A Feasibility and Adaptation study of a physical activity mobile application, “CareFit” for informal carers of people with dementia: Study Protocol

Kieren J Egan, Bradley Macdonald, William Hodgson, Alison Kirk, Barbara Fawcett, Mark D Dunlop, Roma Maguire, Greg Flynn, Joshua Scott, Gill Windle

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Abstract

Background: Physical activity is a critical component of both wellbeing and preventative health: reducing the risk of both chronic mental and physical conditions and early death. Yet there are numerous groups in society who are not able to undertake as much physical activity as they would like to. This includes informal (unpaid) carers where UK national survey data suggests that 81% would like to do more physical activity on a regular basis. There is a clear need to develop innovations including digital interventions that hold implementation potential to support regular physical activity in groups such as carers .

Objective: To expand and personalize a cross-platform digital health app that is designed to support regular physical activity in carers of people with dementia for a period of 8 weeks and evaluate the potential for implementation.

Methods: The CareFit for dementia carers study is a mixed-methods codesign, development and evaluation of a novel motivational cross platform app to support home-based regular physical activity for unpaid dementia carers. The study was planned to take place across 16 months in total (1st September 2022 to 31st December 2023). The first phase will include iterative design sprints to redesign an initial prototype for widespread use supported through a bespoke Content Management System ‘CMS’. The second phase will include the release of the ‘CareFit’ app across Scotland through invitation on the Apple and Google stores where we aim to recruit 50 carers in total and up to 40 professionals. Partnerships for the work will include a range of stakeholders across charities, health and social care partnerships, physical activity groups and carers organizations. We will explore implementation of CareFit, guided by the RE-AIM framework which will include the potential Reach, Effectiveness, Adoption, Implementation and Maintenance.

Results: As of November 2023, 41 carers of people with dementia have been recruited to the 8 week feasibility study. The barriers and enablers for professional staff to signpost/use CareFit will be assessed through interviews/focus groups and round stakeholder meetings. The usability of CareFit will be explored through qualitative interviews with carers and a System Usability Scale (SUS). We will examine how CareFit can add value to carers through examining in app data, pre-post questionnaire responses alongside qualitative work including interviews and focus groups. We will also explore how CareFit could add value to the landscape of other online resources for dementia carerResults from this study will contribute new knowledge including identifying: (i) suitable pathways to identify and support carers to digital innovations, (ii) future design of definitive studies in carer populations alongside, (iii) an improved understanding of the reach, effectiveness, adoption, implementation and maintenance of digital innovations across a range of key stakeholders.s.

Conclusions: Results from this study will contribute new knowledge including identifying: (i) suitable pathways to identify and support carers to digital innovations, (ii) future design of definitive studies in carer populations alongside, (iii) an improved understanding of the reach, effectiveness, adoption, implementation and maintenance of digital innovations across a range of key stakeholders.

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Protocol Paper

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Abstract

Background: Physical activity is a critical component of both wellbeing and preventative health: reducing the risk of both chronic mental and physical conditions and early death. Yet there are numerous groups in society who are not able to undertake as much physical activity as they would like to. This includes informal (unpaid) carers where UK national survey data suggests that 81% would like to do more physical activity on a regular basis. There is a clear need to develop innovations including digital interventions that hold implementation potential to support regular physical activity in groups such as carers.

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Results: Project processes and outcomes were evaluated using mixed methods. The barriers and enablers for professional staff to signpost/use CareFit with clients were assessed through interviews/focus groups and round stakeholder meetings. The usability of CareFit were explored through qualitative interviews with carers and a System Usability Scale (SUS). We examined how CareFit could add value to carers through examining in app data, pre-post questionnaire responses alongside qualitative work including interviews and focus groups. We also explored how CareFit could add value to the landscape of other online resources for dementia carers.

Conclusions: Results from this study will contribute new knowledge including identifying: (i) suitable pathways to identify and support carers through digital innovations, (ii) future design of definitive studies in carer populations, alongside, (iii) an improved understanding of the reach, effectiveness, adoption, implementation and maintenance across a range of key stakeholders.

Keywords: carers, dementia, physical activity, sedentary, cross platform app

Introduction

Recent estimates suggest that in the UK, 10.6 million family members and friends look after a family member or friend due to a disability, frailty or a mental/physical condition [1]. The collective impact of this group (often termed 'informal carers') in the UK is a saving to health and social care services of £132 billion per year [2]: a figure comparable to the entire budget for NHS England [3]. However poignant

this contribution is, the support does not come without personal costs to carers. Many carers report poor mental and physical health: a finding also supported by systematic review evidence [4-6]. Poor carer health is a concern for all in society and has been associated with a reduced quality of life and increased mortality in the person cared for [7, 8].

