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Addressing the Cognitive Care Gap in Parkinson's Disease through Participatory Co-design of a Digital Neuropsychological Assessment Platform

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Article

Keywords:

Posted Date: November 3rd, 2026

DOI: https://doi.org/10.21203/rs.3.rs-11557183/v1

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Additional Declarations: No competing interests reported.

Abstract

Cognitive impairment is a prevalent and clinically significant feature of Parkinson's disease (PD), although systematic neuropsychological assessment remains inconsistently integrated into movement disorder clinical care. Time constraints, limited neuropsychology workforce capacity, and fragmented data infrastructure impede early identification and longitudinal monitoring of cognitive decline in this population. The 'PDCogniCare' program aimed to address this gap by developing best-practice guidelines and a PD-specific neuropsychological toolkit. To implement this program in clinical settings, the PDCogniCare digital platform was co-designed and developed as a web-based tool to improve access to cognitive assessment, support clinician training, competence and confidence, and enable longitudinal tracking of neuropsychological outcomes across Movement disorders and psychology services. A participatory asynchronous co-design methodology was employed across three workshops and an interim system evaluation, across metropolitan health services in Queensland, Australia. Fifteen participants were involved, encompassing all interest holders in the neuropsychological assessment journey. Design activities included journey map refinement, MoSCoW feature prioritisation, low-fidelity prototype development, and iterative platform evaluation. Consumer and caregiver input was integrated throughout. The finalised platform received a mean System Usability Scale score of 82.5, placing it in the excellent range. Participants confirmed broad alignment between the platform and their clinical and lived experience priorities. Remaining concerns, including system integration, client enrolment, clinical pathway gaps, and data governance issues, were identified as priorities for future refinement prior to wider implementation. The findings support participatory co-design as an effective methodology for developing acceptable and clinically grounded digital health tools in neurodegenerative disease contexts.

Introduction

Parkinson's disease (PD) is among the most common neurodegenerative disorders.[1] Specialist care for People living with PD (PwPD) has historically centred on the assessment and management of motor symptoms.[2] This focus has come at the expense of systematic attention to non-motor features, most notably cognitive decline.[3,4] Cognitive impairment is neither a peripheral nor a late complication of PD.[4–6] It is a defining and disabling feature that affects the majority of those living with the condition.[7] The cognitive impairment profile in PD is distinctive, characterised by early difficulties with executive function, visuospatial processing, and sustained attention.[8] This carries serious clinical consequences; cognitive decline in PD predicts falls, affects the safety of pharmacological management, impacts caregiver quality-of-life, and determines eligibility for emerging disease-modifying therapies.[9–11]

Given these implications, early and accurate identification of cognitive impairment should be a routine component of PD care. In practice, however, it is not. Clinicians in movement disorder settings cite time constraints, limited access to neuropsychology services, and uncertainty about assessment and referral pathways as key reasons for infrequent screening.[12] Additionally, early identification of cognitive decline

ensures timely intervention, effective treatment, future planning and support,[13] making the case for a structured, accessible approach to cognitive assessment in PD.

The PDCogniCare programme was established to address this gap, informed by the perspectives of people living with PD and clinical stakeholders across movement disorder, neurology, psychiatry, and psychology services.[12–14] The programme developed best practice guidelines for the diagnosis, evaluation, and management of cognitive disorders in PD, along with an evidence-based neuropsychological toolkit specific to the condition.[15] These outputs established a coherent clinical framework where none had previously existed. What remained was a practical means of delivering that framework within the clinical settings where it was most needed.

Digital clinical support tools offer one way to deliver such an approach, but their value depends on uptake. Research informed by the Technology Acceptance Model indicates that clinical tools are most readily adopted when perceived as useful and aligned with existing workflows.[16–18] Participatory co-design methodology extends this principle. Interventions developed with input from end users, including both clinicians and lived experience experts, are better suited to real-world implementation than those developed without such input.[19] Together, these frameworks suggest that a digital tool for cognitive assessment in PD is most likely to be adopted if it is co-designed with the clinicians and consumers who will use it. Additionally, it needs to be built to fit within existing clinical workflows.

The aim of this study was therefore to co-design, develop and evaluate a web-based clinical tool to create accessible guidelines and toolkit for use within movement disorder and related clinical services. Our goals were to (i) improve access to neuropsychological assessment for people living with Parkinson's disease (PwPD) attending movement disorder clinics; (ii) support clinician competence and confidence through integrated education on best practice guidelines; (iii) enable longitudinal tracking and sharing of cognitive assessment results across services, individuals, and families; and (iv) develop a platform grounded in the priorities and lived experience of all those involved in cognitive care for PD.

Methods

Study Design

A participatory co-design methodology was employed to develop a neuropsychological assessment platform to improve detection of cognitive decline in PD. The co-design process was directly informed by three prior studies examining stakeholder experiences and barriers to cognitive assessment in PD,[12–14] and a scoping review of barriers and facilitators to technology implementation in neuropsychological assessments.[20] Together, these produced a neuropsychological assessment journey map,[12] a synthesis of stakeholder needs across clinical and consumer perspectives, and a candidate set of platform features that collectively provided the empirical foundation for each workshop. Three co-design workshops and an interim system evaluation were conducted between December 2024 and January 2026 across metropolitan health services in Australia. Following each stage, outputs were reviewed by a

Consumer and Community Involvement Group (CCIG) and a project steering group to ensure that emerging design decisions remained grounded in the needs and experiences of those most directly affected by the platform and its implementation.

The CCIG comprised consumers and carers with direct experience of PD and cognitive assessment services, recruited via the health services' consumer engagement networks. The steering group included clinical and research leaders with oversight of the broader PDCogniCare project. Both groups convened between each research stage, providing structured feedback on outputs from a consumer and clinical governance perspective. This model of staged consumer and governance review is consistent with published co-design methodology.[21,22]

Ethical Considerations

The study was conducted in accordance with the Declaration of Helsinki. Ethical approval was granted by the Metro North Health Human Research Ethics Committee (Project ID: 100098), and the University of Queensland Human Research Ethics Committee (Project Number: 2023/HE002029). All participants provided written informed consent prior to participation, and data were de-identified prior to analysis.

Participants

Participants were recruited using snowball sampling, initiated through the professional networks of the research team and extended via referrals from existing participants across both health services. This strategy was selected to ensure representation across the full range of stakeholder groups involved in neuropsychological assessment within PD clinical services, including those whose perspectives may not be readily accessible through formal recruitment pathways. Stakeholders were defined as individuals who deliver, receive, or are otherwise affected by the processes and outcomes of neuropsychological assessment in PD. Participant groups included neurologists, neuropsychologists, movement disorder nurses, psychiatrists, PwPD and caregivers.

