Results of a Feasibility and Adaptation study of a mobile application "CareFit" supporting physical activity for informal carers of people with dementia

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Abstract

Background: Health and social care models worldwide are facing perpetual crisis where the informal (family) caring role is becoming increasingly pivotal. Despite unparalleled societal and economic value, many informal carers face poor mental and physical health with limited opportunities for physical activity. There remains an urgent need to understand and support informal carers to stay well, including evidence based physical activity approaches.

Objective: To codesign, adapt and explore the feasibility of a novel cross-platform approach to support physical activity in carers of people with dementia.

Methods: This was a mixed-methods codesign, development and evaluation study of a smartphone app (CareFit) to support physical activity for unpaid dementia carers. We explored implementation of CareFit for carers, guided by both 'RE-AIM' and MRC Complex Intervention Frameworks in two stages: (i) codesign; (ii) feasibility study findings (i.e. recruitment, intervention and outcome selection). The codesign sessions for adaptation and expansion involved 3 development sprints gaining feedback and identifying priority areas from a range of stakeholders (e.g. carers, support professionals, charities, researchers and developers). This was followed by an 8-week feasibility study with participants recruited from local and national networks alongside Join Dementia Research (JDR) using a closed-testing release app on Google and Apple app stores.

Results: We successfully codesigned, developed and user tested the CareFit app. Codesign resulted in an expanded and adapted CareFit suitable for 8-weeks of use. Final app design included a simplified navigation system, increased video content alongside more personalised delivery of content. Feasibility study results highlighted the challenges of recruiting carers of people with dementia. In total 41 carers of people with dementia were recruited with 21 completing the 8-week study. Study retention was considerably lower for those carers undertaking high levels of physical activity at baseline opposed to those who were not (36% retention vs 58% respectively) providing useful information on the target group of future interventions. CareFit rated well on the System Usability Scale and we observed common user patterns of behaviour (e.g. an initial focus on 'learn' section). Most outcome measures were largely suitable for future use in this group- this included novel measures introduced by the research team around the number of sedentary breakers and muscle and balance activities.

Conclusions: Physical activity in carers of people with dementia remains a largely unmet need. We conclude that our approach

fits largely within the context of preventative medicine where presentation to carers at the 'right' time in their trajectory (i.e. early) is critical for adoption and long-term use. A major challenge remains around recruitment. Despite value recognised by stakeholders including carers, we cannot currently recommend progression to randomised control trial. Of future interest would be to build upon this work further to accumulate evidence on optimising the active ingredients of the intervention.

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Results of a feasibility and adaptation study of a mobile application "CareFit" supporting physical activity for informal carers of people with dementia

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Abstract

Background: Informal carers are critical in caring for people with dementia is valued at over £162 billion to the UK economy alone. However, they are inadequately supported and face poor mental and physical health with limited opportunities for physical activity. There is a public health priority to address such challenges where there has been a lack of innovation around physical activity approaches.

Objective: To codesign, adapt and explore the feasibility of a novel cross-platform approach to support physical activity in carers of people with dementia.

Methods Project stages included a codesign phase followed by a feasibility study guided by both 'RE-AIM' and 'MRC Complex Intervention' frameworks. Codesign involved 3 development sprints gaining feedback and identifying priority areas from a range of stakeholders (e.g. carers, support professionals, charities, researchers and developers). Our feasibility study involved evaluation of our recruitment, intervention and outcome approaches over 8-weeks (target population n=50) with participants. Participants were recruited from local and networks in Scotland alongside study registries.

Results: We successfully codesigned, developed and user tested the CareFit app. Final app design included a simplified navigation system, increased novel delivery of video content alongside more personalised delivery of content. In total 41 carers of people with dementia were recruited with 21 completing the 8-week study. Study retention was considerably lower for those carers undertaking higher levels of physical activity at baseline opposed to those who were not (retention 36% vs 59% respectively). CareFit rated 'acceptable' on the System Usability Scale and we observed common user patterns of behavior (e.g. an initial focus on 'learn' section). Feasibility study results demonstrated that the intervention appeared safe for use (no adverse event reported) and that the novel approach of video content delivery for carers was well received. A greater depth of social elements appears critical for future development. Although professional stakeholders did not demonstrate consensus on the outcome of greatest utility, outcome measures tested were largely suitable for future use in this group, including novel sedentary behavior and muscle and balance measures.

Conclusions: Many carers of people with dementia do not have the same accessibility to physical activity compared to non-carers. The digital approach outlined here evaluated approaches to recruitment, intervention design and outcome assessments. Our findings as presented demonstrate key challenges around recruitment and retention. Although we cannot currently recommend progression to randomised control trial, we conclude that further work is needed to better understand the 'active ingredients' of the intervention outlined including exploring delivery of a preventative intervention earlier in the carer trajectory- something critical for adoption and long-term use.

Introduction

Health and social care models worldwide are facing perpetual crisis. Ageing populations, increasing comorbidities and a shrinking health and care workforce create a 'perfect storm' of continual system decline [1]. Caring roles are increasingly delivered in the community, often relying on informal (family) carers. In the UK setting, 10 million informal carers save £162 billion each year; the cost of a second National Health Service (NHS). NHS data reveals that carer reported quality of life is decreasing year upon year and recent national level surveys in UK setting (engaging >10,000 carers) indicates that 82% of carers see challenging impacts of delivering care on their physical and mental health, [2-4]. There is a compelling need to recognise this paradigm shift and to build much greater resilience in our care system and networks. This includes asking difficult implementation questions as to how scalable solutions for carers can be codesigned, implemented and maintained.

Across a growing array of carer innovation and research[5, 6] the development of digital supports for carers of people with dementia continues to be of significant societal interest [7-9]. With UK data suggesting that 1 in 2 people will be affected by dementia in a lifetime- either with the condition or caring for someone with dementia (944,000 people currently living with dementia in the UK), few interdependencies in society can compare [10]. Understandably, dementia has long been a topic of interest for developing digital interventions including the pioneering iSupport platform developed by the World Health Organization (WHO) that has facilitated evidence-based theory such as personhood and cognitive reframing [11, 12] to become accessible to a global audience through online training and support. While iSupport delivers key material of critical importance (e.g. introducing dementia, dementia related behaviors and carer health and wellbeing), there remains scope to increase capacity of the platform to provide personalised advice to support regular physical activity of carers. More broadly, physical activity in carers is a surprisingly underdeveloped area of current science. Multiple reviews have highlighted that carers are largely overlooked for physical activity innovations (both dyadic and independent carer use) with systematic reviews identifying between 5 and 14 interventions to date: including a strong emphasis on face to face and telephone delivery. [13, 14]. Given this gap in knowledge, a team of multi-disciplinary researchers at the University of Strathclyde co-designed and evaluated (with carers and health professionals) a prototype digital tool 'CareFit': aimed to increase physical activity (and reduce sedentary behavior) in carers (9). Awareness of physical activity guidelines (e.g. WHO, UK government [15]) can be poor in vulnerable groups (10) including carers ([16]). Therefore, the platform was built with an emphasis on 'actionable information', particularly for those starting out in physical activity and our original work was conducted within the COVID-19 pandemic lockdowns. The intervention design was largely influenced by the 'Transtheoretical Model' of behavioral change [TTM] (11)), is self-led by informal carers at their own pace and does not require specialist equipment. The initial (3 week) codesign and pilot study across Scotland [16, 17] successfully demonstrated the initial acceptability, feasibility and usability of the approach, open to use across any carer group. Remaining gaps in knowledge included a more in depth understanding of the practicalities of delivering CareFit within a single post diagnostic pathway across recruitment, adherence and outcomes. This included critical questions around how to personalise the intervention, how to extend the platform beyond 3 weeks of use, and the identification of key barriers and enablers to facilitate more widespread and scalable delivery. Thus, here we set out to codesign, adapt and explore the feasibility of a novel cross-platform approach to support physical activity in carers of people with dementia.

Methods

Objectives

Our aim was to codesign adapt and personalize a cross-platform digital health app (CareFit) designed to support regular physical activity in carers of people with dementia for a period of 8 weeks and evaluate the potential for implementation.

Our objectives were to (1) expand an initial 3-week intervention to an 8-week intervention to support maintenance of physical activity; (2) develop understanding of recruitment pathways and explore barriers and enablers to recruitment for a future definitive trial, including recruiting more deprived socioeconomic groups; (3) improve understanding of usage adherence and develop understanding of the most reliable methods to regularly measure physical activity and sedentary behavior within dementia carers; (4) 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 (5) to explore unexpected benefits including whether people with dementia also see the benefits of CareFit.

Study Design

The CareFit for dementia carers study was a concurrent mixed-methods [18] evaluation of a novel motivational mobile app to support home-based regular physical activity for unpaid dementia carers. Study methodology have been submitted for publication [JMIR protocols reference to follow] and forms a 'stand-alone' element of an existing Randomised Control Trial on "iSupport" [19]. The mixed methods evaluation was informed by both the MRC complex intervention framework [20-22] and RE-AIM [23].

For initial codesign to achieve both adaptation and expansion we designed three development sprints where different elements of the app were sequentially developed in partnership with our local development partner, 'Add Jam'. Feedback was sought from a range of stakeholders such as carers, professionals alongside researchers and developers to create priority areas for app development. Our subsequent feasibility study involved both local and national networks in Scotland alongside use of Join Dementia Research (JDR) (https://www.joindementiaresearch.nihr.ac.uk/) to understand feasibility of recruiting to a larger trial. We aimed to recruit 50 carers of people with dementia for our feasibility study.

