Supplementary Material

Self-Management Systems for Patients and Clinicians in Parkinson's Disease Care: A Scoping Review

Supplementary Table 1. PRISMA-ScR (Preferred Reporting Items for Systematic review and Meta-Analyses extension for Scoping Reviews) 2022 checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	1
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	3
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	3
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	5
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	6
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	6
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	35-36
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	6, 7
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	7
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	7
Critical appraisal of individual sources of evidence	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	7
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	6-7
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	8
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	9-14

Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	14-20
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	14-20
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	9-20
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	20-21
Limitations	20	Discuss the limitations of the scoping review process.	22
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	23-24
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	24

Supplementary Table 2. Endnote search criteria

Pass[a]	Search string	# of references remaining
0	All Results	15,231
1	Duplicates removed	13,548
2	Reference Type = NOT (protocol OR editorial OR conference OR conference proceedings OR perspective paper)	13,401
3	Title OR Abstract = (Parkinson's disease OR parkinson OR parkinson's OR parkinson disease)	7,526
4	Any Field = (electronic OR software OR wearable OR computer OR platform OR system OR telehealth OR home-based OR online OR device	5,795
4b	Any Field = (digital OR technology OR remote OR portal OR telemedicine OR web OR internet OR ehealth OR mhealth OR mobile	
6	Any Field = (self-manag OR monitor OR self manag OR self-care OR database OR rehabilitation OR program OR data management OR data collection OR intervention	4,123
7	Any Field = (evaluat OR assess OR adherence OR efficiency OR efficacy OR attitude OR usability OR feasibility OR impact OR accept	3,908
8	Any Field = NOT (neuro OR cancer OR mutation OR depression OR genetic OR adipose OR molecular OR insulin OR biomarker	3,396
9	Any Field = NOT (deep brain OR plasma OR tuberculosis OR animal OR mice OR rats OR mouse OR metabol OR gene)	1,644
10	Any Field = NOT (polymorph OR transcranial OR adenosine OR rasagiline OR morphine OR alcohol OR arthritis	1,583

[a]Each pass was conducted on the subset of studies retrieved in the previous pass
[b]EndNote limits searches to 10 terms, so passes 4 and 5 were conducted separately and then combined, with duplicates removed

Pass[a]	Search string	# of references remaining
Screening in Rayyan		
10	Duplicates removed in Rayyan (n = 82)	1,501
11	Title and abstract screening in Rayyan (excluded n=1,409)	92