Asynchronous Co-Design

A fully synchronous co-design model, in which all participant groups engage concurrently, was not achievable given the clinical and professional demands placed on participants across metropolitan health services. Identifying mutually suitable meeting times proved consistently difficult. An asynchronous approach was therefore adopted, consistent with models used in similar co-design projects where scheduling constraints or need for flexibility preclude simultaneous participation.[23,24] Asynchronous co-design involves conducting sessions independently with discrete participant groups, with the outputs of each session carried forward and introduced to subsequent groups to enable iterative refinement across perspectives.[25] This approach preserves the collaborative and iterative

character of co-design and reduces participation barriers associated with time constraints, clinical workloads, and geographic distribution.[23–25]

Within each session, activities were structured in two phases. Participants first completed the design activities independently, generating outputs that reflected their own stakeholder perspective without prior exposure to the views of other groups. The outputs of preceding sessions were then introduced for review and discussion, enabling comparison across perspectives and supporting convergence where views differed. This sequential integration of findings ensured that no single stakeholder group's input was privileged in the design process. It also ensured that the platform progressively reflected a synthesis of clinical expertise, technical knowledge, and lived experience. All sessions (Fig. 1) were conducted via videoconferencing (Zoom or Microsoft Teams) and supported by a shared digital whiteboard environment (Miro). Miro facilitated collaborative activities including journey map annotation, card sorting, and prototype review.

Workshop 1

The first workshop focused on evaluating and refining the neuropsychological assessment journey map produced during the prior qualitative interview study. The journey map consisted of a four-phase assessment pathway comprising initiation, brief cognitive screening, detailed neuropsychological assessment, and feedback.[12] Participants were presented with the journey map via screen share and invited to review, critique, and annotate it collaboratively using Miro. Activities were structured to achieve three objectives: first, to identify inaccuracies or gaps in the mapped pathway from each stakeholder's perspective; second, to surface and prioritise key issues experienced across the assessment pathway; and third, to generate candidate technologies and platform features capable of addressing the identified challenges. Two facilitators guided discussion within the group and recorded all contributions directly into dedicated Miro boards for each activity, providing a contemporaneous visual record of the session. The Miro board was shared with participants between sessions to allow asynchronous review prior to subsequent workshops.

Following Workshop 1, a structured summary of the revised journey map, prioritised issues, and candidate features was prepared and presented to the CCIG and steering group. Feedback was sought on whether the outputs accurately reflected the needs and experiences of consumers and carers and whether any perspectives had not yet been captured. Documented feedback was reviewed by the research team and incorporated into the materials prepared for Workshop 2.

Workshop 2

The second workshop focused on prioritising the features and needs identified in Workshop 1, drawing additionally on barriers and enablers identified in the stakeholder study,[13,14] and the scoping review.[20] These were presented to participants at the outset of the session to contextualise the prioritisation task. Prioritisation was conducted using a MoSCoW analysis framework (Must have, Should have, Could have,

Won't have). MoSCoW analysis framework includes a structured consensus method widely used in health technology development to rank and negotiate competing requirements across stakeholder groups.[26,27] This was delivered as a card-sorting activity within Miro. Participants were each presented with a digital card for each candidate feature and asked to individually allocate it to one of the four MoSCoW categories before the group convened to discuss and negotiate a consensus position. Features categorised as Must have or Should have were carried forward to inform prototype development. Following the prioritisation activity, the research team worked with participants in real time to develop a low-fidelity prototype of the neuropsychological assessment platform within Miro. The activity involved translating the prioritised feature set into an initial design that participants could evaluate and iterate upon during the session.

The low-fidelity prototype was subsequently presented to the CCIG and steering group. Feedback was sought on the relevance, usability, and accessibility of prototype features from consumer, caregiver, and clinical governance perspectives. Refinements informed by this feedback were incorporated into the platform prior to platform development.

Platform Development

Following Workshop 2 and the subsequent CCIG and steering group review, the low-fidelity prototype was used as the basis for developing a functional web-based platform. The prototype provided a detailed specification of the prioritised feature set, interface design decisions, and workflow requirements that informed the development process. Platform development was guided by the principle that the resulting system should reflect the synthesis of clinical, technical and lived experience perspectives generated across the preceding co-design stages. The platform was developed as a web-based application to ensure accessibility across the range of devices and operating systems used within clinical services. Further, the installation and maintenance burdens associated with locally deployed software were avoided, which had been identified as an implementation barrier in the scoping review.[20] Features categorised as Must have and Should have in the MoSCoW analysis were prioritised for inclusion in the version of the platform presented for evaluation, with Could have features incorporated where development capacity permitted. The platform was reviewed internally by the research team prior to the system evaluation to identify and resolve technical issues that may have confounded participant feedback on usability and clinical utility.

System Evaluation

A system evaluation was conducted with a purposively selected group of clinical participants, including neuropsychological interns, a neuropsychologist, a geriatrician, and a movement disorder nurse. Participants were selected to represent the range of clinical roles involved in the neuropsychological assessment pathway. Participants were provided with access to the platform and a structured activity document outlining a series of tasks corresponding to core platform functions. For each activity,

participants were required to complete the task and provide open-ended written feedback addressing (i) the usability of the platform, (ii) its clinical utility within their scope of practice, and (iii) any concerns regarding implementation into existing clinical workflows. This evaluation served to identify residual usability issues and assess the degree to which the platform aligned with clinical practice prior to the final workshop. Feedback was compiled and summarised by the research team and used to refine the platform in preparation for Workshop 3.

Workshop 3

The third workshop provided participants with an opportunity to review the refined platform considering the system evaluation findings. Participants were invited to provide final comments on the platform's design, feature set, and suitability for implementation within PD clinical services. The discussions were intended to identify any outstanding concerns and to confirm that the final platform reflected the priorities and requirements established across prior sessions. The finalised platform was subsequently presented to the CCIG and steering group, who reviewed the outputs and indicated that the platform was suitable to progress to further evaluation.

Data Collection and Analysis

All workshops and the system evaluation were conducted via videoconferencing platforms, with automated transcripts generated and reviewed by the research team for accuracy. Transcripts were analysed alongside the visual outputs produced on Miro, including annotated journey maps, MoSCoW prioritisation boards, and prototype iterations, which provided a comprehensive record of the design decisions made across sessions. Analysis was conducted iteratively after each session to generate emerging themes and outstanding design questions. These summaries were used to prepare materials for subsequent sessions and were introduced to the following participant group as part of the asynchronous integration process. Themes identified across sessions were progressively refined through this iterative process, with convergence and divergence across stakeholder perspectives documented and carried forward as the basis for discussion in subsequent workshops.

