dHealth 2024
D. Hayn et al. (Eds.)

doi:10.3233/SHTI240017

User Personas for a "Better Design" of Nation-Wide EHRs Based on Thorough Expert Evaluation and Field Analysis: Modeling Users as Individuals Plus Family Members for an Enhanced Mapping of Healthcare Situations

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Abstract. Electronic Health Records (EHRs) are pivotal in prevention, therapy, and care. Their design necessitates the representation of users, activities, context, and technology. Among various participative and ethnographic design methods, user personas are an effective tool for encapsulating users in the design process. **Goals and methods:** This research focused on the creation of user personas for the design of a nation-wide EHR, specifically the German "elektronische Patientenakte" (ePA). We employed qualitative methods, such as field analysis and expert workshops, to generate, assess, and refine a set of user personas that can cover the complexity of real-life familial care environments. We used an innovative bottom-up approach applying a whole new process for persona generation especially in the context of family management. **Results:** The research yielded an initial set of five personas that accurately represent fictional user types. Importantly, at least two of these personas encapsulate the unique challenges inherent in family care work. These results provide a foundation for future work, which can utilize these personas for EHR design, as well as for further evaluation and refinement.

Keywords. Electronic Health Records (EHRs), User-centered Design (UCD), User Personas

1. Introduction

Taking care for sick relatives is an important familial task. In aging societies, this is not just a marginal phenomenon but an essential part of everyday life. For example, in 2021, over 4 million people (i.e. 84% of all those requiring care) in Germany received care at home, with more than 3 million of them being cared for by family members [1]. A still increasing amount of female part-time work indicates that this care work is predominantly provided by women [2].

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According to the World Health Organization (WHO), more than half of their member states are implementing a national EHR system [3] with the main purpose of ensuring the communication of patient-centered medical data between patients and healthcare institutions [4]. The most evident advantages of EHRs, like an increase in the efficiency in healthcare delivery, reduction of paper-based errors in medical documents, encouragement of patients in health self-monitoring, and overall, in improving the quality of diagnosis and treatments seem promising to also ease the lives of those taking non-institutional care of others by allowing them fast and easy access to the caretakers' relevant data in case they are not yet or no more able to speak for themselves [5-7].

Germany launched the "elektronische Patientenakte" (ePA), a national opt-in EHR system, in 2021, which is offered as mobile applications by health insurers. To use it, the users must request access, allowing them to control which medical documents are shared and for how long [8]. Two years post-launch, only 595,000 enrollees used ePA [9]. actors influencing this low rate include trust issues, the opt-in model, access difficulties due to security measures, and varying attitudes towards data security and digital/health literacy [10] [11]. A user-friendly interface based on user-centered design (UCD) is also expected to be key to increasing the overall usage [10] [12]. UCD, central to this work, emphasizes end-user needs and behaviors in digital solution design and implementation. [12] Various methods are used for user inclusion, like for example personas [13] [14], participatory design [15] and ethnographic methods [16] and user journeys [17].

This study focuses on insured individuals and their health-related activities, including care for dependents. In this work user personas were developed based on established best guidelines (see [18]) in a bottom-up approach, assessing its applicability in resource-limited design and development processes. A comprehensive set of attributes and attitudes has been developed, explored and enriched in a field study, filling a gap in existing literature, where the focus lies on a comparably smaller sets of user characteristics. [19–21]. With Germany's shift to an opt-out ePA by 2025 [22] and the constantly increasing part of people in need for health care, understanding care-providing families through persona creation becomes also crucial.

2. Methods

The used methodology consisted of four big parts, which are outlined below:

(1) State-of-the-art Analysis and development of templates: Based on a thorough research of state of the art, an extensive set of attributes and attitudes to establish a foundation for insightful, relatable, and relevant personas representing the users within the ePA design process was defined. These attributes served as major input for a interview guideline as well as a template, based on which the personas development was set to be founded on.

(2) Field Analysis: 30 qualitative interviews have been conducted in a 2-step-approach: (a) in the first part, participants who were chosen based on a quota sampling representing the main sociodemographic characteristics of German residents with health insurance, were asked in an explorative open interview to tell their story of personal experiences with the health care system and the social environment involved. The goal of this first narrative part of the interview was to delve into the lives of potential users of the ePA to understand social dependences, relations, role-models, and environments. (b) In the second part of the interviews, standardized and structured questions delivered input to attributes and attitudes in case it had not been given by respondents already in

the first part of the interviews. The goal of the second part was to gather specific information around the relevant characteristics as a foundation to build personas in the next step.

(3) Content Analysis and Creation of Personas: (a) Based on the interview transcripts content was analyzed and interpreted qualitatively with the aim to identify further attributes and attitudes that might be important to build deeper and more complex personas. Based on the interview-content, personas have been created. (b) Parallel to this analysis, content of the interview has been used to generate AI-prompts for an alternative user personas creation based on a large conversational language model. The goals of this second set of personas was not only to validate the expert findings, but also to the ability of AI to generate visualization for the personas.

