Co-Designing Accessible Embodied Conversational Agents for Post-COVID Syndrome Patients: A Participatory Case Study

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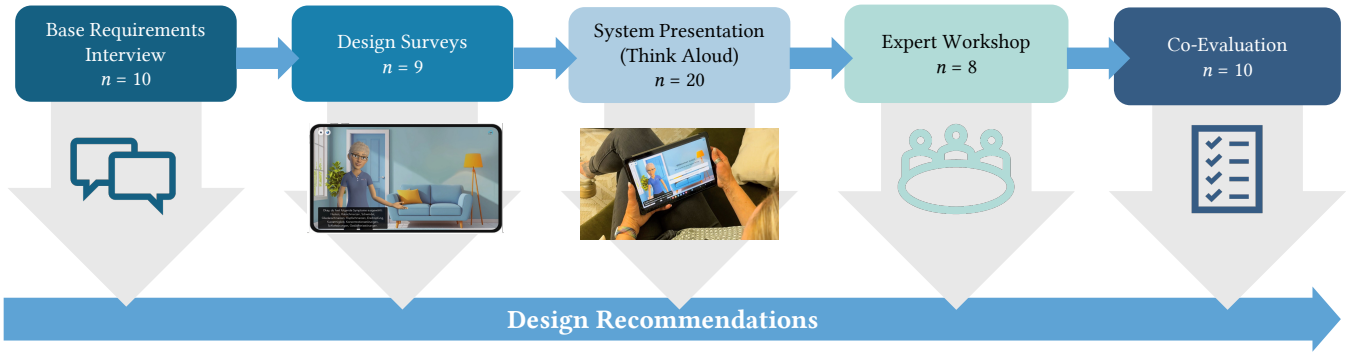


Figure 1: We present a case study employing five participatory formats involving post-COVID syndrome (PCS) patients, medical personnel, human-agent interaction researchers, and ethics consulting resulting in recommendations for designing embodied conversational agents to support PCS care.

Abstract

Designing accessible assistive systems that incorporate embodied conversational agents (ECAs) to support the daily lives of patients with Post-COVID syndrome (PCS) requires a deeper understanding of their needs. In this paper, we present empirical data on the expectations and requirements of such a system, while aiming to raise awareness of the digital barriers faced by those with PCS and other chronic diseases. We conducted an exploratory case study employing five participatory formats. Co-creating and iteratively refining with PCS patients, medical professionals, an ethics consultant, and human-agent interaction researchers, we developed an ECA prototype aimed at providing a barrier-free application for PCS-related support and derived design recommendations for technology development. We found that PCS patients require highly adaptable systems to manage the types and severity of daily fluctuating symptoms. Thus, such systems should be customizable, multimodal, and sensory-adaptive. Assistive (E)CAs can offer accessible and engaging support for monitoring health data. The benefit of agent embodiment is inconclusive – some participants found it helpful, while others reported no effect or a negative impact on their perception. Here, long-term, real-world studies are needed to evaluate sustained use and the impact of embodiment on user acceptance.

CCS Concepts

• **Social and professional topics** → *People with disabilities*; • **Human-centered computing** → **Accessibility design and evaluation methods**; *Interaction design theory, concepts and paradigms.*

Keywords

eHealth, intelligent virtual agents, long-COVID, co-creation, fatigue

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1 Motivation and Related Work

With the 2025 enforcement of Germany's Accessibility Reinforcement Act (Barrierefreiheitsstärkungsgesetz, BFSG), accessibility has become a legal requirement for digital products and services. Manufacturers and developers are now obligated to incorporate accessible design principles [7], creating new opportunities for participation and empowerment in digital healthcare. However, designing accessible digital systems remains challenging, particularly for patient groups whose needs are not yet well understood, such as those with post-COVID syndrome (PCS, also referred to as long-COVID). Furthermore, currently, no universally accepted definition of accessibility exists, allowing for broad interpretations of user requirements and the barriers individuals may face [16]. While recommendations and guidelines for accessible design and development exist [3, 39], they often fail to adequately address the specific and evolving needs of particular patient groups. This limitation becomes especially evident in the context of emerging conditions such as PCS, where new types of barriers are still insufficiently understood and under-researched.

PCS is characterized by a wide range of symptoms and highly individual manifestations. With an estimated 200 symptoms affecting individuals differently, patients also face diverse and dynamic challenges when interacting with digital applications [42]. As symptoms may vary on a day-to-day basis, this can have an impact on sensory and cognitive limitations, which can lead to altered, reduced or abandoned use of technology, including the preference for smaller screen sizes [27]. Long-term symptoms can include shortness of breath, sensory issues, delayed and severe worsening of symptoms (Post-Exertional Malaise, PEM), and chronic fatigue [42]. In severe cases, patients may become bedridden, experiencing prolonged periods of isolation with minimal social contact and reduced engagement in daily activities [34]. One technique which can support PCS patients in managing symptoms such as fatigue is *pacing*, which aims to balance activity and rest to prevent overexhaustion and PEM [11]. Overall, however, the duration and progression of PCS remain uncertain, and to date, no curative treatment exists [8, 14, 32].