Feasibility study Inclusion criteria for carers

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

Feasibility study Exclusion criteria for carers

- Anyone advised by a clinician not to undertake physical activity or make any change in their present level of exercise
- Are already regularly exercising to a significant level outside the home (e.g. running/cycling)
- Residing outside Scotland at the time the study is conducted

- Currently part of a related 'iSupport' study

Feasibility study Inclusion criteria for Professionals

- Adults (18+) living in Scotland and working as a health and social care professional
- 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 for Professionals

- Working exclusively within the National Health Service

Ethical approvals, app development and onboarding

Ethical approval for feasibility work was obtained 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. CareFit was coded using 'React Native' so that we could facilitate use across both Android and Apple mobile phones and tablet devices. As the study was a 'closed' research project (that is, not available freely to the public) onboarding of participants involved a number of steps to contact the research team, confirm that they met the study inclusion criteria, receive a study ID, and then to be sent a bespoke link for the respective Apple and Google stores. This process was thoroughly tested before the implementation study began. See protocol publication for further information.

Data collection, management and app download process

Study adverts (in both paper and digital formats) were shared with study partners in parallel with use of the JDR platform (see Supplementary Appendix A1). Beyond monitoring study interest numbers, our key areas of data collection included: (i) online surveys, (ii) 'In app' data collection and (iii) interviews and focus groups. For online surveys, information was shared using the online platform 'Qualtrics [24]'. Carers who consented were directed to a bespoke hyperlink within the Google Play and Apple app stores where an individual pseudo-anonymized ID was entered after download. For 'in app', data included usage and timestamps for users across the app tabs such as 'activity', 'planner', 'resources' and 'sharing' (see later for breakdowns). Lastly, focus groups and interviews took place both to understand a subsample of the participants experiences and were employed in the closing stages of the project as 'round stakeholder' meetings to understand longer term use and implementation. As we invited a variety of stakeholders to such meetings regardless of their knowledge of CareFit, we shared preliminary data on study findings.

Adaptation of CareFit

We successfully expanded and adapted CareFit for 8 weeks of use within context of dementia caring- see Table 1/Figure 1. This included a redesign of the Graphical User Interface (GUI) based on previous short-term user-study feedback of previous iterations to simplify the navigation and steps required to find key information. We also redesigned the physical activity planner (placed on 'Home' tab) so that users could both add and review activities using the same screen and were able to add their own activities. Simplification ultimately led to four 'tabs': (i) 'Home', (ii) 'Learn', (iii) 'Community' and (iv) 'More'. We established a uniform image

set across all activity videos and colour coded these according to whether the activity is cardiovascular (red), sedentary (gold) or muscle and balance (blue) reflecting U.K. physical activity guidelines. Additional elements included short video clip animations summating key learning information across the learn section, the development of fictional personas that described a variety of dementia caring scenarios across different genders, geographical settings and ages alongside links to local resources within the community tab.

Evaluation Outcomes

Our mixed methods evaluation was underpinned by different data sources including: (i) baseline and follow up questions (e.g. age group, gender, number of years caring/hours caring per week, International Physical activity questionnaire Short Form, [IPAQ-SF] [25], EQ-5D5L [26], System Usability Scale [SUS] [27] (ii) professional survey (e.g. exploring elements of RE-AIM and how CareFit could integrate into working role), (iii) 'in app' collected data, alongside (iv) interviews and focus groups (See Supplementary Appendix A2 and A3).

Analysis

Our approach to mixed methods [18] was to analyze qualitative and quantitative results individually in parallel and combine to form conclusions. Interviews were recorded by encrypted Dictaphone/University approved video software. Thereafter Braun and Clarke thematic analysis process was followed [28]. 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 with 'time stamps' at the time/date of use). Indicators of usability were underpinned by the SUS total scores and on occasion individual questions were used to support the interpretations of qualitative data. For all outcomes, 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.

Results

Description of feasibility study populations

Our baseline demographics data described 41 participants recruited into the study: see Tables 2 and 3. Most carer participants were female (39/41, 95%) and all participants self-identified as 'White' ethnicity. 63.4% were educated to degree-level and age groups were variable ranging from 25 to 34 up to 75 to 84. Almost half of carer participants have been caring between 3 and 10 years (43.9%). Almost a third reported caring 8 hours or more per day (32.5%). There were 19 (of a possible 32) council areas represented. The most common council areas for carer participants were Angus (n=5), Glasgow City (n=5) and Highland (n=4). At baseline the general adiposity (measure through BMI) varied from healthy (31.7%) to morbidly obese (9.8%). Activity levels as per IPAQ-SF scoring were almost equal across vigorous (29.3%), moderate (36.6%) and low (34.1%) groups. Muscular activity guidelines, 2 days or more, was met by 39% (16/41) of participants at baseline.

We recruited 27 professionals into interviews or focus groups of whom 25 completed the detailed follow-up survey on the feasibility and implementation potential of CareFit. This population included: pharmacy staff; those working public sector roles across health and social care; charities/third sector (at national and local levels); public health roles; digital health alongside those working within political roles. We do not detail each position individually to retain the anonymity of quotes. See Table 4.

Feasibility of recruitment

Recruitment consisted of proactively contacting carers alongside individual carers contacting the research team. We contacted 659 volunteers from JDR. In total 88 carers of people with dementia (including 34 from JDR) showed an initial interest in the study where 41 of these progressed to completing the baseline survey. 17 of our 41 (41.5%) our total study population were recruited from JDR. For the 24 carers that were recruited through direct advertisements recruitment took place most notably through Carers Scotland, Social Media, Alzheimer Scotland/Brain Health Scotland Centres. The most successful non-registry recruitment approaches were emails from the research team (57.5%) alongside social media posts (35%). See Table 1 for further information.

Qualitative data further improved our understanding of feasibility of recruitment identified 5 key subthemes below. For overview of all themes and subthemes see Table 5.

Lack of carer self-identification and related terminologies

A key challenge for recruitment with the CareFit study was that people who care for others do not always identify with terminologies such as "carer" or caregiver".

"The trouble, I suppose, is that you know, with carers, a lot of carers don't badge themselves in that way," Professional Participant 5

Such challenges are extended further across more demographic specific barriers to research/accessing healthcare related to gender and/or cultural background, personal viewpoints or cultural beliefs

"And for us in Glasgow ethnic minorities are actually quite a hefty proportion of our population, so non-English speakers, they're really underrepresented at carer centres already, so they're a big worry for us in terms of a community that we don't feel are getting the right support even to

begin with. And so I think at least having it in scope for the medium term to develop some translations. Or more accessible kind of mobile app functionality would be really helpful, yeah." Professional Participant 12

Digital readiness of the informal carers who care for a person with dementia

Stakeholders typically assumed carers of people with dementia to be older, less familiar with technology and difficult to engage due to caring responsibilities.

"One of my questions might be is from the Alzheimer's carers' audience, they might be the ones that are in most need, but they might also be the hardest ones to actually get." Professional Participant 8

The level of responsibility placed upon carers of people with dementia was highlighted by a number of professional stakeholders,

"….obviously a large number of carers are under particularly heavy stress loads and they're getting bombarded with information all the time. And I think another app, another solution, quite often people just don't pay attention to it because they've got enough on their plate as it is." Professional Participant 6

The diversity of the technology confidence and support requirements was highlighted across stakeholder interviews,

"I think it's like you say after you see them, maybe a couple of times, you understand this person's probably confident enough with their phone or tablet. They could probably work to it, whereas someone who comes and asks you to help set up their e-mail and has other problems with technology at home." Professional Participant 25

Catering to different stages of the caring journey

Targeting earlier provision in the journey of a carer was a common suggestion, ensuring the intervention becomes of post-diagnostic support. This could include linking into GP practices, health centres and carer centres. The consensus was as dementia progresses, caring needs placed on the carer would become too demanding to allow CareFit to be as effective or easy to implement. Linking in with other services and organisations would be effective at local level, but wider integration could be achieved if CareFit was able to align with national and regional policies, strategies and agendas.

"Because if a carer is at that point where their stress load is so high. They can't take on doing something else then it it's not really gonna be a benefit to them. But if you can get it in front of them and there's probably quite a narrow window actually. When that is, when they've got, they've got the kind of headspace and the capacity to do it." Professional Participant 6

Increasing breadth and depth of advertising to identify informal carers

Suggestions from stakeholders around advertising varied considerably and included both advertising approaches both in person and at distance such as the use of local radio advertisements, social media, visibility on both Apple App and Google Play stores, telephone contact, leaflets, posters alongside more unstructured approaches such as word of mouth. In terms of the content of such materials, stakeholders mentioned that the benefits of using CareFit could be important to highlight upfront.

"I think it has to be much more direct, either telephone or face to face and finding the way to create like the right language to discuss these different things cause it's a very diverse community. So a leaflet's not gonna suit everybody and sometimes there's a low level of literacy across some patients. So it has to be quite direct." Professional Participant 14

Co-ordination with key stakeholders including using established 'watering holes'.

Many stakeholders highlighted the need to co-ordinate with other services at a local level that carers already frequent including 'less formal' networks which may involve third sector presence and established local services. More broadly, a number of stakeholders highlighted that face-to-face roles remain important for the app uptake and use, where roles such as those in the allied health professional or pharmacy may complement future implementation. To a lesser extent stakeholders also had some suggestions for co-ordination around national level and local level initiatives.

