

## **Participant Information**

'Where is the emergency exit?' – co-creating appropriate and clear COVID-19 messages for the most vulnerable

We invite you to participate in the above research project. This research is being conducted at the University of St Andrews in partnership with NHS Fife, Fife Council and Fife Voluntary Action. The research is led by Dr Mara van Beusekom (mbv4@st-andrews.ac.uk) a Research Fellow from the University of St Andrews, with Co-investigators Jo-Anne Valentine, Dr Andrew Williams, Gill Musk and Dr Gozde Ozakinci.

### **What is the research about?**

'Wash your hands' and 'stay inside' - two messages that have played a central role in managing the COVID-19 outbreak. However, the scale and nature of the pandemic means that messages have not been universally successful. Some people have been avoiding seeking medical attention for urgent non-COVID-19 health needs to not overload the NHS. Others may struggle to cope with the imposed isolation guidelines due to their circumstances.

While high-risk individuals who are advised to 'shield' receive targeted information, central resources are lacking for others who are also at risk. Within communities, voluntary groups often have an insight into needs and ways to offer support. The proposed work aims to develop methods for 1) co-developing effective messages with community groups and 2) identifying channels to ensure these messages reach the intended groups. Such methods will be essential to support the rapid development of relevant, clear messages to support everyone.

### **Why have I been invited to take part?**

A group with representatives from Public Health, Health Promotion Service, Fife Council, Fife Voluntary Action and University of St Andrews are working together to investigate how people in Fife are making sense and understanding the current public health messages around Covid-19.

We're contacting you as a member of the public who may have used the services available at your GP practice during the pandemic.

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

This information sheet has been written to help you decide if you would like to take part. It is up to you and you alone whether you wish to take part. If you do decide to take part, you will be free to withdraw at any time without providing a reason, and with no negative consequences, up to the point your data has been anonymised (within 6 months after completion of data collection). After your data has been anonymised it will not be possible to withdraw.

### **What would I be required to do?**

You would be asked to complete a short survey about yourself. You will then be invited to join Facebook group ('private' and 'hidden'). In this group we will post content and materials to create discussion about your views on access to services provided by your GP practice. We will ask you about the information you have and what we could do to improve this. You will receive a £60 Love2Shop voucher to acknowledge the time you give to the research.

### **Are there any risks associated with taking part?**

We do not foresee any associated risks with this project, however, if you have any concerns, you are welcome to contact the research team whose details are at the top of this sheet.

### **Using Facebook**

Facebook was chosen as the platform to work with to increase accessibility for members of the public. There are some issues around confidentiality to consider. Facebook possess the information on their website. Depending on your settings, others in the Facebook group may be able to view the information you put on your personal Facebook page. To prevent this, please temporarily change your privacy settings to ensure only friends can see your information, future and past posts. We provide full instructions on how to do this in the consent survey. The Facebook group you will be invited to join is 'private' and 'hidden', and therefore, is a private space with only members able to post. This type of group cannot be found or viewed by others. This means that membership of the group will remain anonymous, as no one from outside the group could tell who members of the group are. There will be no reasonable means to connect you to your data after it is anonymised. Ground rules will be set in the Facebook co-creation group, to ensure a safe environment where people can share their thoughts without fear of being criticised.

### **Informed Consent**

It is important that you are able to give your informed consent before taking part in this study and you will have the opportunity to contact us if you have questions in relation to the research before you provide your consent.

### **What information about me or recording of me ("my data") will you be collecting?**

We are interested in the name of your support group and your views and opinions. We are also interested in some brief demographics, for example your age, gender, ethnicity, history of chronic illness and postcode. To invite you to join the Facebook group we will ask you for your Facebook user name and the link to your Facebook account. We will also ask you for contact details (e.g. email address/telephone number in case of any issues with access to the Facebook group. If you are interested in helping with the research further, we will retain your contact details for this purpose only.

### **How will my data be securely stored and used, who will have access to it and how will it be shared further?**

All information will be stored on a secure password protected computer and in accordance with NHS Fife and University of St Andrews privacy policy. Data will be extracted from the Facebook group and survey to be collated in a spreadsheet. Your data will be stored in a **PSEUDONYMISED** form, which means that your data will be edited so that you are referred to by a unique reference such as a code number or different name, and the original data will remain accessible only to the research team at University of St Andrews. Your data will be stored in a specified folder, on the named researcher's, encrypted University OneDrive, and only members of the research team will be able to access it. There will be a 'key' document, which will link your unique reference to your real identity. The key will be kept in a separate folder and file on the named researcher's encrypted University OneDrive, and only members of the research team will have access to it and be able to reconnect your data to you at a later date. The Facebook group will be deleted within 1 month after the data collection period. This will mean it will not be possible for you or anyone else to access the group and data beyond this point.

All possible identifiable data (e.g. age, gender, ethnicity, history of chronic illness and postcode) will be anonymised and stored separately to any contact details provided. Your data will be anonymised when published in research publication(s). As part of these publications we may quote some of the comments or posts you make but it will not be possible to identify you from these quotes. Participants can access the outcome of study from the University of St Andrews website and media sources in around 6-9 months.

#### **When will my data be destroyed?**

5 years after the last point of access.

#### **Will my participation be confidential?**

Yes, your participation will only be known to the project team.

#### **Use of your personal data and data protection rights**

The University of St Andrews (the 'Data Controller') is bound by the UK 2018 Data Protection Act and the General Data Protection Regulation (GDPR), which require a lawful basis for all processing of personal data (in this case it is the 'performance of a task carried out in the public interest' – namely, for research purposes) and an additional lawful basis for processing personal data containing special characteristics (in this case it is 'public interest research'). You have a range of rights under data protection legislation. For more information on data protection legislation and your rights visit <https://www.st-andrews.ac.uk/terms/data-protection/rights>. For any queries, email [dataprot@st-andrews.ac.uk](mailto:dataprot@st-andrews.ac.uk).

#### **Who reviewed this study?**

This research proposal has been scrutinised and subsequently granted ethical approval by the University of St Andrews Teaching and Research Ethics Committee.

#### **What should I do if I have concerns about this study?**

In the first instance, you are encouraged to raise your concerns with the Principal Investigator, Mara van Beusekom E: [mvb4@st-andrews.ac.uk](mailto:mvb4@st-andrews.ac.uk). However, if you do not feel comfortable doing so, then you should contact the School Ethics Contact (Dr Morven Shearer - [medethic@st-andrews.ac.uk](mailto:medethic@st-andrews.ac.uk)). A full outline of the procedures governed by the University Teaching and Research Ethics Committee is available at <https://www.st-andrews.ac.uk/research/integrity-ethics/humans/ethical-guidance/complaints/>