

## **Participant Information Sheet [Version 9.0 08/10/2021]:**

You are receiving this information having expressed an interest in this study by texting CHC to 07770 654 123.

### **Study title**

To assess the feasibility of using real-time data from unpaid carers using mobile short message service (SMS) to theme data using natural language processing

### **Why are we doing this study?**

The study is exploring if mobile technology via text messaging is an acceptable method of reaching and identifying common themes/issues / concerns of unpaid carers in a remote area like Cornwall. We will also test if satellite connectivity enables the results to be viewed on a web-based dashboard. This study is not testing an intervention but looking for common themes within all the data (text messages).

### **Who can take part?**

- Any Adult (18+) unpaid carer
- Provides at least 1 hour of care per week
- Resident of Cornwall, UK
- English speaking

### **What does the study involve?**

Before joining the study, you will need to provide your consent to take part, and then complete a questionnaire about yourself which should take on average 5-10 minutes. This can be done via a web-link sent to a smart phone, email or via paper copies sent to your home address.

Once you are enrolled in the study you will receive the following message “Welcome to the Connected Healthcare Project. You'll now get weekly prompts at your chosen day and time to remind you to text back with your thoughts on your caring role. You'll be able to text this number at any time to tell us your thoughts. If you need to view the participant information sheet click <link>”

The main study will involve participating in but not limited to weekly text-messaging

- **You will receive weekly prompt messaging from 07888 865 058 on your chosen day and time**
- **Participants are expected to text replies into the project at least weekly or as many times as they wish to share their thoughts / feelings relating to their caring role**

Following receipt of a text into the study, participants will receive an automated text saying “Thank you for your message. This is an automatic reply. The researchers review messages between Mond-Fri 9am-5pm. If you need advice or support please contact your GP or NHS 111. If you need to view the participant information sheet click <link>”

All messages to the project will be read by the researchers, during normal working hours (Mon-Fri 9-5) **they will not reply to individual comments**. The researchers will only call participants if there are any safeguarding concerns identified in the text message. **The dedicated number is unable to take phone calls.**

If you wish to take part and do not have access to a mobile phone please write to the university at PO Box 340, St Austell, PL25 9HQ and arrangements can be made for the loan of a mobile phone. If you have a pay-as-you-go account we can provide credit top-ups directly to a pay-as-you mobile, if required. Text messages will be charged at your normal provider's rate and likely to be included in unlimited text message limits. Please check with your provider.

### **How long will I be expected to take part?**

For a maximum of 6 months or until data is complete.

### **Who is funding the study?**

This study is funded by the European Space Agency, The European Union, sponsored by Cornwall Foundation Trust and involves technical partners Goonhilly Earth Station Ltd and The 3<sup>rd</sup> Degree.

### **What are the benefits & disadvantages of taking part?**

To raise the common issues experienced by carers in a web-based dashboard which can potentially be accessed by NHS and Social Care professionals in Cornwall. The risk of harm is low from taking part.

### **Keeping you safe**

Where any information provided to the study suggests a safeguarding issue a follow-up call will be made from a researcher trained in Mental Health First Aid during normal office working hours (Mon-Fri 9-5). Where any concerns are identified a referral to Cornwall Council's Adult Safeguarding Services will be made by the researchers.

### **What will happen to the results?**

A Data dashboard of anonymised data (no personal details) will be hosted at Goonhilly Earth Station Ltd and will allow the researchers to test if satellite technology will allow access to the study findings. A report of study findings will be shared with Cornwall Carers Partnership Board. Publication of study findings will be sought.

### **What will happen to my personal information and data?**

- Your data will be stored under General Data Protection Regulations (GDPR) by the data processor, The 3<sup>rd</sup> Degree.
- Your personal data such as name, mobile telephone number, email (if joined via post your address & landline if you don't have a mobile) will be securely stored by

The 3<sup>rd</sup> Degree for the duration of the study (maximum of 6 months) and then destroyed in accordance General Data Protection Regulations (2021).

- Information collected throughout the project will be kept confidential according to Falmouth University local policy. Your data will be controlled by Falmouth University. Falmouth Data Privacy policy can be viewed [Here](#).

### **Who do I contact if I have any questions or concerns?**

Queries can be emailed to [CHCenquiries@falmouth.ac.uk](mailto:CHCenquiries@falmouth.ac.uk)

If you have any concerns or complaints relating to the study or a researcher you can contact [research@falmouth.ac.uk](mailto:research@falmouth.ac.uk)

### **Do I have to take part?**

Taking part is voluntary.

Participants will have the right to withdraw from the project at any time by texting “STOP” to 07888 865 058.

This study has been reviewed by the Health Research Authority Wales REC 6 committee.

### **Useful contacts**

Consider contacting your own GP for any medical issues

**NHS 111** can help if you have an urgent medical problem and you're unsure what to do – You can call 111 or visit the website

**Cornwall Carers Advice** line opening hours Mon, Weds, Fri 9-5pm and Tues, Thurs 9-7pm on 01736 756655 or email [hello@carersadvice.org.uk](mailto:hello@carersadvice.org.uk)

**Patient Advice & Liaison Services (PALS)** on 01872 25293, email [rcht.patientexperience@nhs.net](mailto:rcht.patientexperience@nhs.net) or visit the website [Here](#)

**NHS 24/07 mental health response line** offers support and advice. Call free on 0800 038 5300 any time day or night if you are worried about your own or someone else's mental health.

**Carers UK 808 808 7777** from **Monday to Friday, 9am – 6pm** or you can contact us by email ([advice@carersuk.org](mailto:advice@carersuk.org)) or visit their website at <https://www.carersuk.org/home>

**Samaritans** can be contacted on 0330 0945717