Findings

A total of 15 participants from Queensland, Australia took part across multiple stages of the co-design process (Table 1). Participants comprised 8 healthcare professionals, 2 neuropsychology student interns, 4 people living with PD and 1 caregiver. Healthcare professionals were recruited from three public hospitals across two health services. Participants ranged in age from 20 to 69 years, with neuropsychology interns completing their first placement year and healthcare professionals having between 5 and 29 years of experience in their current roles. A summary of participant demographic characteristics is provided in Table 2.

Table 1
Level of engagement in the co-design process

Role	Co-Design 1	Co-Design 2	System Evaluation	Co-Design 3
Geriatrician	✓	✓	✓	✓
Nurse Navigator	✓	✓	✓	✓
Neuropsychologist	✓	✓		✓
Person with PD	✓	✓		✓
Person with PD	✓	✓		✓
Neurologist	✓	✓		✓
Neuropsychologist	✓	✓		✓
Neuropsychologist	✓	✓		✓
Caregiver	✓	✓		
Person with PD	✓	✓		
Person with PD			✓	✓
Neuropsychologist				✓
Psychiatrist	✓			
Neuropsychologist Intern			✓	✓
Neuropsychologist Intern			✓	✓

Table 2
Participant demographics

Category	Sub-Category		N	Percent
Expertise	Healthcare Professional	*Neuropsychologist*	4	26.7
		Geriatrician	1	6.7
		Neurologist	1	6.7
		Psychiatrist	1	6.7
		Nurse Navigator	1	6.7
	Intern	*Neuropsychologist Intern*	2	13.3
	Lived experience	*Person with PD*	4	26.7
		Caregiver	1	6.7
Years in current role	0 to 1†		2	13.3
	5 to 9		4	26.7
	10 to 14		1	6.7
	20 to 24		1	6.7
	25 to 29		1	6.7
	Not reported		1	6.7
Gender	Female		7	46.7
	Male		8	53.3

† Years in the Program for Neuropsychologist Interns

Workshop 1

Workshop 1 refined the neuropsychological assessment journey map, surfaced key issues from each stakeholder group, and generated a potential feature set for platform development. The sections that follow report the principal issues identified at each stage of the pathway, before presenting a consolidated summary of technology features.

- **Activity 1a: Journey Map.** Participant discussions identified concerns at every stage of the neuropsychological assessment pathway. Spanning from how clients entered the process, how assessments were conducted and documented, and how findings were communicated and followed up. The sections below report the principal issues identified at each stage.
    - **Initiation.** The initiation stage revealed gaps in both clinical practice and the map's representational scope. The journey map’s terminology excluded non-hospital settings and

used ambiguous labels such as *"younger clients"*. Focused ultrasound was absent as a procedural pathway, while cognitive evaluation was not considered as a definite pathway in movement disorder clinics. Finally, people with lived experience frequently arrived without understanding why an assessment had been recommended. A caregiver captured this directly, noting the need to *"have the option for more information [on cognitive assessments]. You can say yay or nay"*. This also allows for a clear choice to engage or decline with the information provided.

- **Brief Cognitive Screening.** Three interconnected issues characterised the brief cognitive screening stage. Routine cognitive assessments for PwPD being inconsistently administered across services were discussed. The absence of baseline data made longitudinal tracking of cognitive change difficult, consequently limiting the clinical utility of screening in this population. Within the data handling substage, assessment data were recorded inconsistently across integrated electronic medical record (iEMR) and paper charts, and inter-clinician sharing remained reliant on fax transmission: *"…people that want to send in faxes to the referral centre"* (Nurse Navigator). In the physician review substage, variability in clinical expertise and unclear diagnostic responsibility created uneven management of findings. For people with 'normal' cognitive results, the absence of serial assessments and limited non-pharmacological follow-up were the primary concerns. For those with mild-to-moderate impairment, inconsistent referral practices and fragmented longitudinal monitoring dominated.
- **Detailed Neuropsychological Assessment.** The detailed neuropsychological assessment stage was affected by workforce constraints, poor data integration, and stakeholder communication deficits. Limited neuropsychologist availability and the absence of baseline cognitive data were central problems. One psychiatrist advocated for earlier routine assessment so that a reference point exists when cognitive questions later arise: *"maybe people should be doing this 10 years into their Parkinson's so we know what they used to be like"*. Poor integration of imaging, education and clinical history with assessment results compounded these difficulties. As a neuropsychologist noted *"So primary functioning is based on their age, education and vocational history. So I guess that would be helpful to have those information gathered prior… it also could have an impact on the actual, you know, premorbid functioning"*.
- **Feedback and Management.** Fragmented stakeholder coordination, inconsistent follow-up for moderate-to-severe cognitive impairment, and variable reporting practices were the dominant concerns in the feedback and management stage. Non-pharmacological management strategies were frequently absent or inconsistently communicated, and inter-service data sharing remained reliant on fax-based transmission.

- **Activity 1b: Technology Features.** Probable technology features were identified across all four stages of the journey map. Table 3 organises these features by stage and feature area. For instance, participants at the initiation stage prioritised information and education features. These included executive summaries, plain-language materials, and resources addressing dementia stigma and assessment expectations. At the brief cognitive screening stage, features clustered around clinical

decision support (standardised tools, PD-specific norms, motor accommodations), referral and data management (electronic referral, iEMRintegration), and education and resources for all stakeholder groups. At the detailed neuropsychological assessment stage, priorities centred on data integration and reporting (centralised dashboards, longitudinal tracking, AI-assisted reporting), as well as access and communication (role-based access, client portals, multilanguage support). In the feedback and management stage, reporting and coordination features predominated. AI-assisted plain-language reporting, consent management and Deep Brain Stimulation (DBS) -specific education were discussed. Spanning all stages, participants consistently identified interface and accessibility requirements covering layout, voice commands, ergonomic design and cross-platform compatibility.

- **Activity 1c: CCIG and Steering Group Review.** The CCIG and steering group were presented with the findings of Workshop 1. Questions were raised about the generalisability of the mapped pathway to clinical services beyond the two public health services involved in the study. Some members noted that the pathway may not fully reflect the full range of practices across other settings. Feedback also emphasised the importance of drawing on established and verified sources when developing client and caregiver-facing educational resources. Specific recommendations included incorporating materials from Parkinson's Queensland, Dementia Australia, and existing carers' pathways rather than developing new content in isolation. These recommendations were carried forward into the feature prioritisation and prototype development activities of Workshop 2.

