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’If you want to know the road ahead ask those coming back.”: Reflections on PPI input into the CareCoach Study and open call for carers with lived experience of dementia care to join the PPI team.

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Summary

Around 700,000 family carers support 900,000 people with dementia in the UK. These carers are at risk of becoming overwhelmed as their loved one’s dementia progresses, but interventions aimed at developing personal resilience can help carers to cope better.

One intervention that has had a positive impact is an online “coach” which combines self-directed learning (videos and text) with remote input from a support worker. Key benefits include a reduced sense of burden and increased coping with the challenges of caring.

Robust measures of the impact are limited due to methodological inconsistencies. The UK-based CareCoach Programme, funded by the National Institute for Health and Care Research (NIHR), is working in partnership with Join Dementia Research, tide (Together in Dementia

Everyday), Dementia UK, and Alzheimer’s Society, to address this evidence gap by testing the online coach in a clinical trial.

To ensure the intervention realises its full potential the CareCoach team invites applications for public and patient involvement members.

Key points

- An online “coach” developed by a team working in the Netherlands could provide remote support for dementia carers in the UK.
- Research suggests online coaching interventions for family carers of people living with dementia report benefits for wellbeing and decision making
- Key benefits include a reduced sense of burden and increased understanding of coping with the challenges of caring for a loved one living with dementia
- Research is limited due to methodological inconsistencies
- The CareCoach Programme is working towards a clinical trial which will generate more robust evidence
- The CareCoach study is now open and invites applications for public and patient involvement to ensure the study realises its full potential

[Main text]

Around 700,000 family carers support 900,000 people living with dementia in the UK (Lewis et al 2014). As dementia progresses individuals develop more psychological, social and physical care needs that can be hard for carers to cope with, particularly when balancing competing demands from work, family and finances.

Research suggests intervening early helps carers to manage stress and increases their personal resilience (Quinn & Toms 2018). One tool which has proved useful in this context is the Dutch programme ‘Partner in

Balance' (PiB) (www.partnerinbalans.nl) (Boots et al 2017). PiB, which takes a blended care approach combining online resources (videos, text based case studies, self-assessment and goal setting exercises) with a personal coach, was shown to reduce carer stress and burden in a recent feasibility trial (Boots et al 2018).

In that study, after an initial face to face meeting with the personal coach (a trained psychologist or psychiatric nurse), carers were supported to complete an eight-week programme of self-directed learning. Following a pathway tailored by the coach, carers worked through four of nine themed modules, titled as follows: acceptance, balance in activities, communication with family member and environment, coping with stress, focusing on the positive, insecurities and rumination, self-understanding, the changing family member, and social relations and support.

The CareCoach study aims to develop and test an adapted PiB for the UK context. The potential benefits of developing an online coach for carers in the UK has drawn support from Join Dementia Research, tide (Together in Dementia Everyday), Dementia UK and Alzheimer's Society who have formed a partnership with the CareCoach research team.

In a recent issue *JDC* (James 2022) reported on the potential of a digital app for people living with dementia, indicating growing support for such modes of support. Here, we report on feedback from patient and public involvement (PPI) consultations on the PiB resource and call for new PPI members to join the study.

Funding and leadership

The CareCoach programme is funded by the National Institute for Health and Care Research (NIHR) and is targeting research at carers who are at the early stages of their journey as a carer providing support for someone with a recent diagnosis of dementia. The lead research institutions are University of Exeter and the University of East Anglia with support from our partners named above.

Current work on phase 1 of the CareCoach study uses qualitative methods to undertake an accelerated version of Experience-Based Co-Design (EBCD), where existing materials from the PiB resource are shared in an online interview to stimulate discussions (Gardner 2009, Locock et al 2014).

The study aims to recruit a purposive sample of 20 dementia care staff and 20 family carers. Sampling aims for diversity in terms of age, sex, ethnicity, relationship and, for staff, length of time working with people with dementia. Interviews encourage participants to discuss their experiences, give their views on the suitability of the PiB resources and what modifications are required to adapt them to the UK context.

Audio and text-based data generated from this phase will be explored in a series of co-design workshops engaging a further sample of 10 carers and 10 staff. Throughout the analysis process the qualitative data will be analysed using open coding techniques that lead quickly and transparently to robust thematic descriptions of the data to be viewed and assessed by a research team that includes PPI collaborators.

Overall findings will be used to develop a UK version of the PIB intervention to be tested in later work packages of the CareCoach programme. Early findings using the principles of EBCD indicate that the PiB video material will be re-filmed to create visuals with English spoken narrative and a more diverse range of carers to facilitate engagement among different cultural and age groups. Modifications to module headings will also be required to ensure carers feel ownership of the resource.

Patient and public involvement

Our approach to PPI was directed by the values and principles of the NIHR INVOLVE guidelines for inclusion in research and rates of reimbursement. These guidelines prioritise engaging with PPI members (tide, Dementia UK and independent volunteers) in decision-making, study governance and the practicalities around research processes, implementation, analysis and dissemination.

Hands-on practical work has involved PPI members working on the development of recruitment materials, lay summaries, and advising on the study profile on social media. Once phase one data collection is complete, PPI members will engage in qualitative data analysis and generating recommendations for practice, policy and future research. We have also committed ourselves to providing opportunities for them to co-present and co-author publications with other researchers as well as co-produce talks and presentations with carers and people living with dementia.

Among our other initiatives we are establishing a service user advisory group (SUAG), consisting of approximately six carers and four people with dementia to advise and support study progress. SUAG members are supported by specific members of the research team, while working practices are reviewed every six months in line with NIHR engagement guidelines on inclusion and reimbursement.

Phase one research has prioritised a series of consultative interviews and discursive meetings among PPI representatives in leadership roles in third sector organisations (tide, Dementia UK), and volunteers recruited from dementia cafes and community leaders supporting black, Asian and minority ethnic groups living with dementia.

Consultation feedback

Consultation with PPI has been key to the project development from the outset; G[FULL NAME] Fenwick, a co-author of this article, is a co-applicant on the project and sees the work of PPI as mutually beneficial:

As a co-researcher and existing carer my involvement in the project will bring vital first-hand experiences to help model the training programme… Personally, it will be a boost for my own mental health wellbeing and hopefully I will learn a few new tricks along the way, as well as being able to share ideas that have worked for us. If you want to know the road ahead ask those coming back (UEA 2020).

Experience and insight obtained from wider consultation exercises, including informal interviews and meetings, are being fed into project dissemination and recruitment strategies to maximise impact across social media and other outlets. The idea and content for this article was fielded during a PPI meeting and supported by the wider team as part of the ongoing effort to inform researchers and the public of our research programme and advertise for PPI members to join the study.

Feedback from PPI consultations during the set-up phase of the CareCoach study suggests that the PiB online information resource has the potential to provide information that is relevant and useful for people starting their journey as a dementia carer. It also addresses service gaps in current provision where budgetary limitations prevent health and social care professionals from undertaking frequent or extensive face to face consultations in the community.

Consultations and interviews have helped to identify and target areas for further investigation and to develop the PiB resource to meet needs arising in relation to:

- male carers' emotional experience of care work
- perceptions and experience of carers living in faith-based communities
- carers who negotiate caring through the lens of role reversal, notably where adult children care for a parent living with dementia
- maintaining a representative body of PPI members over the life of the programme to compensate for life-course attrition due to other commitments.

The research team invites further interest and involvement from *JDC* readers. Just contact us at carecoach@uea.ac.uk.

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