identifiable individual person's data. Interview quotations are anonymized.

Availability of data and materials

The datasets generated and analysed during the current study are not publicly available due to data protection requirements and the potentially identifying nature of qualitative interview transcripts, particularly in a small and specific participant group. Anonymized excerpts relevant to the findings are included in this article. Further information may be available from the corresponding author on reasonable request and subject to ethical and legal restrictions.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

SM conceptualized the study, contributed to the methodological design, analysed and interpreted the data, and drafted the manuscript. RD contributed to the conceptualization of the study, the methodological design, data analysis and interpretation, and drafting of the manuscript. JS conducted the data collection and contributed to the interpretation of the findings and revision of the manuscript. MM contributed to the interpretation of the findings and critically revised the manuscript for important intellectual content. GB contributed to the development of the manuscript, interpretation of the findings and critical revision of the manuscript. SG contributed to the development of the manuscript, interpretation of the findings and critical revision of the manuscript. LS contributed to the development of the manuscript, interpretation of the findings and critical revision of the manuscript. SSp contributed to the development of the manuscript, interpretation of the findings and critical revision of the manuscript. FM contributed to the conceptualization of the study, the methodological design, data analysis and interpretation, and drafting of the manuscript. All authors read and approved the final manuscript.

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Authors' information

Not applicable.

