

# **Acceptability and impact of an educational app (iCare) for informal carers looking after people at risk of pressure ulceration: A mixed methods pilot study**

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# Acceptability and impact of an educational app (iCare) for informal carers looking after people at risk of pressure ulceration: A mixed methods pilot study

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## Abstract

**Background:** Pressure ulcers are areas of skin damage resulting from sustained pressure. Informal carers play a central role preventing pressure ulcers amongst older and disabled people living at home. Research highlights the paucity of pressure ulcer training for informal carers and suggests pressure ulcer risk is linked to high levels of carer burden.

**Objective:** This pilot study evaluated a smartphone app with a specific focus on pressure ulcer prevention education for informal carers. The app was shaped by the principles of micro-learning. The study aimed to explore carer perspectives on the acceptability of the app and determine whether the app increased carers' knowledge and confidence in their caring role.

**Methods:** In this concurrent mixed methods study, participants completed quantitative questionnaires at baseline, and at the end of weeks 2 and 6, which examined caregiving self-efficacy, preparedness for caregiving, caregiver strain, and pressure ulcer knowledge, as well as app acceptability and usability. A sub-sample of participants took part in a 'think aloud' interview in week 1 as well as semi-structured interviews at the end of weeks 2 and 6.

**Results:** In total, 23 (71.9%) participants completed the questionnaire at the end of week 2 and 16 (50%) at the end of week 6. For the qualitative component, 21 carers participated in 'think aloud' interviews, 18 went on to participate in semi-structured interviews at the end of week 2, and 13 at the end of week 6.

Pressure ulcer knowledge scores significantly changed ( $F(1, 6.112)=21.624, p<0.001$ ) from baseline (mean=37.5, se=2.926) to the second follow-up (mean=59.72, se=3.985). In relation to the qualitative data, the theme 'I'm more careful now and would react to signs of redness' captured participants' reflections on the new knowledge they had acquired, the changes they had made to their caring routines, their increased vigilance for signs of skin damage, and their intentions towards the app going forwards. There were no significant results pertaining to improved preparedness for caregiving or caregiving self-efficacy or related to the caregiver strain index. Participants reported relatively high usability scores on a 0-100 scale (mean=69.94, SD=18.108). The app functionality and information quality were also rated relatively highly on a 0-5 scale (mean=3.84, SD=0.704; mean=4.13, SD=0.452). Two themes pertaining to acceptability and usability were identified, 'When you're not used to these things, they take time to get the hang of', and 'It's not a fun app but it is informative'. All participants liked the micro-learning approach.

**Conclusions:** The iCare app offers a promising way to convey information and improve informal carers' pressure ulcer knowledge. However, to better support cares, the findings may reflect the need for future iterations of the app to employ more interactive elements, and the introduction of gamification and customisation to user preferences. Clinical Trial: Not applicable

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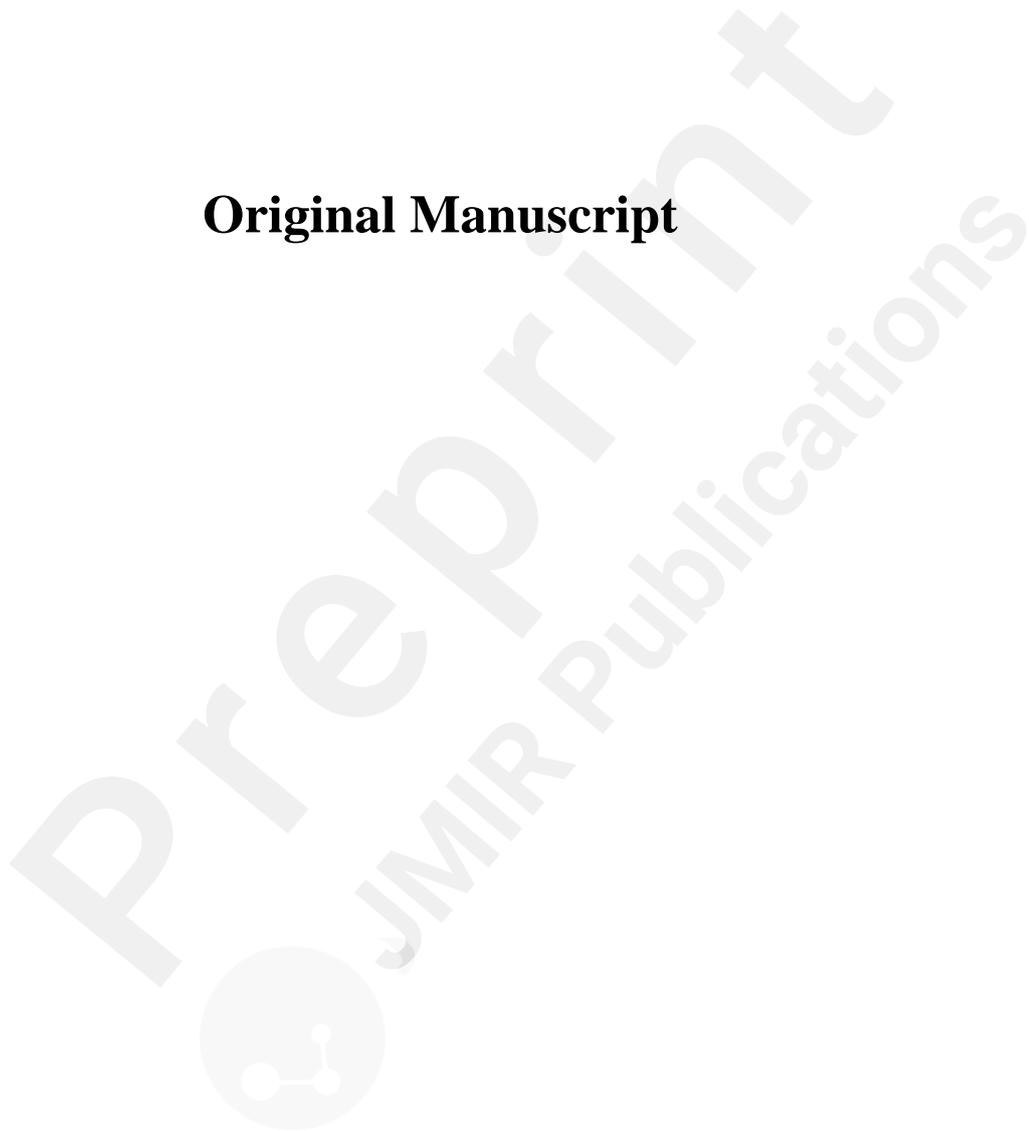
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## Title

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## Abstract

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This pilot study evaluated a smartphone app with a specific focus on pressure ulcer prevention education for informal carers. The app was shaped by the principles of micro-learning. The study aimed to explore carer perspectives on the acceptability of the app and determine whether the app increased carers' knowledge and confidence in their caring role.

