

VIVALDI COVID-19 in Care Homes Study: PPI Advisor Information Sheet/ Role Description

Patient and Public Involvement (PPI)

The VIVALDI Study is investigating the effect of COVID-19 in care homes. Questions we are asking include: how many people in care homes have been infected with COVID-19?; how the infection spreads in care home?; whether you can be infected more than once and how well the vaccine works. Furthermore, we want to compare how different groups of people fight the infection.

To make sure that the research has the largest possible impact and reaches as many people as it can, it is important that the findings are accessible to a wide variety of audiences. In order to do this, we want to involve people with personal experience of COVID-19 in care homes to help us develop summaries of the research findings suitable for a general audience.

You might be a current or past member of care home staff, a resident or a relative. We believe that involving you in our research will make it more relevant and will provide more information about the needs of those living and working in care homes. We also believe that it will be a valuable use of your time as you may make valuable connections and acquire new skills. We hope that you will enjoy yourself!

It's important to find out what is involved in becoming a PPI Advisor before deciding to join us in contributing to our research. We have provided details of what is involved.

What is the VIVALDI Study about?

As you will be aware, the pandemic has hit care homes especially hard. However, there is little good quality information about exactly what is happening in care homes. The goal of the VIVALDI Study is to provide important information to local and government decision-makers and public health officials, as well as to other researchers on how to prevent further spread of COVID-19 in care homes in England.

The study started in June 2020 and will run until March 2022. We have recruited over 3500 people from 100 care homes and are aiming to eventually include 12,000 people from 350 care homes in total. We are taking regular blood tests that look for evidence of past infection from care home staff and residents. We are also using results from nose/ throat swabs to look for current infection in the same study participants and whether or not these people had any symptoms when they were tested. Using routinely collected information we can see what happens to these people over time and which care home features might play a role in the spread of infection. We have collaborated with a number of national and independent care home chains to undertake this study.

The study was funded by the Department of Health and Social Care (DHSC) and we have partnered with researchers at University of Birmingham.

How can I be involved?

In March 2021, we plan to publish the first results from the study. This will be in the form of a scientific paper that will be published in international academic journals.

We want this work to have the maximum impact and to be seen by people who don't usually read academic journals: i.e. patients; the public; and the non-scientific community. Therefore, we want to produce a plain English summary of the scientific paper.

What will I need to do as a PPI Advisor?

Your role would be to advise and offer your unique perspective on how you would like the scientific paper to be presented in a plain English summary. This includes the type and format of the language used and how the information is distributed to make sure that it reaches as many people as possible. We would also like to raise the profile of research in care homes and would like your ideas about potential research priorities in the future. We would like to hear about what you think the potential impact of this research might be in your place of work or the care home that you live in. You will be undertaking this activity with researchers at UCL. Being an advisor does not mean that you are a research participant in the VIVALDI study.

What skills do I need?

Essential

- Have time to attend a training session and a further session discussing your ideas. These will be approx. 1 hour long each.
- Have time to read the research paper and a draft plain English summary beforehand and bring ideas on how to improve it.
- Can participate in training provided.
- Be interested in research about COVID-19 and its impact on care homes in England.
- To be able to represent the views of relatives, staff or residents of care homes in how you would like to read and understand the findings of the research.
- Have access to a computer or smart phone, a reliable internet connection and an email address. (If you have problems using or accessing technology and want to be involved, please contact us to discuss this further).

What will I get in return?

You will be reimbursed £120 to attend both sessions for your time. You will meet other like-minded people who may have similar experiences to you and may gain new skills and learn about COVID-19. Most of all, we hope that you enjoy yourself.

You will be provided with feedback about the impact and outcome of the sessions. We also welcome feedback on how we did.

We may do further patient and public engagement activities in the future, in the next 12 months or so, and you may be offered to be involved in future events. However, you can opt out of this if you wish.

What support will be available?

You will be provided with bespoke training. Additionally, the following link may be useful: <https://www.invo.org.uk/resource-centre/jargon-buster/>

How can I join?

To express your interest in joining as an advisor, please complete the online form available here: <http://bit.ly/3bC7xjr> All your personal data will be stored securely.

If you have any further questions regarding the role or completing the online form, we would be happy to hear from you. Please contact: vivaldi.covid19@ucl.ac.uk

Privacy Notice

For more information, please see: <https://www.ucl.ac.uk/health-informatics/research/VIVALDI-study/VIVALDI-privacy-notice>