"You need to understand the habits of the people that you're trying to reach. What sometimes people talk about it in terms of watering holes, so where do they go? Where do those other carers go? Do they have support groups? Professional Participant 8

Feasibility (and usability) of intervention

We first examined the feasibility of intervention through the lens of safety: there were no adverse events reported from any of the participants involved in the work. In terms of usability, were examined SUS responses completed by 18 participants. The average score was 'acceptable' [29], (m=72.6, SD =21.5 range 35 to 100). Based on the responses to the individual questions, participants were primarily positive towards the CareFit app e.g. 45% strongly agreed they would like to use CareFit frequently (Q1) and 83% disagreed or strongly disagreed CareFit required learning a lot of things to use it (Q10).

Adherence and practical considerations for using CareFit

41 participants initially joined the study whereas 38 participants downloaded the app. Attrition within the 8-week study was relatively high, 33 participants used the app across the 8 weeks. 21/41 (51%) of participants submitted the follow up surveys. We explored overall use through 8 weeks of Content Management System (CMS) data. Our overall 'tag counts' (from 2,891 instances) identified that the most prominently used parts of CareFit were the 'Learn' tab (44.8%, 1,296 events), followed by 'Activities' (34.5%, 996 events) tab and the 'Planner' tab (8%, 230 events). Other available tabs were used to a lesser extent such as 'Own activity' (5.6%, 163 events), 'Sharing' (5.5%, 159 events) and 'Resources' (1.6%, 47 events).

We used timestamps on events to further understand app use over time (see Figure 2). We observed a large initial engagement with CareFit, particularly around the 'Learn' tab (e.g. week 1), alongside a subset of users who established steady engagement with the 'activity' section throughout the 8-week study. Small peaks of app use can be noted at the 3- and 5-week point. This timing coincided with two 'keep in touch' emails sent directly to users on the platform to offer technical and then more general study support. Figure 3 demonstrates usage across different times of day, where we observed higher usage during pre-office hours, a reduction in usage middle of the day, and a late-afternoon to late-evening usage.

We further explored adherence and practical considerations through themes generated from carer data (21 questionnaire responses and 8 qualitative interviews). We summarise these data through five key subthemes below:

Caring routines

Regardless of the physical activity level achieved during the study period, most carers highlighted that accessibility to physical activity was associated with the demands of the caring role and being able to partake in activities 'when you want'.

"No, I enjoyed it. I didn't use it probably as much as I should have, but that's just because of things going on in my life." Carer Participant 1

Initiating physical activity around busy routines was something mentioned as a specific challenge to carers, where the earliest stages of change were supported with an appreciation of the value of physical activity for carers own health.

"it's not a kind of 24 hour seven day a week thing, you know, she's not in the house with me, but it certainly impacts on any kind of routine that you would have had previously. So it really does help in in establishing a kind of routine and I suppose that reminder that you need to look after yourself if you're going to be able to look after somebody else." Carer Participant 7

Motivation for physical activity

"I really enjoyed [using CareFit]. I thought it was easy to use and it fitted round about my caring duties. I found it very motivational at times and it made me think about my health. My physical health which I've ignored." Carer Participant 4

Motivation for physical activity was an important point raised by many carers. While many carers felt they knew why undertaking physical activity would be important, both the impact and uncertainty of the caring role limited the opportunity for carers to undertake regular physical activity.

"I think it would be really useful for people like myself who are stuck at home. Who can't get to a gym or even can't go a walk. When I go a walk, It's not far, because I can't really go away and leave my husband. He's not able to be left. So I find it it's a good idea, it just maybe needs a bit of tweaking." Carer Participant 1

Other carers also commented on barriers to motivation for physical activity such as feeling 'exhausted' or environmental challenges such as poor weather.

"My well-being is really important and there are some days where I'm very very tired and you don't always feel you have the energy to do the exercises." Carer Participant 3

A number of carers mentioned that the app had helped to change their perceptions around physical activity.

"Essentially that was what it did for me. It gave me motivation, even if it was only for a minute. And I felt quite positive at the time. And then other times I would look at it and go oh, can't be bothered. But that's my own. You know, that's just me." Carer Participant 1.

The value that friends and family, people with dementia hold around physical activity informal carers was also important to carers.

"Other carers or other people who've been through the same thing. Not quite giving permission. But you know saying, this is good. This will [...] help you. This will make you feel better and that you are important and because you spend well for me as a carer you spend so much of your time advocating for the person you're looking after and you know fighting services to get something in place. It's quite exhausting. It's actually being allowed to say you need time too." Carer Participant 7

Accessibility and usability of CareFit

Accessibility and usability of digital devices was a prominent topic in carer feedback. For example, first and early use of CareFit involved a number of steps to follow directed by the research team. From 18 carer replies, installation was described as 'easy' or 'fine' by 15 participants with 3 participants noting some issues or need for technical support.

"[You] made it really simple. I work in a in a fairly similar role so I understand what the need for satisfying ethics and making sure that everything's done so, no, I thought you did it very well actually." Carer Participant 2

Regarding longer term use of CareFit, systemic challenges around technology (e.g. mobile signal) were raised by participants alongside more specific challenges around the design of

CareFit.

"Part of that was because it's on my phone, so it's working via Wi-Fi. And our Wi-Fi goes down quite a bit here." Carer Participant 1

Over the course of 8 weeks of use a number of carers highlighted specific technical challenges around the use of CareFit. One challenge highlighted by a number of participants was the size of the physical activity videos on a phone screen particularly when viewed at distance. This included the need to maximise video size by putting the phone in a landscape orientation.

"the size of the screen that they offer for some of them. You know, and put your phone this way, put your phone that way. And it's like when my phones way over there and I can't quite see it." Carer Participant 7

In the earliest stages of the study, there were also specific technical issues with the activity planning and recording section of the app that a number of participants commented on. We also received more broad feedback around accessibility including potential future challenges such as those regarding costs where free at the point of use would be particularly attractive.

"I did find the planner a little bit frustrating at times as it didn't show the exercise I had added or had undertaken straight away. I did contact your team regarding this and you explained the reason behind that." Carer Participant 4

Content engagement

When asked which feature or part of the CareFit was most useful, survey responses received highlighted activity videos (n=13). Other responses included the activity planner (n=3), community tab (n=1) and learning tab (n=1). Notifications were suggested to hold utility in reminding participants to use the app, particularly within the earliest stages of use but were also associated with pressure.

"I liked the videos because they were short and you could just get on and do like a very short burst of something and it felt manageable and it felt like he could achieve something rather than signing up to a 30 minute exercise class which you just were dreading" Carer Participant 6

There were a range of comments regarding the Learn tab and associated content. Some carers found such information beneficial, but others pointed out that they felt that they already knew enough information to start on a physical activity plan prior to engagement.

"It really got me thinking about how little physical activity I was doing and how important it was for me particularly in my caring role. I don't think there's anything else I would have added. It was straightforward it is well laid out and it was easy to read." Carer Participant 3

"Don't wanna sound ignorant like I know what I need to do. I just need to actually do it. Like, yeah, so the whole purpose of the app for me was really more about getting me doing stuff rather than learning about what I needed to do" Carer Participant 6

The activity planning and recording was highlighted as a key strength by a number of participants.

"I really enjoyed how I could see exactly what I've been doing and measure time wise. I'm quite a competitive person anyways, yeah. Quite enjoyed that element of seeing if I could do better than the last time." Carer Participant 2

Suggestions of improvements to CareFit for future use

A number of participants suggested ways to improve CareFit going forward. As mentioned above, this included technical improvements suggested for the planner. Feedback included a focus on integrating additional devices, additional physical activities, increasing community elements and improving aspects around the reminder notifications. For example, use of a laptop would allow a better screen size for participants to use.

"I think I would have preferred the videos to be a little bit larger as I sometimes struggle to see them on my phone and I suppose if I could have downloaded them onto my laptop then that would have been ideal for me" Carer Participant 3

Adherence and Practical considerations for use: professional data

Study adherence and practical considerations were explored through interviews follow on surveys with professionals who work with dementia carers. Five key themes identified are listed below.

Addressing different levels of the digital divide

Stakeholders highlighted that the initial adoption of CareFit requires overcoming numerous barriers including different levels of the digital divide. For example, dependency on having suitable technology and means to access the app can empower some and limit others. Connecting through Wi-Fi and mobile data, or potentially needing to pay a regular subscription to access CareFit may not be viable if carers' finances are limited. Such barriers also extend to human and wider cost elements.

"….it gets down to you actually have to practically show people how to use things. So you know apps being solutions on their own I think is never the answer. You need to have human interaction to show people the benefits of these things…" Professional Participant 6

Digital literacy and skill were noted as potential barriers, especially where carers are typically assumed to be older, and any new technology requires time to build familiarity and skill, among existing burdens. Data privacy and quality of the app would need to be assured as well. There was also the recognition that some carers will simply not wish to engage with digital interventions and prefer traditional offline alternatives. At the same time, stakeholders felt that the prevalence of technology and recent experience of providing services online throughout the COVID-19 pandemic had demonstrated that these concerns can be overcome with this population. Creating an 'offline' version of CareFit reassured some concerns.

Digital divide concepts also extended to existing routines and practices. For example, carers may utilise other digital resources, whether they choose to or out of necessity, but others may see a further burden on them i.e. another account, another password to remember. Digital literacy and language barriers may also prevent carers from accessing the support CareFit can provide and would require an accessible and useable interface to be effective e.g. minimal use of text, with interactivity and images more important. Given the limited time and opportunity carers have for physical activity, streamlining the process of using the app to complete intended tasks should be prioritised e.g. minimal steps to starting an activity.