### Methods:

In this concurrent mixed methods study, participants completed quantitative questionnaires at baseline, and at the end of weeks 2 and 6, which examined caregiving self-efficacy, preparedness for caregiving, caregiver strain, and pressure ulcer knowledge, as well as app acceptability and usability. A sub-sample of participants took part in a 'think aloud' interview in week 1 as well as semi-structured interviews at the end of weeks 2 and 6.

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In total, 23 (71.9%) participants completed the questionnaire at the end of week 2 and 16 (50%) at the end of week 6. For the qualitative component, 21 carers participated in 'think aloud' interviews, 18 went on to participate in semi-structured interviews at the end of week 2, and 13 at the end of week 6.

Pressure ulcer knowledge scores significantly changed ( $F_{(1, 6.112)}=21.624$ ,  $P<.001$ ) from baseline (mean=37.5, se=2.926) to the second follow-up (mean=59.72, se=3.985). In relation to the qualitative data, the theme '*I'm more careful now and would react to signs of redness*' captured participants' reflections on the new knowledge they had acquired, the changes they had made to their caring routines, their increased vigilance for signs of skin damage, and their intentions towards the app going forwards. There were no significant results pertaining to improved preparedness for caregiving or caregiving self-efficacy or related to the caregiver strain index. Participants reported above average usability scores on a 0-100 scale (mean=69.94, SD=18.108). The app functionality and information quality were also rated relatively highly on a 0-5 scale (mean=3.84, SD=0.704; mean=4.13, SD=0.452). Two themes pertaining to acceptability and usability were identified, '*When you're not used to these things, they take time to get the hang of*', and '*It's not a fun app but it is informative*'. All participants liked the micro-learning approach.

### Conclusions:

The iCare app offers a promising way to convey information and improve informal carers' pressure ulcer knowledge. However, to better support cares, the findings may reflect the need for future

iterations of the app to employ more interactive elements, and the introduction of gamification and customisation to user preferences.

## Key words

- Pressure ulcers
- Informal carers
- Smartphone apps
- mHealth
- Educational technology
- Health education

## Introduction

### Background

Pressure ulcers are defined as localized damage to the skin and/or underlying tissue, typically over a bony prominence, resulting from sustained pressure, which may present as intact skin or an open ulcer [1]. They are usually caused by prolonged sitting and/or lying in one position. Populations at high risk include frail older people [2] and people with spinal cord injuries [3]. According to one cross sectional study, the prevalence of pressure ulcers is between 0.40 and 0.77 per 1,000 community dwelling adults in England [4].

Pressure ulcers are a significant source of burden. They cause pain, exudate and odor [5] and impact on a person's ability to participate in rehabilitation [6]. Pressure ulcers are also slow to heal. Most are treated using dressings and topical agents; however, some require surgical repair. Complications include soft-tissue and bone infections. Infection can cause sepsis and even death. Annually, the United Kingdom National Health Service (NHS) treats 202,000 people for pressure ulcers, at a yearly cost of £571.98 million [7].

The essential elements of pressure ulcer prevention and management are: providing appropriate support surfaces (such as pressure relieving cushions and mattresses); conducting regular skin inspections; supporting patients to keep moving; ensuring incontinence and moisture are managed; and, maintaining adequate nutrition and hydration [8]. In terms of nursing management, depending on ulcer severity, most people with pressure ulcers receive between one and three nursing visits per week for wound care [9].

Research exploring the factors influencing the implementation of evidence-based practice in pressure ulcer prevention and management in community settings has identified how healthcare practitioners regard informal carers as central to both pressure ulcer prevention and wound-healing [10]. Four recent studies have explored carer input into pressure ulcer prevention and management, and their perspectives of the factors affecting pressure ulcer care in the home [11, 12, 13, 14]. The findings emphasized high levels of carer burden and highlighted the paucity of carer training and the importance of communication with healthcare practitioners.

### Supporting carers

For the purposes of this paper, the term "informal carer" is defined as someone providing unpaid care to an older dependent person where there is an existing social relationship (for example, a spouse or other relative). All subsequent references to carers will be to those working in this informal capacity. In 2015, NHS England pledged to raise the profile of such carers and how to support them [15]. Recent systematic reviews suggest that web-based interventions may result in a range of improved health outcomes for carers, including reductions in depression, stress, anxiety, social isolation, and relationship problems [16, 17]. Moreover, these studies have suggested robust web-mediated carer education has the potential to enhance management of the caring role with a concomitant reduction

in the requirement for healthcare practitioner input.

With improved accessibility of smartphone devices, the role of smartphone healthcare applications (or apps) is expanding. Smartphone apps can support carers by providing access to information, support, and resources at any time where the person has internet connection. App information is also easier to update and alert users to (via a notification in the app) than equivalent paper versions which would be more costly and difficult to ensure that users are reached. Previous studies have assessed the use of healthcare apps amongst carers of people with cancer [18] and carers of people living with dementia [19]. Whilst these studies found a positive attitude towards apps amongst carers [18, 19], they also identified barriers to their use including concerns about time constraints and not being familiar with technology [19].

## Contribution of this study

To our knowledge, no healthcare app has been evaluated amongst carers to people at risk of pressure ulceration. The aim of our study was to (i) explore carer perspectives on the acceptability and usability of a pressure ulcer app, and (ii) determine whether the app increased carers' knowledge and confidence in their caring role.

## Methods

### Design

This was a 6-week, concurrent mixed methods pilot study in which participants were given access to a Smartphone education app, which had a specific focus on carers and the care, management and prevention of pressure ulcers. The study involved two components: (i) online Qualtrics-based questionnaires completed by carers in weeks 1, 2 and 6, and (ii) 'think aloud' interviews with carers in week 1 and semi-structured interviews with carers in weeks 2 and 6. The Good Reporting of a Mixed Methods Study guidelines [20] are adhered to in the reporting of this study.

#### Ethical considerations

Ethical approval for the study was granted by the School of Health Sciences Research Ethics Committee at City, University of London (Ref: ETH1819-1600), and relevant governance approvals were received from the local NHS provider organization.

### iCare app

The app was developed by Care City, a Community Interest Company, which aims to work with residents and organisations to improve health and wellbeing in Northeast London, by bringing together health, social and third sector partners, technology experts and researchers. Employing the Agylia Learning Management System, the app design and format was shaped by the principles of micro-learning where short, focused pieces of content are provided to an audience, when and where they need it [21]. The app's content was organized into 14 units, with each unit consisting of a video presentation, written information and interactive learning objects (**see Table 1**). Each of the learning units was designed to take approximately 3 minutes to complete. The content of the app reflected information contained within an educational pack for carers developed by the local NHS provider organization [22]. The app was available to download on iPhone and Android.

## Sampling and Recruitment

The study took place in London, England. Individuals meeting the following inclusion criteria were eligible to participate: (1) aged 18 years or over; (2) identifiable as an informal carer for a person with or at risk of a pressure ulcer; (3) able to participate in the interview in English; (4) have access to an iPhone/iPad or Android device.