Table 3
Identified technology features at various stages

Stage	Feature area	Probable feature
Initiation	Information & education	Executive summaries
		Plain-language explanations of assessment processes and results
		Accessible feedback sheets
		Resources addressing dementia-related stigma
		Materials explaining assessment purpose, expectations, duration, and procedures
Brief cognitive screening	Clinical decision support	Standardised screening tools with consistent, shareable scores for longitudinal comparison
		PD-specific clinical norms
		Flexible (non-algorithmic) decision support
		Voice command functionality; ergonomic stylus and tablet design for tremor
		Pen-and-paper fallback for non-digital settings
	Referral & data management	Electronic referral management with automated pathways
		iEMR integration as single source of truth
		Easy search across medical records
		Clinician training and accreditation pathways
		Controlled release of results prior to clinical discussion
	Education & resources	Structured modules for PwPD, carers, and clinicians
		Short captioned videos with downloadable plain-language PDF summaries
		Caregiver access to cognitive test results
		Links to rehabilitation resources and support group directories
Neuropsychological assessment	Data integration & reporting	Centralised cognitive dashboard (single-click access to reports, MoCA, bloods, imaging)
		Longitudinal cognitive tracking with graphical and icon-based plain-language outputs

Stage	Feature area	Probable feature
		Automated tablet-based data capture with direct upload
		AI-assisted reporting with draft summaries and plain-language versions
		PD-specific clinical norms
	Access & communication	Role-based access controls
		Client portal for results and treatment recommendations post-discussion
		Multilanguage support with interpreter-assisted assessment
		Adaptive neuropsychological battery selection
		Client-facing preparation information
Feedback & management	Reporting & coordination	AI-assisted plain-language reporting
		Centralised dashboard integrated with iEMR
		Technology-supported consent management
		Secure clinician messaging
		Staged client portal release
		DBS-specific education (pre/post-surgical cognitive and personality impacts)
		Medication interaction information
All stages	Interface & accessibility	Uncluttered layouts with large font sizes
		Voice command functionality; ergonomic design accommodating tremor
		Cross-platform compatibility (mobile, tablet, desktop)
		Simplified login and secure data sharing
		Cross-platform accessibility for rural and remote users

Workshop 2

Building on the candidate feature set generated in Workshop 1, Workshop 2 comprised two activities; (i) MoSCoW prioritisation of candidate platform features across participant groups, and (ii) collaborative low-fidelity prototype development within a shared digital workspace. Together, these activities

translated the issues surfaced in Workshop 1 into a structured, negotiated feature set and an initial design direction for platform development.

- **Activity 2a: MoSCoW Prioritisation.** Prioritisation decisions across participant groups were shaped by four cross-cutting considerations. First, features were evaluated for alignment with the platform's primary focus on cognitive assessment in PD rather than general disease management. Some participants actively revised their ratings during discussion, downgrading DBS treatment information and broader disease management features to ensure focus on neuropsychological assessments. Second, implementation feasibility within Health service infrastructure was a consistent moderating factor. Features dependent on iEMR integration, including automated data import and easy referral management, were deprioritised or assigned to ‘Won't have’ by participants.. Third, controlled access and data security were treated as non-negotiable design requirements across all groups. Participants consistently anchored features related to consent management and role-based sharing in the ‘Must have’ category. Fourth, usability considerations were prioritised to support adoption by clinicians and clients with varying levels of digital literacy and physical capacity. These included simplified navigation, minimal clicks and uncluttered interfaces.

Notable divergences emerged in three areas. AI-assisted reporting was rated ‘Should have’ by neuropsychologists, who valued its potential to reduce report-writing burden. One neuropsychologist describing the dual demand of producing formal clinical reports and accessible patient summaries as taking *“a chunk out of the day”* and proposing that AI could draft the latter from the former as a starting point. However, other healthcare professionals classified this feature as ‘Won’t Have’. Another feature, support for users with physical limitations, was rated ‘Must have’ by PwPD and caregiver groups but ‘Won't have’ by neuropsychologist participants, who considered it outside the scope of a clinician-facing platform. The simple login with Remember Me option was rated ‘Must have’ by most clinical groups for ease of client access, but ‘Won't have’ by neuropsychologists citing security concerns. This divergence was not resolved during prioritisation and was carried forward as a design constraint into prototype development.

- **Activity 2b: Low-Fidelity Prototype Development.** Following prioritisation, the research team worked with participants in real time within Miro to translate the carried-forward feature set into a low-fidelity prototype. Features rated ‘Must have’ and ‘Should have’ were consolidated across participant groups, with overlapping items merged and scope refined to reflect the platform's focus on neuropsychological assessment in Parkinson's disease. The resulting prototype comprised four core components: a login interface, a clinician dashboard, a client or PwPD portal, and an education module, each developed iteratively with participants annotating, revising, and negotiating design decisions in real time.

The login interface incorporated a Remember Me function. A role-differentiated design emerged from a divergence between participant groups: the neuropsychologist group recommended omitting the

Remember Me function from the clinician-facing interface on security grounds, a position not shared by other clinical groups, resulting in separate login configurations for clinician and client-facing access.

The clinician dashboard was designed around top-side navigation, a client search bar, a recent client list with notifications, and tabbed navigation across clinical notes, investigations, referrals, and reports (presented in landscape format). A data sharing icon for controlled report distribution was included following consistent demand across groups. The neuropsychologist group proposed excluding a dedicated scheduling component within the platform as it could introduce the risk of missed appointments and double bookings: *"we'd have two separate ones to then check in on and then that's risk of like double booking"*.

The client portal consolidated demographics, medical history, care team details, and longitudinal cognitive data, with colour-coded graphical cognitive scores and a toggle to show or hide graph detail. Individual clinician selection for report sharing was included, with no select-all option. Pre-populated metadata fields were discussed among PwPD and caregiver groups. A notable tension emerged around the client-facing view: one group recommended restricting it to text-based summaries rather than graphical or numerical data. Others, however, supported graphical display for transparency and engagement, with one PwPD pointing to the limitations of text-only formats for those with language or literacy difficulties: *"if you've got a deficit in the word area, just reading your report is probably not going to be the best thing to do"*.