(4) Expert Evaluation of Personas in 2 steps: (a) In (3a) generated personas have been compared, adapted, and validated by experts in a workshop to capture any possible bias. Included experts represented the domains of user experience design, product management, requirements engineering and e-health. (b) After the evaluation of the personas based on qualitative analysis the AI-generated personas have been analyzed as well. Both were compared and evaluated and led to the final set of user personas.

3. Results

Based on the described methodology five personas have been deducted and validated. These personas (see Figure 1) include specific images, as well as systematically chosen psychographic, socio-demographic and medical attributes and attitudes. They also provide insights into the role families play in matters of non-institutional, informal health care, as at least two of them (Persona 2 and Persona 4) represent typical familial care constellations: parents taking care of their children (Persona 2), grown-up family members taking care of other grown-up, mostly older, family members (Persona 4). In addition, another persona (Persona 1) contains a transition into a period of life with increasing medical issues and hence need for support or even care by others. Involved experts have found the AI-based visualizations to be adequate to represent the described user types.

Also, attitudes across all personas deliver insights that need to be considered for the further design and development process of ePA, as 3 out of 5 personas are rather skeptical towards digitalization in general. It will be important to involve representatives of these user groups in the process and explore their reasons and how a user-centered designed ePA might be able to add value to their lives and overcome their skepticism. A hint may be found in Persona 4 who is not very interested in digitalization but finds the idea of ePA useful when it comes to organize her mother's health life and/or serve as her representative for certain tasks. In this regard, also the social environment of users will need to be explored deeper in the future as very often skepticism towards new tools, services or systems can be overcome by observing positive role models in the peer group. Methodologically this could mean that it might be reasonable not only to include individuals in the evaluation and optimization of artefacts but to work in groups to get more useful insights in social dynamics that influence the users' experience.

In total, the following characteristics were included for persona creation: Basic demographic attributes such as age, name, and gender as well as an image to improve the designers' empathy and imagination of the fictional users. The socioeconomic background of the personas was described through the income level, education, living

situation, and place of residency. Psychographic attributes like needs and expectations and factors that drive motivation and goals regarding ePA were included. A set of attributes described medical characteristics regarding possible medical challenges personas might face and how they interact with the healthcare system in general. Persona attributes additionally included aspects of the users' lifestyle, interests, and dietary habits. Attitudes of users towards, digitalization, data privacy, the healthcare system and ePA itself revealed additional insights into possible acceptance patterns. A description of the social environment was also essential to understand the potential impact family and friends have on the personas' behavior. Further attributes were health and digital literacy that reveal relevant information regarding the interaction with the ePA system. Additionally included was an attribute describing the devices and software that are used daily. Furthermore, aspects of accessibility, like limitations the personas might perceive while using technology were considered. This collection of attributes has been perceived as relevant to the design process according to the expert validation.

ID-Name-Age	Persona 1 – Gertrud – 73 years	Persona 2 – Max – 32 years	Persona 3 – Klaus – 57 years	Persona 4 – Andrea – 45 years	Persona 5 – Ayesha – 27 years
Image					
Background information	• Widowed, 2 adult children • Lives alone • Owns a house in the Bavarian countryside	• In a relationship, 1 child (3 years) • Rental flat in Frankfurt am Main • Works in marketing • Stressful lifestyle	• Married • Owns a house in a small town • Works in metal production • Unhealthy habits (alcohol, exercises rarely)	• Married, 1 child (17 years) • Rental house in the suburbs • Works in retail (part-time) • Takes care of her mother (dementia)	• Single • Shared apartment in Berlin • Studies and has a part-time job • In Germany for 1 year already, is learning German
Medical characteristics	• Problems with the thyroid gland, osteoporosis • Regular medical check-ups • Often forgets to take her prescribed thyroid medication • Low health literacy, high trust in her long-term GP	• A herniated disc, contracted while playing football • Regular physiotherapy • Highly motivated to implement the therapy recommendations • Low health literacy, relies mostly on expert opinions	• Regular severe headaches • Visits doctor rarely, afraid of diagnosis • Tries to keep a headache diary, often forgets to keep track • Low health literacy, relies mainly on his wife	• Diabetes mellitus type 2 • Regular medical check-ups • Takes her medication regularly • Joins her mother for doctor visits • Has acquired medical knowledge	• Suspicion of endometriosis, no diagnosis yet • Sees a doctor once a month • High treatment adherence, wants clarity about her condition • Low health literacy
Attitudes	• Sceptical toward digitalisation • Positive towards the healthcare system, aware of its advantages • Positive interest in ePA, supported by her children and her GP	• High interest in digital trends • Neutral towards the healthcare system • Sees a great benefit in the ePA, especially for the management of his child's medical records	• Sees digitalisation as a constraint, is afraid of AI • Sceptical about the healthcare system • Unsure if he benefits from the ePA	• Follows digital trends only casually • Often finds the healthcare system tedious due to regular interactions • Interested in using the ePA to manage her mother's healthcare	• Appreciate the convenience caused by digitalisation • Lacks understanding of the healthcare system (language barrier) • Sees the benefit of the ePA
Digital characteristics	• Low digital literacy • Uses her smartphone only for messaging and calls • Supported in digital matters by her children	• High digital literacy • Uses several digital tools both professionally and privately • Uses health apps regularly	• Average digital literacy, basic technical understanding • Uses mainly social media and messaging on his smartphone	• Average digital literacy, confident in using technology • Uses mainly social media and messaging on her smartphone • Her son supports her	• High digital literacy, confident in using new unfamiliar technology • Uses several different devices and software • Uses a period-tracking app
Social environment	• Her friends are in her age group and share her views on digitalisation	• His girlfriend has a stressful lifestyle as well • Friends and Family have similar attitudes	• His wife trusts in alternative treatments and is sceptical about the healthcare system	• Her husband and sister support her in caring for her mother • She has a close circle of friends who support her morally	• Her friends are mainly international students from various countries
Motivation and Goals	• Easier access to medical records for doctor visits • Overview of her medication	• Wants to implement therapy recommendations successfully • Taking care of his child's medical affairs	• Keep a consistent headache diary • Overcome fear of going to doctors • Actively work on his health	• She wants to manage her diabetes effectively • Organise her mother's healthcare effectively	• She wants clarity about her health conditions • She wants a better understanding of the healthcare system

