

The feasibility and acceptability of a digital intervention to support care partners of people with Parkinson's with cognitive impairment – The iSupport PD study

Hand, A.^{1,2 *}; Turton, S.³; Cartner, H.¹; McCarthy, A.¹; Aspinal, B.¹; Rippon, D.¹; Greenwell, K.⁴

1. Faculty of Health and Life Science, Northumbria University, Newcastle, UK; 2. Newcastle Hospitals NHS Foundation Trust, Newcastle, UK; 3. Expert by Experience; 4. Primary Care Research Centre, University of Southampton, Southampton, UK: * Presenting author email address: a.hand@northumbria.ac.uk

Background

- Cognitive impairment (CI) is a well-recognised complication of Parkinson's.
- As symptoms progress, People with Parkinson's (PwP) require increasing support from an informal (unpaid) care partner to help maintain quality of life.
- Lack of adequate support leads to care partner breakdown and avoidable hospital and social care costs.
- Despite their important role, there is a scarcity of support for care partners of PwP with cognitive impairment (PwP-CI).
- We adapted iSupport (P13.01 and P13.07), and developed SPARC, a digital intervention to prevent and/or decrease the mental and physical health problems associated with caring and improve the quality of life for care partners.

Study aims

- To assess the feasibility and acceptability of SPARC.
- To conduct a) a prospective economic evaluation to develop and refine methods for a subsequent definitive trial b) a multi-methods process evaluation to explore the acceptability of the intervention and trial methods.

Methods

- This was a parallel, two-arm, feasibility Randomised Control Trial (RCT) with an embedded pilot health economic analysis and mixed-methods process evaluation.
- Data on numbers of participants identified, recruited, commenced and finished were collected.
- Secondary outcomes included validated measures of quality of life, mental health, carer burden and positive aspects of caring. Participant demographics included age, relationship to PwP, and gender.
- The pilot economic evaluation collected data on National Health Service (NHS) and social care resource use for care partners and PwP.
- Consented participants were randomised using a 1:1 ratio to either the intervention or usual support (control group).
- Data were collected at baseline, 3, 6, 12 months.
- SPARC usage data was collected to understand engagement.
- Semi-structured interviews were conducted to understand the acceptability and usability of SPARC.

Results

- A total of 87/100 (87%) participants were randomised to take part in the study (see figure 1).
- The participants were well balanced between the baseline variables (see table 1).
- All follow-up rates were between 70% and 78% and were similar between arms with a high rate of outcomes measures were completed by participants (>92%) (see table 2).
- The usage data demonstrated good engagement with SPARC at 84%, the total median usage time was 23.82 minutes (range 1.85 to 196.97 mins) and median modules viewed per user was 6 (1-14).
- There were high completion rates for resource use and health related quality of life data.
- There was limited uncertainty regarding the Health-Related Quality of Life measures and high uncertainty regarding cost data, in particular social care costs varied considerably.
- In the interviews, carers reported that SPARC was easy to use, the information was clear, and the content was relevant and meaningful to them.