Supplementary Table 3. Search strings of sample search

Database	Search String	Retrieved
PubMed	((((("Parkinson disease"[MeSH Terms]) OR ("parkinsons") OR ("Parkinsonism" OR ("parkinson's") OR ("parkinsonian disorders"[MeSH Terms])) AND ((telemedicine[MeSH Terms]) OR ("internet-based intervention") OR ("digital health") OR ("remote") OR ("home-based") OR ("electronic") OR ("technology") OR ("software") OR ("m-health") OR (""computing methodologies") OR ("system") OR ("self-management system") OR ("portal") OR ("computing methodologies"[MeSH Terms]) OR ("e-health") OR ("wearable electronic devices"[MeSH Terms]) OR ("self-help devices"))) AND (evaluation)	6,041
CINAHL	AB (parkinson disease or parkinson and disease or parkinson disease or parkinson's disease) AND TX (software or system or remote or portal or technology or digital health or telemedicine or telehealth or ehealth or e-health or mhealth or m-health) AND TX (evaluation or analysis or perspective or attitude or user-experience or acceptability or usability or perspective or UX or barriers or perception)	5,172
Scopus	TITLE-ABS-KEY (("Parkinson disease" OR "parkinsonian disorders" OR "parkinsons") AND ("telemedicine" OR "digital health" OR "internet-based intervention" OR "remote" OR "home-based" OR "wearable electronic devices" OR "computing methodologies" OR "electronic" OR "technology" OR "software" OR "m-health" OR "system" OR "portal" OR "e-health" OR "self-help devices") AND ("attitude" OR "user-experience" OR "acceptability" OR "usability" OR "perspective" OR "UX" OR "barriers" OR "perception"))	7,820
ACM digital library	[[Full Text: "parkinson disease"] OR [Full Text: "parkinson's disease"] OR [Full Text: "parkinsonian disorders"]OR [Full Text: "parkinsons"] OR [Full Text: "parkinson"]] AND [[Full Text: "telemedicine"] OR [Full Text: "digital health"] OR [Full Text: "internet-based intervention"] OR [Full Text: "remote"] OR [Full Text: "home-based"] OR [Full Text: "wearable electronic devices"] OR [Full Text: "computing methodologies"]OR [Full Text: "electronic"] OR [Full Text: "technology"] OR [Full Text: "software"] OR [Full Text: "m-health"] OR [Full Text: "system"] OR [Full Text: "portal"] OR [Full Text: "e-health"] OR [Full Text: "self-help devices"] OR [Full Text: "mhealth"]] AND [[Full Text: "evaluation"] OR [Full Text: "attitude"] OR [Full Text: "user-experience"] OR [Full Text: "acceptability"] OR [Full Text: "usability"] OR [Full Text: "perspective"] OR [Full Text: "ux"] OR [Full Text: "barriers"] OR [Full Text: "perception"]]	1,855
IEEE Xplore	("All Metadata":"Parkinson disease" OR "All Metadata":"parkinsonian disorders" OR "All Metadata":"parkinsons") AND ("All Metadata":telemedicine OR "All Metadata":digital OR "All Metadata":remote OR "All Metadata":internet OR "All Metadata":electronic OR "All Metadata":technology OR "All Metadata":software OR "All Metadata":system OR "All Metadata":portal OR "All Metadata":"e-health" OR "All Metadata":"m-health" OR "All Metadata":"self-help devices" OR "All Metadata":"internet-based intervention" OR "All Metadata":"remote") AND ("All Metadata":evaluation OR "All Metadata":attitude OR "All Metadata":user OR "All Metadata":acceptability OR "All Metadata":usability OR "All Metadata":perspective)	222

Supplementary Table 4. Summary of study characteristics for included articles

Author	Year	Study type	Name of system	Symptom category	Outcomes examined	Study method	Evaluation method
Albani et al [69]	2019	Experimental Study	Not reported	Motor symptoms	Validity, Accuracy, Usability	Mixed	· Accuracy: Specialists assessment based on patient videos recordings · Usability: A study-specific questionnaire of 19-items related to ease of use, learnability, effectiveness, simplicity, adequacy, and availability of information and feeling about the user interface.
Beijer et al. [51]	2010	Case Study	EST (e-learning based speech therapy)	Motor symptoms: Speech training	Intelligibility, Satisfaction	Mixed	Intelligibility: 20 untrained listeners orthographically transcribed SUS sentences recorded at different times Listening ratings for each SUS sentence on a 10-point scale (1 = extremely bad intelligibility to 10 = extremely good intelligibility. Randomized Block Design: Time as a within-subject factor (five levels). Satisfaction: Study-specific questionnaire captured qualitative information on individual experiences with EST using a 10-point scale.
Bendig et al. [41]	2022	Observational Study	Not reported	Motor and non-motor symptoms	Usability, Confidence, Independence	Mixed	System Usability Scale (SUS) and compared with empirical confidence scores (patient-rated) and the task-based independence scores (investigator-rated)
Brown et al. [26]	2022	Survey Study	PD-Bridge	Motor and non-motor symptoms	Usability, Validity, Clinical Relevance, Confidence, Independence, Clinician Experience	Mixed	Usability, Validity/ Clinical Relevance: Focus Groups using System Usability Scale (SUS) Confidence, Independence: Empirical comparison of confidence scores (patient-rated) and task-based independence scores (investigator-rated) Clinician Experience: Study-specific survey with clinicians
Chang et al. [53]	2023	Prospective, Comparative Study	Not reported	Motor symptoms: Speech training	Acoustic measurement, Auditory-perceptual assessment, Voice handicap index, Satisfaction	Mixed	Acoustic measurement: Maximum phonation time (MPT), mean fundamental frequency (F_0), jitter, shimmer, and noise-to-harmonic ratio (NHR) Auditory-perceptual assessment by speech therapists. Each parameter was rated on a five-point scale, from 0 (normal) to 4 (severe impairment). Voice handicap index: VHI questionnaire of 10 items (K–VHI10) Satisfaction: Qualitative five-point scale survey
Chaudhuri et al. [55]	2022	Modelling Study	Parkinson's KinetiGraph (PKG)		Cost-Utility, Comparison of PD progression	Mixed	Cost-utility model: De Novo Markov Model Assessment methods: Comparison of MDS-UPDRS II and III scores
Connor et al [27]	2020	RCT			Knowledge of PD self-care and helpfulness of nurse care	Mixed	· Routine assessments of 140 participants through the CHAPS Assessment, 6-month follow-ups, and annual reassessments.

