An agile co-creation approach for designing a comprehensive digital motor assessment test for Parkinson's Disease patients

Beatriz Alves
ft.beatriz.alves@gmail.com
Faculdade de Motricidade Humana, Universidade de Lisboa
Lisbon, Portugal

Ghada Alhussein
Faculdade de Motricidade Humana, Universidade de Lisboa, Portugal/Khalifa University of Science and Technology
Lisbon/Abu Dhabi, Portugal/UAE
ghada.alhussein@ku.ac.ae

Filomena Carnine
CIPER, Faculdade de Motricidade Humana, Universidade de Lisboa
Lisbon, Portugal
fcarnide@fmh.ulisboa.pt

Nikos Grammalidis
Information Technologies Institute, Centre for Research and Technology Hellas
Thessaloniki, Greece
ngramm@iti.gr

Kosmas Dimitropoulos
Information Technologies Institute, Centre for Research and Technology Hellas
Thessaloniki, Greece
dimitrop@iti.gr

Dhaval Trivedi
King's College Hospital, NHS Foundation Trust
London, United Kingdom
dhavalbai.trivedi@kcl.ac.uk

Mónica Kurtis Urra
Neurology Department, Hospital Ruber Internacional
Madrid, Spain
mkurtis@ruberinternacional.es

Stelios Hadjidimitriou
Dept. of Electrical & Computer Engineering, Aristotle University of Thessaloniki
Thessaloniki, Greece
shadjidim@ece.auth.gr

Leontios J. Hadjileontiadis
Dept. of Biomedical Engineering & Biotechnology, Khalifa University/Dept. of Electrical & Computer Engineering, Aristotle University of Thessaloniki
Abu Dhabi/Thessaloniki, UAE/Greece
leontios.hajileontiais@ku.ac.ae
leontios@auth.gr

Sofia B. Dias
Interdisciplinary Centre for the Study of Human Performance (CIPER), Faculdade de Motricidade Humana, Universidade de Lisboa
Lisbon, Portugal
sbalula@fmh.ulisboa.pt

ABSTRACT

Digital assessment tools have recently gained significance in the context of Parkinson's Disease (PD) management, by offering innovative means for accurate symptoms' monitoring. At the same time, co-creation approaches have been used to ensure that these tools meet users' needs and requirements, which are essential for their acceptance and broad use. As part of the Horizon Europe AI-PROGNOSIS project, this study presents the results of an agile co-creation session conducted within an iterative design process to develop a novel digital motor assessment test for people with PD (PwPD), namely Comprehensive Motor Function Test (CMFT). The constructs of the Technology Acceptance Model (TAM) were explored with the feedback from 15 PwPD and clinical/technical experts who were presented with design concepts of the first working prototype of the proposed CMFT. In this vein, three TAM-based main themes emerged from the thematic analysis, i.e., Usability (Theme 1), Ease of Use and Accessibility (Theme 2), and User Engagement (Theme 3). Overall, PwPD found the CMTF straightforward and easy to use. Several improvements were suggested, including the need for clearer written instructions and visual aids to ensure patients fully understand the proposed CMFT. Concerns about privacy and ethical transparency, as well as the psychological burden of long-term symptom tracking were also underlined. These insights will guide future design iterations to ensure that the CMFT better meets the needs and expectations of PwPD. Ongoing

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work focuses on refining the CMFT for the forthcoming clinical validation trials.

KEYWORDS

Parkinson's Disease, Co-creation design, Digital Assessments, Motor skills assessment, AI-PROGNOSIS

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1 INTRODUCTION

Parkinson's Disease (PD) is the second most prevalent neurodegenerative disease [1], affecting nearly 8.5 million individuals in 2019, and causing 329,000 deaths in the same year, reflecting over a 100% since 2000 [2]. Without an available cure and characterized by significant motor and non-motor symptoms, PD is associated with a high disease burden, resulting in 5.8 million disability-adjusted life years (DALYs), an 81% increase since 2000 [2]. From a socioeconomic perspective, healthcare costs from PD-related care are anticipated to rise with disease progression [3].