"I think in this modern day and age, I think that we can't really hide under that stone anymore. I think is that if 2020 taught us nothing else, it's that people actually can, when necessary, embrace technology and that is the sort… The reality is the sort of people who are going to use this, they're going to be some people are into apps that that's your target group, you know, it's not the… some person is gonna ask if you have the video on VHS." Professional Participant 26

Timing and target group for intervention

Stakeholders were cognisant that creating new habits in carers requires careful consideration about the transient nature of caring, and that presentation of CareFit at an optimal upstream timing was critical.

"I see the caring journey in stages cause we try to adapt our thinking not to what we do, but what they do. So many organisations really get involved with carers when the caring is really critical

and impactful, at which point are very unlikely to have time to think about the app, so you would want to go to the downstream, the green where the early intervention and getting things in there." Professional Participant 7

A critical barrier to achieving regular physical activity remained around habit and the ability to change a societal norm that carers are the last people that will look after themselves given their existing pressures and commitments.

"One of the biggest things that I hear from carer organisations is carers are the last people that will look after themselves and perhaps I don't know what some of the statistics around carers are. But you know it's beyond a full-time job. And it's getting people to rethink their pre-existing habits I suppose." Professional Participant 16

The expectation placed upon carers that they should be exercising and utilising interventions like CareFit has the potential for harm or burden, with stakeholders suggesting they could experience a sense of guilt if they could not effectively do so amongst other caring responsibilities. Guilt may also rise from the idea of taking time for themselves, rather than focusing on caring, despite the possible benefits of self-care can offer for both. They are limited in available time and resources, especially as the condition progresses and this can be even less if replacement care is not available or leaving the home is not possible. They may also simply value other ways to use their downtime instead of exercising or physical activity. Culture and language differences may play a part, with stakeholders describing the difference in engagement having a BAME (Black, Asian and minority ethnic) worker can have.

Facilitators for habit forming included both being able to design an app that accommodates for rapidly changing situations due to events such as hospital admissions, carer or cared for illness alongside carers' anticipatory grief, especially in later stages of dementia. All carers may face some limitations around opportunities for physical activity, and between individuals, the rate of behavior change, personal goals and endpoints, and activity levels can vary, requiring an adaptive approach to enable habit forming. Equally the caring role can also change when the carer transitions from their role (e.g. cared for passes on or responsibility of caring taken by another), or if the carer reaches a stage where they no longer depend on CareFit to continue their new physical activity behaviors.

Integration with other services and providers

Stakeholders stressed that CareFit should not be delivered in isolation, but instead, should leverage value and visibility from a wide variety of existing services and providers at local, regional and national levels to integrate into a suite of existing tools. However, similar to many novel interventions and services, there remains a risk that the promotion and use of CareFit becomes another thing to do that may not be practical given current workloads and roles.

"If you're able to bake that into what they're already doing. Then you're kind of winning on it." Professional Participant 16

Suggestions how such an intervention could be both introduced and maintained included a number of professional roles and services. For example, this could include support from professional staff on house visits where informal carers would be present,

"I suppose it's just, the health professionals, the ones whose health is their bag and wellbeing's their bag to actively promote it as much as they possibly can. And thinking again people who go into people's houses so, [Occupational Therapists] and staff, home care staff and things like that. Just making sure that they're aware of it and just bring it into conversation. If "you used your app today? I will have the next half hour, why don't you go and have shot at it?" Professional Participant 3

Feedback around integration included established digital health resources and tools from both National Health Service providers and charities in dementia or caring. An example being local

council physical activity websites and/or health and social care mobile applications (e.g. the Carers UK developed 'Jointly' or also 'Medicare').

"Charities with access to carers and used by carers as a trustworthy source of information and already have an established relationship" Professional Participant 23

Suggestions around integration also extended to wider digital commercial sectors and 'consumer' marketplace. Given that the space for physical activity and digital is already "busy" connectivity to existing resources common devices and platforms such as Apple Watches and Fitness, Fitbit and Strava can make interventions like CareFit more attractive to users, especially those already using these different physical activity tools.

"So I've got one of those with things, the smart watches. And also like takes your heart rate and all that kind of stuff and when you go into the app, there is... There's simply just here's your reading. But click here for more information. It's not busying the page, but it's gonna say if you want, here you go, off you go and go and find that information... Delivery of information, don't muddy it up too much." – Professional Participant *16*

The need to embrace human elements and increase social connections

Alongside suggestions of integrating into services and staff roles was also a broader need to embrace human elements across the trajectory of care. Persistence of the app throughout the carers' local communities and environments was a strategy proposed to secure engagement, through demonstrations, testimonials from "champions" and presence at regular activities and events within the community e.g. "DigiPals" library tech support, coffee mornings or social events. This included the perspective from use of CareFit including initial onboarding to long term sustainable use. At the onboarding level this included critical conversations professional stakeholders such as pharmacist, have with carers

"Referring to carers we identify in the community when they are collecting for patients and chatting them through what care fit is and how it could benefit them." Professional Participant 13

Motivators for carers to adopt CareFit included carers championing their own use and stories with case studies and testimonials highlighting the benefits and minimal demand on time and energy required to utilise CareFit. The potential value of CareFit could also be expanded to directly reduce isolation, possibly through participation with other carers in group activities, social features or even as a topic of discussion within the community. Linking to existing platforms including those outside of health and social care settings (e.g. social media, Alexa, Strava, etc.) could also encourage more adoption from carers.

"So you know and maybe monitor your CareFit progress or how you're using it, how're you going and you know make it more of a kind of social element to it. So I suppose that's a lot of people, you know, like that team type thing with their friends and stuff like that. So any opportunity to maybe kind of you know make it with a kind of social thing would help at all." Professional Participant 3

Facilitators to support implementation and longer-term use

Facilitators to support implementation and longer-term use included suggestions at both the professional organization role alongside the individual informal carer role.

At the organizational level, addressing the financial and structural models was raised by a number of stakeholders. This included establishing knowledge of the organizational infrastructure to establish which key decision makers could initiate use of CareFit even on a small scale. The cost, resources and effort to maintain such an intervention were also raised by stakeholders, more so if they aim to provide technology and means to access the intervention, alongside training and support.

"The commissioners are the ones that you typically you would need to convince" Professional Participant 8

Organisations may also be hesitant to implementation of new technology, with developing, providing and maintaining digital interventions imposing financial costs and more demand on already burdened staff, who like carers, may be opposed to the introduction of technology where the existing system and way of things is established. A strong evidence base and assured uptake with users is required to assure organisations there is minimal risk in implementing the proposed technology, and that existing inequalities will be addressed rather than exacerbated e.g. having to provide access and connectivity to utilise an intervention for those who may not have the means.

"I think the payor is most likely to be the public sector but ideally CareFit is being delivered as a business solution or service to that market." Professional Participant 8

Professional stakeholders largely appreciated that longer term delivery of CareFit would require financial sustainability, although there was not a consensus on how this could be achieved.

"As decision-makers and commissioners as well as policy-makers, if an intervention had clear benefit it might be able to benefit from some kind of national funding. But more likely that we would expect local providers to fund from existing budgets." Professional Participant 11

At an individual carer level, several suggestions were made to support the use of CareFit longer term- including beyond the initial 8-week study outlined in this study. First, CareFit must be accessible and available to carers, whether this is through incorporating it into a suite of existing tools and resources or advertising through leaflets and posters with QR codes. For specific devices, CareFit should be available through app stores and utilize native functionality and services to ensure the application is passive and requires minimal effort to start using. Updates and new content would also be required to keep interest in the app but should not compromise familiarity or fundamentally change the CareFit app, which may discourage users instead. This would ideally see carers' feedback resulting in effective changes and improvements, and keeping information and content up-to-date and relevant.

Prompts, reminders, and notifications from the app itself could be important tools to ensure consistent engagement across long periods but should be designed to be motivational and encouraging the user to want to engage in physical activity, rather than just remind them of a need to complete another task. Gamification and rewards, such as challenges and goals, where a defined target needs to be reached, can likewise encourage engagement. Rewarding continued engagement such as streaks e.g. completed an activity each day or week, can also be essential to habit forming but can be dismaying where punishing disengagement, which may not be possible for this user group to control or predict. Competing with other users such as leaderboards or group progression towards a shred goal were also suggested as engaging features, suitable for some users.

"that's the that's the trick with exercising that, like, you find something that's fun, you know, and it ends up being good for you as a byproduct, you know. So if you can make it engaging then, more the more the better." Professional Participant 16

Social connectivity was described in other features besides competing, such as social feeds or forums to share successes and receive support from peers in-app or utilizing physical offline groups, activities or classes to encourage use and check-in on how CareFit is working for carers. These were particularly supported ideas, where the caring role can be isolating and have limited opportunity to connect with others. There were also suggestions to integrate physical activities that could be completed by both carer and person living with dementia (e.g.

chair-based exercises or joint walks) removing the need to find separate time and space.

Feasibility and suitability of outcomes

We explored the feasibility and suitability of outcomes across: outcome measure response data completeness, and the subjective utility of measures through professional stakeholder interview feedback (including unintended consequences). Outcome measures were broadly well completed at both baseline and follow up- see Table 6. Some scales such as the IPAQ-SF showed completeness for some but not all questions, for example measures around walking activity and sedentary behavior had a >95% completion rate. However, IPAQ-SF vigorous and moderate activity were less well completed with response rates of 65.9% and 73.2% respectively at baseline. It was not clear whether omitted values were because individuals did not complete activities in specific intensity group or instead if they missed the question altogether. We included a question around breaking up sedentary behavior alongside a question on muscle and balance (see Supplementary Appendix A4) as these are included components of the current physical activity guidelines and were integrated into the CareFit app. Both our sedentary 'breaker' question and Muscular Activity (days) questions were relatively well completed with response rates >75% at baseline and follow up.