For pilot studies, a sample size for quantitative components is suggested to be 30 [23, 24], which would allow parameter estimates, and loss-to follow-up rates for subsequent larger studies. The sample size for the 'think aloud' interview and semi-structured interviews were influenced by the concept of data saturation [25]. Given the topic area was clearly defined, a sample of 15 participants was expected to achieve data saturation. Previous studies using the 'think aloud' approach to usability testing for healthcare apps have used sample sizes of 10 [26] and 24 [27] respectively.

The study was advertised on posters displayed in public areas on NHS sites in East London (including general practitioner surgeries and rehabilitation wards). The study was also promoted by Care City staff attending local carer support group events. At these events, staff set out the purpose, methods and intended uses of the research. They also explained that, depending on carer preference, participation would entail either (i) the completion of three online questionnaires or (ii) the completion of three online questionnaires plus participation in one face-to-face 'think aloud' interview and two additional semi-structured interviews. In total, 14 events were attended, at which there were approximately 150 carers, although not all attendees met the study inclusion criteria. Twenty-nine eligible carers expressed an interest in taking part and were provided with a Participant Information Sheet and consent was obtained for their contact details to be shared with both the app registration team and the research team. According to Care City, reported barriers to recruitment included the perceived relevance of pressure ulcers, and digital exclusion. In relation to the former, many of those attending the carers events did not consider the person they cared for as being at risk of pressure ulceration and therefore did not think the app would be of benefit to them. In relation to digital exclusion, many carers reported that they did not have access to the right technology whilst others did not feel sufficiently technologically confident to engage with an app.

Following agreement, the app registration team set up individual user accounts and emailed carers their account details and instructions for downloading the app. Only carers who expressed an interest in being interviewed as part of the study were referred to the research team, who telephoned them to confirm their ongoing interest and arrange a convenient time and location for the first interview.

## Data Collection

All participants were asked to use the app for a period of 6 weeks. Data were collected between October 2019 and April 2020.

### Online Questionnaires

Participation for the whole sample comprised completion of online questionnaires at three time points: (i) at the start of week 1, (ii) at the end of week 2, and (iii) at the end of week 6. The questionnaires were administered via an online platform, Qualtrics. On the first page of each questionnaire was a consent statement. Participants were only directed to complete the questionnaire after they read the statement and agreed to participate. Participants were prompted to complete the questionnaires via automatic emails sent at the start of week 1, and at the end of weeks 2 and 6. Anyone not completing the questionnaire within seven days of the specified date received a telephone reminder from the app registration team. Participants received a £5 e-voucher after completing each questionnaire to compensate them for their time and effort.

#### Week 1 (baseline)

The baseline questionnaire comprised three main sections. In the first section, participants were asked to provide demographic information pertaining to their gender, age, ethnic background, highest level of education, relationship to the care-recipient, previous care related training, and the age and gender of the care-recipient as well as their primary diagnosis. They were also asked whether or not they had previously used any health app(s).

The second section measured existing pressure ulcer knowledge by way of a 20-item questionnaire,

which was used to produce two parallel forms of 12 items each, at different timepoints (weeks 1 and 6). Items were generated from the educational pack developed by the local NHS provider organization for carers on how they can support family members at risk of pressure ulceration [22] and the Pressure Ulcer Knowledge Assessment Tool (PUKAT 2.0) questionnaire for registered nurses and nursing assistants [28]. Items were then clustered around four categories (i) support surfaces, (ii) nutrition and hydration, (iii) keep moving, and (iv) skin care and inspection.

The third section measured participants self-reported outcomes including confidence in dealing with caregiving situations using the Caregiving Self-Efficacy Scale (CSES) [29]. The choice of responses ranged from 1 (not at all confident) to 5 (extremely confident). This section also measured how prepared participants were for their caregiving role, using the Preparedness for Caregiving Scale (PfCS) [30]. The choice of responses ranged from 0 (not at all prepared) to 4 (very well prepared). Finally, strain related to the caregiving role was measured using the Caregiver Strain Index (CSI) [31].

The week 1 questionnaire took approximately 30 minutes to complete.

### Week 2 (first follow-up)

This questionnaire comprised just one section where participants were asked to complete the System Usability Scale (SUS) [32] and the Mobile App Rating Scale (MARS) [33]. The former is a 5-point Likert scale (ranging from 1 – ‘strongly disagree’ to 5 – ‘strongly agree’), giving a global view of subjective assessments of usability. The MARS again uses a range of Likert type scale responses. The questionnaire took approximately 10 minutes to complete.

### Week 6 (second follow-up)

At the end of week 6, participants were asked again to complete the CSES, the PfCS, and the CSI, as well as answer follow-up questions on their pressure ulcer knowledge. The questionnaire took approximately 10 minutes to complete.

### *‘Think aloud’ interviews*

The ‘think aloud’ interviews took place with a subgroup of participants at the beginning of Week 1. They were conducted face-to-face in a place with internet access chosen by the participant. The ‘think aloud’ approach [34] was selected on the basis that it would provide a useful reflection on the carers cognitive processes and attitudes whilst downloading and using the app for the first time. In order to gain experience with the think-aloud method, the interviewer (PH) conducted two pilot interviews; one with someone who had no prior exposure to this approach and one with someone who had extensive experience.

Written consent was obtained from participants prior to interview. During the interview, the participant downloaded the iCare app from either the iPhone App Store or the Google Play Store. Participants were then encouraged to interact with the content whilst the interviewer asked them to verbalise their thought processes (e.g. to voice any confusion or trouble they were having navigating the app) and attitudes towards the content. All interviews were audio recorded with participant permission. At the end of the interview, the interviewer made an appointment with the participant for their first semi-structured interview (see below).

### *Semi-structured interviews*

The subgroup who participated in the ‘think aloud’ interviews were invited to participate in one-on-one semi-structured interviews at the end of weeks 2 and 6. The topic guide for these interviews asked about participants use of the iCare app since the previous interview, their perceptions of using the app, the changes they had made as a result of using the app, their plans for continuing to use the app, the best thing about the app, how the app might be improved, and what other sources of pressure ulcer information they had accessed since the previous interview. Interviews were conducted by PH and took place via telephone. Written consent was obtained prior to interview. Interviews were

digitally recorded with participant permission. At the end of the first semi-structured interview, the interviewer made an appointment for the second.

## Data Analysis

### *Statistical analysis*

Quantitative data was entered into SPSS and analyzed for (i) description of the sample at baseline, (ii) descriptives of the sample's mobile app rating at the first follow-up, (iii) relationships between continuous and ordinal variables using Pearson's or Spearman's correlations, and (iv) changes in outcomes from baseline to second follow-up using linear mixed models analyses. Descriptive statistics (e.g. means and standard deviations) have been produced and are presented in the results section. Data was screened to check they meet assumptions of parametric statistics, and appropriate inferential statistics were conducted. The statistical analysis was performed by SH.