Digital assessment tools have recently gained significance in optimizing treatment and improving the quality of life for people with PD (PwPD). Using technologies, such as wearable sensors and mobile apps, these tools not only provide a comprehensive and granular view of symptom fluctuations compared to sporadic in-clinic assessments [4], but are also advantageous in the context of remote assessments [5]. Since their successful implementation heavily rely on high user retention rates, grounding the development of digital assessment tools in established theoretical frameworks may address this potential shortcoming. In particular, the Technology Acceptance Model (TAM) [6] theorizes that perceived ease of use and perceived usefulness positively influence usage intentions, which drive the adoption of new technologies. This underscores the importance of aligning technology features with user needs and requirements, which can be attained through a user-centered and iterative design process. This process incorporates user feedback, resulting in meaningful and efficient solutions [7]. Therefore, engaging users in idea generation, design, and testing using agile co-creation methodologies significantly enhances the acceptability, usability, and adoption of the final product [8]. During co-creation activities, mock-ups and fidelity prototypes are used to visualize key components, explore user interaction features, validate design decisions, and test user responses, offering significant value through multiple iteration cycles [9].

In this work, we introduce the Comprehensive Motor Function Test (CMFT), a novel digital assessment tool for PwPD. The CMFT includes a series of motor tasks, particularly focused on the assessment of balance and posture, grounded by the PD gold-standard assessment, the Movement Disorder Society - Unified Parkinson's Disease Rating Scale (MDS-UPDRS) Part III. Overall, the CMFT aims to provide valuable insights into motor symptom assessment (perceived usefulness) and make it easy for either PwPD or health professionals to operate (perceived ease of use), aiming to motivate its regular use. This tool will be integrated into a mobile application, under the scope of the AI-PROGNOSIS project (https://www.ai-prognosis.eu/). Here, we present the results from the first AI-PROGNOSIS co-creation patient session, which aimed to gather feedback on the mock-ups comprising the CMFT assessment tasks.

This work is organized as follows: Section 2 provides background information; Section 3 presents the methodology, including study context, design, CMFT presentation, sample, data collection, validation, and analysis; Section 4 outlines the main findings and their discussion, and Section 5 concludes the work.

2 BACKGROUND

In the field of digital assessment technologies, personalized interventions and motor assessment solutions have been explored to enhance the quality of life and outcomes for PwP [10, 11]. Despite strong support in the literature for digital assessment technologies, their successful adoption depends on their ability to meet users' needs and preferences. By involving end-users in iterative feedback cycles throughout the design process, co-creation approaches help tailor these tools to the specific requirements of the PD population [8, 12]. Since co-creation approaches help tailor digital tools to user requirements, several studies have used similar frameworks to develop these technologies for PD. For example, Wannheden and Revenäs [13] investigated co-care in PD management through eHealth services, by exploring the needs and expectations of PwPD and healthcare professionals. Using a participatory design approach, a series of workshops resulted in a functional eHealth prototype to support PD co-care [13]. Similarly, Kessler et al. [14] focused on integrating medical and self-management approaches to improve the quality of life of PwPD. A co-design approach was used to gather feedback from PwPD, carers, and healthcare providers, highlighting the need for a collaborative care model including active patient engagement and comprehensive support [14]. Grosjean et al. [15] developed the eCARE-PD platform to address the needs and expectations of PwPD and provide home care management advice. A user-engagement approach identified key design features and solved key issues, leading to a more interactive and acceptable end product [15]. This work was extended by Monje et al. [16] in the iCARE-PD project, where a co-design approach was used to improve the usability and acceptability of sensor-based solutions towards a community-centered integrated care model [16].

Understanding the unique needs and preferences of PwPD is crucial for the successful development and implementation of these technologies. This study presents the results of a co-creation session focused on designing a novel digital assessment tool for PwPD, specifically targeting motor skills such as balance and posture.