					managers, perceptions of the CHAPS Assessment, health care Notebook, nurse care manager and PD specialist knowledge, beliefs, and attitudes about CHAPS and their perceptions of participants' self-management, Usability		· Knowledge of PD self-care and helpfulness of nurse care managers + perceptions of the CHAPS Assessment + health care Notebook: 14-item anonymous paper surveys about the CHAPS intervention. · Usability: For PD specialists, additional questions asked about awareness of the Siebens Domain Management Model in the CHAPS documentation. If they responded "yes," then they were asked if they felt it was a helpful way to organize participants' problems/issues (yes, no, unsure).
Debelle et al. [69]	2013	Cross-sectional study			Medication adherence, feasibility, Usability	Mixed	· Feasibility + Adherence: Smartwatch, inertial measurement unit, and smartphone. Daily · Usability: Study-specific Questionnaire
Dorsey et al [52]	2010	Randomized, controlled pilot trial			Feasibility, QoL, Satisfaction, Motor Performance, Mood, Cognition	Mixed	In-person evaluations, and motor examination assessed by one of the study physicians, a cognitive examination and multiple self-report questionnaires regarding QoL, satisfaction and depression.
Erb et al. [28]	2020	Observational study			Utility/Reliability, Agreement on the presence of motor complications, Ability of video raters to accurately assess motor symptoms, Dynamics of tremor, dyskinesia, and bradykinesia	Mixed	· Utility/ Reliability: Self-Reports for Motor Fluctuations + Evaluation of completion rates and timing of entries + Questionnaires of Likert scales or categorical responses · Agreement Between Participants and Clinical Raters: Applied part III of the MDS-UPDRS by PD specialists · Ability of Video Raters to Assess Motor Symptoms: Utilized a linear mixed model to fit MDS-UPDRS part III total scores. · Dynamics of Tremor, Dyskinesia, and Bradykinesia: Administration of MDS-UPDRS
Ferreira et al. [70]	2015	Feasibility and Usability Study			Acceptability, Adherence, Usability	Mixed	· Acceptability + Adherence: Calculated number of participants who discontinued or dropped out of the study during the 12-week period via visits by health professionals · Usability: standardized interviews and regular phone contact.
Fleisher et al. [71]	2022	Non-randomized, controlled study			· Health-related Quality of Life (QoL)	Mixed	· Health-related Quality of Life (QoL): measured by the Parkinson's Disease Questionnaire-39 (PDQ-39) at home visits
Flynn et al. [56]	2020	Randomized controlled Pilot study			Feasibility, Adherence, Acceptability	Mixed	· Feasibility: Measuring the time taken to develop the exercise program · Adherence was determined by recording the number of exercise sessions attempted. · Acceptability was examined using a participant questionnaire about the program, conducted in weeks 5 and 10. Participants were