As global populations continue to age, our health and social care systems are beginning to reform, driven through a combination of factors (e.g. staff shortages, risk of infection in hospital settings, cost savings) to pivot further towards care in the community [9, 10]. With this shift, there is a growing call to build more holistic approaches around health and wellbeing in carers [11, 12]. Achieving such major reform looks certain to embrace digital components including building up evidence into digital interventions that could both alleviate pressure on health and social care staff and empower carers. Yet realizing such digital implementation remains challenging, not least because the requirements list for successful implementation of digital solutions is both long and intricate [13, 14]. For example, this includes both technical and operational readiness/rigor but also [15] development of a strong evidence base, [16] an inclusive and authentic codesign approach (ideally early and including a wide variety of key stakeholders), [17] alongside early recognition and management of risks around non-adoption and abandonment [18].

Across a wide array of carer innovation and research[19, 20] the development of digital supports for carers of people with dementia continues to be of significant societal interest [21-23]. For example, the pioneering work of the World Health Organization -led ‘iSupport’ platform for carers of people with dementia[24] has facilitated evidence-based theory on personhood and cognitive reframing [25, 26] to become accessible to a global audience through online training and support, with anticipated impacts including reducing burden and anxiety. The content delivered is multidimensional including an introduction to dementia, reducing stress, supporting activities of daily living, being a carer and caring for yourself, and dealing with behavior changes. As the evidence base for iSupport continues to grow (including adaptation and evaluation in 33 countries [27]), there remains scope to complement and augment global resources such as iSupport across other unmet needs in carers. This includes areas of physical activity where UK survey data suggests that 81% of carers are not able to do as much physical activity as they would like to [2], alongside a lack of digital innovations in development for this specific group. An added challenge is that owing to their caring role many of carers spend much time indoors (limiting the value of location/step count of based approaches that is more accessible to other population groups)[28, 29].

We previously reported on our initial ‘CareFit’ progress [29, 30] after building a first version of the app as an Android Package Kit ‘APK’ and testing a minimum viable concept during the COVID-19 pandemic lockdown across Scotland. The original app was designed to support carers to undertake early steps in physical activity,

informed by U.K. national physical activity guidelines and is based around the Trans-Theoretical Model of behavioral change (TTM)[31]. While initial results identified acceptability, usability and feasibility of the app and concept, the work marked only the first step to develop an evidence base for future use and explores a relatively new area of research around sedentary behavior in informal carers. We demonstrated limited implementation findings around the reach (the app was only available on Android phones), sustainability (the app was designed for 3 weeks of use only) and lacked wider engagement with health and social care professionals and providers. Thus, we concluded significant insights could be gained from a redesigned version of the app (e.g. a completely new build using React Native), introducing a higher quality of user experience covering multiple platforms, more personalized user journey, alongside establishing how we could design a future definitive study for sustainable use alongside implementation. Further insights that remain critical include those relating to future study design (e.g. relating to the MRC complex intervention framework[16, 32, 33]) through the lens of a single post-diagnostic pathway such as dementia.

Study aims and objectives

This work aimed to improve current uncertainties around social care pathways to implementation, and gain understanding of facilitators and barriers to the Reach, Effectiveness, Adoption, Implementation and Maintenance (RE-AIM)[34] of ‘CareFit’ in a real-world setting. Our objectives were to: (i) expand an initial 3-week intervention to an 8-week intervention to support maintenance of physical activity. (ii) develop understanding of recruitment pathways and explore barriers and enablers to recruitment for a future definitive trial, including recruiting vulnerable/lower socioeconomic groups, (iii) improve understanding of usage adherence and develop understanding of the most reliable methods to regularly measure physical activity and sedentary behavior within dementia carers, (iv) explore how ‘CareFit’ could provide added value for dementia carers with the existing solution of other digital interventions (such as ‘iSupport’) through qualitative interviews or focus groups with key stakeholders and to, (v) explore unexpected benefits including whether people with dementia also see the benefits of CareFit.