3 METHODOLOGY

3.1 Study context

This study is part of the AI-PROGNOSIS project, a Horizon Europe research and innovation initiative that aims to advance PD diagnosis and care through novel predictive models combined with digital biomarkers from everyday devices. Considering the overall concept of AI-PROGNOSIS, this study aims to identify the needs of relevant stakeholders (e.g., PwPD, healthcare professionals, researchers, developers) and effectively engage them in the co-creation of the AI-PROGNOSIS toolkit for PD. In this line, the main objective of the first AI-PROGNOSIS co-creation session was to gather relevant feedback from PwPD concerning the proposed CMFT, aiming to be integrated in the AI-PROGNOSIS mobile application. The co-creation session was guided by design thinking principles, fostering empathy, ideation, and collaborative problem-solving to develop a user-centered assessment tool [7]. The feedback was based on discussing aspects regarding usability, user engagement, accessibility and suggestions for improvement. By engaging patients in this process, we aimed to align the proposed motor tests more closely with the needs, preferences, and expectations of PwPD, thus enhancing its relevance and effectiveness.

3.2 The proposed Comprehensive Motor Function Test (CMFT)

The proposed CMFT includes a sequence of four motor items adapted from the MDS-UPDRS, namely "item 3.8" (leg agility), "item 3.9" (arising from chair), "item 3.10" (gait), and "item 3.13" (posture). These selected items included in the CMFT sequence focus on balance and posture, which are fundamental motor features affected by PwPD [17]. Patients can either perform the CMFT independently or with assistance. In this context, we created the first mock-ups using the Figma design tool to visually represent the CMFT, including: a) Main menu screen: lists the four motor tests in the CMFT sequence (leg agility, arising from chair, gait, and posture); b) Set-up instructions screen: provides materials needed (chair, phone) and explains phone placement 2 meters from chair at a 45-degree angle; c) Motor test instructions screen: details each motor test with written and video instructions; d) Countdown screen: displays countdown before starting CMFT; and e) Motor test recording screen: after performing the CMFT, a feedback message is displayed, concluding the test (see Figure 1).

3.3 Study Design

Overall, the structure of the co-creation session was organized into several parts, as follows: a) welcoming the participants and presentation of the session objectives; b) introduction of facilitators/observers and clinical/technical experts; c) introduction of PwPD, where they were prompted to share previous experiences with assessments through mobile apps; d) presentation of the overall perspective of the AI-PROGNOSIS project; e) mock-ups presentation followed by an interactive panel discussion about the CMFT; f) summary of key takeaways from the session and presentation of next steps; and g) explanation of the online questionnaire regarding participants' satisfaction with the session. The main activity of this co-creation session was the presentation of the CMFT mock-ups, which were shared on the screen, aiming to provide a comprehensive view of the proposed motor tests and its key elements (see Figure 1). To ensure consistency and guide the interactive panel discussion, the following questions were addressed based on the TAM constructs:

- **Usability and perceived usefulness**: *How useful do you find the CMFT for assessing your motor function, particularly balance and posture, compared to traditional methods? Considering ease of navigation and clarity of instructions, how confident are you in using the CMFT effectively?*
- **Easy of use and accessibility**: *How easy do you anticipate learning to use the CMFT, especially with Parkinson's-related motor difficulties in mind? Do you foresee any accessibility barriers hindering your ability to interact effectively with the CMFT?*
- **User engagement-intention to use**: *How likely are you to incorporate the CMFT into your routine for motor function assessment? To what extent do you find the CMFT engaging compared to other assessment tools?*
- **User engagement-attitude towards using**: *How do you perceive the overall user experience of the CMFT, and how does it influence your enthusiasm to use it?*

3.4 Sampling and Recruitment

The selection process of this co-creation session employed purposive sampling, allowing for a deliberate and targeted selection of participants who possessed relevant experiences and perspectives. Individuals aged $\geq$ 18 years, with a PD diagnosis confirmed by a neurologist, capable of understanding and communicating in English through an online platform were considered eligible and invited to participate. Moreover, the involvement of researchers and clinical/technical experts from the AI-PROGNOSIS consortium further enriched the session by bringing additional insights and perspectives to the discussions. The participation in the session was entirely voluntary, and participants were not offered any form of compensation for their involvement. Participants provided verbal informed consent before participating in the study.