Conversational AI (CAI) is extensively researched in terms of design, behavior, bonding and user rapport, interaction modalities (text, speech), but also embodiment type (i.e., chatbots, virtual agents, social robots), due to its wide variety of applications [18, 19, 40]. Digital CAI-supported health tools are also relevant to the diagnosis and treatment of PCS, which was has been recognized since the early stages of the pandemic [31]. To this end, chatbots can be used as accessible tools to distribute individually relevant information regarding symptoms and treatment options, and as data acquisition agents to gain insight into the individual course of the disease or other healthcare services, where they achieve high engagement rates [17, 25, 40, 44]. In [44, p.833], effective engagement is defined as "sufficient engagement with the intervention to achieve the intended outcome". While high engagement in users with chatbots could be shown, it commonly declines over the course of usage of a healthcare assistant application [44].

To support sustained long-term engagement through enhanced multimodal interactions, voice assistants and embodied conversational agents (ECAs), also referred to as intelligent virtual agents, are employed [5, 38, 41]. ECAs appear as virtually embodied characters with multimodal communication abilities. Such agents have been shown to enhance engagement in the context of chronic diseases [15]. They can improve disease-specific health knowledge and psychological wellbeing, however their long-term benefits still require more research [35]. When comparing voice assistants and ECAs for the collection of patient-reported data among multiple sclerosis (MS) patients, preference of one system over the other was influenced by their specific disease-related disabilities, such as cognitive impairments and fatigue [41].

At the same time, ECAs can also improve user acceptability and satisfaction by employing verbal, facial and gestural expressions during health care-related interviews [22]. This effect is particularly beneficial for long-term patient support, which is especially demanding in PCS due to the vast variety of symptoms. However, to the best of our knowledge, no work has been published yet on the application of ECAs in the context of self-management and decision support for PCS-care. New, more general applications targeting PCS are steadily appearing and are being researched worldwide [9, 21, 24, 28, 30]. These studies indicate that PCS patients want digital symptom management interventions they can use for short session durations on their smartphones [30], which support their self-management [21, 24] through health diary features [13] which capture context [9], to help them manage their health and reintegrate into everyday life [28]. They also highlight that there is a discrepancy between what patients wish to track and communicate and the information needs of clinicians [9]. Few apps have been developed specifically for PCS, while others have been appropriated for use by PCS patients [29]. Additionally, the combination of health data from wearables with self-reported assessments from mobile app questionnaires can support PCS symptom tracking and predicting fatigue, stress, and pain [6]. However, existing work has not yet examined how fluctuating PCS-related cognitive, sensory, and fatigue constraints shape the design of multimodal ECA interactions for repeated health-data collection and reflection. In particular, it remains unclear how users should be enabled to regulate interaction effort, modality, timing, and information density according to their current state.

To address this gap, we investigate the following research question (RQ): *How should embodied conversational agents (ECAs) be designed to meet the needs of patients with post-COVID syndrome (PCS)?* A large proportion of PCS patients have highly individual requirements for digital healthcare solutions [21, 24]. Existing conversational health care assistants seldom address these unique needs, leading to barriers in accessibility and efficacy for this population [43]. Thus, there is a pressing need to improve the understanding of these requirements and to adapt their design towards more inclusive and user-centered health technologies.

This paper makes three contributions. First, we provide empirically grounded design knowledge on the accessibility, expectations, and requirements of PCS patients for long-term conversational health-data interaction. Second, we introduce *pacing-by-design* as

an interaction-design perspective for systems used under fluctuating cognitive, sensory, and fatigue-related constraints. Rather than referring only to scheduled breaks, *pacing-by-design* concerns users' ongoing control over interaction timing, duration, effort, modality, information density, and opportunities to pause or discontinue an interaction. Third, we translate these findings into design recommendations at three levels: PCS-specific requirements, ECA-specific interaction considerations, and broader implications for accessible eHealth systems. Our contribution is therefore not a novel ECA architecture, but a participatory and empirically grounded account of how multimodal conversational interaction can be designed around fluctuating user capacities.

2 Methods

To investigate the expectations and accessibility needs of PCS patients for ECA-based healthcare assistants, we employed a multi-step co-creative study design (see Figure 1) supported by a conceptual prototype system, as detailed in the following.

