

FAQs for VIVALDI Study Care Homes

1. Why is this study important?

The COVID-19 pandemic has severely affected care homes and many residents have died from the infection, but we still lack information about what care homes can do to stop infections. We also need to monitor how well vaccines are working in residents and staff. The VIVALDI study is working to answer these questions. Our research results are regularly fed back to the government and to public health agencies so that they can make the best decisions about how to protect care homes from infection. To make sure that the study can produce the best quality evidence, it is important to collect information about everyone in the care home. Without this information, it is difficult to measure how well vaccines are working or to work out how COVID-19 spreads between people (because lots of people will be missing from our dataset).

In an ideal world, we would get written consent from everybody in the care home to use data. Unfortunately, this is not possible because 1) lots of residents can't consent to share their data (because of conditions like dementia) and 2) there are lots of new staff and residents joining/leaving the care home, so we would have to keep consenting every few weeks. This just isn't possible in care homes during the pandemic because getting consent takes a lot of time. This is why we are asking people to share their data without getting their consent first. This approach is sometimes used in research studies, but these studies must be approved by a Government appointed group called the Health Research Authority (HRA).

For more information visit the VIVALDI study website: <https://www.ucl.ac.uk/health-informatics/research/vivaldi-study>

2. What information will you collect?

We will be collecting information that is already being collected by the government National Testing Programme and by the NHS. This includes your COVID-19 swab test results, COVID-19 vaccinations, any A&E attendances or hospital admissions, and month and cause of death for any residents who have died. Until June 30th 2022, we are able to access this information under the COPI Notice (Control of Patient Information), which was introduced by the Government during the pandemic to support the public health response. COPI allows confidential patient information to be shared between health organisations and appropriate research bodies, to help monitor and manage the COVID-19 outbreak.

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11. How long do you plan to do this for?

We will continue to collect anonymised (names and all identifiers removed) information about staff and residents in care homes taking part in VIVALDI, including anyone who joins the care home, until April 2023. For one year after this (until April 2024), we will collect information on swab results, vaccination, hospital admissions and deaths only from people who were already in the care home in April 2023.

12. What if I leave the care home?

If you leave a care home that is part of VIVALDI, we will keep any anonymised information that we have already collected about you while you were at the care home and use it in our analysis and reports. We will NOT be able to access any information about you after you have left the care home unless you move to another care home that is taking part in VIVALDI.

13. How long will you keep my information?

We will keep the dataset that we create using your non-identifiable information for 10 years from the end of the study which is in keeping with UCL policy. This is stored securely within the UCL Data Safe Haven which has data security accreditation and is regularly maintained and monitored.

For more information on the UCL Data Safe Haven, follow this link:

<https://www.ucl.ac.uk/isd/services/file-storage-sharing/data-safe-haven-dsh>

15. I am next of kin to someone who lives in this care home, and I don't want their information to be used in this study. What should I do?

In the first instance please speak to the manager of your care home. If your next of kin has the capacity to decide whether or not they would like their information to be included in the study, then you should speak to them about whether they want to take part. If they do not have the capacity to make this decision, then you should consider whether taking part in the study is something that is in line with their wishes. If you believe that it is not, then please follow the steps outlined in Q14.

16. Who can I talk to if I have a complaint about the study?

If you would like to make a complaint, please contact the UCL research complaints team: research-incidents@ucl.ac.uk