The education module was designed with (i) left-side category navigation, (ii) short-captioned videos, (iii) downloadable PDF summaries, integrated note-taking with auto-save, (iii) progress tracking, (iv) a quick resource-sharing button, (v) breadcrumb navigation, (vi) a search function, and (vii) cross-platform consistency across desktop, tablet, and mobile. No substantive divergences were recorded for this component, suggesting broad agreement across groups about the core requirements for accessible, structured educational content. The low-fidelity prototype created by participants is included in **Supplementary Appendix A.**

- **Activity 2c: CCIG and Steering Group Review.** Reviewing the low-fidelity prototype, the CCIG and steering group confirmed that the design was clear and accessible. The overall layout and navigation considered appropriate for the intended user groups. Members recommended that the platform support multiple communication channels for delivering information and notifications to clients. For instance, both email and SMS as necessary options to accommodate different preferences and levels of digital access.

Two substantive design questions were also raised. The first concerned whether the platform would require a formal data sharing consent mechanism, given the sensitivity of cognitive assessment data. The second asked whether caregivers should be granted a comparable level of access to client information as the client themselves, and under what conditions. Finally, the inclusion of an appointment booking system was discussed. This arose from plans to involve medical interns and externs in conducting neuropsychological assessments during the trial, as these clinicians do not have access to

the tools available to neuropsychologists in the clinical setting. The questions were forwarded to the research team for consideration during platform development.

System Evaluation

System evaluation was conducted with a purposively selected group of five clinical participants representing the range of roles involved in the neuropsychological assessment pathway. The clinical groups included neuropsychological interns, a geriatrician, a person with PD, and a movement disorder nurse. The evaluation produced both quantitative and qualitative findings as discussed below. The feedback was compiled and summarised by the research team and used to inform platform refinements prior to Workshop 3.

- **Quantitative activity: System Usability Scale (SUS).** Individual scores ranged from 75.0 to 97.5, with a mean score of 82.5. This placed the platform in the excellent range and above the recognised industry benchmark. The mean SUS scores are presented in Fig. 2.
- **Qualitative Activity: Thematic Usability Findings.** The platform was described as clean, easy to navigate, and intuitive for core clinical tasks. This view was shared across clinician and consumer groups alike. For instance, a geriatrician noted it was *"clean, straightforward"* and a PwPD echoing that it was *"clear and clean"*. The most substantive feedback arose within the training module and the notes functionality. Several technical issues and interface improvements were identified. Findings and recommendations by platform component are summarised are reported below.
- **Training and Education Module.** Course enrolment was described as seamless and the overall layout well-received. The placement of the Mark as Complete button at the top of course pages was, however, consistently identified as counterintuitive across participants. One neuropsychologist intern noted *"a bit confused why the "mark as complete" button is at the top of the page and not the bottom?"*. The note-taking functionality was valued conceptually but raised several concerns. Auto-save was absent, the save/clear confirmation pop-up was described as intrusive, and a split-screen layout was proposed to allow simultaneous content viewing and note-taking. Technical issues included note functionality failing in the first module, videos not loading, and a multi-factor authentication re-verification prompt blocking progression despite active login. Incomplete quiz feedback for partially correct responses and training progress failing to reset correctly across clinical roles were also identified.
- **Clinician Dashboard.** The client list format was regarded as clear and efficient, and the notification system was described as helpful. Participants recommended that notifications be made clickable to navigate directly to the relevant client record or calendar view. The deactivate client action was considered too easily triggered accidentally, and assessment request status was insufficiently visible within the current layout. Technical issues included enrolled clients disappearing following enrolment, a discrepancy between client counts in the appointments and clients' tabs, and the training tab failing to navigate correctly.

- **Scheduling Interface.** The availability management interface was described as intuitive, with break-time support commended as a practical feature. The display of all individual time slots in a single list was, however, identified as unwieldy when recurring monthly availability was set. An edit function for existing availability entries was also absent. Repeat appointment times failed to appear on the calendar, an issue identified as likely to affect clinical workflow if unresolved.
- **Client Portal.** The portal structure was considered logical and appropriate for the target demographic. The locking of results until clinical discussion was noted as appropriate by multiple participants, with clinicians and people with lived experience alike identifying the risks of unsupported access. Participants emphasised the potential for distress when results are received without clinical context, warning that individual may *"misinterpret information"* and become *"distressed and upset"* before any explanatory conversation has taken place. A PwPD raised a related concern, noting that premature access could prompt unsupported internet searches, given that *"[Online search] has a tendency of giving the worst news possible"*. Icon inconsistency between the show to client and view details functions caused confusion. The completed assessment count reflected only assessments currently visible to clients rather than all completed assessments. This discrepancy participants flagged as potentially misleading.
- **Assessment Management.** The option to submit assessments electronically or via PDF upload was specifically commended as accommodating of real-world clinical practice, with one neuropsychologist intern welcoming the ability to *"drag and drop the PDF into the patient file"* as a practical convenience. Several technical issues were identified, including the save draft function submitting the form rather than saving it, assessment graphs failing to generate despite complete data entry, and duplicate entries in the visual memory domain. The absence of a report download function was flagged as a significant gap for clinical documentation workflows.
- **Resource Sharing.** The resource sharing function was consistently described as a valuable and well-conceived feature. A geriatrician highlighted the time-saving benefit of centralised resources, noting that consolidated access removed the need to search externally for relevant links and materials: *"that's saving me time, because if it's all there in one place I don't have to go hunting the web"*. Participants were uncertain whether shared resources were automatically visible to clients upon sharing and whether client access to resources could be monitored. These uncertainties, if unresolved, could affect clinicians' confidence in using the function reliably.
- **Notes and Clinical Observations.** The note-taking concept was well-received, though the character limit rendered notes beyond approximately 105 characters unviewable in full. Editing after saving was not possible, and notes were lost when the edit details button triggered a page refresh. Therapist accounts were able to edit and delete notes written by other users. This included clinicians that was considered a permissions issue identified as a significant clinical governance concern. Flagged observations also appeared unexpectedly as medical notes in the client overview. This suggested a misalignment between intended and displayed categorisation that would require resolution before deployment.

Workshop 3

Workshop 3 began with a presentation of system evaluation findings, orienting participant discussion toward the refined platform. The platform screenshots are included in **Supplementary Table B**. Participants were invited to provide final commentary on the platform's design, feature set, and suitability for implementation within PD clinical services.