2.1 Participants and Recruitment

Participants were recruited through a PCS care center at the University Hospital Cologne in Cologne, Germany and from support groups for PCS patients in the Cologne area. Inclusion criteria comprised a confirmed PCS diagnosis, an age of at least 18 years, and a stable health condition. Eligibility was verified by a medical professional based on a PCS-specific case history prior to obtaining informed consent. In total, 27 individuals participated in the study (10 male, 16 female, 1 non-binary/diverse). Seven additional individuals initially expressed interest but withdrew due to time constraints or health-related reasons. A subgroup (n = 15) participated in the pre-assessment to characterize the participant sample. The study duration and data collection lasted from March 2025 to November 2025.

Participants were encouraged to reflect on both their current condition and more severe phases of their illness when expressing system requirements, in order to capture a broader range of needs. Given the heterogeneity of the PCS population's health, the study was designed to allow participants to contribute meaningful data without completing all study components, leading to different participant samples for each step. The study was conducted in accordance with the Declaration of Helsinki and approved by the Institutional Review Board of the University Hospital Cologne (application number 24-1042_1). All participants provided written informed consent prior to participation. Data was pseudonymized, and no financial compensation was provided.

2.2 System Design

To explore design implications for ECA-based healthcare assistants in a tangible context, a conceptual conversational system was developed and implemented as a functional prototype. The system integrates a web-based conversational frontend, dialog management, backend services, and interfaces to wearable health devices. The system is conceived as a conversational interface for collecting and reflecting on self-reported symptoms and wearable data, visualizing changes over time, and preparing information for communication with healthcare professionals. It is not intended to diagnose PCS, recommend treatment, replace clinical consultation, or autonomously make therapeutic decisions. Concrete requirements and features were assessed through a participatory process, as detailed in the following subsections.

The frontend was implemented using Plural.io (Humanizing Technologies GmbH, Germany), a low-code platform for designing conversational flows with embodied agents, shown in Figure 3. It enables the creation of customizable agents with configurable visual characteristics such as gender, skin tone, facial features, and clothing, and supports multimodal interaction through text input, buttons, and voice. The ECA interacts in natural language via Speech-to-Text (STT) and Text-to-Speech (TTS) and provides subtitle support to enhance accessibility. To enable flexible and adaptive interaction logic, dialog management was integrated via the open-source framework Rasa (Rasa Technologies Inc., USA), which was connected to the frontend via custom application programming interfaces (APIs). A Flask-based web server (Pallets, 2024) implements additional user interface components, handles database operations, and manages authentication processes. The system was connected to the Withings public API (Withings SA, France) to integrate data from smart health trackers, including sleep quality, body temperature, blood pressure, heart rate, and activity levels.

The visual design of the ECA and its interaction environment was developed through an iterative co-creation process involving multiple feedback rounds and questionnaires, in which participants expressed their preferences and requirements (see Section 2.3). The resulting design reflects user preferences for agent appearance and interaction style, as illustrated in Figure 3. Although parts of the technical infrastructure were functional, participants did not evaluate a fully autonomous or clinically deployed ECA. The evaluation focused on the presented interaction concepts, visual and conversational design, accessibility mechanisms, and anticipated use scenarios. Claims about clinical benefit are therefore outside the scope of the present study.

To ensure data protection, the system was deployed within local infrastructures following a privacy-by-design approach. The prototype was hosted on secure servers with user authentication and pseudonymized data storage. Access was restricted to authorized project staff, and all user data was pseudonymized and encrypted. The data protection framework includes GDPR-compliant processing via Plural.io and third-party providers (Google STT and Withings). Google STT transcribes input without persistent storage, and health data from wearables is securely managed. All data is processed only with user consent, stored on EU servers, transmitted securely, limited to essential information, and managed according to legal retention, deletion, and transparency requirements.

2.3 Study Design

To capture both in-depth user perspectives and complementary quantitative insights, we conducted a multi-step participatory case study, combining qualitative participatory approaches with supporting surveys. Participants, all of whom had a confirmed PCS diagnosis, were considered experts in their lived experience and were actively involved through a co-creation approach. This participatory framework enabled a deeper understanding of user needs while ensuring continuous involvement of participants throughout the

research process [1]. Participants were invited to define their preferred level of involvement and specify individual requirements for participation. To accommodate fluctuations in participants' health status, the study allowed flexible participation, resulting in varying numbers of participants across the different study stages. At the beginning of the study, questionnaires were used to assess participants' relationship with technology (see Section 2.4).