Professional stakeholders highlighted both short term and utility metrics of interest including those based upon measuring: usability including from professional perspectives, Direct improvements around physical activity levels and sedentary behavior, Broader (secondary) impacts and unintended consequences alongside inclusiveness for marginalised groups and those facing inequalities.

Measuring usability including from professional perspectives

Initial assurances for uptake included usability, ease of use and acceptability of CareFit. For example, early evidence for use could be ascertained by facilitating continued feedback from users, and testing with disability organisations or those that advocate for disabilities needs. Stakeholders were largely reassured of the quality of the project having incorporated co-design from the outset. They suggested that use cases and real experiences of users would be useful demonstrations of effectiveness and ease of use.

"For example, disability organisations… Getting them to even test it and see how they can actually use it is it is it actually usable, you know? And we do they understand is it easy, easy to use? And does it tell them then in a way that they would then understand so, you know?" Professional Participant 24

Measuring broader (secondary) impacts including unintended consequences

In terms of measuring changes over time, stakeholders were interested in seeing increases to initial physical activity levels, particularly continued or maintained physical activity. While physical activity increases are recognisably positive, providing support for users to understand the outputs and results of CareFit are also necessary to assist them in sustaining such behavior long-term. To deliver the right type and level of support to an individual is also important. This may involve linking into other services, such as more intensive referral programmes that run for several months before they reach a stage where tools like CareFit become viable for more independent exercise and activity.

"And yeah, that someone might need that really intensive part to get them on their feet. But once they've got the tools etcetera to be active. This could really help them maintain that, so yeah." Professional Participant 4

Other broader outcomes described were broad and included: quality of life, wellbeing, number of crisis points (i.e. care unable to cope and admission to healthcare provided), hopelessness, frailty and mortality improvement measures. These measures may also provide helpful insights, other than measuring just physical activity and help describe a better representation of an individual's progress. The topic of person-centred support and informed goals were also mentioned when discussing effectiveness, giving the control of goals and progress to the individual carer rather than applying formative assessments to the population as a whole. Stakeholders often discussed how individual carers presented with need for different types of support (e.g. health and wellbeing, legal, financial, emotional, etc.) alongside their own goals. Addressing these with individual carers was often the approach of many stakeholders, with personal goals still linking into the goals of the wider service or organisation. Empowerment of carers and the building of confidence and skills for effective self-management was encouraged.

"So move to personal outcomes, a formative assessment, have people -what you're asking people to invest in 'what are you gonna do, not what we're going to do for you'. What are you going to do for yourself? And then benchmark that, three months ago, or whatever time scale, a week ago. You said you would do this. How have you done this week? ...But empower and enable people to be in control of that rather than do it to them." Professional Participant 7

From professional feedback, common unexpected consequences of CareFit that were discussed included increased carer resilience, more effective self-management and be more confident and able carers.

"But for me, one of the biggest factors of this is carer resilience, for us is a huge support in terms of preventing admission, supporting early discharge. Professional Participant 26

The subject of unintended consequences were additionally explored through carer feedback. While the majority of carer data did not suggest any unexpected benefits, feedback included the person with dementia taking part in physical activity, completing physical activities but not noting the activity within the app, and becoming more competitive with themselves as a carer.

Inclusiveness for vulnerable groups and those facing inequalities

While promoting self-management and resilience may benefit the system supporting carers, concerns were raised that marginalised and vulnerable groups continue to struggle even if CareFit were to be successfully implemented. Directly addressing a range of public health behaviors in carers through the use of CareFit would be valuable to sectors such as public health and for gaining support, but require long-term usage and longitudinal data collection, with thoroughly planned methods and measures. While dementia is a long-term condition and there is potential to support carers over these periods, unpredictable routines can make continued regular use hard to guarantee and enforced timescales less feasible.

"We've been, ideally, from my perspective, sitting in public health, we would like to see a narrowing of health inequalities. So for me, I would like to see improved access to physical activity, improved access to mental health through the app, so that kind of sign posting or navigation to local service for me feels really important. And I think a consequence of the opposite stands at the minute might be a widening of inequalities because actually we're helping the well-resourced, wealthy, perhaps or well educated." Professional Participant *12*

Discussion

Principal Results

We successfully codesigned, expanded, personalized and evaluated the implementation potential of a mobile health app to support physical activity in carers of people with dementia. Throughout, our approach was to learn about the real-world practicalities around

implementation guided by both the MRC Complex intervention framework [20-22] and RE-AIM [23]. Our codesign outputs build significantly on existing research through establishing a greater depth and improving the functionalities of CareFit. By building a bespoke CMS, we initiated a future capacity within the platform to capture real time knowledge on carer wellbeing and to deliver key messages to carers both in local community settings, including at scale. Self-identification around being a carer appears critical for uptake: early introduction of CareFit including through face to face interactions appear extremely useful. Intervention uncertainty findings highlight positive feedback on the Graphical User Interface (GUI) however dropout of carers at 8 weeks was notably high at 49%. Lastly, while completeness of outcome measures was relatively good there remained gaps around key validated measures such as the IPAQ-SF. We included two novel measures of sedentary breakers and muscle and balance activities and these were largely well completed. These are important components of the current physical activity guidelines, that remains particularly easy to overlook.

Limitations

Despite a number of achievements, there remain a number of limitations. Due to time constraints we did not apply for UK Health Research Authority (HRA) approval to recruit participants in receipt of National Health Serivces. This additional recruitment channel may have increased reach and helped us achieve the target sample size. In terms of suitability of outcomes, our reliance on self-reporting around physical activity levels permitted individuals to join our study who were already regularly undertaking physical activity at higher levels beyond that desired in our target population, and thus less likely to benefit from our intervention design. The research purpose of this question was as a baseline/follow up measure, not a 'screening' question hence why such values are possible. Contributing factors may include that our explanations around physical activity levels on information sheets and consent forms however these were highlighted. Future research will ensure eligibility criteria are revised and participants' activity levels are considered more clearly ahead of consenting into a study. Lastly, our use of RE-AIM was ultimately focused on the planning and conduct of the data gathering opposed to the evaluation phases. While flexibility around the use of RE-AIM is both permitted and encouraged, as a research collaboration our focus from the outset of this work has been to better understand uncertainty around recruitment, intervention design and suitability of outcomes following elements of the MRC complex intervention framework. We chose to focus on these elements to provide a clearer narrative throughout.

Comparison with Prior Work and future direction

A key finding is that carers of people with dementia were recruited at a slower than anticipated rate. In the context of a randomised controlled trial (a future consideration for this work) our recruitment rate of approximately 1 to 2 carers a week through one centre is higher than medians reported elsewhere [30]. Nonetheless, we did not achieve our intended target of 50 carers of people with dementia and future work should consider ways to mitigate such risks including increasing the length of the recruitment period (i.e. beyond 6 months) and/or considering multi-site centre recruitment over a larger geographical area and broader carer groups. The self-identification and visibility of all carers has been highlighted across a wide array of recent literature[31, 32] and other recent work has also highlighted limited uptake of interventions for carers even in sizable population groups integrated with healthcare service delivery [33]. Future work should consider stronger emphasis on face-to-face conversations, which can be critical for uptake and retention [34]. Despite efforts to add more representation of carers (e.g. gender, ethnicity, geographical settings) inequity in the reach of CareFit was a prominent observation. This may be related to intersecting sources of inequity and

disadvantage, for example, much carer research demonstrates a high prevalence of individuals who are female, white and highly educated [33]. Further qualitative work is required, building upon foundational knowledge [35-38] as to how we can design preventative approaches to reach those traditionally marginalised in a more equitable manner.

Arguably, one of the most pertinent findings around our uncertainty of intervention findings is a study dropout rate of 49%. While this is high in comparison to clinical trials [39], systematic review evidence suggests that high attrition can be common for app based observational studies [40]. Our additional exploratory analysis of data identified that retention was considerably lower for those carers undertaking high levels of physical activity opposed to those who were not (retention 36% vs 59% respectively). Thus, future work needs to consider how to achieve stricter enforcement of inclusion criteria. It may also be opportunistic to expand CareFit to cater for more stages of change according to the TTM and signpost such users onto other providers and professionals where required. While our technical issues were few in number, such occurrences are likely highly impactful to carers- both we and others recognise the heterogeneity of motivations present in this population where personalised delivery is key [41]. Future work would ideally leverage learnings on the digital divide that both we and others [42, 43] have noted. For CareFit, this could include reducing the number of download steps to first use, improving the flow of the planner (including creating a menu of potential plans) alongside increasing opportunities to use larger screen sizes such as laptops.

More broadly, facilitators for use across carers and professional stakeholders include to integrate the realities of caring routine, and to sustain motivations for physical activity within this context. Many participants highlighted that the app as delivered was fun and motivational and the delivery of short videos (e.g. including content for use in 1 minute) in particular could fit into the caring role. While this type of delivery method is relatively novel, technical challenges remained, some relatively addressable (e.g. optimisation of the planner) but also some more substantial including those regarding the phone screen size being too small to allow physical activities to be easily conducted. Participants also mentioned that deepening links between the learn and activity sections would support carers with content 'more about getting me doing stuff'. Analyses also highlighted an appreciation that human elements are critical to convert autonomy and competency around physical activity in carers into long term maintenance. This includes 'championing' of CareFit by other carers: mirroring the importance of social influence across a broader range of behavioral change interventions [44]. We hypothesise that future efforts could leverage value both from face-to-face settings (e.g. working alongside employers) and also from community pages already set out in the app to date, including facilitating more content generation from other carers on a regular (e.g. weekly) basis. Stakeholder analysis identified that optimal delivery and support could include a variety of different settings including the use of regular carer assessments, linking in closer with front line community staff such as pharmacists and those conducting home visits to support adoption and regular use.