3.5 Data Collection

The co-creation session took place on April 2024 and it was conducted online, using the Microsoft Teams platform. The session had a group size of 15 participants, including two facilitators/observers, one clinical researcher, three technical experts, three senior researchers on AI applications, and six PwPD (Table 1). This diverse composition ensured a comprehensive exchange of perspectives and expertise. To maintain a record of the co-creation session, audio recordings were made, which were later transcribed to verbatim and pseudo-anonymized to preserve confidentiality. The online setting allowed for seamless communication and ensured that all participants could actively engage in the discussions. The session was guided by a female researcher with expertise in qualitative research (last author SD), primarily posing questions and encouraging group discussions to elicit participants' opinions and experiences. Participants were assured of the confidentiality of the discussions and were informed that their involvement was voluntary. Prior permission to audio-record the sessions was obtained. Transcriptions were pseudonymized to maintain anonymity. To enhance the participants' comprehension of the session topics, relevant mock-ups related with the CMFT were presented (see Figure 1). The session followed a scripted guide consisting of seven main questions designed to explore the opinions of participants regarding the design

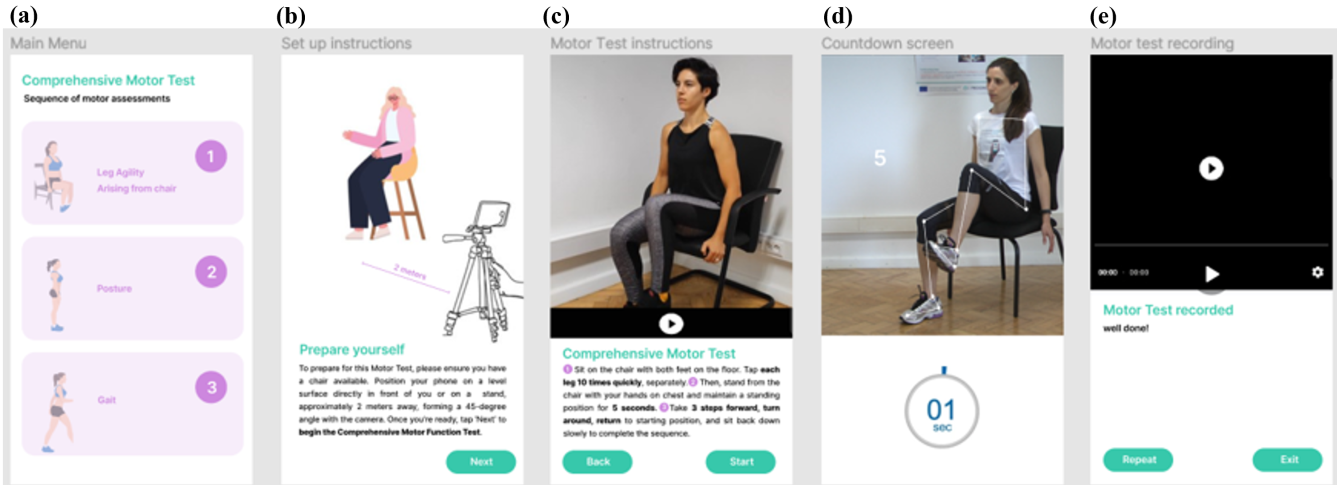

Figure 1: Mock-ups of the Comprehensive Motor Function Test prototype presented during the co-creation session, including: (a) Main menu screen, (b) Set-up instructions screen, (c) Motor test instructions screen, (d) Countdown screen, and (e) Motor test recording screen.

of the CMFT for assessing motor skills, particularly balance and posture (see section 3.3). A dedicated time frame of 70 minutes was allocated for this session, allowing for in-depth discussions and comprehensive exploration of the topics. After the co-creation session, an online questionnaire was shared via Google Forms[1] to assess participant satisfaction and gather valuable insights for improving future sessions. The questionnaire comprised five questions, including two closed and three open-ended questions.