The co-creation process was structured into several iterative phases, as shown in Figure 1. First, initial requirements were elicited through interviews with ten participants to understand their needs and expectations regarding a potential system. Based on these findings, two brief online design surveys were conducted to gather feedback on specific design aspects (see Figure 2), with nine participants contributing. Subsequently, a prototype of the system was presented through a video demonstration to explore user perceptions of the interaction design. A total of 20 participants took part in this phase using the Think-Aloud protocol [37]. Insights from the interviews and the video-based evaluation were synthesized into preliminary design recommendations. These recommendations were further refined in a co-creative evaluation workshop involving eight experts from technical and medical domains as well as ethical consulting. In a final step, the refined recommendations were presented again to the participant group, with additional feedback provided by ten participants. The resulting insights were iteratively integrated into the prototype system for demonstration purposes.

2.4 Pre-Assessments and Participant Descriptions

At the beginning of the participatory case study, participants completed a survey assessing health literacy, digital health literacy, frailty, technology affinity scores, and sociodemographic characteristics. This information was collected to contextualize the sample and to identify potential biases, such as unusually high technical affinity, when interpreting the results.

The Affinity for Technology Interaction Scale (ATI) [10] was used to assess individuals' propensity and motivation to actively engage with technical systems through nine items on a six-point Likert scale. Higher scores on the Likert scale indicate a greater affinity for technology and a greater interest in using technical devices and digital applications. The short form of the European Health Literacy Survey (HLS-EU-Q16) [33] was applied to measure general health literacy, capturing how well individuals can find, understand, evaluate, and apply health information in the context of healthcare decision-making. Higher scores indicate a greater ability to understand and implement health-related information.

Digital health literacy was assessed using the eHealth Literacy Scale (eHEALS) [26], which measures individuals' perceived competence in handling health-related information from the internet. Higher mean values indicate greater digital health literacy. To capture frailty, the SELFY-BRIEF version of the Multidimensional Prognostic Index (MPI) [23] was used, providing a multidimensional assessment across domains such as daily functioning, cognition, comorbidities, and mobility. The final score is a number between 0 (lowest risk) and 1 (highest risk), enabling stratification into established frailty risk categories.

Of the participants who completed the preliminary survey (n = 15), all were German citizens and native German speakers. Regarding educational background, the majority had completed an apprenticeship (n = 8; 53%), followed by participants with a university degree (n = 6; 40%). One participant reported a school leaving certificate (7%). Affinity for technology (ATI) was in the medium range (M = 4.16, SD = 1.21). Health literacy (HLS-EU-Q16) was low to medium (M = 2.84, SD = 0.94), while eHealth literacy was also moderate (M = 3.39, SD = 1.34). Frailty (SELFY-BRIEF-MPI) was low overall (M = 0.22, SD = 0.12), with 93% of participants classified as "low risk." Descriptive statistics are summarized in Table 1.

Table 1: Descriptive results of the pre-assessments

***n*=15**	***Possible Range***	***M***	***SD***	***Median***
ATI	1-6	4.16	1.21	4.00
HLS-EU-Q16	1-4	2.84	0.94	3.00
eHEALS	1-5	3.39	1.34	4.00
Selfy-Brief-MPI	0-1	0.22	0.12	0.21

2.5 Co-Creation: Requirement Interviews and Design Surveys

To asses the system requirements, we conducted expert interviews with ten PCS patients following the qualitative approach of Gläser and Laudel [12]. Interviews lasted up to two hours and were conducted either in person or remotely, depending on participants' health conditions. To ensure participants' well-being, they were able to take breaks or discontinue the session at any time. The interviews explored participants' lived experiences with PCS as well as their requirements and expectations for an ECA-based assistant. Key topics included expectations regarding co-creation, ECA design, communication and language, accessibility, data extraction and visualization, and pacing. Interviews were conducted until thematic saturation was reached, i.e., no new themes emerged from additional data collection.

To further validate the design decisions, a short mixed-methods survey was conducted. Nine participants were asked to select their preferred ECA and background design, as shown in Figure 2, using Likert-scale items and were given the opportunity to provide additional open feedback. The results informed the final interface design shown in Figure 3, which was subsequently used in the video-based system demonstration and incorporated into the final design recommendations.

2.6 Co-Creation: System Presentation

To evaluate user perceptions of the system design under conditions that are accessible and considerate of participants' health constraints, the prototype was presented through a condensed video-based demonstration. This approach was chosen due to ethical and practical considerations, as direct and continuous testing of all system features could have imposed additional cognitive or physical strain on participants. The video was developed based on the conceptual system described in the previous section and incorporated insights from the expert interviews and design surveys.