Methods

Study design

The CareFit for dementia carers study was a mixed-methods evaluation of a novel motivational smartphone app to support home-based regular physical activity for unpaid dementia carers. The study took place across 16 months (1st September 2022 to 31st December 2023) and formed a ‘stand-alone’ element of an existing Randomized Control Trial on “iSupport” [27]. Initial codesign and adaptation of an existing prototype [29] facilitated this feasibility study. In brief, the codesign sessions for adaptation and expansion, involved 3 development sprints: gaining feedback from a range of stakeholders such as carers, professionals who support carers (e.g. charity partners) alongside researchers and developers to create priority areas for app

development. At the conclusion of participation in the CareFit feasibility study (designed for up to 8 weeks use), all carers completing their final evaluation survey received information about regional support services and a shopping voucher as a thank you for their participation in this work.

Participant Recruitment: Feasibility study

Professional study collaborators/organizations were sent a media pack of adverts across text, image and video formats. Informal carers of people with dementia were identified and recruited through our partner organizations' networks, the Join Dementia Research (JDR), [35] database, and were supported by other stakeholders through advertising via posters, emails, social media and centre referrals as required. Staff from our partner organizations were invited to contribute to the evaluation across this work, along with a broader group of stakeholders (e.g. including organizations who did not take an active role in recruitment) at the conclusion of the work, for 'round table' stakeholder meetings and interviews. Throughout, staff were not obliged to participate in the evaluation even where their organization was a collaborator in this work. All participants were free to withdraw at any time without any impact on their future health and care or working role. Participant data collected to the point of withdrawal were used in the analysis unless consent for this was specifically withdrawn.

Feasibility study Inclusion criteria

Carers

1) Adults (18+) living in Scotland who self-identify as an unpaid carer (partners, children, friends, etc.) of a person with dementia (self-reported)
2) Contemplating or preparing to undertake physical activity
3) Ability to undertake simple exercises such as arm raises or stretching
4) Be able to read and write in English
5) Have access to a smartphone (Android or Apple) alongside access to the internet
6) Normal or corrected to normal eyesight

Health and Social Care Professionals

1) Adults Aged 18 and over
2) Based in Scotland
3) Working as a health and social care professional
4) Willing to engage with the study (e.g. share information about 'CareFit' with carers of people with dementia) through their professional role for a period of at least 3 months (to ensure timely follow up).

Feasibility study Exclusion criteria

Carers

1) Anyone advised by a clinician not to undertake physical activity or make any change in their present level of exercise

2) Are already regularly exercising to a significant level outside the home (e.g. running/cycling)

3) Residing outside Scotland at the time the study is conducted

4) Currently part of a related 'iSupport' study

Health and Social Care Professionals

1) Working exclusively within the National Health Service (NHS)

CareFit intervention

'CareFit' is a smartphone application (app) designed to support carers of people with dementia. It was designed to be accessible on both Android and Apple smartphones and tablet devices. It was developed to support the early steps in physical activity in line with the Transtheoretical model of behavior change [31], co-designed with carers, health and social care professionals and physical activity experts over a series of phases.

For participants who did join the study, they were sent an 'invitation only' link to download the app on their own smartphone/tablet device and were supported to do this over a number email steps and correspondence with the research team as part of a 'closed' study on Google and Apple Stores.

Ethical considerations

Human subject ethics review: Ethical approval for feasibility work was obtained both through Bangor University School of Medical and Health Sciences academic ethics committee (approval number 2021-16915). The initial codesign/adaptation work was supported through approval '2022' from the University of Strathclyde, Department of Computer and Information Sciences.

Informed consent: For the feasibility study, both carers and professionals were provided with online information sheets before involvement in the study. Informed consent was demonstrated by the online signing of a consent form in Qualtrics[36]. Participants electronically selected individual items in the online form, corresponding to the paper consent form, in order to confirm they had read and agree to each item. Their electronic signature was achieved by entering their first and surname, and then either typing or drawing their signature next to a declaration. During the consent process potential participants were

supported by a researcher in an online meeting (e.g. Skype, Zoom) or telephone call wherever requested, and any questions were answered. They then completed an online form, or the form registered that they declined.

Privacy and confidentiality: The research team and app developers undertook a number of steps to ensure the security of information collected. While the use of secure, GDPR compliant online survey forms is standard for such studies, privacy for the development and use of the app was ensured through the development of a secure content management system 'CMS ' to store pseudo-anonymized 'top level' information from participants about overall app use. Information that is personal to the participant, such as barriers and enablers to physical activity, was kept on the individual handset and not shared further and did not cross between devices even where the user remained the same. Any information stored by the University of Strathclyde was stored within university approved password protected encrypted storage sites.