Our third key area of interest was the suitability and utility of different outcome measures to measure the (future) impact of CareFit. Qualitative findings from professional stakeholders indicate suggest no clear consensus on what or how to measure around impacts. We conclude that from a provider perspective, current economic and staffing pressures mean that cost effectiveness and reducing demands in care is likely to be a key driver of uptake. Concerns that health is not valued as an outcome it its own right have been raised in other literature [45]. While increasing physical activity levels in marginalised groups could yield significant long-term benefits for individuals and providers, the short-term impact is critical. Our findings highlight value in aligning to carer described goals: something that would align to multiple potential models of carer empowerment [46, 47] and of significant interest for future work.

Throughout the work presented, we relied largely upon self-report measures. While the validity of measures such as the IPAQ-SF has been well demonstrated across many different population groups [25], a recent meta-analysis identified low criterion validity for single items such as single item sedentary behavior questions [48]. Further development of (single or multiple) measures with greater validity could be of interest to variety of stakeholders: this could include further exploration of the new outcome measures introduced here. In respect to CareFit, measures could take a dual role as both mediators (advancing theoretical understanding of CareFit) and creating evidence based and personalised feedback to carers. Missingness around physical activity measures included both our activity recording within the app alongside the use of IPAQ-SF. A more systematic and focused approach on understanding the recording of physical activity in marginalised groups appears of value. We propose that a helpful extension to CareFit (at least for some users) would be to integrate more automated data collection such as the use of wearables or step counts (e.g. collected by mobile phones). Such integration would have to be considered carefully so that those carers with lower health literacy and/or are subject to the digital divide are still able to receive intervention delivery equity.

Conclusions

Accessible physical activity in carers of people with dementia remains an unmet societal need. Our work demonstrates self-recognition and reach of carers of people with dementia appears critical. While we cannot currently recommend progression of CareFit to randomised control trial, both the safety and the usability of CareFit was promising. Further, our work builds new knowledge optimal components for delivery and to measure outcomes: not least a large delivery of carer content through videos that were positively received. We conclude that CareFit sits largely within the context of preventative medicine where many informal carers are facing additional barriers to physical activity compared to non-carers. Further work is warranted to build founding knowledge how to further enhance both the reach and adherence across key public health behaviors for this critical societal group.

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Figure 3: Overview of CareFit use in terms of the time of day across all users. Figure demonstrates the total count across all users for different elements of the app such as 'activities', 'own activities', 'planner', 'learn', 'resources' and 'sharing'. Note that use during the night numbers are very low.

Appendices

Supplementary Appendix A1: Example of study advertisements for CareFit participants for Carers (left) and Professionals (right).

Supplementary Appendix A2 Example semi structured interview/questionnaire for Informal Carers of people with dementia.

Supplementary Appendix A3 Example semi structured interview/questionnaire for professionals

Supplementary Appendix A4 Novel question on sedentary breaks alongside muscle and balance activities

Table 1: Overview of components developed for CareFit including the : (1) Home, (2) Planner, (3) Learn, (4) Community and (5) More sections alongside the Content Management System

Section	Purpose	Implementation and personalisation detail
'Home-Activities section'	To allow participants can easily access all app functions including the exercise videos, weekly progress planner and can review their progress/plan ahead	We developed a wide breadth and depth of video content including: 10 cardiovascular, 10 muscle and balance, 4 sedentary breakers and 2 mindfulness videos alongside 2 mindfulness audios including videos of up to 10 minutes. All videos developed were hosted on a 'hidden' YouTube channel that enabled full captioning for those who are deaf/hard of hearing.
'Home-Planner section'	To allow users to develop their physical activity plans at a range of starting points.	Users were provided with three simple statistics on how their progress- the number of tasks completed, the number of minutes undertaking physical activity and the number of different categories of physical activity undertaken. Users were provided with additional information around the number of activities and minutes planned with a comparison of how many minutes were undertaken. We designed the planner so that participants could build a weekly 'rolling' routine so that habits could be built up over time. Adding carers own activities (e.g. going for walk) was a functionality we also added to the planner in a prospective manner. Ability to set your own physical activity target and green ring fills up around this according to the percentage you have/have not met.
'Learn'	Introduce physical activity for those contemplating increasing current levels	There were 7 stages developed in total. Each 'stage' was designed to take no more than 10 minutes. We developed both fictional personas of carers across Scotland in collaboration with Carers Scotland and a graphic illustrator to represent different ages, genders and ethnicities and also to represent different geographical locations. In total 6 different backgrounds were developed with 6 different people to represent carers (e.g. different ages/ethnicities/genders). We developed a series of summary 'quick cards', alongside video summaries of key points/purpose of different sections (See Figure 1). We developed novel videos for guided meditation to support carers including working with

		a specialist who works with carers on a regular basis. This resulted in two carer meditation videos alongside two carer audio meditations.
'Community'	Provides external links to outside agencies, stakeholders and support groups and physical activity projects such as 'Paths for All'	We developed a list of 25 local resource links within the app across the domains of physical activity, mental health and carer support. For example, specific community links (including hyperlinks that give direct access to websites included, NHS physical activity and mindfulness material and physical activity support groups such as Couch to 5K, Cycling Scotland, Paths for all and walking groups. There was also the functionality built in to create user 'stories; so that individual carers and/or organizations could share updates around the app use as the user base grows.
'More'	To allow users the ability to update the app, share CareFit app, set alarms alongside delete data	The more section allowed a variety of additional functions as a quick list, including facilitate users to change alarm permissions for activities, delete data, alongside an area for sharing CareFit, sharing the app and see updates/learn more about the research team.
Content Management system, 'CMS'	In addition to the above was the development of a bespoke Content Management System that allows the research team to upload materials into the app schema in real time according to the project needs	In addition to the above was the development of a bespoke Content Management System that allows the research team to upload materials into the app schema in real time according to the project needs. For example, this means that all the images shown in Figures 1 to 3 could be added, deleted or modified by the research team wherever this was required. The system also facilitated the collection of user data (see later) so that we could explore individual patterns of use for carers using the app.

Table 2: Carer sample recruited at baseline

Gender (n=41)	n	%	Location (n=41)	n	%
Woman/Female (incl. trans woman)	39	95.1	Angus	5	12.2
Man/Male (incl. trans man)	1	2.4	Glasgow City	5	12.2
Preferred not to say	1	2.4	Highland	4	9.8
Described in another way	0	0	Dumfries and Galloway	3	7.3
Ethnicity (n=41)			Falkirk	3	7.3
White	41	100	North Lanarkshire	3	7.3
Mixed/multiple ethnic groups	0	0	Perth and Kinross	2	4.9
Asian/Asian British	0	0	East Renfrewshire	2	4.9
Black/African/Caribbean/Black British	0	0	Midlothian	2	4.9
Other ethnic group	0	0	Moray	2	4.9
Education level (n=41)			South Lanarkshire	2	4.9
Degree or equivalent	26	63.4	Aberdeen City	1	2.4
Higher education	9	22.0	Aberdeenshire	1	2.4
SVQ	4	9.8	Clackmannanshire	1	2.4
Other qualifications	2	4.9	East Ayrshire	1	2.4
School qualifications	0	0	Scottish Borders	1	2.4
No qualifications	0	0	South Ayrshire	1	2.4
Age group (n=41)			Stirling	1	2.4
18 to 24	0	0	West Dunbartonshire	1	2.4
25 to 34	2	4.9	**Study recruitment channel (n=41)**		
35 to 44	4	9.8	JDR	17	41.5
45 to 54	9	22.0	Other	7	17.1
55 to 64	14	34.1	Carers Scotland	6	14.6
65 to 74	10	24.4	Social media	4	9.8
75 to 84	2	4.9	Alzheimer Scotland/ Brain Health Scotland	4	9.8
85 and older	0	0	Health and social care	2	4.9
Years caregiving (n=41)			Age Scotland Newsletter	1	2.4
1 year or less	0	0	The ALLIANCE	0	0
Up to 2 years	6	14.6	Pharmacy advertisement	0	0
Up to 3 years	15	36.6	**Study advertisement method (n=40)**		
Up to 10 years	18	43.9	Email from research team	23	57.5
10 years or more	2	4.9	Social media posts	14	35.0
Average hours caregiving (n=40)			Conversations with health and social care professional	2	5.0
Up to 4 hours	19	47.5	Paper flyers	1	2.5
Up to 6 hours	5	12.5	**Approx. number of apps installed (n=40)**		
Up to 8 hours	3	7.5	More than 20	22	55.0
8 hours or more	13	32.5	11 to 20	7	17.5
Mobile device (n=41)			6 to 10	5	12.5
Apple	22	53.7	1 to 5	4	10.0
Android	19	46.3	None	2	5.0
Other	0	0			

25

Table 3: Carer Baseline Health and Activity Data

BMI (n=41)	n	%
Healthy	13	31.7
Overweight	12	29.3
Obese	12	29.3
Morbidly obese	4	9.8
Underweight	0	0