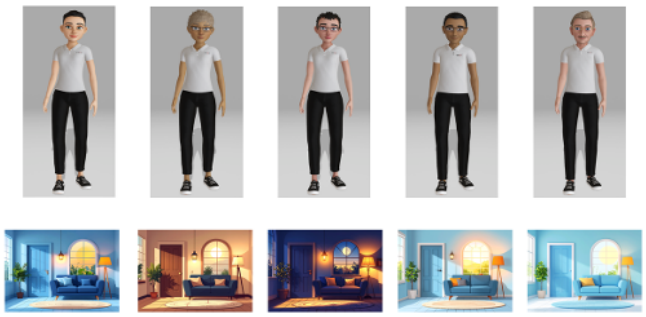


Figure 2: ECA and background design options developed based on initial participant interviews.



Figure 3: Illustration of the ECA and background design based on the feedback from the mixed methods study. The background image was generated by generative AI and then manually fine-tuned. The ECA was designed using Plural.io's integrated virtual character builder.

It illustrated user interaction with the system in a controlled and standardized manner.

The demonstration consisted of a 10-minute video structured into four segments reflecting the system's main interaction phases: onboarding, initial data acquisition, long-term data acquisition, and data visualization. It further illustrated key interaction concepts such as pacing mechanisms, including conversational breaks, adjustments in speech speed and complexity ("easy read"), as well as user control over screen brightness and audio output. Participants attended the demonstration either online or in person, depending on their preferences and health conditions. To capture immediate user feedback, a Think-Aloud protocol [37] was employed during the presentation, allowing participants to verbalize their thoughts while observing the interaction scenarios. As direct interaction with the system was not feasible, the findings were interpreted with consideration of this methodological limitation. A total of 20 participants took part in the demonstration, eight of whom had previously participated in the interviews, while twelve joined the study at this stage. The Think-Aloud data were analyzed following the same qualitative approach as the expert interviews [12].

2.7 Co-Creation: Design Recommendations, Expert Workshop, and Co-Evaluation

The final recommendations were developed through an iterative, data-driven refinement process integrating insights from the expert interviews, the Think-Aloud evaluation, and subsequent participant feedback. An initial set of recommendations was derived from the requirements elicited in the interviews and was subsequently adapted, extended, or removed based on the analysis of the video-based system evaluation.

In this process, we refined the first set of recommendations based on the more detailed information obtained from the system presentation. Recommendations were either tailored to a more specific context, their strength was adjusted according to the number of participants expressing similar views, or they were removed if contradicted by the newly collected information. The refinement process was carried out in an expert workshop format by an interdisciplinary team comprising experts from medicine, ethics, psychology, sociology, computer science, and human–machine interaction. The resulting recommendations were further discussed and refined in an online co-evaluation workshop led by an external ethics expert, involving eight study participants. Additional feedback was collected from two participants via e-mail and incorporated into the final set of recommendations.

3 Results: Preferences for Developing an ECA-Based Assistant for PCS Patients

This section presents the findings from our participatory case study. The interview data revealed a wide range of user preferences, which we organized into three main categories: (1) mechanisms to support pacing (*pacing-by-design*), (2) design and interaction, and (3) data acquisition and visualization.

Given the recurring importance of pacing across the study phases, we use the term *pacing-by-design* to describe an interaction-design approach that enables users to continuously regulate the demands imposed by a system. This includes control over when an interaction takes place, how long it lasts, how much information is presented, which modality is used, and whether the interaction is paused, shortened, skipped, or discontinued. *Pacing-by-design* therefore extends the clinical principle of balancing activity and rest into the design of multimodal conversational interaction. Within these categories, additional subcategories were defined to further structure the results and improve clarity.

3.1 Pacing-by-Design

Participants emphasized the need for extensive adaptability of interaction parameters. Interface elements such as speed of ECA speech, brightness, volume, and font size should be easily adjustable (e.g., P1, P8, P13, P17). Similarly, the timing, frequency, and duration of interactions must adapt to individual abilities, with reported preferences ranging from daily to monthly health screenings and interaction durations between 1 and 30 minutes (e.g., P1, P10, P13, P19). Flexibility in data acquisition was considered essential. Participants highlighted that data collection should be voluntary, adjustable, and adaptable to fluctuating conditions. The system should support pacing by proactively suggesting breaks and offering optional, customizable notifications in terms of frequency, type, and intensity

(e.g., P1, P3, P10, P13). Users must also be able to pause, skip, or cancel interactions at any time, with transparent communication regarding potential data loss (P10, P23, P24).

Clear and accessible communication was identified as a key requirement. Participants emphasized the need for concise spoken and text-based explanations, with optional examples that can be hidden when not needed. Interaction should adapt to the user's current functional status, for example by incorporating assessments such as the Bell Scale [4] to account for fatigue and disability levels (e.g., P3, P8, P18, P20).

