VIVALDI Social Care

Information for Relatives of Care Home Residents

What is the VIVALDI Social Care Project?
The VIVALDI Social Care Project is a national, government-funded research project led by the Outstanding Society, Care England, and University College London. We are working together to tackle the problem of infection and outbreaks in care homes.

What are we doing?
We are collecting NHS numbers from residents in your care home and will link these NHS numbers to other data already held by the NHS. The research team, public health experts from the UK Health Security Agency (UKHSA), care providers and people who live and work in care homes will work together to agree on the best way to use these data to measure infections and outbreaks. Examples might include measuring:

- How many residents had a urine infection
- How effective vaccines are at protecting residents from serious illness
- The number of outbreaks in each care home

We expect to develop about 10 measures and will ensure that the measures we use do not disadvantage any homes that take part in the study. We will also use the data to create an anonymized research database that can be used by researchers to find new ways to protect people living, working, and visiting care homes. Only projects that have been approved by people who live and work in care homes will be allowed to use the research database.

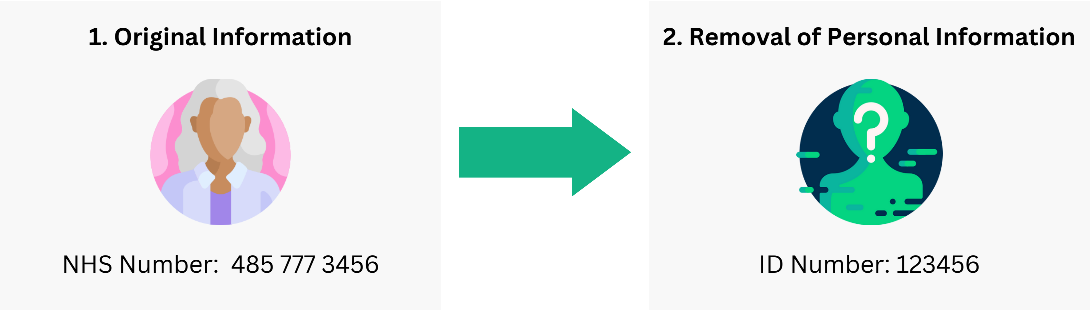
Why are we doing this?
During the COVID-19 pandemic, people in care homes worked together with researchers and the Government to work out how to stop COVID-19. We want to build on what we learned in the pandemic to tackle other infections and outbreaks, like flu, and norovirus which have a major negative impact on residents and their families. The first step to do this is to measure infections and outbreaks in each care home, which is why we seek permission to access residents' data. The NHS already measures infection levels in hospitals, but no one measures infections in care homes.

What should I do if I do NOT want my relative's information to be used in this study?

If you do not want your relative's data to be included, please tell someone who works in the care home. They will make sure your relative's details are removed from the list. Alternatively, you can email:

How are we collecting data?

The company that supplies electronic care records in your relative's care home will send NHS numbers for residents taking part to NHS England. NHS England will convert these NHS numbers into individual, de-identified codes that can be linked to other data already held by the NHS and will delete the NHS numbers.



NHS England will receive NHS Numbers for residents to build the research dataset. Your relative's personal information is removed and replaced with an ID number.

This is done by NHS England in line with the General Data Protection Regulations (GDPR) 2018. The data (which only contains information that cannot be used to identify your relative) is sent to the VIVALDI study team by NHS England.

The datasets (data) that we will link to include:

- Hospital admission: dates and the reason for admission
- A&E attendance: dates and the reason for attendance
- Vaccination records: dates and type of vaccine
- Death records: date and cause of death
- Lab test results for infection: dates, type of test and result
- Antibiotic prescriptions: date and type of antibiotic prescribed

No other information will be accessed and all identifiable information about your relative will be removed before the data are shared with the project team. We are planning to collect data from around 500 care homes. The study will run for 18 months however we will only collect data from each care home for a maximum of 12 months within this period. Once your relative leaves the care home, we will no longer collect data about them.

Why are we collecting data without consent?
Normally in research studies people consent to take part and sign a form. But many people in care homes can't do this, for example, because they lack capacity. It's not fair to automatically exclude these residents and excluding them means they might not benefit from what we learn in the study. The research should better represent the population of care home residents if everyone is included and then all might benefit from what is discovered.

One way of including residents who cannot consent is to seek permission from their relatives. This might work in some homes, but would place a huge burden on teams, to phone every family to see if they are happy for their relative to take part. Having talked to residents, relatives, care home staff, and care providers, we think the fairest option is to give everyone the chance to take part, but residents can still 'opt-out' if they don't want to share their data. This is a pilot study, so we are trying to learn if this approach works and is acceptable to residents and families. Throughout the project, we will talk to residents and relatives to understand their views on how we are using residents' data.

Will we be able to see any of your relative's personal information?
No - residents' personal information will not be visible to anyone who analyses the data. NHS England will remove residents' NHS numbers before the project team receives any data. This is completed in line with the General Data Protection Regulations (GDPR) 2018.

Who has approved this project?
The ways in which the study will use care home residents' information have been approved by the Health Research Authority and the Secretary of State for Health and Social Care on advice from the Confidentiality Advisory Group(CAG). CAG are responsible for reviewing the plans for studies in health and social care that use data that have been collected without consent. They make sure these studies are ethical and protect and promote the interests of the patients and the public. The project will also be overseen by an oversight group which will include residents, relatives, and care home staff.

What are the benefits of sharing residents' data?
By taking part, your relative can help us answer important questions about infections and outbreaks. This could help us prevent and reduce infections, hospital admissions, and deaths in care homes. It may also help us to reduce the frequency and severity of outbreaks, reducing how often homes are closed to visitors or admissions.

What are the risks of taking part?

The only risk is that someone who does not have permission sees your relative's data. This risk is very low because we are only collecting one piece of identifiable information for residents (NHS numbers), all the data processing will take place within the NHS, and identifiable information will be removed before it is shared with the project team.

What will happen with the results?

The results from the research and the surveillance will be published in scientific, medical, and social care journals and presented at conferences attended by professionals with an interest in the area. Reports will be shared with care homes and policymakers to improve care quality. We will also share the results directly with residents and their relatives, as well as the staff working in this care home. No resident, relative, staff member or care home will be identifiable in any publication.

What if something goes wrong?

If you are unhappy about something that has happened in the study and want to discuss it with the project team, please contact:

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

More information and contact details:

Website: www.theoutstandingsociety.co.uk
Email:

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