							also interviewed specifically about their experiences of exercise at home and in a center and this will be the topic of a separate report.
Gassner et al. [29]	2022	Pilot Interventional Study			Usability, Feasibility, Impact, Functional status, and Quality of Life (QoL)	Mixed	Usability + Feasibility: System Usability Scale (SUS), Parkinson Disease Questionnaire (PDQ-39) · Impact, Status and QoL: UPDRS-III, Timed Up and Go (TUG) test, 2-minute walking test, and sensor-based gait analysis.
Gao et al. [47]	2021	double-blind, parallel RCT			Effectiveness	Mixed	Measuring overall effect of medication management and rehabilitation training through self-rating scale by patients completing a self-assessment form (WOQ-9 questionnaire, PDQ-39, FOGQ, CSI, MFS, nM-EDL, M-EDL, ADL)
Karni et al. [30]	2022	Pilot Study			· User Interface Evaluation · Patient Empowerment	Mixed	· User Interface: Semi-structured interviews and observations made by task completion · Patient Empowerment: Using the ICT4PEM to formulate ICT strategies
Landers et al. [60]	2020	Single-Cohort Pilot Study			· Feasibility, Safety, and Signal of Efficacy	Mixed	· Feasibility (app usage and usability questions): Participation data (minutes of use) were recorded by the app. Additionally, participants were asked questions about the usability of the app. · Safety (adverse events and falls): Data were tracked via an in-app question every 2 weeks of the 12-week study. Fall data were tracked via an in-app question after every exercise session. · Signal of efficacy: Assessed at baseline, 8 weeks, and 12 weeks using 30-second STS, Timed Up and Go (TUG) and Parkinson's Disease Questionnaire 8 (PDQ8) · The STS and TUG tests were preceded by a demonstration video and an explanation of the test prior to the assessment using a built-in timer. In addition to the STS, TUG, and PDQ8, the Global Rating of Change score was asked at the conclusion of the 12-week study.
LoBuono et al. [31]	2021	Mixed-methods Study			Acceptability, Perception	Mixed	· Acceptability + Perception: Qualitative data was collected through in-person semi-structured, dyadic interviews, and questionnaires from 20 dyads (20 PwPD and their caregivers) · Quantitative data were analyzed using independent samples tests and Fisher's exact tests. Qualitative codes were transformed into variables and compared to digital competence scores to integrate the data.
Maggio et al. [61]	2022	Pilot Study			Feasibility, Usability	Mixed	· System Usability Scale (SUS) consisting of 10 items based on the subjective experience of usability. The items are rated on a 5-point Likert scale ranging from 'strongly agree' to 'strongly disagree.' · Goal Attainment Scaling (GAS) to evaluate the achievement of objectives. The GAS assesses the patient's perception of the goals