In addition, participants stressed the importance of multimodal and accessible interaction. The assistant should be available in the user's native language, with all content accessible in both spoken and written form and optionally simplified. All functions should support both voice and user interface interaction, with clear indications of available input options. Users should also be able to disable specific output modalities, such as speech, text, or visual elements, to avoid overstimulation (e.g., P10, P17, P20, P21).

3.2 Design and Interaction

Participants emphasized that the interface design should account for increased sensory sensitivity in PCS by using calm, dark backgrounds, pastel tones, and low contrast (e.g., P1, P10, P21, P24). The conversational behavior of the ECA was considered equally important. Participants highlighted the need for a respectful, supportive, and empathetic interaction style, fostering an informal and approachable conversational atmosphere. Flexibility in forms of addressing the user (e.g., using the German informal *du* or the formal *Sie*, which are the two ways of addressing someone, i.e. saying *you*, in German) was also seen as beneficial (e.g., P3, P19, P8, P20).

Regarding embodiment, appropriate facial expressions, gestures, and overall demeanor were considered critical for supporting interaction. Conversely, excessive visual detail or extensive customization of the virtual character and background were perceived as potentially distracting or overwhelming. A limited selection of ECA styles (fewer than five) was suggested to support acceptance, while ensuring that functionality remains independent of the chosen embodiment and is clearly communicated (e.g., P3, P17, P20, P19). Voice characteristics were also discussed as an important design factor. Participants preferred clear voices that align with the ECA's appearance, with a medium to deep pitch and an age-appropriate tone. Lip synchronization was considered important to support natural interaction (e.g., P3, P17, P10). Beyond interaction design, participants expressed a need for features that support health literacy, agency, and community building. These include access to information about local support networks, healthcare services, and opportunities for peer exchange. Integrated support tools such as meditation or mindfulness exercises were perceived as helpful for responding to negative data trends (e.g., P8, P13, P23, P20).

3.3 Data Collection & Data Visualization

Participants emphasized the importance of comprehensive and adaptable data collection. During onboarding, a detailed assessment should capture individual symptoms, which are then regularly updated. In particular, differentiated recording of symptoms such as pain was considered beneficial (e.g., P3, P16, P18, P23). Long-term data collection was regarded as essential to enable meaningful visualization and interpretation of changes over time (e.g., P3, P15, P20, P24). Participants further highlighted the need to inform users in advance when more complex information, such as medical history, is required, allowing for sufficient time for preparation (e.g., P3, P10, P13, P19).

Regarding data visualization, participants emphasized the need for simple, clear, and concise representations suitable for both users and third parties. A variety of visualization formats, including interactive options and explanatory elements (e.g., text or images), was considered beneficial to accommodate individual preferences (e.g., P10, P20, P23). Consistency in data representation was highlighted as important for comprehension, for example by using uniform formats and ensuring that values are interpreted consistently (e.g., higher values indicating positive outcomes) (P17, P19, P24). At the same time, sensitive handling of negative trends, particularly over longer periods, was considered essential to avoid distress (P19, P24). Participants also expressed the need to contextualize data through the recording of key events, such as activities, medications, or therapies, in a diary-like format (P19, P17). In addition, individualized verbal or textual interpretations of data were perceived as highly valuable, provided that their reliability is ensured (e.g., P23, P11).

Finally, transparency in data use was identified as a key requirement for trust. Participants emphasized the importance of clearly communicating data storage, usage, and access rights. An export function was also considered essential to enable data sharing with healthcare professionals while maintaining full user control (e.g., P3, P16, P19, P23).

4 Design Recommendations

Building on the findings from the co-creation process, we derive design recommendations for ECAs to support PCS patients in long-term use. The recommendations synthesize evidence from the qualitative interviews, open and closed responses in the design surveys, the Think-Aloud evaluation of the video demonstration, the interdisciplinary expert workshop, and the final co-evaluation. The design surveys primarily informed the visual ECA and background design, whereas the interviews and Think-Aloud data formed the main basis for interaction and accessibility recommendations. Expert review and co-evaluation were used to refine the scope, wording, and applicability of the recommendations. They were developed through an iterative, data-driven process involving continuous collaboration with an interdisciplinary group of stakeholders, including patients, medical professionals, researchers, developers, and ethical consulting. Rather than representing isolated study outcomes, the recommendations reflect a synthesis of findings across all stages of the co-creation process. As such, they consolidate and operationalize the identified requirements into actionable design guidance. In the following, we present the recommendations structured from PCS-specific to more general recommendations: (1) recommendations for PCS patients, and (2) recommendations for general eHealth applications. Within both groups, we further distinguish between ECA-based recommendations and those that are not agent-specific. Their broader implications and relation to existing work are further examined in the Discussion (Section 5).