- **Final Design Commentary.** Across participant groups, the platform was broadly received as clean, visually accessible, and well-suited to clinical use. Simplicity and minimal interaction steps were consistently highlighted as strengths. Participants noted that direct access to client information without excessive navigation reduced cognitive load in busy clinical settings. A nurse navigator observing that the interface was *"much better than having to manually search for things when you have less time"*. The use of large, clear typography and a dementia-friendly colour scheme were specifically commended as appropriate for the target population. The clinician dashboard was well-regarded for its client search functionality and structured list format. The Provide Resources tab was noted as saving clinical time, and the appointment booking interface was described as intuitive. The locking of assessment results until clinician discussion was considered appropriately designed. Calendar integration with existing health system scheduling tools remained absent, a gap participants flagged as likely to affect adoption in time-pressured clinical environments.

The education module was generally well-received for its structure and mixed content formats, though preferences diverged on content delivery. Most groups valued short, captioned video content alongside downloadable summaries. Others favoured text-based materials for quick reference in busy clinical environments, and podcast-style content was suggested as a further flexible alternative. A neuropsychologist elaborated on the case for text, noting that written materials better support note-taking and allow clinicians to locate specific content quickly without re-watching recordings: *"it's always there for them to quickly read rather than having to go and re watch a video"*. The neuropsychologist group recommended making training resources accessible as an optional self-directed library rather than structured mandatory modules. Minor refinements were also proposed, including relocating the Mark as Complete button to the bottom of training pages and repositioning the notes section to allow simultaneous content viewing.

- **Alignment with Prior Priorities.** Participants confirmed strong alignment between the refined platform and the priorities established across Workshops 1 and 2. The platform's emphasis on simplicity, minimal clicks, and quick access to client data was consistent with feedback from all prior sessions. The goal of supporting early cognitive assessment in Parkinson's disease remained its organising principle throughout. Specific prior recommendations had been incorporated and were confirmed as addressed, including (i) summary boxes within reports, (ii) separate report versions for clients and clinicians, (iii) data sharing preferences, and (iv) the integration of PD resources. A PwPD confirmed that navigational improvements reflected earlier suggestions, noting *"I like the breadcrumb at the top. I mean, I think I mentioned in one of the earlier things, [it] should have*

a breadcrumb line that you could see where you're at and where how far you need to go and that type of stuff. So all of that I like".

- **Outstanding Concerns.** Despite the broadly positive reception, participants identified a set of outstanding concerns across four themes. The principal concerns were around the implementation aspects that warrant consideration.

    - *System integration emerged as the most consistently raised concern.* Integration with iEMR was identified as critical for long-term adoption but remained unachieved. Health services IT infrastructure was described as a significant implementation barrier. A neuropsychologist noting *"now this is depending again on iEMR integration and we we cannot just take all the data and upload it in another platform, that's additional work"*. For the trial phase, a standalone platform was considered acceptable, though iEMR integration was emphasised as essential for sustained adoption beyond the trial period. A downloadable desktop application was recommended for Health service computers to reduce login friction, alongside exploration of Health service credential integration to minimise password burden. Other consideration included cross-browser compatibility, particularly between Safari and Chrome, and server stability under clinical load conditions were also flagged as requiring resolution prior to full deployment.
    - *Client enrolment and access raised a distinct set of concerns.* The feasibility of tablet-based enrolment during appointments was questioned given time constraints. Low at-home capture rates were anticipated without active follow-up. Older clients without email access represented an additional accessibility gap. Participants recommended replacing the term *"study"* with *"assessment"* or *"programme"* to reduce perceived barriers to participation. A concern voiced directly by a PwPD *"you don't want to feel like you're a guinea pig... I'm struggling cognitively, and so I want you to tell me that my cognitive abilities to be assessed"*. Providing both digital and physical enrolment options was also recommended to maximise reach.
    - *Clinical pathway and content gaps were also identified.* The absence of a defined Mild Cognitive Impairment pathway was raised as a significant gap requiring resolution before deployment. Assessment battery flexibility remained unresolved, including clarity on mandatory measures and the capacity to incorporate additional tests based on clinical judgement. Training content was still under development at the time of the workshop. Copyright restrictions on resources from Dementia Australia and Parkinson's Queensland required resolution before content could be embedded. A quality control process for uploaded resources was recommended to ensure clinical relevance and accuracy.
    - *Data governance concerns* centred on four issues. The first was whether digital tick-box consent was sufficient or whether physical signatures would be required. The second concerned restricting the ability to share assessment results with clients to the assessing clinician alone. The third involved the technical handling of sensitive clinical notes not intended for client view. The fourth was the psychological impact of delivering notifications related to cognitive findings without prior clinical discussion. These concerns did not challenge the platform's design in

principle but reflected the particular sensitivities of cognitive assessment data and the population for whom it was intended.

All participant groups confirmed that the platform was suitable to progress to further evaluation in PD clinical services, with minor adjustments recommended prior to full deployment.

- **CCIG and Steering Group Review.** The CCIG and steering group reviewed the finalised platform and provided targeted feedback across several areas. On the enrolment interface, members noted that required fields such as email address and phone number should be clearly marked to guide users through the process without confusion. This refinement was considered particularly important for older users or those with lower digital confidence navigating the form independently.

For the training module, it was recommended that video content be embedded and displayed selectively based on the user's role or participant type. This would ensure that clinicians, clients, and carers each received contextually relevant material rather than an undifferentiated content library. For users who encounter difficulties navigating the platform, members suggested that one-to-one support be made available rather than relying solely on self-directed use. Members also recommended that preferred communication methods be established during initial enrolment to the trial, ensuring subsequent contacts reached each individual through the most appropriate channel.

Two broader clinical concerns were also raised. Members highlighted the role of general practitioners in the care pathway, recommending that the platform facilitate timely sharing of assessment results with GPs given that follow-up neurologist appointments can take between six and nine months to occur. Without a mechanism to reach GPs in the intervening period, clients may receive no clinical response to their results for a significant and potentially distressing period. The group identified this as a gap that the platform was well placed to address, through data sharing and clinician training in how to deliver results. Finally, members identified the value of enabling clients to communicate with a neuropsychologist or other health professional ahead of their assessment or appointment as a means of reducing anticipatory anxiety and improving preparedness. This recommendation resulted in the addition of a new feature in the platform.