Figure 1. Overview of the five ePA user personas.

For the further development of ePA the 5 personas will be applied to the practical work in a variety of ways, like for example as guidelines for specific design decisions, or to serve as a feature-prioritizing guideline.

4. Discussion

This work set out to create user personas that are ready to be used in the design process for the German „Elektronische Patientenakte" (ePA) - a nationwide EHR system. In addition, we expected these personas to provide valuable insights into non-institutional and informal care-work environments that mostly are and increasingly will be found in

familial settings, as western societies - such as the German - are constantly aging. An „ePA for all" will have to provide solutions for every kind of health problem and personal social setting, which makes a user-centered approach to tackling specific patient tasks even more urgent. A secondary goal of this research was to apply a specific bottom-up process for persona creation, assessing its applicability in resource-limited design and development processes and exploring the possibilities of a thoughtful use of generative AI. As a result, this work presents and contributes a set of five user personas that can be used for designing nationwide EHRs on a regular and continuous base.

When choosing suitable methods for creating the user personas, we followed established best guidelines (see [18]). Qualitative evaluation with design experts showed that our approach worked very well. The careful use of AI by selectively picking basic information about personas from literature in combination with expert evaluation limited the potential bias. Also, thorough qualitative research, systematically deducted sets of attributes and attitudes as well as persona templates proved to be crucial for the creation of comprehensive and coherent persona descriptions. However, during this research, specific limitations and need for future work have been identified:

- Collaboration on the same health record: It is very likely that one and the same health record will be used by more than one user (outside the medical or insurance systems, like picking up prescriptive medicine. In this regard, future research will have to provide more detailed insights into inner-familial care settings and enrich and very likely extend the initial set of five personas.
- Extreme user personas: The set of five personas will also have to stand the test of patients with very frequent and constant touchpoints with the medical system, like for example people with severe and/or chronic illnesses, pregnancy, etc.
- Prospective and Anti Personas: It will also be necessary to learn more about potential users who have not yet shown interest or the need to engage with ePA. Also, the creation of an „anti-persona" could be helpful in the process of prioritizing improvements and marketing communication.
- Practicability: The found personas will be applied in real-world design processes, as planned by the authors. This will enable further qualitative evaluation on a continuous base.
- Quantification: Based on the qualitative research, a quantitative study will have to follow, that includes a representative sample of the German population as a further way to validate and enrich our set of personas. That way, segments of society that might be under-represented in the quota sampling or the areas of expertise and experience of the experts of this study can be included in the set of personas.
- Methodological plurality: With an "ePA for all" on the horizon, the inclusion of users in the design process should be established as a matter of course. Besides continuous forms of user testing it will also have to include participatory and ethnographic methods as well as methods that are able to tackle social dynamics that are relevant for the acceptance of ePA as a national EHR system.

In summary, we conclude that user personas can be deducted based on a thorough qualitative research setting that is also the fundament for logic and consistent persona descriptions and images delivered by AI-tools. These personas also deliver valuable insights in real-life care environments within the family without having to specifically address or deduct these aspects in the interviews or AI prompts.

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