4.1 Recommendations for PCS patients

ECA-based recommendations

- The visual environment should minimize sensory load, for example through calm layouts, restrained use of color, and reduced brightness. At the same time, text and interactive elements should maintain sufficient contrast for readability. Preferences for darker or pastel-toned backgrounds varied and should therefore be configurable rather than prescribed as a universal visual style.
- Users must be able to turn off speech output, text output, and/or visual displays if required, to prevent overstimulation.
- Regarding the voice, PCS patients preferred a clear voice that matches the ECA's appearance, with a steady, medium to deep pitch. Lip synchronization of the ECA should be ensured to enable natural interaction. The preferred age of the virtual character generally corresponds to the user's own age.
- It is important to find a good balance of customizability in the interaction, while avoiding an excessive level of detail in customizing the ECA and background design, as this may be overwhelming or burdensome and can be perceived as unnecessary.

Other recommendations

- Many technical and content-related factors play a role in the design of an interactive assistant system to support the care of people affected by PCS. On the technical side, the speed of ECA speech, brightness, volume, and font size should be easily adjustable via the interface of the assistant system.
- In terms of content, the timing, frequency, and duration of the screenings and the interval of breaks during assessments must be adaptable to the individual's ability level.
- The assistant system should proactively remind the user about breaks during the conversation, either verbally or textually.
- Setting up reminder notifications is helpful but should be voluntary, with the frequency, type (push, email, SMS), and intensity of the reminders being adjustable to avoid it being burdensome.
- During interaction with the assistant system, it must always be possible to skip, pause, or cancel the conversation, with clear indications if this leads to data loss or not.
- For all functions, extensive spoken and text-based explanations, as well as examples, should be available.
- Adapting the scope and modalities of queries to the user's current functional status can be beneficial. For example, the functional state could be routinely assessed using the Bell Disability Scale [4], which assesses the symptoms of patients with fatigue-related diseases, or a similar evaluation tool, allowing the assistant system's behavior to be adjusted accordingly.
- There is a strong need among PCS patients to strengthen their own agency through health literacy and community. Specifically, the assistant system should provide information on local networks and support services, as well as options for networking and exchanging strategies for managing everyday life.
- Support tools such as meditation, mindfulness, and similar practices could also be offered directly within the assistant system. These could serve as immediate interventions in response to negative trends in user data.
- All elements should be operable both verbally and through interaction with the UI elements. If this is not technically possible, it must be made explicitly clear which input options are available at the current stage of the conversation.
- At the start of using the system, a detailed assessment should be conducted to record the symptoms relevant to the individual.
- After this detailed initial assessment, the individually relevant symptoms should be updated regularly.
- Negative data presentation must be handled sensitively to avoid distress, especially when displayed over extended periods of time.
- The option for differentiated pain tracking is advantageous.

4.2 Recommendations for eHealth

ECA-based recommendations

- In terms of ECA design, appropriateness of facial expressions, gestures, and overall demeanor in the given situation matters most. It is essential that the virtual character supports the interaction and does not distract from the content with excessive gestures or flashy clothing and/or accessories.
- The style of presentation (artistic style, degree of realism) of the ECA may also influence user acceptance, so offering a small selection of ECA styles is recommended. The choice of ECA design should not affect the functionality of the assistant system, and this should be clearly communicated during selection.
- The ECA should have a respectful and competent character, communicating with users in an appreciative and supportive manner. The conversational atmosphere should be empathetic, simple, and informal, allowing for communication on an equal footing using either the German informal *du* or the formal *Sie* forms (ways of addressing someone in German).

Other recommendations

- The use of the assistant system should be possible in the user's native language.
- All content must be available both in text and spoken form as well as simplified language changeable to the user's current requirements.
- Developers must ensure that the system supports long-term collection of relevant data, enabling changes to be visualized and interpreted over time.
- Before the assistant asks for information that cannot be answered offhand (e.g., details of one's own medical history), it should give users advance notice so they have enough time to gather the necessary data.
- The input and presentation of the collected data should be as simple, clear, and concise as possible so that it can be easily used and understood by both users and third parties (e.g., family members or partners).
- Major events (e.g., activities, vaccinations, medications, therapies) must be recordable in a diary-like format so they can be displayed along the data timeline, thus facilitating the interpretation of their effects.
- A function that provides individualized verbal or textual interpretations of the displayed data is considered extremely helpful. To this end, the reliability of these interpretations must be ensured.
- It is essential to establish trust in data use through transparency. It must be made clear where sensitive data are stored, for what purposes they are collected, and who has access to them.

- An export function for the collected data should be available to facilitate sharing with healthcare professionals, while ensuring that users retain control over their data.