Compensation details: Carers who participated in this work were offered a £20 shopping voucher to thank them for their involvement.

Data collection, management and app download process

There were four key areas of data collection: (i) study advertisement and recruitment impact (including proactively contacting carers through the JDR platform), (ii) online surveys, (iii) 'In app' data collection (namely the usage across the different domains of the app such as the 'activity' , 'planner', 'resources' or 'sharing elements including a 'time stamp' at the time/date of use), alongside (iv) interviews and focus groups. For online surveys, the online platform 'Qualtrics' was used. Study adverts (in both paper and digital formats) were shared with study partners alongside use of the JDR platform. Carers who consented to the study were directed to a bespoke hyperlink within the Google and Apple Play stores where an individual pseudo-anonymized ID was entered after download. The CareFit research team offered support to individuals at any stage as requested through email and/or telephone/videocall support. Focus groups and interviews both took place to understand a subsample of the participants experiences and were employed in the closing stages of the project as 'round stakeholder' meetings that explored in conversation future steps around key themes and points identified through the use of the RE-AIM methodology.

Evaluation Outcomes

Our mixed methods evaluation was underpinned by a number of different data sources, including: (i) baseline carer demographic survey (e.g. age group, gender, number of years caring/hours caring per week) and 8 week follow up (e.g. International Physical activity questionnaire Short Form, [IPAQ-SF] [37], EQ5D[38], System Usability Scale [SUS] [39] (ii) professional survey (e.g. elements of RE-AIM and how CareFit could integrate

into working role), (iii) ‘in app’ collected data, and (iv) interviews and focus groups. Following the format of the RE-AIM framework, our outcomes were guided wherever possible by the elements of Reach, Effectiveness, Adoption, Implementation and Maintenance and were also interpreted with support of the Complex Intervention Framework[16, 32, 33]. See Table 1 for further information.

Analysis

Our approach to mixed methods [40] was to analyze qualitative and quantitative results individually to form conclusions. Where possible we synthesized further interpretations of the quantitative results through the qualitative findings. Interviews were recorded through the use of an encrypted Dictaphone/University approved video software where Braun and Clarke thematic analysis was followed[41]. For quantitative outcomes, basic statistics relating to feasibility were gathered (e.g. description of key recruitment numbers, adherence to CareFit from our ‘in app’ data included summaries across the ‘activity’, ‘planner’, ‘resources’ and ‘sharing’ elements including a ‘time stamp’ at the time/date of use). Indicators of usability were underpinned by System Usability Scale (SUS) total scores and on occasion individual questions were used to support the interpretations of qualitative data. For all outcomes assessed, differences in measures between baseline and follow up were analyzed primarily around metrics that support our understanding of feasibility and suitability of outcomes such as completeness of information and correctness of data gathered such as percentage completion and error value rate. Secondary analyses may be used at a later timepoint (e.g. app engagement vs. outcome improvements) for hypothesis generation but were not a primary purpose of the current work.

Table 1: Example research questions and example data sources based on the RE-AIM framework.

RE-AIM component	**Example Research question(s)**	**Example Data source(s)**
Reach		
	What is the participation rate within the study?	Registry data for ‘Join Dementia Research’ (JDR).
	What is the drop out rate within the study?	Study monitoring of overall numbers Interviews/Focus groups and roundtable discussions.
	What are the key barriers/facilitators to reach?	
Effectiveness		
	What are the indications around the usability of ‘CareFit’?	Patient reported outcome measure (e.g. System Usability Scale (SUS), International Physical Activity Questionnaire (IPAQ- short), Individual items, bespoke measures including sedentary,

		knowledge and support outcomes).
	What are the early indications on effectiveness for increasing physical activity/reducing sedentary behavior and increasing knowledge of physical activity?	Interviews/Focus groups and roundtable discussions.
	What (if any) are the unintended consequences of using the app?	'In app' collected data (e.g. 'activity' , 'planner', 'resources' or 'sharing elements including a 'time stamp' at the time/date of use).
	What is the overall carer engagement with app?	
Adoption		
	What is are the characteristics of organizations that support the work	Interviews/focus groups questions that focus on experience of adoption activities.
	What is the organizational staff understanding of why CareFit was/was not adopted?	
Implementation		
	What are the key barriers/facilitators to implementation?	Interviews/Focus groups and roundtable discussions.
	How can we measure the cost implications (e.g. financial and time for organizations)?	Patient reported outcome measures (e.g. EQ5D).
Maintenance		
	What are the facilitators and barriers to maintaining the program? Do participants continue engaging with the app across 8 weeks of use?	Interviews/Focus groups and roundtable discussions.
	What could encourage use of the app beyond 8 weeks?	'In app' collected data 'In app' collected data (e.g. 'activity' , 'planner', 'resources' or 'sharing elements including a 'time stamp' at the time/date of use).

