

Development and Feasibility Trial of iSupport-PD, a Digital intervention for care partners of people with Parkinson's and cognitive impairment

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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).
- The digital intervention 'iSupport' was developed by the World Health Organization (WHO) and is freely available globally to improve the physical health and wellbeing of dementia carers.

iSupport Study aims:

- To adapt iSupport to meet the specific needs of care partners of people with PwP-CI (iSupport-PD) (Work Stream 1 (WS1)).
- Conduct a 12-month feasibility randomised control trial (RCT) with a mixed methods process evaluation to assess feasibility and intervention acceptability (Work Stream 2 (WS2)).

WS1 - Methods

- The person-based approach to intervention development, which combines stakeholder and Patient and Public Involvement (PPI) co-production with in-depth qualitative research, was adopted.
- This approach helps to understand and accommodate the perspectives of carers of PwP with cognitive impairment to ensure their needs are met.

WS1 - Results

- 25 think-aloud interviews, with 22 people, were conducted to gain feedback on the intervention.
- Participants included 16 females, 6 males, and were mostly spouses.
- Age range was 30 - 78 years and length of providing care was 1.5 - 23 years.
- Participants viewed our SPARC website (Fig 1.) while on a video call and were asked to say out loud any thoughts they had as they worked through it.
- We made modifications in line with our Guiding Principles and prioritised them based on the MoSCoW criteria (must have, should have, could have, would have).

Fig 1.

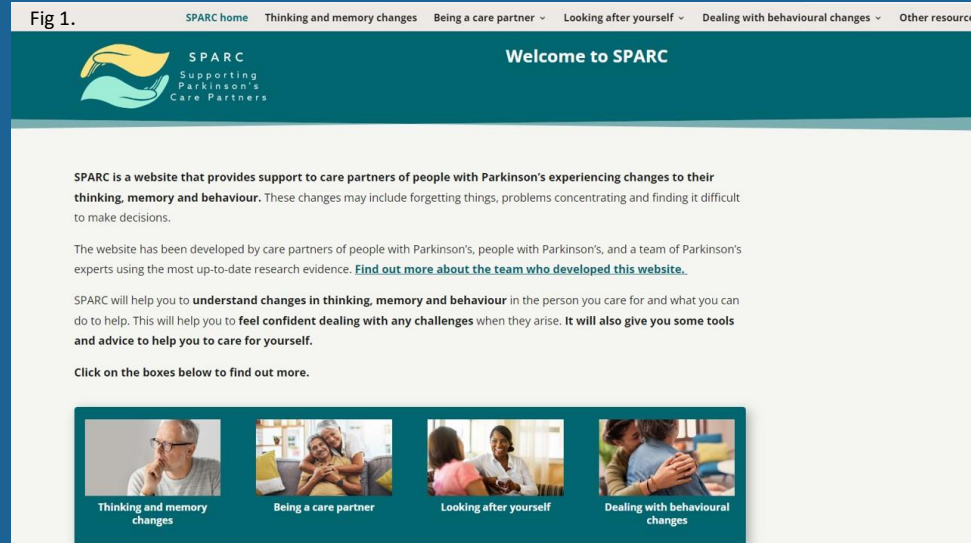
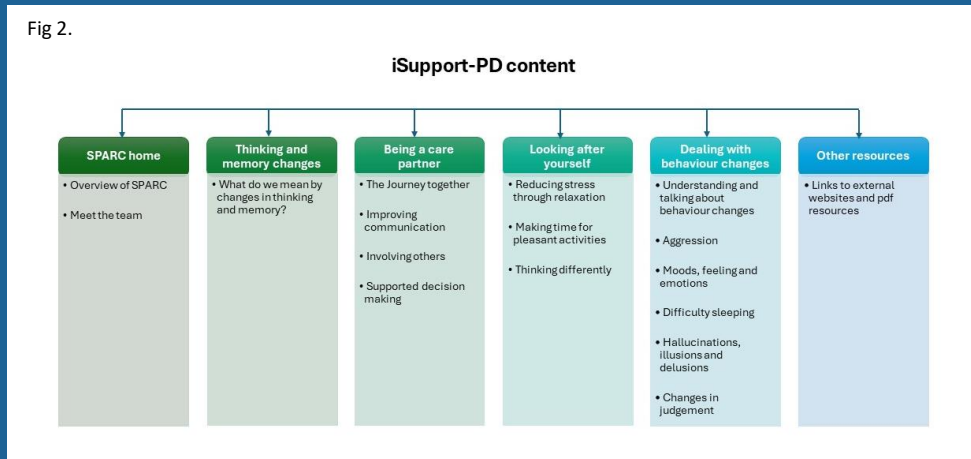


Fig 2.



WS1- Findings

- Participants liked the look and the content of the website (Fig 2).
- Based on feedback, modifications were made to improve the visual design and relevance of content.
- They found the information relevant, helpful and easy to understand.
- They liked that the intervention focused on them and provided information on how to deal with symptoms of cognitive impairment, and the non-medical aspects of caring.

WS2 – Methods

- To conduct a feasibility RCT with 100 carers (50 active /50 control group).
- Recruitment commenced in July 2024.
- Our Patient and public involvement (PPI) group has been instrumental in designing our recruitment strategy to ensure we reach a diverse group of carers.
- Primary outcome is the feasibility of the trial design, including recruitment and follow-up (3, 6 and 12 months) rates and intervention engagement.
- Secondary outcomes will include aspects such as formal and informal care use, quality of life, depression and anxiety and resilience.
- We will also conduct a mixed methods process evaluation and collect health economic data.

Conclusion

- We plan to conduct a full RCT to evaluate the effectiveness of our intervention.
- Ultimately this resource could support carers of people with Parkinson's around the world.
- Visit [SPARC | \(northumbria.ac.uk\)](https://www.northumbria.ac.uk/sparc), our website for further information.