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Figures

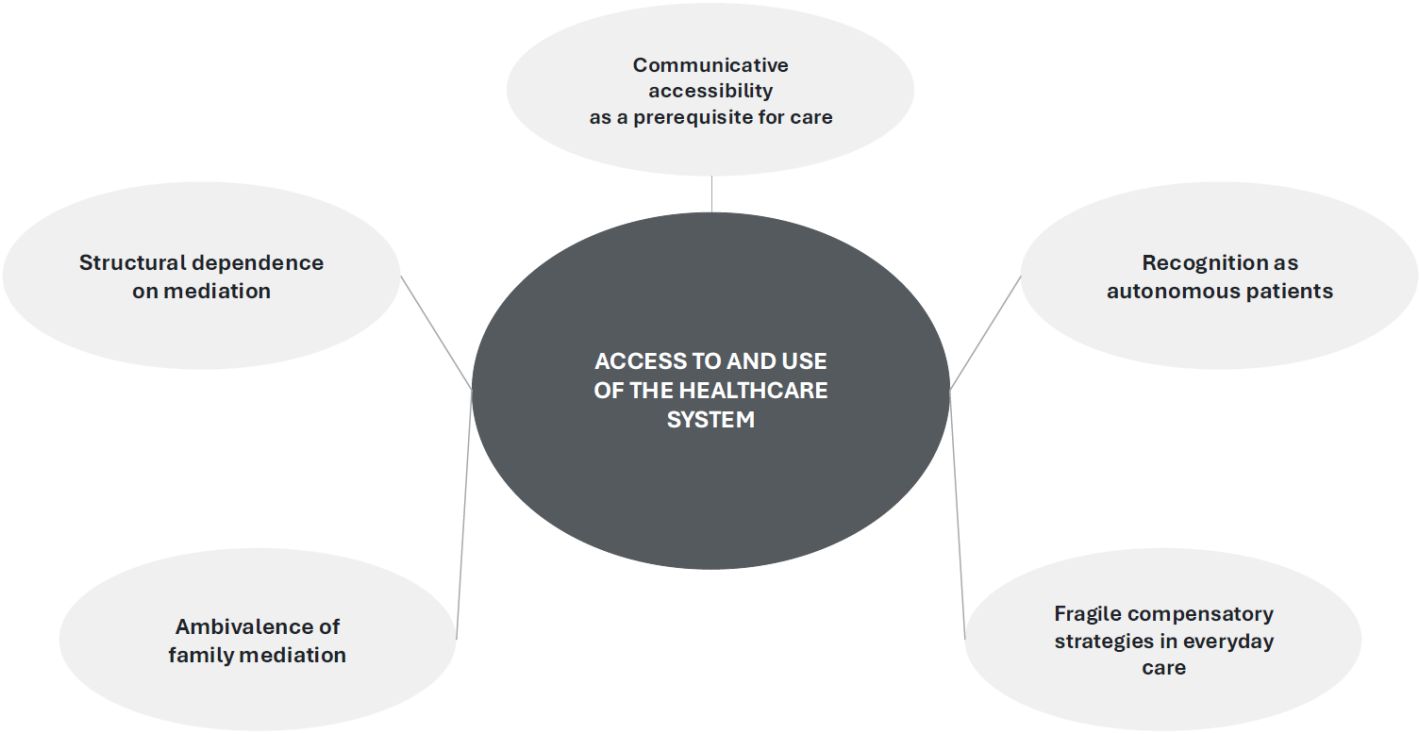


Figure 1

Analytical main categories describing access to and use of the healthcare system from the perspective of deaf and hard-of-hearing participants (Coding tree).

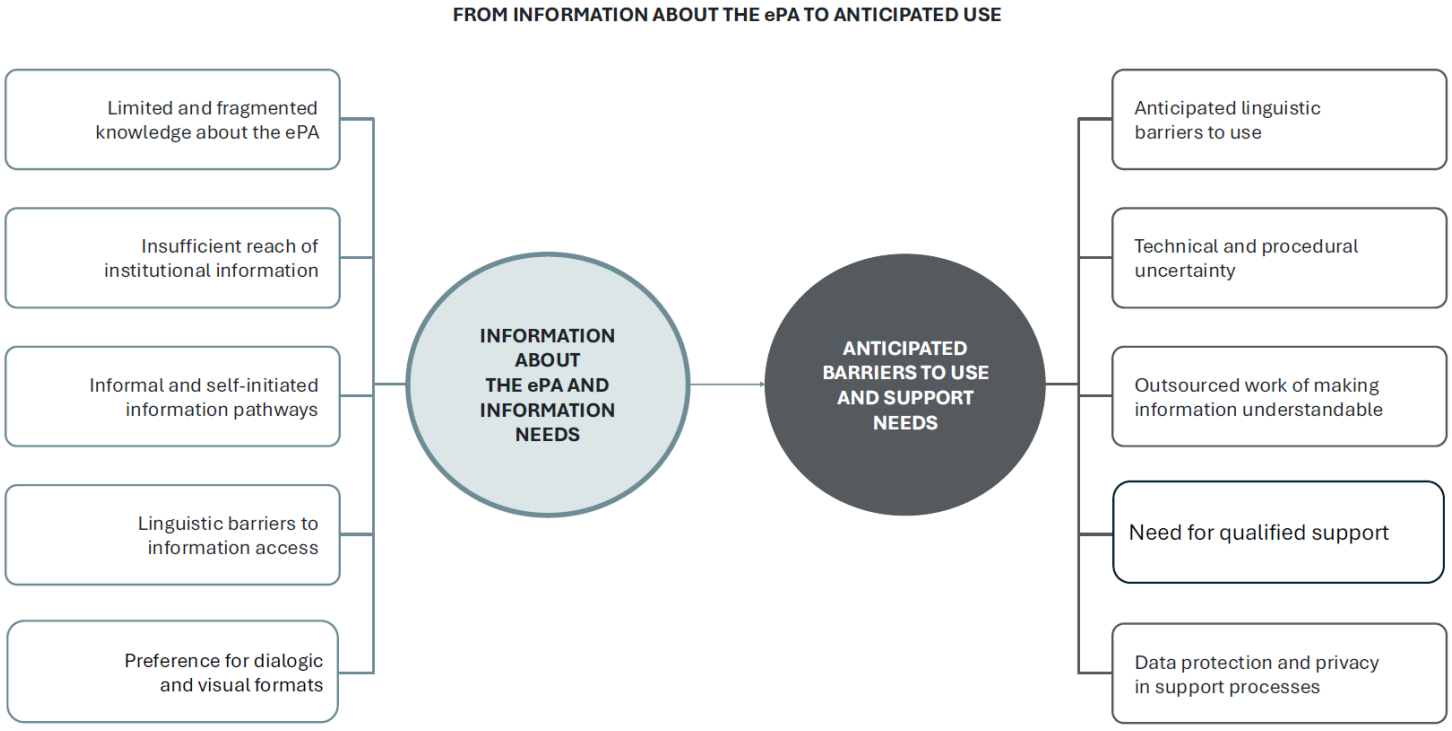


Figure 2

Analytical main categories linking information about the ePA and related information needs with anticipated barriers to use and support needs (Coding tree).