Results

At the time of publication (July 2024) to date we recruited 41 participants into the CareFit study with a results peer reviewed publication to follow.

Discussion

Principal Findings

Here we aimed to expand, personalize and evaluate the implementation potential of a cross platform digital health app (i.e. accessible on both Google and Apple stores) to support regular physical activity in carers of people with dementia for a period of 8 weeks. The results build significantly on existing research across the breadth of materials offered (e.g. number and range of physical activity videos) and the new functionalities, look and feel, and interaction capabilities of the app overall. The publication of this protocol serves a number of functions to help benefit others in the field including to maximize the transparency, accountability and reproducibility of the work, particularly given that CareFit constitutes a complex intervention[16, 32, 33]. For

the first time, we have explored different implementation pathways and will be in a position to report on how well different routes to 'marketing' for carers performed in detail- an important outcome given that carers are often difficult to identify and support in society. Further, our use of both implementation focus groups guided by the RE-AIM framework provides a comprehensive understanding of how carer-focused digital health approaches (including those in dementia) can move forward at both local and national levels.

We anticipate that results will contribute new knowledge in a number of ways including: (i) recommendations of suitable pathways to identify and support carers through digital innovations, (ii) future design of definitive studies in carer populations (e.g. suggestions for drop out levels and suitable measures of physical activity), alongside (iii) an improved understanding of the reach, effectiveness, adoption and maintenance for a range of key stakeholders. Such results support the future design of this work including the identification of an optimal and sustainable route forward for CareFit including a pilot randomized trial use over an extended period. This is likely to also include furthering our understanding of costs- we are currently exploring options for CareFit or future iterations to be free/as low cost as possible for carers at the point of use (July 2024).

Limitations

There were a number of limitations of this study. First, our routes for implementation and recruitment were varied and included stakeholders directly advertising the study, but also included the JDR online registry for carers of people with dementia. Registry routes may not always reflect the wider carer demographic; however these are increasingly recognized/used by charity partners and it was pragmatic to use JDR within a time-limited recruitment period. Further, our work identified strengths and limitations of these different recruitment approaches. Second, there were a number of steps involved in downloading and accessing the 'CareFit' app (e.g. email exchanges with the CareFit research team were required to onboard participants). Such steps would not take place if the app was freely available in app stores, but we opted to design our study for 'closed' testing so that so that we only collected app usage data from consented participants and could build up evidence in an iterative way. Lastly, there were some limitations regarding our analysis of study data. While our mixed methods approach consists of many comprehensive datasets, we opted not to analyze the personal goals, barriers, and enablers participants expressed, in order to protect their privacy. Should future research be conducted in this project or similar, it may be of use to expand these opportunities with the full consent of app users/study participants as an opt in/out selection.

Conclusions

As the role of community care in health and wellness continues to grow there are new opportunities emerging to support the role of the informal carer. Our mixed methods approach to adapt, implement and evaluate CareFit will not only inform the design of future similar studies, but will also give early indications about a

wide array of impacts such as: marketing, reach, acceptability and the feasibility of implementation.

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Data availability

We will release quantitative data with a results publication stored on the Strathclyde “PURE” data repository.

Conflicts of Interest

None declared.

Author Contributions

Kieren Egan: Conceptualization (lead), Methodology (lead), formal analysis, writing, review and editing, funding acquisition (lead), **Roma Maguire;** Conceptualization, writing and editing, funding acquisition, **Mark Dunlop:** Conceptualization, writing and editing, formal analysis funding acquisition, **Alison Kirk:** Conceptualization, writing and editing, funding acquisition, **Gill Windle:** Conceptualization, writing and editing, funding acquisition, **Joshua Stott** Conceptualization, writing, review and editing, funding acquisition, **Greg Flynn:** Conceptualization, writing, review and editing, funding acquisition, **Bradley MacDonald:** Conceptualization, formal analysis, writing and editing, **William Hodgson:** Conceptualization, formal analysis, writing, review and editing

Abbreviations

TTM: Transtheoretical model of behavioural change

CMS: Content Management System

JDR: Join Dementia Research

IPAQ: International Physical Activity Questionnaire

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