3.6 Data Validation and Analysis

In terms of capturing demographic information, the educational backgrounds of the patients were categorized into distinct levels, using the International Standard Classification of Education (ISCED) (from ISCED 0=Early childhood education to ISCED 8=Doctoral degree or equivalent tertiary education level). This classification allowed for a comprehensive understanding of the patients' educational attainment and its potential influence on their perspectives and experiences. Moreover, to ensure the rigor of the qualitative analysis, a meticulous approach was followed. Two independent researchers (BA and SD) undertook the analysis of all qualitative data. Following the process of thematic analysis, an initial set of codes was generated after familiarization with the data by reading through the transcription and taking notes to identify potential topics for analysis [18]. The codes were then grouped into potential themes and sub-themes, which were reviewed to ensure that they were aligned with the data. Finally, the themes and sub-themes were identified using clear and concise wording. The use of different researchers enhanced the credibility and reliability of the analysis, as it allowed for the cross-validation and consensus-building of the identified themes and interpretations. Agreement on code assignment was assessed using the kappa statistic, ensuring consistency in the analysis process. A number of direct quotations from participants supporting the identified (sub)themes are included in the following Section (Main Findings). Note that following each illustrative quotation, there is an indication of which participant stated it (PwPD=People with PD, CE=Clinical Expert, R=Researcher, TE=Technical Expert).

[1]https://forms.gle/22Jd5spUqg6gF6mQ8

Table 1: Demographic characteristics of study participants.

Participants	Characteristics	Value
PwPD (n = 6)	Age	49.83 ± 9.22 years
	Sex (% males)	66.67 %
	PD duration	2.40 ± 0.55 years
	Education level	Bachelor's or Equivalent (66.67 %)
		Master's or Equivalent (16.67 %)
		Doctoral or Equivalent (16.67 %)
	Technology literacy	Basic (16.67 %)
		Intermediate (33.33 %)
		Advanced (50 %)
Researchers (n = 5)	Age	39.80 ± 11.10 years
	Sex (% males)	60.00 %
	Years working in the field	12.20 ± 7.43 years
Clinical Expert (n = 1)	Age	42 years
	Sex	Male
	Years working in the field	15 years
Technical Experts (n = 3)	Age	48.00 ± 8.54 years
	Sex (% males)	66.67 %
	Years working in the field	19.33 ± 3.06 years

4 RESULTS AND DISCUSSION

4.1 Main findings

The co-creation session included two facilitators/observers, one clinical researcher, three technical experts, three senior researchers on AI applications, and six PwPD (15 participants in total-Table 1). The mean age of PwPD was 49.83 ± 9.22 years, with two females. The average time since PD diagnosis was 2.40 ± 0.55 years, and the majority of patients had an advanced level of technology literacy (50%). The mean age of the technical experts was 48.00 ± 8.54, with one female. The clinical researcher, a male, has over 15 years of clinical experience (see Table 1).

The main findings are outlined in Figure 2. Three main themes emerged from the thematic analysis, namely: Usability (Theme 1), Ease of Use and Accessibility (Theme 2), and User Engagement (Theme 3). From the main themes identified in the session, various subthemes were derived to further explore the discussions. The level of agreement between the two researchers in identifying these subthemes was assessed using the Kappa statistic. The obtained score of 0.93 indicated an almost perfect agreement between the two researchers. At the points of doubt, a discussion between the researchers resulted in a reworked text, arriving to an 100% final agreement across all subthemes.

