Graphical user interface, application

Description automatically generated

**Invitation**

**to participate in**

***I-Can-Do: Developing digital accessibility for dementia volunteer service***

**[Date]**

**[Address]**

**Participant Information Sheet**

***I-Can-Do: Developing digital accessibility for dementia volunteer service***

## Invitation to research

We all have memory gaps and for many reasons: too busy, nervous, distracted, getting older, tired, born with, or general fast pace of life. It helps to remind ourselves to that we also have many interests, experiences and skills. This is what the I-Can-Do Service aims to offer.

The service has been co-designed to support people with dementia to join local volunteer services with their strength and interests. Over three consecutive sessions, people with dementia and their wellbeing mentor explore their strengths and interests, find out about volunteering services in their local area, and identify suitable volunteering opportunities based on your interest.

In the past, the service was delivered through a booklet. We received feedback from the wellbeing mentor that a digital version would be better to enable them to take notes during the sessions and to share them with people with dementia and their care partners.

We invite you to participate in this research to help us design the digital version of the I-Can-Do Service to make the Service available publicly.

We will ask you to join two face-to-face workshops to explore how the digital version of the I-Can-Do Service should work for you and to find out about your experience after you have had an opportunity to try out the first design of the digital Service. We will ask you what you liked or found difficult, and suggestions for improvement. There are no right or wrong answers. We will not publish your name.

Your thoughts and feelings about the I-Can-Do Service are important to us, and we hope you will join us.

This research is organised by researchers from Manchester Metropolitan University, and you will meet with Kristina and Bell [and insert further names if applicable].

Please let **Emma Gerrard**, Age UK Salford, [contact] know if you are happy to take part, or you can ask someone to let Emma know on your behalf.

for more information on [k.niedderer@mmu.ac.uk](mailto:k.niedderer@mmu.ac.uk) or call her on 07966 892 879.

Thank you from **Kristina and Bell**

## Why have I been invited?

We want to work with you because you are an expert with lived experience.Your feedback on our design will help us make it work well so that it is fit for use.

## Do I have to take part?

No, it is up to you to decide. We will describe the study and go through the information sheet, which we will give to you. We will then ask you to sign a consent form to show you agreed to take part. You are free to withdraw at any time, without giving a reason.

## What will I be asked to do?

You will be invited to attend two sessions. The first session will last approximately – 1.5-2 hours, and here is the indicative programme:

|  |
| --- |
| **Welcome**  Introduction of all participants to each other: who we are, how we feel today in one sentence, and why it is important to be here today [or similar question as appropriate on the day] |
| **Introduction to the I-Can-Do Service**  Introduction to how the I-Can-Do Service has come about, what the two sessions are for, how we will work together, and you can ask questions about the sessions. |
| **Co-design of the digital version of the I-Can-Do Service**  We will work together to find out what the Service should look like: You will have an opportunity to see some pictures of the service to tell us what you think about its look and feel, about your experience of using digital application, and what features you might like the service to have. You will also have an opportunity to ask any questions you may have about the service and how it works. |
| **What we think and feel**  Final roundup session with overall feedback on the session |

The second sessions will last 1.5 - 2 hours, and here is the indicative programme:

|  |
| --- |
| **Welcome**  Introduction of all participants to each other: who we are, how we feel today in two sentences, and why it is important to be here today [or similar question as appropriate on the day] |
| **Trying the digital I-Can-Do Service**  You will have the opportunity to try out the first digital mock-up of the I-Can-Do Service. |
| **Discussion and Feedback on the digital version of the I-Can-Do Service**  You will have the opportunity to explore the prototype and to tell us what you think about its features, its look and feel, and anything else you might think of. Together, we want to find out what works well and what not and how we can improve the design. |
| **What we think and feel**  Final roundup session with overall feedback on the session |

## Are there any risks if I participate?

We hope this will be a positive experience for you, but there is a small possibility of thinking about difficult issues that may cause distress to you. If you feel at all distressed you do not need to participate in what is being asked of you, you may take a break and have the right to decide whether or not I want to continue participating.

## Are there any advantages if I participate?

We cannot promise that the study will help you directly, but it may improve the wellbeing of people with dementia and their carers, and we hope you will enjoy the activities. We will also offer you a £50 voucher for each workshop as a thank you for helping us.

At the end of the project, if you would like a description of the major findings, they will be available on our project website [[tbc]](http://www.designingfordementia.eu) or you can write to the project leader, Professor Kristina Niedderer [k.niedderer@mmu.ac.uk](mailto:k.niedderer@mmu.ac.uk)

## Informed consent

If you are interested in taking part in this project, you will receive this Participants Information Sheet (PIS) and consent sheet at least 7 days before we collect any data from you. You will have time to read through this information and decide if you wish to take part in this project. If you have any questions before you decide, you can let us know by email or call us on the phone numbers provided above. On the day of the session, we will also go with you again through this information and answer any questions. If you are happy to take part in this project, we will ask you to sign this consent sheet. It means that you agree to take part this project. Even if you agree, you are free to withdraw at any time, without giving a reason.