Discussion

This study demonstrates that a co-designed digital platform can translate evidence-based recommendations for PD cognitive assessment into a practical tool for use in movement disorder and psychology clinics. The PDCogniCare platform integrated standardised cognitive screening tools, PD-specific norms, referral support, clinician education, longitudinal dashboards, graphical outputs and staged result sharing. It achieved excellent usability, with a mean System Usability Scale score of 82.5, placing it in the excellent range and exceeding the industry benchmark of 68.[28] Further, it was endorsed by clinical and consumer participants as ready for further evaluation. The significance of these findings is not that they add another cognitive screening resource, but that they demonstrate an implementation-

focused system designed to address known barriers to routine, guideline-based cognitive care. This was made possible by embedding standardised screening procedures, PD-specific norms and referral prompts into a single clinical workflow that supports clinicians to apply best-practice recommendations throughout PD care where it is needed the most.

The findings also suggest that access to neuropsychological assessment should be understood as a pathway-level problem rather than a referral problem alone. Participants prioritised features supporting assessment initiation, interpretation, referral, longitudinal review, and communication of results. This aligns with implementation science evidence showing that clinical innovations are more likely to be adopted when they fit existing workflows, reduce burden and provide decision support within routine practice.[29–31] The platform's longitudinal tracking functions are further supported by prior research demonstrating that cognitive change in PD is clinically meaningful over time.[32] Pigott, et al. [33] found that approximately half of participants with normal cognition at baseline developed cognitive impairment within six years. Similarly, Pedersen, et al. [34] found that progression from PD to Mild Cognitive Impairment (MCI) within 27% of the cohort in a period of 3 years, and corresponding to an annual progression rate of MCI to dementia of 9% in early PD. The platform's centralised dashboards and graphical displays therefore address a recognised limitation of current models, in which cognitive information is available to compare over time and difficult to understand among individuals and families.[35,36] Participants with lived experience specifically advocated for visual presentation of cognitive results. This is particularly important for individuals who may experience language, literacy, cognitive or physical barriers. This input directly shaped result presentation and accessibility features. Thereby, indicating that co-design functioned as more than consultation.

The primary implementation challenge identified by participants was integration with the iEMR of current Health Services. Health informatics research consistently shows that electronic health interventions are more likely to be adopted when they are interoperable with existing systems.[37] Polk, et al. [36] further demonstrated that EMR interoperability is associated with dimensions of care quality and patient safety, consequently, reinforcing the importance of data continuity across services. Participants accepted a standalone platform for trial use but viewed interoperability as necessary for sustained adoption. This is consistent with evidence that usability alone is insufficient when digital tools create duplication or remain disconnected from routine documentation systems.[29,37] Overall, this study contributes an implementation-focused model for improving access to cognitive assessment in movement disorder services that incorporates the priorities of all stakeholders involved in the journey.

Limitations and Future Directions

Several limitations should be considered when interpreting the findings of this study. The participant sample of 15 individuals was drawn from metropolitan health services in Queensland, Australia. While appropriate for a co-design methodology, this sample may not fully represent the range of clinical practices and service configurations across regional, rural, or private sector settings. Snowball sampling,

while appropriate for reaching clinically embedded stakeholders, may have introduced selection bias. Participants with existing engagement in PD cognitive care may have been overrepresented. Such overrepresentation may potentially diminish perspectives from services where cognitive assessment is less established. The absence of participants from culturally and linguistically diverse backgrounds further limits the representativeness of findings. The system evaluation was conducted with a purposively selected clinical group of five participants. Usability findings should therefore be treated as indicative rather than definitive.

Future research should progress the PDCogniCare platform to a formal clinical evaluation in movement disorder settings. This evaluation should incorporate quantitative assessment of cognitive screening rates, clinician confidence, and patient-reported outcomes. Evaluation design should include participants from regional and rural services, where access to neuropsychology is most constrained and the potential benefit of the platform is likely greatest. The outstanding implementation questions identified in Workshop 3 should be addressed iteratively during and following the trial phase. These include iEMR integration pathways, mild cognitive impairment clinical decision support and data governance frameworks. Longitudinal follow-up of platform engagement will be necessary to assess whether usability at initial exposure is sustained over time and across clinical roles. As the platform is embedded in routine practice, future co-design iterations should examine the perspectives of participants not represented in the present study. This will ensure the platform remains responsive to the full diversity of the PD population it is intended to serve.

Declarations

Competing Interests

The authors declare no competing interests.

Funding

The author(s) declare that financial support was received for the research and/or publication of this article. This research was supported by the 2022 MRFF Dementia Ageing and Aged Care Mission Grant. ND is funded by the University of Queensland Amplify Fellowship.

Author Contribution

EL, ND, LM, NP and DB conceived and designed the study. EL and DS collected the data. EL analysed and interpreted the data and used the findings to develop the co-design activities. EL drafted the manuscript. All authors (EL, DS, DB, LM, NP and ND) critically revised the manuscript for important intellectual content, approved the final version, and agree to be accountable for all aspects of the work.

Acknowledgement

The authors are grateful to the members of the Consumer and Community Involvement Group for their valuable input on the study procedures. The authors also thank the members of the PDCogniCare team: Tiffany Au, Dr Peter Worthy, Dr Dana Pourzinal, Dr Ji Hyun Yang, Dr Jacki Liddle, Prof Elizabeth Beattie, A/Prof Annette Broome, Prof Gerard Byrne, A/Prof Mark Chatfield, Anna Kelder, Dr Sabrina Lenzen, Prof Sharon Naismith, Prof Peter Nestor, Stuart Robertson, Kumar Sivakumaran, Dr Donna Spooner, Helen Tinson, Dr Ada Lo and Prof Martie-Louise Verreynne. The support of the PDCogniCare partner organisations is also gratefully acknowledged: Parkinson's Queensland Inc., Dementia Australia, Royal Brisbane and Women's Hospital, Princess Alexandra Hospital, OPN365 Pty Ltd, ADNeT, Lions Club of Brisbane Inner North, and Lions District 201Q3.

Data Availability

All data generated or analysed during this study are included in this published article (and its supplementary information files).

Code availability

Code used to generate the figures is available upon request.