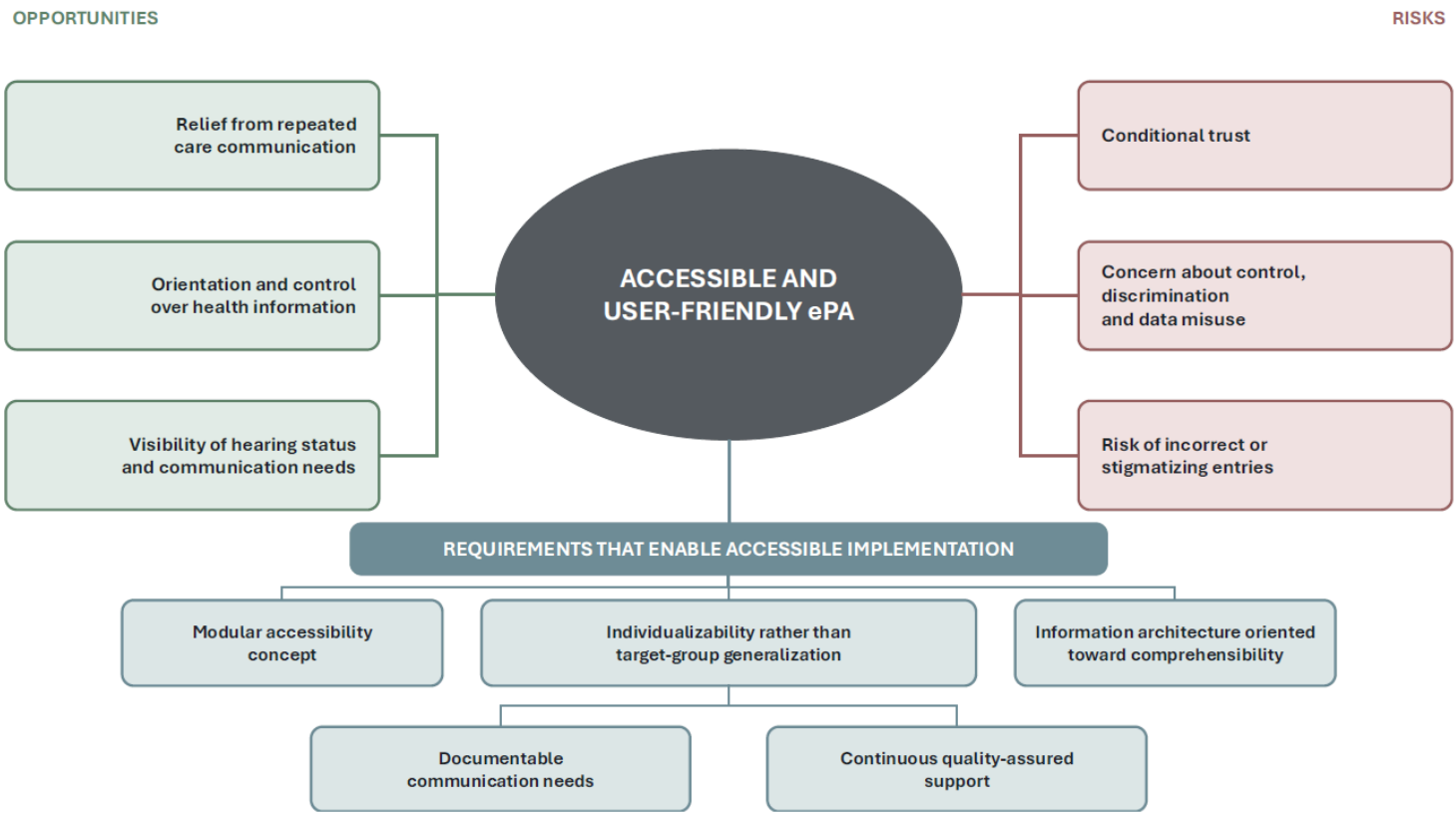


Figure 3

Analytical main categories describing perceived opportunities and risks of the ePA and requirements for its accessible and user-friendly implementation (Coding tree).

Supplementary Files

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- SupplementaryMaterial2InterviewGuideePA4all.pdf
- SupplementaryMaterial3Categorysystems.pdf