IPAQ Scores (n=41)		
Low	14	34.1
Moderate	15	36.6
Vigorous	12	29.3

Sedentary behaviors (n=37)		
Av. proportion of day sedentary	5.9	Hours
SD of average	2.4	
Min	2	
Max	10.5	

Sd breaks per day (n=31)	n	%
Over 20 times	1	2.4
11 to 20 times	3	7.3
6 to 10 times	15	36.6
1 to 5 times	12	29.3
(Don't know)	10	24.4

Muscular activity days (n=32)	n	%
0	4	9.8
1	12	29.3
2	7	17.1
3	4	9.76
4	3	7.32
5	2	4.88
6	0	0
7	0	0
(No answer)	9	22.0

Familiarity with activity guidelines (n=41)	n	%
Not heard of	5	12.2
Heard of but very unfamiliar	10	24.4
Heard of but mainly unfamiliar	13	31.7
Broadly aware	10	24.4
Very aware	3	7.3

Awareness of benefits of physical activity (n=41)	n	%
Not aware	0	0
Aware of, very unfamiliar	1	2.4
Aware of, mainly unfamiliar	4	9.8
Broadly aware	20	48.8
Very aware	16	39

Current physical activity levels (n=41)	n	%
Not active and no intent to start in next 8 weeks	0	0
Not regularly active, but intent to start in next 8 weeks	10	24.4
Some activity but below guidelines	17	41.2
Regularly active, started less than 8 weeks	1	2.4
Regularly active, started over 8 weeks	13	31.7

Muscular activity minutes in last week (n=30)	n	%
None	6	14.6
Less than 10	7	17.1
10 to 60	11	26.8
61 to 120	3	7.31
121 to 180	0	0
181 to 240	0	0
Over 240	2	4.88
(No answer)	11	26.8

Table 4: Description of Professional sample

Self-reported Role	Experience (yrs)
Member of the Scottish Parliament	16-20
Health and Social Care Partnership	6-10
Carers Lead, Health and Social Care Partnerships	0-5
Senior Role, Public Health Scotland	11-15
Digital Assistant Director, Health and Social Care Charity	0-5
Charity Chief executive Officer	6-10
Principal Officer Social Work	21-25
Leadership role, Digital Health & Care Innovation Centre	0-5
IT director	0-5
Public Health Improvement Practitioner	0-5
Professional Adviser	6-10
Public Health Programme Manager	11-15
Pharmacist Manager	0-5
Pharmacist	0-5
Pharmacist	0-5
Community engagement coordinator	0-5
Co-Manager, Local Carers Centre	11-15
Nurse Consultant Telehealth and Telecare	11-15
Programme Manager	0-5
Technology Enabled Care Implementation Officer	0-5
Planning Manager	0-5
Trainee pharmacist	0-5
Medical doctor	26+
Local Area Coordinator with a Health and Social Care Partnership	6-10
Principal Officer	11.15
National Health Service	n/a
Charity role	n/a

Table 5: Major and minor themes across feasibility of: recruitment, intervention, and feasibility and suitability of outcomes.

Major theme	Minor themes

Feasibility of recruitment	• Professional generated themes
	  • Lack of carer self-identification and related terminologies
	  • Digital readiness of the informal carers who care for a person with dementia
	  • Catering to different stages of the caring journey
	  • Increasing breadth and depth of advertising to identify informal carers
	  • Co-ordination with key stakeholders including using established 'watering holes'.

Feasibility (and usability) of intervention	• Carer generated themes
	  • Caring routines
	  • Motivation for physical activity
	  • Accessibility and usability of CareFit
	  • Content engagement
	  • Suggestions of improvements to CareFit for future use
	
	• Professional generated themes
	  • Addressing different levels of the digital divide
	  • Timing and target group for intervention
	  • Integration with other services and providers
	  • The need to embrace human elements and increase social connections
	  • Facilitators to support implementation and longer-term use

Feasibility and suitability of outcomes	• Professional generated themes
	  • Measuring usability including from professional perspectives
	  • Inclusiveness for vulnerable groups and those facing inequalities.
	
	• Both professional and carer generated themes
	  • Measuring broader (secondary) impacts and unintended consequences

Table 6: Completeness of data at baseline and follow up

		Baseline	**Follow Up**
	Total Responses per Question	N=41	N=21
Question Group	Question	Number of responses (% of total)	
International Physical Activity Questionnaire-Short Form (IPAQ-SF) & Additional Physical Activity Measures	1. Vigorous Activity	27 (65.9)	17 (81.0)
	2. Moderate Activity	30 (73.2)	16 (76.2)
	3. Walking Activity	40 (97.6)	19 (90.5)
	4. Sedentary Behavior	37 (90.2)	20 (95.2)
	5. Break Up Sedentary*	31 (75.6)	16 (76.2)
	6. Muscular Activity (days)*	32 (78.0)	16 (76.2)
	7. Muscular Activity (minutes)	30 (73.2)	16 (76.2)
Confidence and Barriers to Physical Activity	8. Tiredness	41 (100)	20 (95.2)
	9. Bad Mood	41 (100)	20 (95.2)
	10. Not Having the Time	41 (100)	20 (95.2)
	11. Vacation	41 (100)	20 (95.2)
	12. Raining or Snow	40 (97.6)	20 (95.2)
Knowledge and Awareness of Physical Activity benefits and Guidelines	13. Knowledge of Physical Activity Guidelines	41 (100)	20 (95.2)
	14. Awareness of Benefits of Physical Activity	41 (100)	20 (95.2)
	15. Stage of change	41 (100)	20 (95.2)
EQ5D5L	16. Mobility	41 (100)	20 (95.2)
	17. Self-care	41 (100)	20 (95.2)
	18. Usual Activities	41 (100)	20 (95.2)
	19. Pain or Discomfort	41 (100)	20 (95.2)
	20. Anxiety or Depression	41 (100)	20 (95.2)
	21. Numerical Scale of Health	41 (100)	20 (95.2)
System Usability Scale (SUS)	22. Full scale (10 Items)	*n/a*	18 (85.7)

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Conflicts of Interest

None declared

Data availability

The data sets generated during this study will be available on the University of Strathclyde PURE data repository. Please contact Kieren.egan@strath.ac.uk for further information.

Acknowledgements

Abbreviations

TTM: Transtheoretical model of behavioral change
CMS: Content Management System
JDR: Join Dementia Research
IPAQ: International Physical Activity Questionnaire
WHO: World Health Organization
BMI: Body Mass Index
MRC: Medical Research Council