### *Qualitative data analysis*

Interviews were transcribed verbatim by an independent professional transcription service. Pilot data is not included in the analysis. Data were sifted and interpreted using the Framework Approach to qualitative data analysis [35], which allows the analytical process to be informed by issues designated in advance as well as new and emergent themes [36]. In the steps to this approach, transcription is followed by familiarisation, coding, analytical framework development, indexing, charting, and interpreting. Deductive coding was guided by the research aim and used pre-defined codes derived from the MARS [33], the Service User Technology Acceptability Questionnaire (SUTAQ) [37], and the Treatment Acceptability Framework (TAF) [38]. Two members of the research team (CM and EM) independently coded a sample of the transcripts. The remaining transcripts were coded by CM and an analytical framework developed. After the framework was developed and data charted into the matrix, the data were interpreted by CM. All interpretations were discussed and interrogated by other members of the research team (EM and SH).

## Results

The quantitative and qualitative results are integrated and presented in two parts to meet the aim of the study: (i) acceptability and usability of the iCare app and (ii) impact of the iCare app on carers' knowledge and confidence in their caring role.

### Sample characteristics

In total, 32 participants were registered with the iCare app. The majority of participants were carers who had attended one of the aforementioned carers events, rather than carers who had responded to posters advertising the study in public areas on NHS sites. **Table 2** shows the characteristics of participants.

The mean age of the sample was 57.9 years (SD=11.15), with 22 (68.8%) females and 10 (31.3%) males. Eleven participants (34.3%) had an education level of degree or above. Most participants (n=21, 66.6%) identified as white (British/Irish), of the remainder, most identified as Asian of sub-continent origin (n=6, 18.8%). Although all participants spoke English, 8 (25.0%) spoke a different language at home.

In relation to the person participants cared for, the mean age of the cared for person was 71.4 years (SD=23.15). It is noteworthy that this distribution was bi-modal with a small number of young cared for people (less than 38 years) (n=6) and a larger number of older cared for people (older than 60 years) (n=24). More than half of those receiving care were classified as female (n=18, 56.3%). There were 8 (25%) carers looking after a spouse or partner, 11 (34.4%) looking after a parent, and 11 (34.4%) looking after a son/daughter. Just over half (n=17, 53.1%) lived with the person they were caring for.

The most common condition/disability given for the cared for person was depression (n=11, 34.4%) followed by rheumatoid arthritis (n=10, 31.2%) and osteoarthritis (n=9, 28.1%). Importantly, many participants reported caring for persons with multiple conditions and disabilities (n=22, 68.7%).

At baseline, only 5 participants (15.6%) reported using a health app before, and 8 (25%) reported taking part in health education training in relation to caregiving (including diabetes care, parenting for autism, and moving and handling).

In total, 21 carers were recruited to the subgroup participating in the 'think aloud' and semi-structured interview component of the study, including 14 females and 7 males.

## Loss to follow-up

All 32 participants completed the week 1 (baseline) questionnaire. Twenty-three (71.9%) participants completed the week 2 (first follow-up) questionnaire and 16 (50%) completed the week 6 (second follow-up) questionnaire, with data available for 13 carers (40.6%) at all three timepoints. There were no significant predictors of withdrawal (neither carer characteristics, care recipient characteristics, pressure ulcer knowledge, nor participant reported outcome measures) from the study at the  $P<.01$  level.

Comparisons of pressure ulcer knowledge, CSES, PfCS and CSI were between the baseline and second follow-up measure. The linear mixed models analyses, ensured all available data was used for analyses across timepoints.

In terms of the qualitative subgroup, 21 carers participated in the 'think aloud' interview, 18 of whom went on to participate in a semi-structured interview at the end of week 2 (85.7%), and 13 of whom also participated in the semi-structured interview at the end of week 6 (61.9%). **Figure 1** shows follow-up of participants across the study.

## Acceptability and usability of the iCare app

At first follow-up, participants completed the SUS and MARS to provide feedback on how they found using the iCare app. **Table 3** shows the mean scale scores on these measures. The SUS shows that the app has an above average usability score (mean=69.94, SD=18.108). The MARS scores back this up and show the app overall mean score (mean=3.62, SD=0.540) as being above the midpoint, with the subscales indicating this is mainly due to the information conveying capabilities of the app (mean=4.13, SD=0.452) and its functionality (mean=3.84, SD=0.704). However, the engagement score (mean=3.03, SD=0.669) is mid-range and the perceived impact score (mean=2.01, SD=0.936) is relatively low based on the scale ranges.

In relation to the study aim, two key themes were identified from the qualitative data: (i) '*When you're not used to these things, they take time to get the hang of*', and (ii) '*It's not a fun app but it is informative*'. The key themes, subthemes and illustrative quotations are provided in **Table 4**.

'*When you're not used to these things, they take time to get the hang of*' captured participants perceptions and experiences relating to usability. Few participants felt proficient in the use of modern technology at baseline, with many describing using only the basic features of their smartphones. Varying levels of familiarity with smartphones and apps in particular were reflected in the amount of time it took participants to find and install the iCare app from the iPhone App Store or the Google Play Store, with downloading times ranging from 1 minute 22 seconds to 15 minutes 34 seconds (average 4 minutes 52 seconds).

Once the app was downloaded, some participants found navigating the content more intuitive than others. Whilst some barriers to navigation were related to the design of the app (such as the indistinguishable nature of pictures on the direct links (tiles) to set modules in the app), others related to relatively common computing functions such as vertical and horizontal scrolling and screen orientation settings. These functions were not considered simple or obvious by those new to smartphone apps and were identified as a source of frustration in the 'think aloud' interviews.

Despite these frustrations, many participants thought that they would, with time, learn how to use the app. Indeed, at the end of the second week, most participants recounted that they had become proficient in the use of the app, which reflects the high usability scores reported using the SUS in the first follow-up questionnaire. However, there were exceptions, including two participants who had forgotten their passwords and who had been unable to reset them again. One area that remained an area of concern across the 6 weeks was the size of the font on the app. For this reason, some participants expressed a preference for printed forms of information or suggested a desktop version of the app be made available. However, others recognised that having pressure ulcer information held in an app on their mobile devices ensured that advice and support was always available.

The second theme, *'It's not fun but it is informative'*, captured participants' perceptions and experiences of the performance of the app in terms of conveying information, as well as its functionality and engagement. Participants who were familiar with digital technologies, highlighted a missed opportunity by creators to generate an experience beyond the content itself and drew attention to the advantages of app to app linking and game mechanisms, which were missing from the iCare app. These participants felt that the addition of these features would have increased their engagement with the app. In contrast, some participants were irritated by animated features (such as the use of flip cards) because they required more user effort. Whilst participants disagreed about whether the app should be more entertaining, several did agree that greater customisation and more personalised content would have increased engagement. In terms of customisation, participants suggested the addition of bookmarking and favouriting tags, which would have allowed them to return quickly to preferred content, as well as an activity tracker, which would have tracked their progress. In terms of personalisation, one participant suggested the addition of an algorithm that would generate content relevant to each user's personal circumstances. These findings go some way to putting into context the mid-range scores for engagement on the MARS in the first follow-up questionnaire.