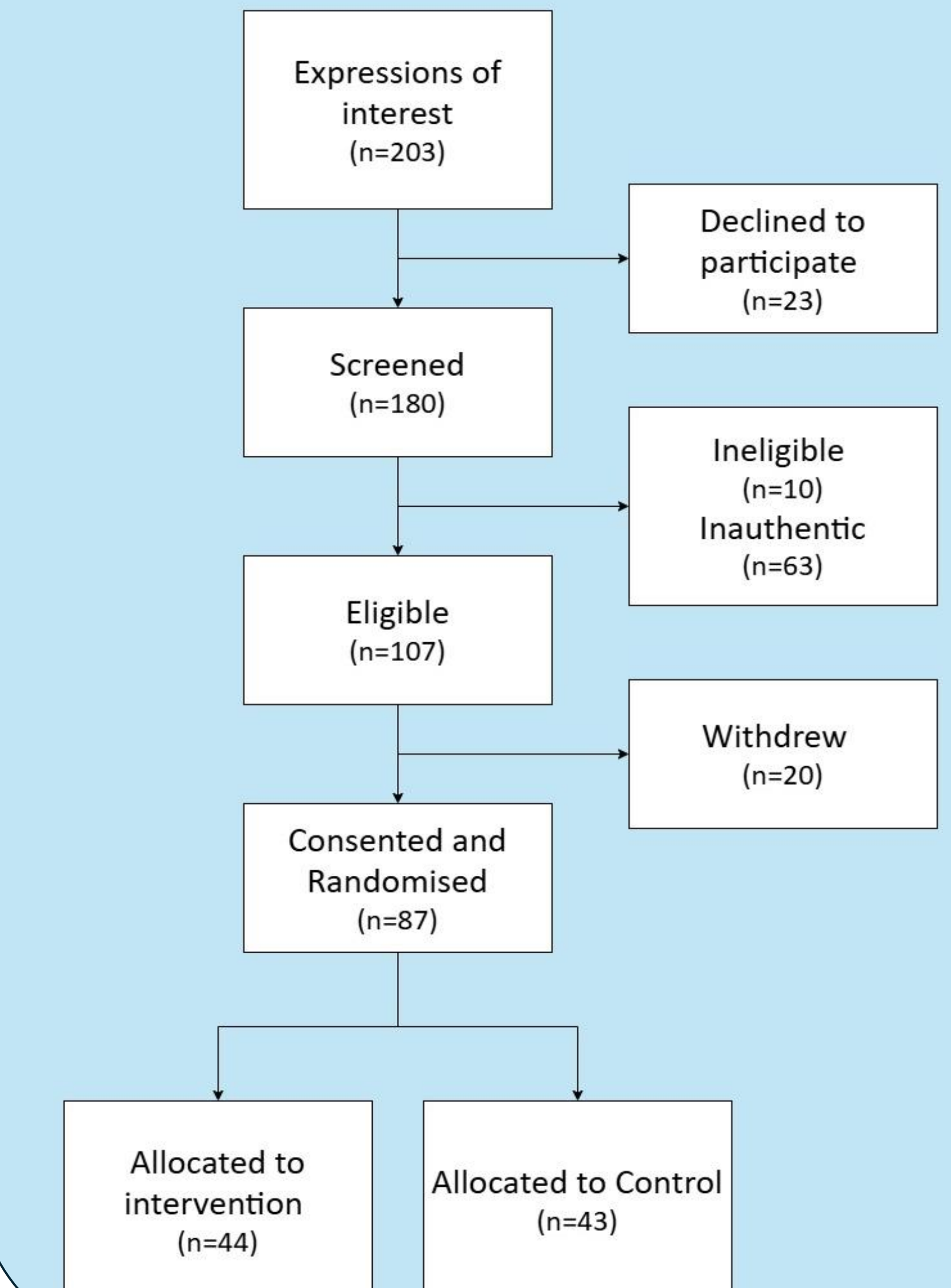
Table 1: Participant baseline demographic data

Variables	SPARC (n=44)	Usual care (n=43)
Age mean ± SD	64.9 ± 11.2	64.8 ± 11.2
Female n(%)	37 (84%)	36 (84%)
Ethnic Group		
White n(%)	42 (95%)	41 (95%)
Global majority n(%)	2 (5%)	2 (5%)
Sexual Orientation		
Asexual n(%)	2 (5%)	0 (0%)
Gay/homosexual n(%)	0 (0%)	2 (5%)
Straight/Heterosexual n(%)	42 (95%)	38 (88%)
Employment status		
Not in paid work n(%)	4 (9%)	4 (10%)
Paid work -full time/ part time n(%)	15 (34%)	13 (30%)
Retired n(%)	23 (52%)	26 (60%)
Relationship to PWP		
Child n(%)	2 (5%)	3 (7%)
Family member n(%)	2 (5%)	3 (7%)
Spouse/ partner n(%)	39 (90%)	37 (86%)
Year of Parkinson's diagnosis median	2018	2016
Year caring role began	2020	2019
Receiving formal (paid) care n(%)	9 (20%)	10 (23%)

Table 2: Trial Feasibility Criteria and results

Trial Feasibility Criteria	Green	Amber	Red	Result
Recruitment of participants based on target of n=100	>75	50 - 74	<=50	87
Intervention engagement: assessed by number of intervention participants who have used SPARC	>=70%	50-69%	50%	84%
Recruited participants completing 3-month follow-up	>=75%	50-74%	<50%	71%
Recruited participants completing 6-month follow-up	>=75%	50-74%	<50%	78%
Recruited participants completing 12-month follow-up	>=75%	50-74%	<50%	70%
Ability to collect outcome data	>=85%	70-84%	<70%	92% to 100%

Figure 1: CONSORT Diagram



Conclusion

- We were able to successfully recruit to our feasibility RCT, demonstrating good trial retention, intervention engagement and acceptability.
- We now plan to secure further funding to conduct a fully powered clinical effectiveness study. We also want to explore implementation plans to embed SPARC into health and care services across the UK.
- Ultimately this resource could support care partners of people with Parkinson's around the world.

For further information about iSupport-PD and SPARC, please use the QR code:

