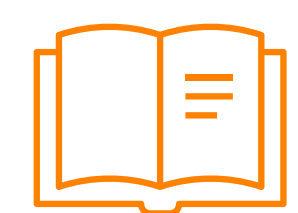


Adaptation of a digital intervention for carers of people with Parkinson's and cognitive impairment

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Background

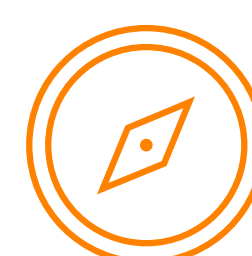
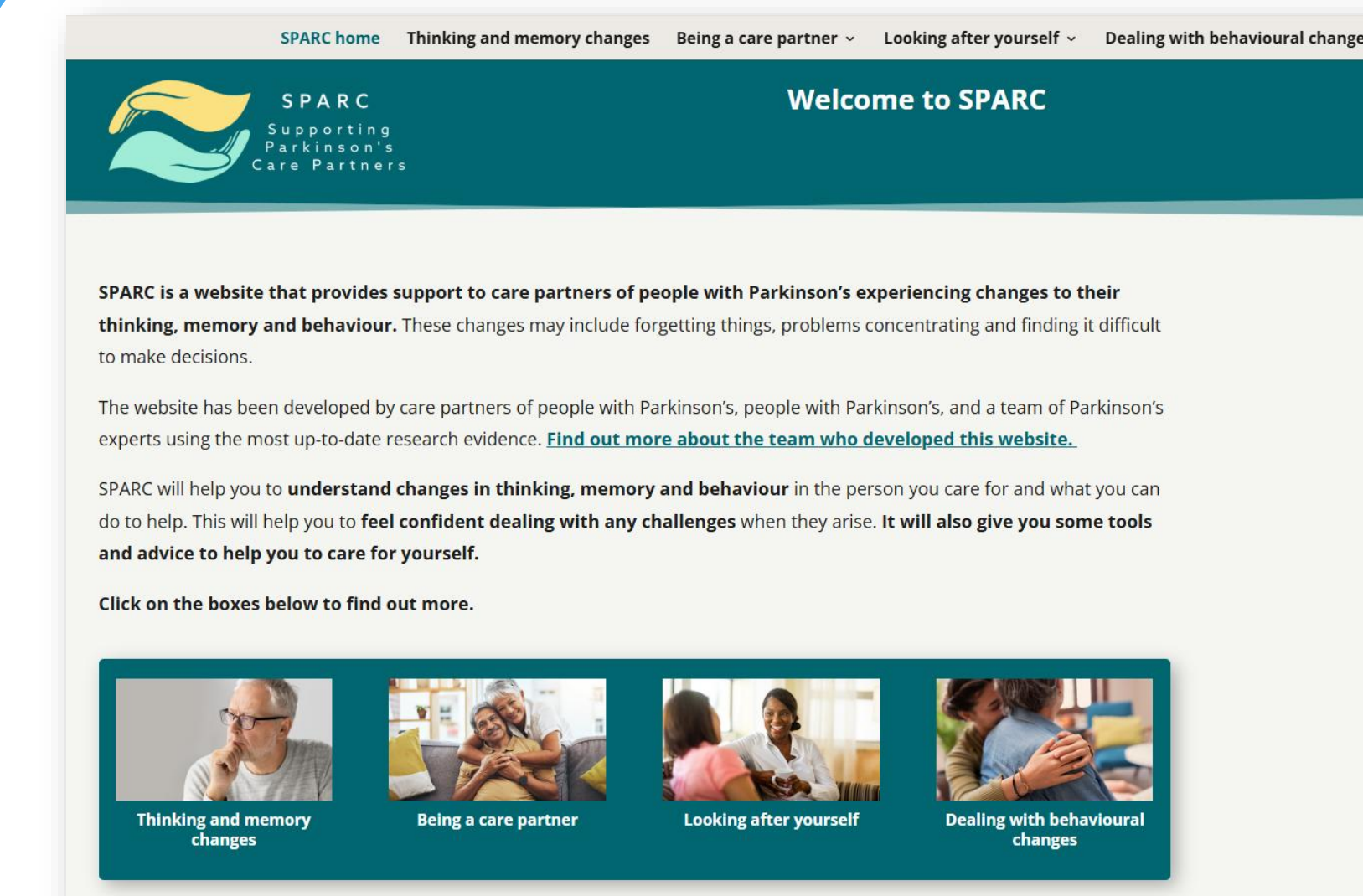
- Most care needs of people with Parkinson's with cognitive impairment (PwP-CI) are met by informal carers, but the caring role is associated with increased carer distress¹ and there is a lack of support for these carers.
- iSupport is a globally available digital intervention for dementia carers². However, it:
 - Does not capture the unique and complex challenges of Parkinson's CI;
 - Is less relevant to carers of those without a formal dementia diagnosis; and
 - Has been informed by some carer feedback, but further carer engagement would maximise engagement.



SPARC intervention

SPARC (Supporting **P**ARkinson's **C**are partners) aims to improve the quality of life of carers of PwP-CI through:

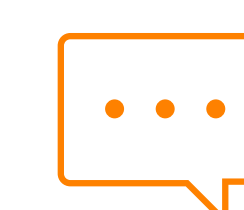
- Increasing confidence in providing support and care to the person with Parkinson's (e.g. dealing with complex behavioural changes, supported decision making, planning for the future);
- Empowering carers to attend to their physical and emotional needs;
- Improving communication between the person with Parkinson's and the carer;
- Empowering carers to seek support from others (e.g. friends and family, health professionals).



Results: Guiding principles

- Following the PBA common guiding principles, we implemented several intervention features to promote carer autonomy, carer competence and a positive emotional experience and sense of relatedness.
- We also developed guiding principles highlight key intervention design objectives and features to address the needs of this target group.

Key design objectives (examples)	Intervention features (examples)
To empower carers to talk about and seek help with the symptoms of CI and behavioural changes in the person they care for with the PwP-CI; friends and family; and health and social care professionals	- Provide education about Parkinson's CI - Stories from other carers about their experiences to normalise talking about CI - Provide advice on when and how to talk to health professionals about CI and how to involve others in care - Signpost to Parkinson's carer groups to seek support and talk confidentially with others in a similar situation
To engage a diverse group of carers who care for people with Parkinson's who may experience different CI symptoms	- Provide core modules that most carers may find helpful, e.g., 'Thinking and memory changes in Parkinson's', 'Involving others' - Provide optional modules carers can choose depending on their current needs and PwP symptoms - Using inclusive terminology (e.g., 'Care partners') and imagery and stories from different carer demographics
To improve carer's confidence regarding the non-medical aspect of the carer role	Minimising medical content and including modules focusing on carers' own health and wellbeing and their relationship with the PwP-CI



Results: Think-aloud interviews

- Carers generally liked the website content and found it relevant, helpful and easy to understand.
- They valued the stories and advice from other carers, that the intervention focused on them, and how it addressed the non-medical aspects of caring (e.g. communication, involving others).
- In response to feedback, we made several intervention modifications, such as adding in more practical advice on dealing with challenging behaviours and re-organising information to avoid overwhelm.

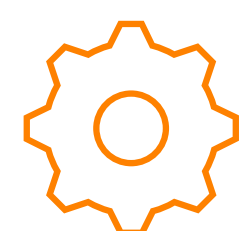
"Everybody thinks it's [Parkinson's] this physical, shaky issue when it isn't...it's the memory and the mental health issues that I'm finding the hardest to manage. So, the fact that it's recognised straightaway it's great!"

"Oh, my gosh, it sounds like me. [laughs] Yes, I like that quote from Fatima. That's... I like that very much. Yeah, I agree with that."



Study Aim

- To adapt the iSupport digital intervention to meet the specific needs of carers of PwP-CI.



Methods

- The adaptation was guided by the Person-Based Approach (PBA)³, informed by:
 - co-production with carers, people with Parkinson's, health and social care professionals, and the Parkinson's UK charity;
 - literature on Parkinson's carer needs and experiences; and
 - think-aloud interviews with 31 diverse carers of PwP-CI
- Think-aloud data was analysed using the PBA table of changes⁴.



Conclusions

- Our guiding principles highlighted key design objectives and features to consider when developing interventions for carers of PwP-CI.
- Think-aloud interviews helped optimise intervention engagement and demonstrated that SPARC is likely to be acceptable to this population.
- A randomised control trial subsequently assessed intervention feasibility and acceptability (P13.06).

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