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Figures

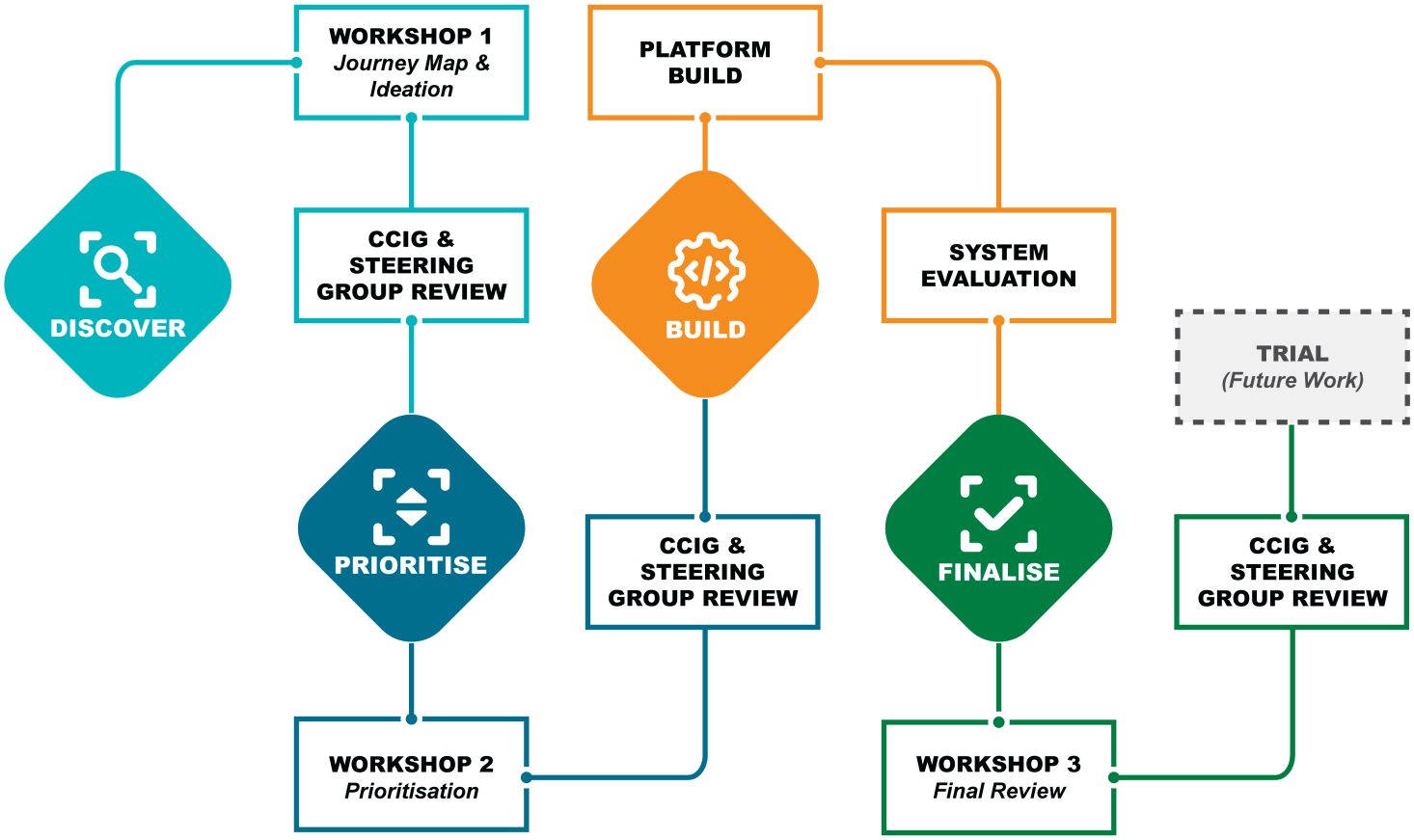


Figure 1

PDCogniCare platform co-design stages

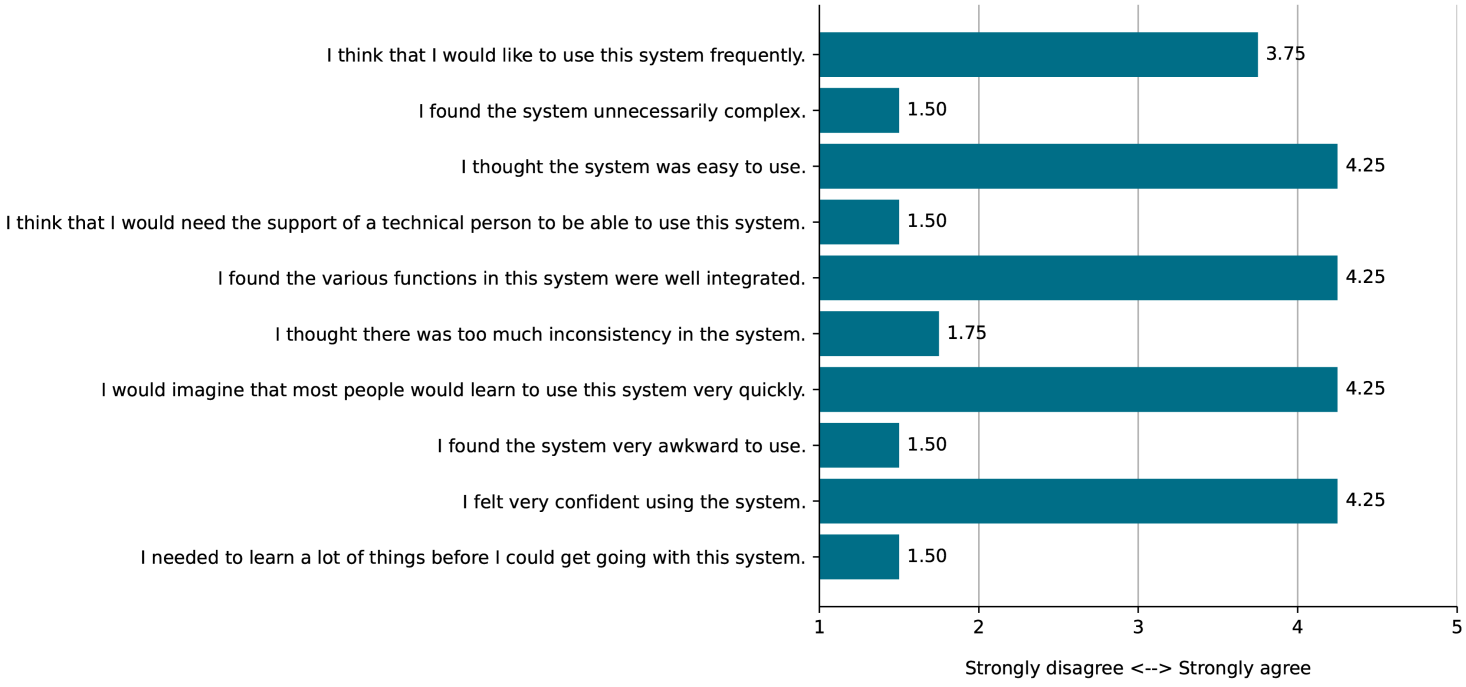


Figure 2

System usability scale for the PDCogniCare platform

Supplementary Files

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- supplementaryappendix.pdf