Overall, the CMFT assessment tool was generally perceived as clear and comfortable to use, with both written content and video demonstrations being considered helpful. The perceived psychological burden of long-term symptom tracking was considered an additional challenge. Participants found the concept of regular symptom tracking feasible and preferred conducting assessments at home for convenience. Several participants acknowledged the practicality and time efficiency of the CMFT and expressed willingness to engage in regular assessment using this tool. Data protection and ethical considerations were discussed, which further underlined the importance of transparency and privacy. The main findings for each identified theme are briefly presented.

Usability (Theme 1). Most participants found the CMFT straightforward and easy to use. They reported feeling comfortable performing this assessment, which was considered useful for symptom monitoring between clinical appointments. Providing both written content and video demonstrations was considered helpful for understanding how to perform the CMFT. However, it was suggested that written instructions should be clearer. One participant highlighted the need of clarifying the intended movement speed for each component of the motor tests. For example, while the leg agility test should be performed as fast as possible, patients should use a comfortable speed during the sit-to-stand, gait, and posture tests. Nonetheless, the value of using both video and written instructions was recognized, as follows: "*I agree that the videos are very useful because I thought there was slight ambiguity in the written text and in the third frame... For me, it becomes very clear what to do when I see the video*" (PwPD#5). Moreover, a Clinical Expert noted, "*It can be seen as a complementary tool to clinicians*" (Clinical Expert). This perspective is aligned with the recognized role of digital technology for PD, by supporting clinical decision-making, improving patient outcomes and satisfaction, and thereby enhancing the quality of care [19]. Overall, the panel discussion on usability aspects aimed to ensure that the CMFT considers the ISO 9241-11:2018 guidelines, promoting effectiveness, efficiency, and user satisfaction within the intended context of use [20].

Ease of use and Accessibility (Theme 2). Participants reported few practical issues with the CMFT, emphasizing the importance of clear, standardized instructions and technical feedback. During the discussion, proper smartphone placement and camera positioning were considered crucial for increased accessibility, particularly for patients with severe symptoms. For instance, having a smartphone stand/support was considered useful for better camera adjustment considering at-home assessments. In fact, the relevance of addressing these practical considerations is consistent with principles of user-centered design in mHealth apps [4]. In this line, one patient anticipated some difficulties for PwPD at later disease stages or with more sever motor and/or cognitive impairments to perform the CMFT in a home setting, as follows: "*I was just wondering how useful this would be for people in later stages of the disease. If you're in the later stages of the disease, when standing up, there could be balance issues, there could also be issues understanding the instructions.*" (PwPD#4). In this context, the following was added: "*For those cases, the CMFT can be performed with or without the caregiver or family member*" (Researcher#1). This highlights the importance of caregivers and healthcare providers in supporting PwPD to improve long-term compliance with digital assessment tools [4].

User engagement (Theme 3). All participants expressed willingness to use the CMFT regularly due to its feasibility, convenience, and time efficiency, especially if real-time updates are provided. All patients found the concept of regular assessment every 2-3 weeks through the CMFT both feasible and engaging. Most preferred to do the assessment at home for convenience, such as saving time on travel. One patient remarked, *"For me, doing it at home would make life a lot easier. What I would find engaging is having not necessarily real-time feedback but regular updates*" (PwPD#6). In addition, a researcher added insights on future developments, as follows: *"Feedback is also a part of the whole AI-PROGNOSIS app, so in the future, there will be a discussion on how we give the feedback to the patients. Later on, it will be defined which part of the information is given to the patients, to the doctors, and to the caregivers*" (Researcher#1). When prompted to share their insights on using the app, participants considered the CMFT practical and time-efficient (2-3 minutes). One patient noted, *"This would definitely be the sort of thing I like to do! It does seem very straightforward and something that wouldn't take up too much time. So that makes it something that I could see myself doing*" (PwPD#1). In general, participants' positive remarks on aspects related to usability, accessibility, and engagement potential are in line with the theoretical constructs of the TAM model, namely perceived usefulness and perceived ease of use, which determine user acceptance of health technologies [6]. During the session, discussions have also arisen regarding the psychological impact of long-term symptom monitoring. In fact, this practice can be challenging for some people, who may feel overwhelmed by regularly confronting symptom progression or fluctuation; however, healthcare professionals can help address these concerns by providing support, guidance, and resources [21]. Moreover, data protection and ethical issues were discussed, such as transparency and privacy aspects. To address these concerns, it was clarified that the video assessment will not be stored, only the motion tracking data from the extracted features: *"Just to clarify, what we capture are the nodes (landmarks) of the body. These are the data used to extract the biomarkers of assessment and not the real video, so there's no information about personal characteristics or anything about yourself. There is no video going outside of your mobile phone*" (TE#2). The Clinical Expert confirmed that the app will ensure user consent, ethical considerations, and compliance with European data protection guidelines. In this line, WHO have been emphasized that ethical considerations and human rights should be central to AI health technologies to ensure their positive impact [22].