Despite these limitations, participants were united in their description of the app as one that was informative. The highlight for many were the videos, where the presenter was commended for her pace and use of plain English, and who provided a welcome break from the written content. Regardless of baseline levels of knowledge, all participants liked the micro-learning approach, and endorsed it across the 6-week period. These findings contextualise the high information scores using the MARS in the first follow-up interview. Participants described having to juggle their caring responsibilities alongside other responsibilities and the time they had available to dedicate to learning about pressure ulcers was limited.

## **Impact of the iCare app on carers' knowledge and confidence in their caring role**

Mean scores for pressure ulcer knowledge and participant reported outcome measures (PROMS) (i.e. CSES, PfCS, and CSI) at baseline and 6-week follow-up are reported in **Table 5**. In terms of the Pressure Ulcer Knowledge Assessment, at baseline, participants had a relatively low score on a 0-100 scale (average= 37.5, SD=16.55). Items on the questionnaire were clustered around four key themes (i) support surfaces, (ii) nutrition and hydration, (iii) keep moving, and (iv) skin care and inspection. Knowledge – albeit limited – was mainly based on nutrition and hydration (mean=46.8, SD=26.7) and keep moving (mean=37.50, SD=25.40) scale scores. There were deficits on skin care and inspection knowledge (mean=25.63, SD=27.47) and support surfaces knowledge (mean=33.04, SD=20.6).

In terms of the participant reported outcome measures, at baseline, PfCS scores (mean=19.59, SD=6.339) indicated that the group were between 'somewhat' and 'pretty' well prepared for caring, and were on average 'somewhat' confident in their ability to care (mean=3.10, SD=0.815) on the CSES. In terms of the CSI, carers scored a mean of 11.91 (SD=6.428), representing strain

‘sometimes’.

Overall, pressure ulcer knowledge scores significantly changed ( $F_{(1, 6.112)}=21.624$ ,  $P<.001$ ) from baselines (mean=37.5, se=2.926) to the second follow-up (mean=59.72, se=3.985). From the subscale scores, this difference was likely to changes in the ‘support surfaces’ knowledge category, which increased from baseline scores of a relatively low mean of 33.04 (se=3.653), to a relatively high score (mean=71.11, se=3.906). Trends towards significant increases in knowledge were found on the subscales for ‘nutrition and hydration’, ‘keep moving’ and ‘skin care and inspection’.

There were no significant results pertaining to participant reported outcomes across the 6 week period, neither the PfCS (baseline: mean=27.59, se=1.121; 2<sup>nd</sup> follow-up: mean=28.11, se=1.110;  $P=.60$ ), the CSES (baseline: mean=3.10, se=0.144; 2<sup>nd</sup> follow-up: mean=3.38, se=0.172;  $P=.12$ ) nor the CSI (baseline: mean=11.91, se=1.136; 2<sup>nd</sup> follow-up: mean=12.85, se=1.425;  $P=.47$ ) showed any significant change.

In relation to this study aim, just one key theme was identified from the qualitative data: ‘*I’m more careful now and would react to signs of redness*’. This theme describes participants’ reflections on the new knowledge they had acquired, the changes they had made to their caring routines as a result of this new knowledge, their increased vigilance for signs of skin damage, and their intentions in relation to the app going forwards. Related subthemes and illustrative quotations are provided in **Table 6**.

Participants reported acquiring new knowledge as they progressed through the different modules. Prior to using the app, some had only a rudimentary understanding of the factors contributing to pressure ulcer development, as shown in the baseline pressure ulcer knowledge scores, and had not considered the person they cared for to be especially vulnerable to pressure ulceration because they were neither wheelchair users nor confined to bed. At follow-up, several participants described how they had changed their caring routines as a result of this new knowledge, particularly routines related to movement, patient positioning, and moving and handling in particular. However, most participants felt the person they cared for was not at high risk of pressure ulceration. As such, the primary learning outcome had not been a change in caring behaviour, but an improved understanding of the dangers of pressure ulcers and an increased readiness to react to signs of skin damage. Given most participants felt the person they cared for was not at high risk of pressure ulceration, at the final follow-up, most felt they had learnt enough about the prevention and management of pressure ulcers and did not envisage returning to the app in the immediate future. However, nearly all wanted to retain the app in case their circumstances were to change.

## Withdrawal analysis

There were no significant baseline predictors of withdrawal from the study at the  $P<.01$  level. Only pressure ulcer knowledge regarding mobility was associated with withdrawal from the study at the  $P<.05$  level, with an odds ratio of 1.035 (95% CI, 1.000 – 1.071;  $P=.047$ ). A 10-point increase in this knowledge increasing the chances of withdrawal by 3.5% (original probability of 16/32, with related odds of 1.00).

## Discussion

### Principal findings

Pressure ulcers are a significant source of burden to informal carers [11, 12, 13, 14]. Smartphone apps offer a promising way to support carers by providing access to information and resources at any time where the person has internet connection [18, 19]. To our knowledge, no healthcare app has been evaluated amongst carers to people at risk of pressure ulceration. The aim of our study was to explore carer perspectives on the acceptability and usability of a pressure ulcer app, and determine whether the app increased carers’ knowledge and confidence in their caring role.

Despite wide variability in the ease with which carers were able to download and access the app on

first use, we found relatively high levels of usability and acceptability amongst our sample, which comprised informal carers with and without previous exposure to healthcare apps. We did not measure SUS and MARS at the second follow-up to limit responder burden (especially as loss to follow-up was a concern), but taking these measures again (in a full trial) would be helpful to determine usability/acceptability following a longer period with the app, as users mentioned it would take time to get use to the app in the interviews. The information quality was deemed especially useful and participants demonstrated that it improved their knowledge in relation to pressure ulcer prevention over the pilot period. While retention of knowledge over the longer term is harder to predict, a number of participants expressed their intention to retain the app and return to the content if they needed to in the future.

The micro-learning approach was positively received by participants, who enjoyed the short, focused pieces of content. Participants described having to juggle their caring responsibilities alongside other responsibilities and the time they had available to dedicate to learning about pressure ulcers was limited. iCare does not represent the first use of the micro-learning approach in healthcare apps for informal carers, for example, it is an approach adopted in a mobile app for supporting dementia relatives [39]; however, this study is potentially the first to report carer perspectives and experiences of knowledge acquisition and skills development using this approach.

There were no significant results pertaining to changes in participant reported outcomes across the 6-week period. In its current form, the app is generally didactic and underdeveloped in terms of customisation and personalised content, which could include, for example, reminders for tasks and deadlines, and live support for carers via groups and chats with other carers and/or professionals. The inclusion of such features could potentially address outcomes including preparedness for caregiving, caregiver self-efficacy, and caregiver strain. This is supported by Grossman et al, who suggested the integration and interaction of five types of app functions successfully relieved caregiver burden: (i) information and resources, (ii) practical problem-solving involving behavioural solutions, medication management, safety, and personal health record tracking, (iii) memory aids, (iv) family communication, including coordinating care, calendars for appointments and sharing, medical and emergency contact lists, ability to share important information, photos, and messages among caregivers and family members, and (v) caregiver support (i.e. care for the caregiver) [40].