							achieved during the intervention. Each goal is agreed upon with the patient and is evaluated on a 5-point scale.
Morgan et al. [25]	2022	Nonrandomized Qualitative Study			Acceptability	Qualitative	Study-specific semi-structured interviews with a cohort of PD and control participants who lived freely for several days in a home-like environment
Omberg et al. [68]	2021	Observational Study			Performance	Quantitative	· Collection of raw data: Finger tapping activity measured dexterity, speed, and abnormality in kinesis (including hastening, faltering and/or freezing), Voice, Walk, Balance. Then compared the mPower symptom severity score with MDS-UPDRS, the SE-ADL and the Hoehn and Yahr score.
Ozanne et al. [63]	2017	Focus Group Study			Perceptions regarding the use of wearables	Qualitative	· Focus group interviews were used to gain a deeper insight into various perceptions through group discussions. The interviews were observed, and mind maps were made.
Ozinga et al. [62]	2017	Experimental Study			Performance	Quantitative	· Postural stability test: Acceleration range (P2P) in multiple movement directions (i.e., ML, AP, and TR) during a variety of sensory conditions while wearing mobile device to waist (level with the sacrum)
Pastana et al. [54]	2023	RCT			Feasibility, Efficacy	Mixed	· Feasibility: Measured by adherence + safety: Adherence was defined as the percentage of sessions attended. Based on the percentage of the sessions attended, participants were categorized as high adherence (>80%), partial adherence (20%−80%), and non-adherence (< 20%). · Safety was evaluated by tracking the cumulative number of AEs and severe AEs from the baseline through the end of follow-up. · Efficacy: Gait and dynamic movements were evaluated by the TUG test, 5STS, and ABC scale. The global motor status was evaluated by MDS-UPDRS Part III. Patient-reported outcomes were evaluated by the PDQ-8.
Piro et al. [32]	2014	Experimental Study			Project Vision, Usability, Interoperability	Mixed	· Project Vision: Inertia sensors and perform standardized motor tasks · Usability/ Interoperability: Expert interviews were conducted with neurologists and collaborations with PD support groups · UPDRS rating by physician based on movement of the avatar
Rodrigues et al. [33]	2023	Cross-sectional, observational Study:			Usability	Mixed	· 5 individuals (PwP, family members, caregivers, students and healthcare professionals) used the app for 5 days and were individually observed using the Think aloud technique. · The System Usability Scale (SUS) questionnaire was used with 10 statements with an intensity measurement from the Likert scale

							of 1–5, where close to 1 refers to strongly disagree, close to 5 strongly agree.
Santos et al. [57]	2022	Cross-sectional study			Feasibility	Qualitative	· Feasibility: Study-specific interview and England Activities of Daily Living (ADL) scale was used.
Schmidt et al. [58]	2022	RCT			Accuracy, patterns of miss reporting	Mixed	· 12-week, home-based upper limb exergame program and analysis providing an objective electronic measure of adherence for comparison with self-report logbooks.
Tzallas et al. [66]	2014	Pilot trial			Accuracy and acceptability	Mixed	· Short-term and long-term recordings from several PD patients, wearability analysis was performed to identify if the wearable multi-sensor monitor unit (WMSMU) is acceptable by patients and how the design could be improved using the Clinician Graphical User Interface (C-GUI) Evaluation.
Virmani et al. [65]	2022	Feasibility Study			Feasibility	Mixed	Modified version of the Unified Parkinson's disease Rating Scale (UPDRS) that excludes the motor assessments of tone (UPDRS item 22) and balance (UPDRS item 30) was utilized. · Freezing of gait determination and quantification for freezing of gait questionnaire (N-FOGQ). · Cognitive function was assessed using the Montreal Cognitive Assessment (MoCA) · Handwriting samples were obtained with a Pilot G2 ballpoint pen mailed to participants · Gait was assessed using the Timed-up-and-go test (TUG). · Voice samples were collected using a secure voicemail · REDCap survey instruments were developed for participants to complete the self-filled Parkinson's disease quality of life scale-39 (PDQ-39) · At the completion of their visit, participants were asked to complete a study-specific survey to gauge their satisfaction with the visit and their perception of audio-video quality
Xu et al. [59]	2022	Survey Study			Awareness, Utilization, Satisfaction	Mixed	· For all outcome measures survey and questionnaires were used · Descriptive statistics were used to summarize survey responses · Responses to quality questions were compared across different service delivery methods (in-person, video, or phone) using chi-square tests. Fisher's exact test was applied when applicable.
Zhang et al. [17]	2019	Experimental Study			Effectiveness	Mixed	· Effectiveness based on: Accuracy, precision, recall · Gait assessment through the on-board sensors of smartphones.

Zhao et al. [64]	2016	Mixed Method Study			Motion data, User experience	Mixed	· Motion data were collected using an MVN motion capture suit · User experience: A study-specific, semi-open interview using a five-point Likert scale and suggestions for future implementations of the app