Overall, the co-creation session provided valuable insights for enhancing the design of CMFT for integration into the AI-PROGNOSIS

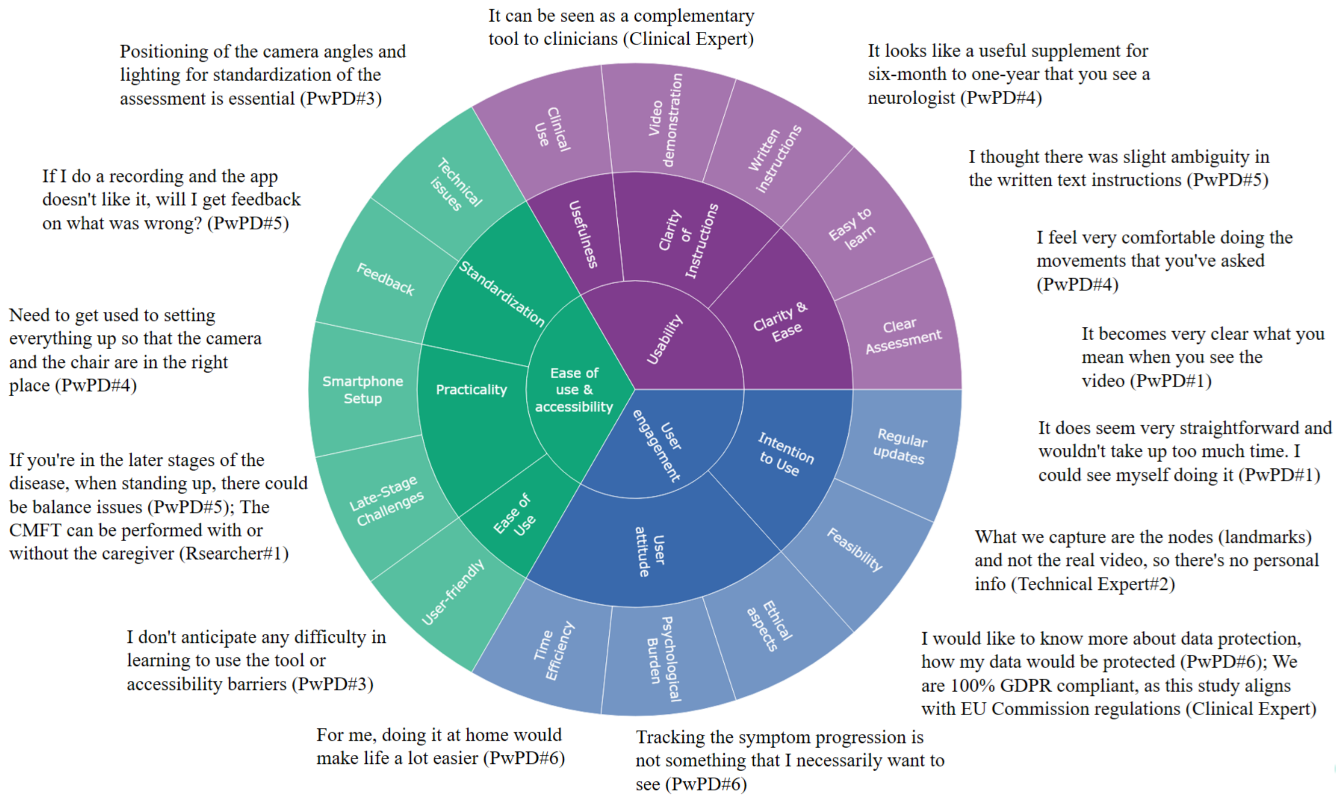

Figure 2: Overview of the main findings derived from the thematic analysis

app, suggesting its potential to provide clinicians with comprehensive and objective data. Additionally, CMFT can empower PwPD to proactively manage their condition through symptom self-assessment, while enabling remote symptom monitoring has the potential to reduce healthcare costs and improve the overall quality of life of PwPD [19, 23].

4.2 Co-creation evaluation feedback

The online questionnaire responses, collected from eleven anonymous participants, aimed to evaluate overall satisfaction and provide insights for enhancing future agile co-creation design processes. Main results are briefly summarised below.

Overall satisfaction. The majority of participants reported a very positive experience, with 45.5% indicating a high level of satisfaction and another 45.5% expressing satisfaction. Additionally, all participants expressed their willingness to attend future co-creation sessions. Participants appreciated the insights provided by PD patients to improve the design of the proposed CMFT. They valued the presentation of innovative aspects, such as objective techniques to assess motor skills related to posture and balance. Some participants also expressed satisfaction in being involved in PD research that could benefit others and contribute to the development of an innovative mobile app. The simplicity and straightforwardness of the CMFT were specifically recognized.

Areas for improving. Some participants emphasized the importance of better planning the duration of the session and providing clarity regarding the future sessions and the specific aims of the app. There was some uncertainty about whether the app was intended for research data collection or algorithm development for predicting PD conditions. Suggestions for improvement included extending the session duration to allow for more in-depth discussion and providing regular feedback to keep stakeholders engaged. Clear, detailed instructions and visual representations were emphasized as necessary, particularly due to language barriers. One participant also suggested to include interactive demo materials to help convey what needs to be developed.