## What information about me will you collect and why?

You will take part in discussions and talk about your needs, experiences and feedback of using the I-Can-Do Service. We will audio record the discussions. We may also take pictures during the workshop. After each workshop, we will analyse the information collected to understand better how people will use of the I-Can-Do Service and improve the design.

## How will my information be stored and how will you look after it?

The research team will be responsible to look after your information and data. After we collect the data from you, we will anonymise the data. It means that we will remove all your personal data in the audio recording so that you cannot be identified from the data. We will store the data on the secure system provided by Manchester Metropolitan University to protect the data and your privacy.

## How will you use my information?

Your data will only be used by the research team. After we have anonymised the data, we will analyse the data from the first discussion to understand the user needs to help us design the first digital version of the I-Can-Do Service. We will analyse the data from the second discussion to understand your experience and feedback of the first digital version of the I-Can-Do Service. We will write up reports and publish the result in journal articles.

You have an option to allow us to use data from the co-design workshop discussions. You can let us know within 7 days after each workshop if you would like to withdraw any of the information.

## Will my data be sent anywhere else, or shared with other people or organisations?

If you agree to participate in this research, we will collect some data from you. Those data will be shared with Reason Digital and TypeItWrite Limited as the research team are working with them. Reason Digital will be present in co-design sessions to help develop the digital version of I-Can-Do-Service. TypeItWrite Limited will transcribe the audio recordings of the sessions to provide researchers with transcriptions. We will store your personal information safely and only retain your personal data for as long as is necessary to achieve the research purpose.

The anonymised research data will be stored in an open access research data repository that may be used to support other research in the future and may be shared anonymously with other researchers.

## When will you destroy my information?

Your personal data will be stored less than 3 months after the project has ended. Other data will be stored securely for 5 years.

Paper data will be disposed of as confidential waste, and electronic data will be deleted.

## Data Protection Law

In the case of research, this is ‘a task in the public interest.’ If we use more sensitive information about you, such as information about your health, religion, or ethnicity (called ‘special category’ information), our basis lies in research in the public interest.

You have the right to make choices about your information under UK law. If you have any questions or would like to ask us to do something with your information, you can ask the researcher or a parent or guardian, or someone else at the University. Contact details are shown at the end of this document.

You can stop being a part of the study at any time, without giving a reason. You can ask us to delete your data at any time, but it might not always be possible. If you ask us to delete information within 7 days after data collection*,* we will make sure this is done. If you ask us to delete data after this point, we might not be able to. If your data is anonymised (where we take out your name and any other information that lets us know the information is about you), we will not be able to delete it, because we will not know which data is yours.

## What will happen to the results of the research study?

Your comments and experiences about activities and social participation will be anonymised and grouped together with other participants’ comments and looked at by our research team. We will write a summary of the themes talked about. This summary will be published, but no information that could identify you will be presented.

## Who has reviewed this research project?

All research is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Manchester Metropolitan University, Faculty of Arts and Health, Psychology & Social Care Research Ethics Committees.

## Who do I contact if I have concerns about this study or I wish to complain?

If you have a concern about any aspect of this study, please talk to **Emma Gerrard**, Age UK Salford, [contact] or the researchers [add name] on the day.

You can also contact the principal investigator, Professor **Kristina Niedderer**, by email or phone for general questions about the project:

Prof **Kristina Niedderer** (Lead investigator)

Manchester Metropolitan University, Manchester School of Art, Chatham Building (CH309), Boundary St West, Manchester M15 6BR

Email: [k.niedderer@mmu.ac.uk](mailto:k.niedderer@mmu.ac.uk)

Phone: 0161 247 1662

If you have a concern about the project, about GDPR, or wish to complain, you can contact the Faculty Research Ethics contact:

Prof **Susan Baine**

Manchester Metropolitan University, Ormond Building, Room G12, Cavendish Street, Manchester, M15 6BG

Email: [s.baines@mmu.ac.uk](mailto:s.baines@mmu.ac.uk)

Phone: +44 161 247 2511

**Manchester Metropolitan Data Protection Officer** [dataprotection@mmu.ac.uk](mailto:dataprotection@mmu.ac.uk)

Tel: 0161 247 3331Legal Services, All Saints Building, Manchester Metropolitan University, Manchester, M15 6BH

**UK Information Commissioner’s Office**

You have the right to complain directly to the Information Commissioner’s Office if you would like to complain about how we process your personal data:

<https://ico.org.uk/global/contact-us/>

**THANK YOU FOR CONSIDERING PARTICIPATING IN THIS PROJECT**