## Limitations

We met the sample size for a small pilot study to provide some indicative parameters that can be built upon for a larger randomized controlled trial. However, most participants felt that the person they cared for was not at high risk of pressure ulcers. It would have been useful to have had the pressure ulcer risk assessment score (e.g. scores generated using validated tools such as the Waterlow [43] and Braden [44] scales) for the cared for person to better understand the context within which informal carers were providing care. Furthermore, a larger proportion of carers for higher risk cared for people might have produced more promising results.

The use of linear mixed models analyses helped with the loss to follow-up by allowing all available data to be utilised, however that the reasons for drop out need to be investigated further.

## Recommendations

This study has demonstrated that micro-learning (presenting bite sized chunks of information) is acceptable and useful for users, so a strategy that can be pursued in further studies and apps of this nature, especially with carer users. However, this must be done with careful thought to the accessibility of mobile apps amongst the wider population. Not having either a suitable device or an Internet connection is the first barrier to the usefulness of mobile apps and may exacerbate inequalities and care. Solutions may include provision of devices and training on downloading and using apps for those first time users that require additional support, which would need to be 'costed'

into any wider scale roll out. There are also some limitations in the current implementation of the iCare app that if addressed could improve its usability and usefulness. Increasing interactive elements, gamification (potentially using evidence based behaviour change techniques) and customisation to user preferences are potential alterations that could achieve better results on carer based outcomes.

## Conclusions

This study provides insight into the perceptions of carers on the acceptability of the iCare app and the impact of the app on their pressure ulcer knowledge and confidence in their caring role. The mixed methods analysis found the app was acceptable to most participants, who endorsed the micro-learning approach and perceived the app to be highly informative. In addition, at the end of six weeks, carers demonstrated a significant increase in their pressure ulcer knowledge. However, there were no significant results pertaining to participant reported outcomes. The findings may reflect the need for upcoming iterations of the iCare app to employ more interactive elements, and the introduction of gamification and customisation to user preferences. Future studies will need to capture the risk assessment scores for the cared for person and sample a broader range of informal carers, including carers for people at high risk of pressure ulceration.

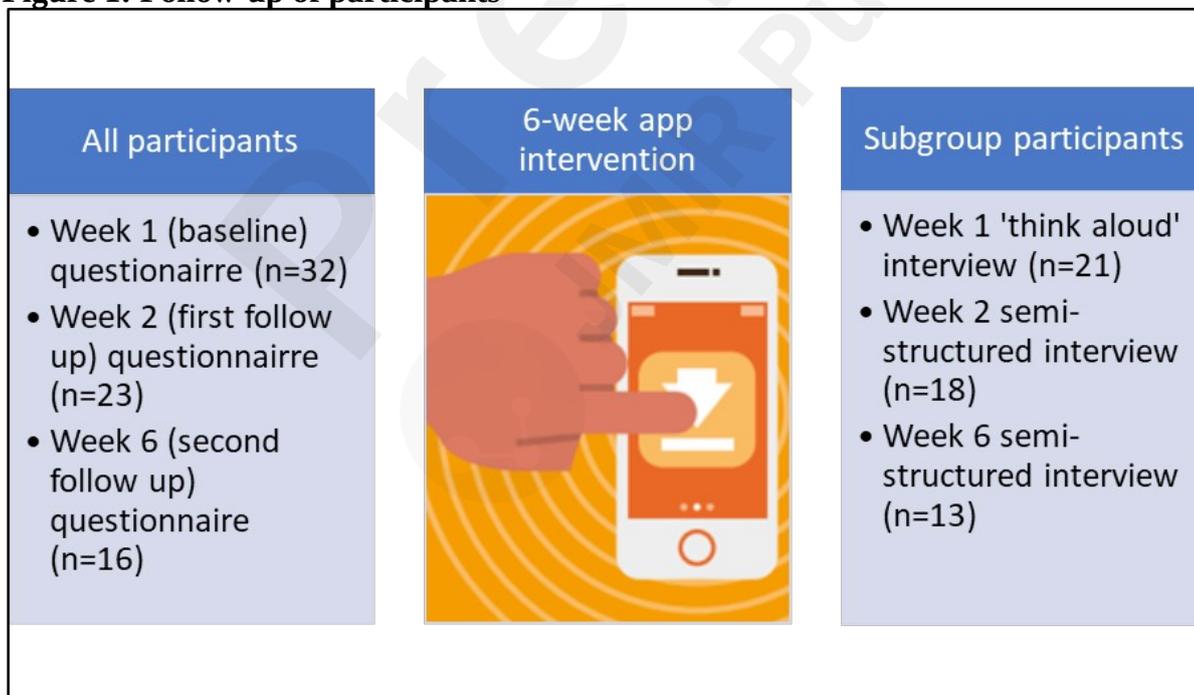
## Acknowledgements

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## Conflicts of interest

None declared

### Figure 1: Follow-up of participants



**Table 1: iCare app – learning unit topics and unit format**

No.	Learning unit topic	Learning unit format
1	What are pressure ulcers?	Video (2m 46s)

2	Frequently asked questions about pressure ulcers	Video (40s), written FAQs, pictures of pressure ulcers
3	Five things you should know about keeping people moving	Bullet pointed list, interactive components
4	Five things you should know about keeping skin healthy	Bullet pointed list, interactive components
5	Five things you should know about nutrition	Bullet pointed list, interactive components
6	Five things you should know about support surfaces	Bullet pointed list, interactive components
7	How to ensure adequate nutrition	Video (1m 19s), interactive components
8	How to help people keep moving	Video (1m 40s), interactive components
9	How to keep skin healthy	Video (1m 27s), interactive components
10	How to support people at risk effectively	Video (1m, 37s), interactive components
11	Pressure ulcer triggers	Interactive checklist
12	Skin inspection guide	Interactive checklist
13	Sources of help	Colour-coded reference chart
14	Identifying who is at risk of getting a pressure ulcer	Colour-coded reference chart

**Table 2: Characteristics of participants and care recipients**

	Frequency	Percentage
<b>Gender</b>		
Male	10	31.3
Female	22	68.8
<b>Education level</b>		
No formal education	5	15.6
Other	2	6.3
CSE/GCSE/O-Level/City and Guilds or NVQ Levels 1 - 2	6	18.8
A-Levels/Higher National Diploma/NVQ Level 3/Diploma	8	25
Degree or equivalent	6	18.8
Higher degree/Post graduate qualification	5	15.6
<b>Ethnicity</b>		
White British/Irish	21	65.6
Asian or British Asian (Indian, Bangladeshi)	6	18.8
Black or Black British	2	6.3
Other	3	9.4
<b>Relationship to care recipient</b>		
Spouse/Partner	8	25
Daughter/Son	11	34.4
Parent (mother, father, mother in law, father in law, grandparent)	11	34.4
Other	2	6.3
<b>Live with care recipient</b>		
Yes	17	15.1