5 Discussion and Conclusion

To the best of our knowledge, this is the first work considering the PCS-specific requirements regarding an ECA-based healthcare assistant. Schröder et al. investigated the general expectancies and needs of PCS-patients regarding e-health symptom management interventions [30]. Their quantitative results showed that most patients preferred interventions accessible via smartphones (95.3%). Our findings align with this. However, it is important to note that specific needs can differ, particularly when health information is communicated orally and in public settings, where data privacy becomes a concern. Additionally, most participants preferred session lengths of 10–20 minutes and expressed interest in topics such as quality of life, information on physical activity limits, adjustment to new life situations, and coping with physical changes [30]. These results generally align with the findings in our study but take the information-providing approach rather than our data-recording oriented method.

Many of the features and their implementations mentioned by our participants align with findings from general PCS-support apps [29], such as logging symptoms which support their self-management [21, 24], health diary features [13], and including wearables [29], which can be used in predicting PCS symptoms like fatigue [6]. Differences in individual preferences stated by the participants also aligned with prior findings in literature, as PCS can manifest in very different ways among patients [21, 24]. This also extends to the wish for individual customization of the ECA interaction on a day-to-day basis, depending on the user's health state on each given day [27].

Our recommendations differ in their relationship to prior work. Several findings confirm established accessibility and eHealth principles, including multimodal access, adjustable presentation, transparent data use, and user control over data sharing. Other findings extend prior PCS and chronic-disease research by showing how these principles need to be dynamically adjustable within a single interaction according to fluctuating capacity. The main conceptual extension is *pacing-by-design*: rather than treating accessibility settings as static preferences, the interaction should allow users to repeatedly regulate timing, modality, information density, and effort. Finally, preferences concerning particular character appearances, voices, colors, or session durations should be interpreted as sample-specific design inputs rather than universally applicable requirements.

While the results presented in this work were conceptually validated in a multi-step, co-creative process, a major limitation is the lack of experimental and practical validation of the system. This was delayed due to the heavy regulations of technical systems when including AI in the context of German healthcare. Thus, the recommendations in this paper should be iteratively re-evaluated during development and validation in practical tests to realize such an assistant for PCS-care.

The potential of using the acquired data in patient-doctor communication was identified during these studies. Due to the limited time per patient in the clinical context, doctors often do not have the appropriate data basis to recommend interventions which leads to a collaborative trial-and-error period until the individual therapeutic measures are found [36]. Providing doctors access to such data could accelerate the diagnosis and therapeutic process [2]. As we could not obtain real patient data with this study, the visualization of data for the doctors was not yet iteratively optimized. It is also not trivial to realize direct interfaces from the assistant platform to medical facilities due to data privacy concerns. As an interim solution, we therefore recommend an export format that can be generated and shared with clinicians by patients themselves.

Our studies involved a small number of participants, which may introduce bias related to group-specific requirements. This should be taken into account when interpreting the quantitative participant describing variables. However, these results could now be validated in a larger PCS patient group to confirm, extend, or adapt them for practical application. Furthermore, the main results were derived from a saturated qualitative data set.

ECAs have been shown to be beneficial for engagement in long-term use of assistive systems for chronic diseases [15]. Participants' desire for multimodal interaction with the ECAs, including increased expressiveness through gestures, aligns with findings from literature [20]. Whether or not ECAs are useful in the context of PCS-care support specifically, could not be answered conclusively in this study. The reactions towards the ECA in our interviews were mixed. Some found the ECA appealing, others did not care about it while a few rejected our particular ECA design in general. This aligns with findings for other chronic conditions, such as MS, where the preference of an ECA over a voice assistant was connected to individual factors such as the severity of the disease-related disabilities like fatigue [41]. Thus, the personalized and customizable (de)activation of ECAs, in terms of user preference, timing/setting, situation, and support task should be the focus of future work.

Overall, our findings show that PCS patients share many preferences and user requirements for ECA-supported, but also general, eHealth applications with other disease-specific patient groups. At the same time, these insights emphasize the need for further research and development to prioritize adaptable, patient-centered design approaches that can accommodate the complexity and variability of PCS in real-world, long-term use, by leveraging patient-directed concepts such as *pacing-by-design*.

6 Safe and Responsible Innovation Statement

This work explores assistive ECAs to support individuals with PCS, with particular attention to inclusivity and accessibility. Although the study focuses on inclusivity by developing a multilingual system, most participants were native German speakers; therefore, the broader societal generalizability is somewhat limited. The greater societal goal is to increase access to assistive technologies for PCS patients. This work specifically addresses key themes in the development of safe and responsible multimodal interaction for this group. Given the sensitive nature of health data, safeguards for data privacy, security, and user consent were implemented throughout the study.

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