**Supplementary Files**

Figures

(A, left) Fictional personas developed for the CareFit app used throughout 'learn' section and (B, right) demonstrates 'home' tab explaining pictorially how the user interface was designed.
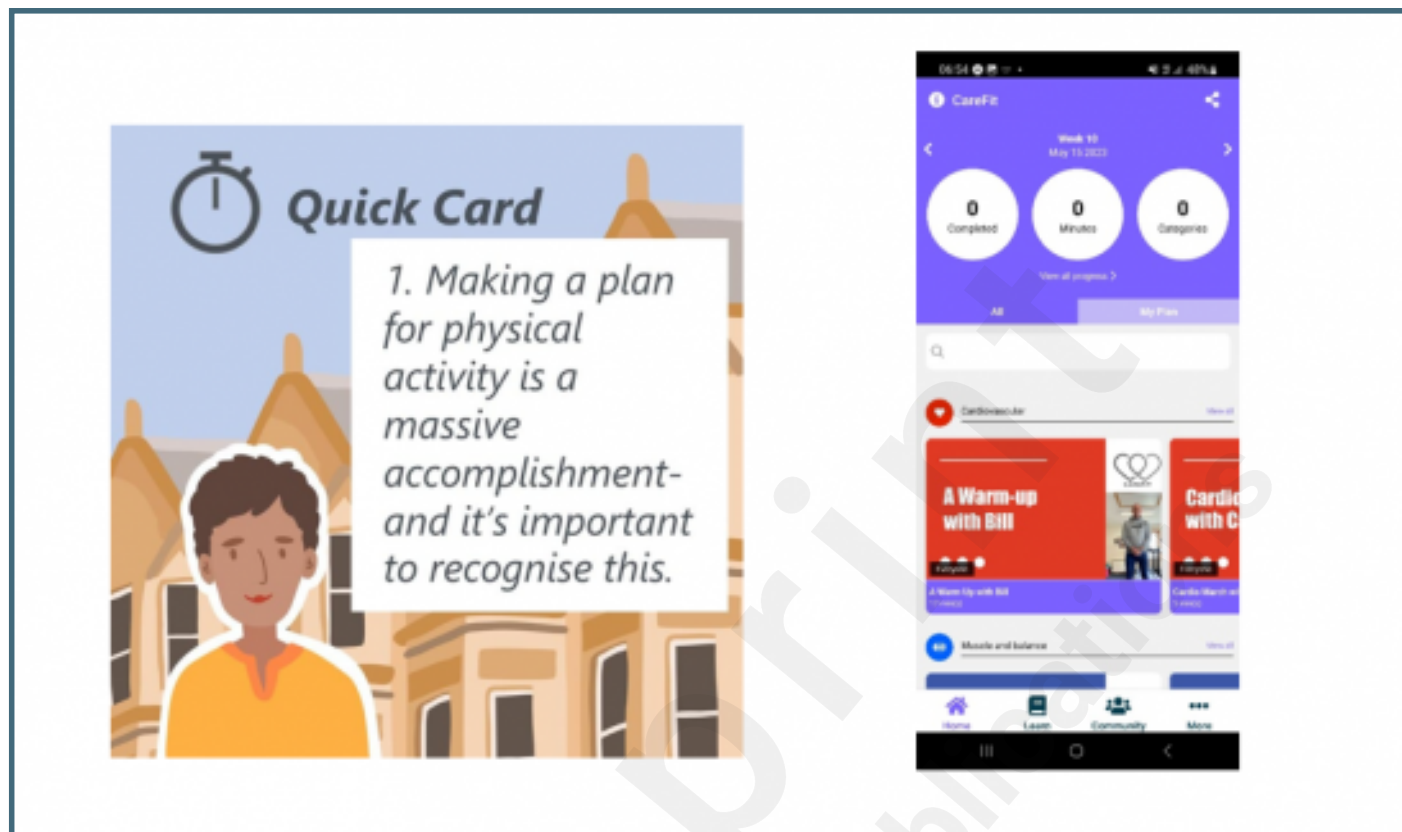
Overview of CareFit use by participants across the 8 weeks of the study relative to each user. Figure demonstrates the total count across all users for different elements of the app such as 'activities', 'own activities', 'planner', 'learn', 'resources' and 'sharing'.
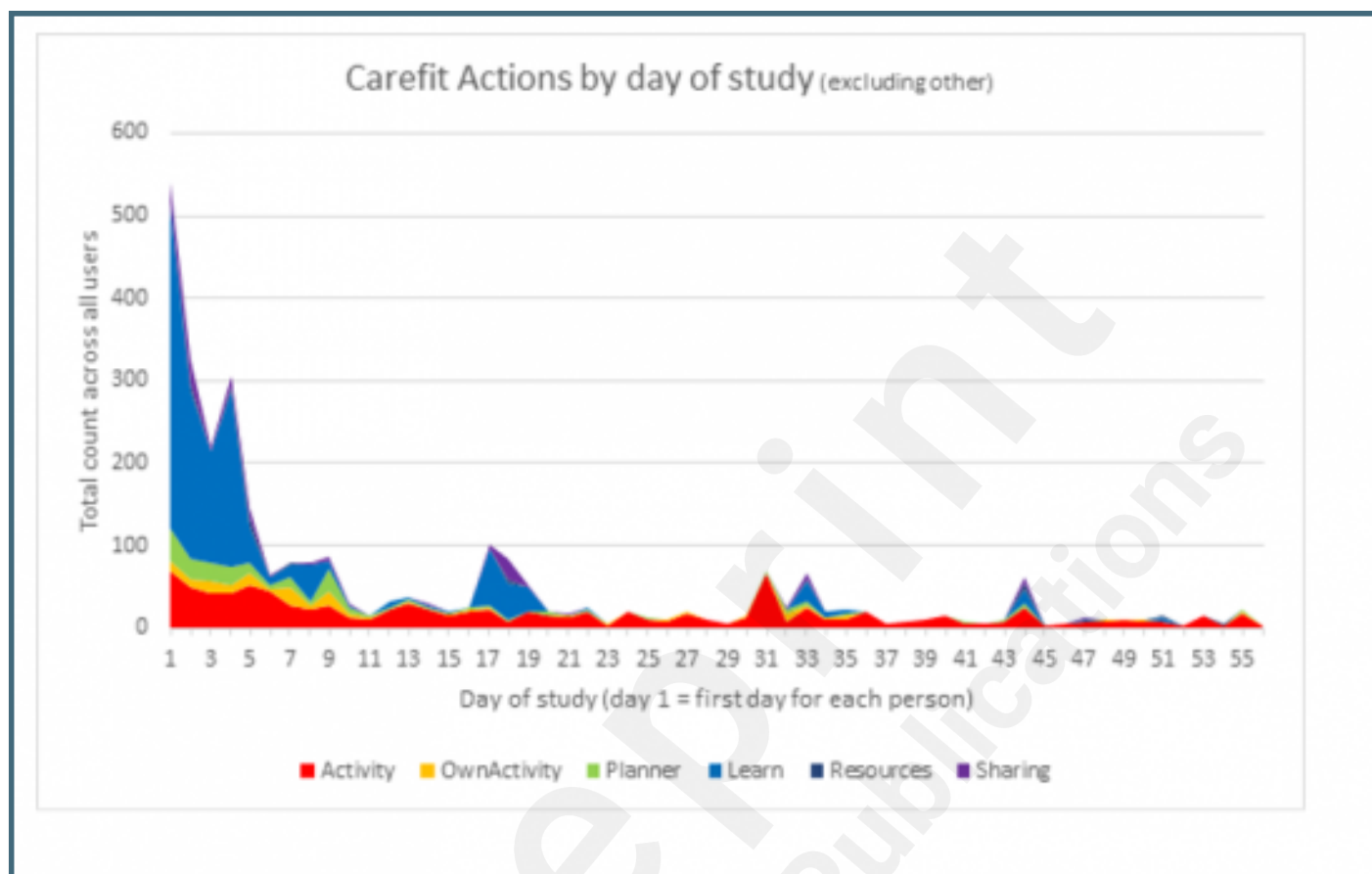
Overview of CareFit use in terms of the time of day across all users. Figure demonstrates the total count across all users for different elements of the app such as 'activities', 'own activities', 'planner', 'learn', 'resources' and 'sharing'. Note that use during the night numbers are very low.
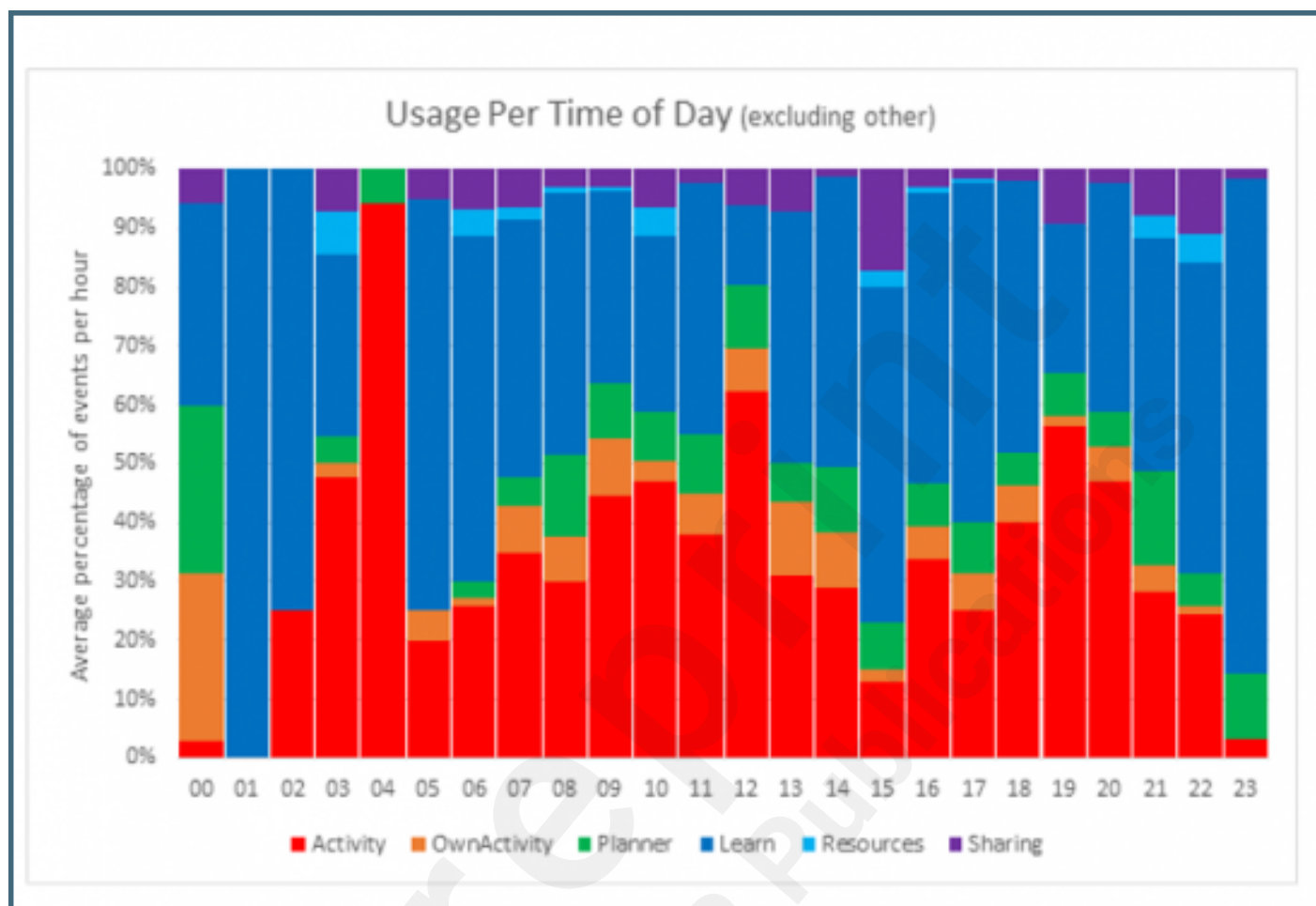
Multimedia Appendixes

A1: Example of study advertisements for CareFit participants for Carers (left) and Professionals (right). A2: Example semi structured interview/questionnaire for Informal Carers of people with dementia. A3: Example semi structured interview/questionnaire for professionals. A4: Novel question on sedentary breaks alongside muscle and balance activities. URL: http://asset.jmir.pub/assets/6243e1db1183b62e3622c18a14e1f85b.docx