No	15	46.9
<b>Gender of care recipient</b>		
Male	12	37.5
Female	18	56.3
Other	2	6.3
<b>Condition/Disability of care recipient</b>		
Depression	11	34.4
Rheumatoid Arthritis	10	31.2
Osteoarthritis	9	28.1
Respiratory conditions	8	25
Diabetes	8	25
Dementia	8	25
Learning disabilities	5	15.6
Gastrointestinal conditions	4	12.5
Cancer	4	12.5
Visual problems	4	12.5
Cardiac conditions	3	9.4
Multiple Sclerosis	2	6.3
Stroke	2	6.3
Other	8	35
	<b>Mean</b>	<b>Std. Dev</b>
Participant age (years)	57.9	11.15
Care recipient age (years)	71.4	23.15

Table 3: App related scale scores at the first follow-up

	Mean	Std. Dev
System Usability Scale (0 – 100, higher scores indicate greater usability)	69.94	18.108
<b>Mobile App Rating Scale (1 – 5, higher scores indicate better)</b>		
Engagement	3.03	0.669
Functionality	3.84	0.704
Aesthetics	3.46	0.876
Information	4.13	0.452
Subjective Quality Score	3.17	0.978
App Perceived Impact	2.01	0.936
App Quality	3.62	0.540

Table 4: Themes, subthemes and illustrative quotes (acceptability and usability of the iCare app)

<b>Theme 1: When you are not used to these things, they take time to get the hang of</b>	
<b>Limited proficiency in the use of modern technology</b>	<ul style="list-style-type: none"> <li>• <i>I don't use mobile phones very often, only for rings (Talk aloud, P104)</i></li> <li>• <i>I don't really do apps... I just use the phone to check my, have I got a text message (Talk aloud, P108)</i></li> <li>• <i>I don't often use [the phone] as a web, for webbing (Talk aloud,</i></li> </ul>

	<p>P114)</p> <ul style="list-style-type: none"> <li>• <i>I'm not very digitally minded... Literally, I brought my iPhone to take pictures (Talk aloud, P105)</i></li> </ul>
<b>Learning over time</b>	<ul style="list-style-type: none"> <li>• <i>I went to school in the 70s and university in the 80s, so this is not my kind of thing but I could adopt it, I could try (Talk aloud, P116)</i></li> <li>• <i>The more I use it, I'll get the hand of it better (Talk aloud, P101)</i></li> <li>• <i>Many people love technology, I love it, I'm crap at it but I want to try and learn (Talk aloud, P110)</i></li> <li>• <i>I find it okay because I've got used to it now. I've looked at it a few times and then I get used to it (Week 2, P114)</i></li> <li>• <i>It seems pretty easy to navigate once you know how it works... Once you learn how to use it, it's pretty intuitive (Week 6, P117)</i></li> </ul>
<b>Small font size</b>	<ul style="list-style-type: none"> <li>• <i>I have to wear glasses to read and I get tired eyes, watery. I think the writing is, should be a bit bolder (Talk aloud, P108)</i></li> <li>• <i>I think I have already said it before, I think the wording needs to be a bit bigger and bolder (Week 2, 109)</i></li> </ul>
<b>Theme 2: It's not fun but it is informative</b>	
<b>Creating an experience beyond the content itself</b>	<ul style="list-style-type: none"> <li>• <i>I think perhaps you could consider other things like linking it to other systems. For example, like Patient Access... It's like a GP practice app where patients can log in, book appointments, repeat prescriptions and things like that. Perhaps you could link it to that because on there, there's information and support for carers as well (Think aloud, P106)</i></li> <li>• <i>There's nothing about connecting with... other carers. Nothing about having a discussion about something that you've just seen... You could gamify this, that would be more fun... because we spend the entire time reading which is, I get fed up with... being told 'read this'... I don't have the time, the energy or the capacity (Think aloud, P121)</i></li> <li>• <i>I suppose they are trying to make it a little bit more interesting, but they could have just done it as bullet points (Think aloud, P104)</i></li> <li>• <i>Because it is not a game. I don't see [the point] of an extra click. And it makes me feel like I am doing an exam, a multiple-choice exam and it doesn't make me feel like this is something [I'm going to want to do], I think I would get bored of it (Think aloud, P111)</i></li> </ul>
<b>Customisation and more personalised content</b>	<ul style="list-style-type: none"> <li>• <i>I think it would be useful to have some favourites, so sections that you know you'd want to go back to more easily (Think aloud, P106)</i></li> <li>• <i>There isn't any [customisation]. It's led by the app. It's just a whole bunch of lines... I can't customise anything... There isn't anything that says, I've done this bit, and these are the bits that are next (Think aloud, P121)</i></li> <li>• <i>I don't need that [information] at the moment but if it [was] relevant to my situation... What do they call them now... a flow chart! Now that would be useful... so you're going down a tree until you hit the specific point that you are looking for... I think you have to try and tailor these things (Think aloud, P113)</i></li> </ul>
<b>Good use of videos</b>	<ul style="list-style-type: none"> <li>• <i>I quite like the video content... You don't want to just read loads and loads and loads of information (Think aloud, P106)</i></li> </ul>

	<ul style="list-style-type: none"> <li><i>I like the way she is talking... a good pace and she was very clear in describing what to look out for... the language she used – it wasn't really hard terminology (Think aloud, P107)</i></li> </ul>
<b>Information provision is short and to the point</b>	<ul style="list-style-type: none"> <li><i>Everything seems just short and to the point to keep me engaged because, especially as the care you just, your concentration level is just, you've just got to be on it, you're doing other things and also tired... I just need something to spark a little something in me and be simple (Think aloud, P121)</i></li> <li><i>It's not really a fun topic, but it's very interesting... It was just concise information that someone in my position would need to know, it wasn't [over the top] with lots of unnecessary information. It was just enough so that I know what to look for and what to do (Week 2, P118)</i></li> <li><i>I think it's very quick and straight to the point most of the time... it's a very good introduction (Week 6, P119)</i></li> </ul>

**Table 5: Pressure ulcer knowledge and participant reported outcome measures (PROMS)**

	Baseline		Second follow-up (week 6)		Test of Fixed Effects of Time		
	Mean	Std. Error	Mean	Std. Error	F <sub>(1, xx)</sub>	Denom. df	Sig
<b>Pressure Ulcer Knowledge Assessment (0-100)</b>							
<b>Support surfaces</b>	33.04	3.653	71.11	3.906	50.415	22.457	<.001
<b>Nutrition and hydration</b>	46.88	4.538	58.62	4.302	6.122	21.624	.02
<b>Keep moving</b>	37.50	4.490	57.58	6.857	7.365	16.949	.02
<b>Skin care and inspection</b>	25.63	4.856	46.90	7.611	7.349	17.299	.02
<b>Total score</b>	37.25	2.926	59.72	3.985	29.452	17.850	<.001
<b>Preparedness for Caregiving Total (0 – 32)</b>	27.59	1.121	28.11	1.110	0.286	16.640	.60
<b>Caregiving Self-Efficacy Scale mean (1-5)</b>	3.10	0.144	3.38	0.172	2.716	16.617	.12
<b>Caregiver Strain Index total (0-24)</b>	11.91	1.136	12.85	1.425	0.553	14.602	.47

**Table 6: Themes, subthemes and illustrative quotes (Impact of the iCare app on carers' knowledge and confidence in their caring role)**

<b>Theme: I'm more careful now and would react to signs of redness</b>	
<b>Acquiring new knowledge</b>	<ul style="list-style-type: none"> <li><i>There are two pictures and I can see with the pictures it's going to the lady's heel, which shows obviously that if you're sitting too long with your feet up on a surface you could develop a pressure ulcer on</i></li> </ul>

	<p><i>your heel, which is something I wouldn't have ever thought of... So, I think there is a lot of good information there, already I can see things that I never knew about pressure ulcers, I just thought it was for people in bed (Think aloud, P118)</i></p> <ul style="list-style-type: none"> <li><i>• That was really, really interesting... You mainly assume, I know about people in wheelchairs, people that are bed ridden but I didn't realise that it could also be people like my mum that's not well for a couple of days... So that's really interesting... that's shocking (Think aloud, P104)</i></li> </ul>
<b>Changing care routines</b>	<ul style="list-style-type: none"> <li><i>• I don't pull him up the bed anymore... I'm turning him more... (Week 2, P101)</i></li> <li><i>• I've just made sure, I guess that when I put my wife on the bed... I should lift her up and not drag her... I'm [also] looking... I keep an eye on [her skin]. And one district nurse, some time ago, gave me a [skin barrier] spray [to protect it from excessive moisture], which I spray. But I guess as a result of this video, I'm spraying it more often (Week 2, P109)</i></li> </ul>
<b>Alert to signs of redness</b>	<ul style="list-style-type: none"> <li><i>• Well I certainly know the signs of redness now... so obviously there's a sort of thing to look out for (Week 2, P110)</i></li> <li><i>• If my mother did have bedsores... I'd know what to look for.... Whereas before I had the app, I wouldn't have had a clue really (Week 2, P112)</i></li> <li><i>• I understand when I'm looking at something now better about soreness (Week 2, P114)</i></li> <li><i>• The little red, I wouldn't have ever thought of that, if I'd seen a red mark, I would have just thought, oh, wouldn't have thought much of it. But after looking at this, if I ever saw anything like that then that would prompt me to see further help (Week 2, P118)</i></li> </ul>
<b>Learnt enough for now/keeping the app in case of changing circumstances</b>	<ul style="list-style-type: none"> <li><i>• There's only so much of it that's relevant to me at the moment. But I know if I need to, like if my godfather for instance gets worse... then I will be able to refer back to it. Yeah, so... if the situation comes up then it's good to have it... I'll definitely keep it on my phone (Week 6, P108)</i></li> <li><i>• I don't [use it] as my wife hasn't, at the moment anyway, hasn't got the starting of an ulcer.... [But] I'd like to keep it there.... I will refer to it from time to time, because it's always a good idea to keep on top of the situation (Week 6, P109)</i></li> <li><i>• Because I know it's there if I need it, but like I say, the person I look after, they're quite mobile and I'm quite aware to look out for things... I know its there so I can go back to it... It's only like if the situation occurred, I might go and double check something (Week 6, P119)</i></li> </ul>

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## Supplementary Files

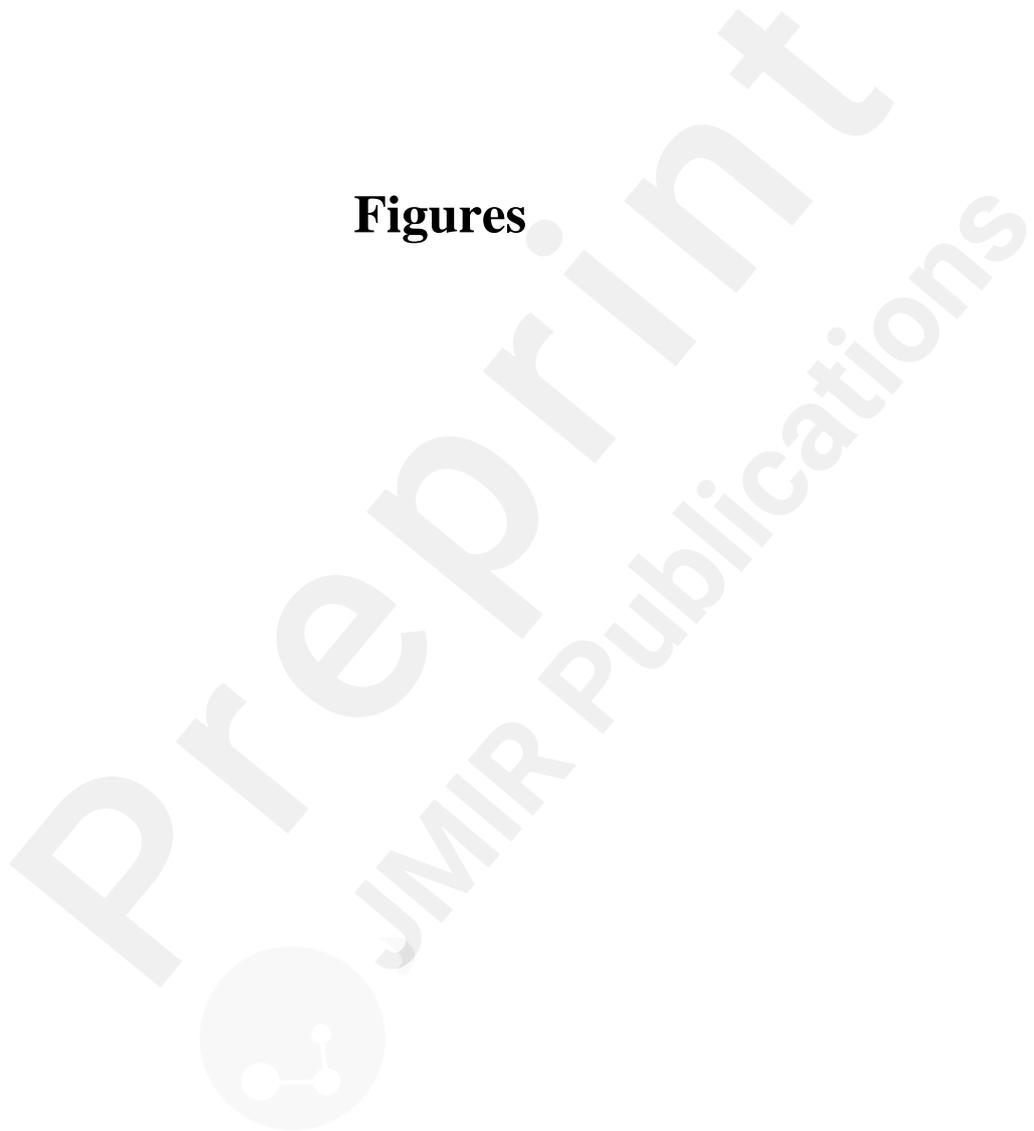
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## Figures



## Participant follow-up.