Overall, the collected feedback from all participants, including PwPD and technical/clinical experts, highlighted several concerns and suggestions for improving the proposed CMTF. To address these, the following actions will be implemented: i) extending future session duration for more in-depth discussions; ii) providing clearer instructions and visual representations to ensure patients' full understanding of the proposed motor tests; and 3) incorporating regular feedback and eventual interactive materials to keep patients engaged. Moreover, future work involves transitioning the CMFT to full scale development and implementation using real-time MediaPipe Human Pose Landmark for the identification of key 3D body landmarks. Experimental work yielding promising results in this direction is discussed in [24]. In addition, it is our intention to continuously integrate stakeholder feedback and in parallel refine the algorithms for data collection towards the preparation of the clinical validation trials. Finally, comprehensive user testing in a larger cohort including different countries (i.e., UK, France, Spain, Germany) and clinical centers is also expected to be conducted to assess effectiveness of the CMFT in real-world settings.

5 CONCLUSION

Agile co-creation methodologies hold significant value within user-centered design. The presentation of mock-ups and interactive discussion allowed for a thorough exploration of usability, accessibility, and user engagement. The collaboration between the research team and PwPD throughout this session was crucial for ensuring that the CMFT meets the needs and preferences of its end users. While the small sample size limits the generalizability of the findings, the feedback from this session will inform further developments of the CMFT within the AI-PROGNOSIS mobile app. Future steps will include additional patient feedback and real-world user testing to evaluate feasibility, acceptability, and user acceptance.

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