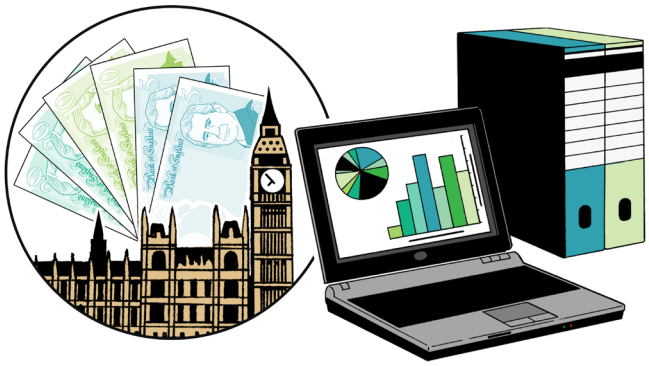
VIVALDI Social Care

vivaldi SOCIAL CARE
Shaping social care through research

Information for relatives of care home residents

easy read

What is the VIVALDI Social Care Project?



The VIVALDI Social Care Project is a national government funded research project. This means it was paid for by the government.

The project is led by:

The Outstanding Society

This is an organisation that shares information and support for social care providers.

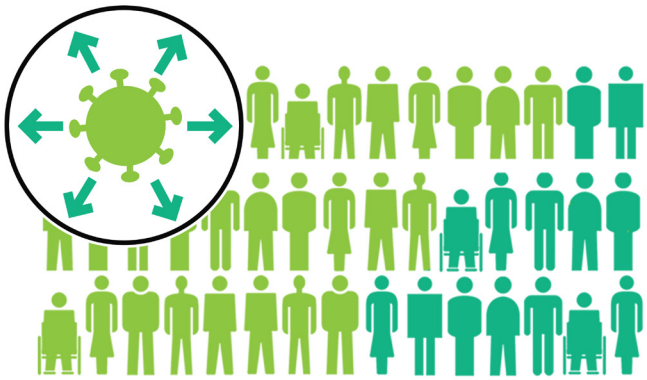
Care England

This is a charity that supports independent social care providers. This means social care that is not provided by the government.

University College London (UCL)

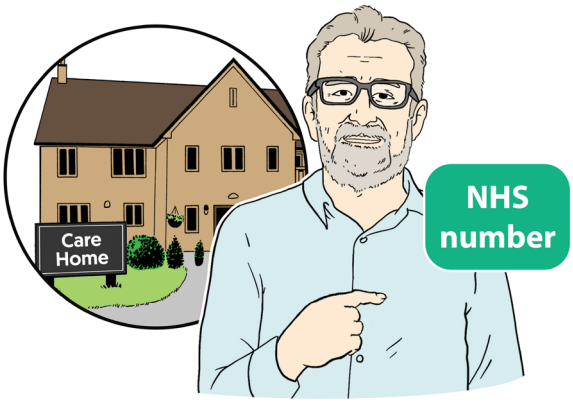
This is a research and teaching university in London.

The VIVALDI Social Care Project looks at the problem of **infection** and **outbreaks** in care homes, and ways to stop them.

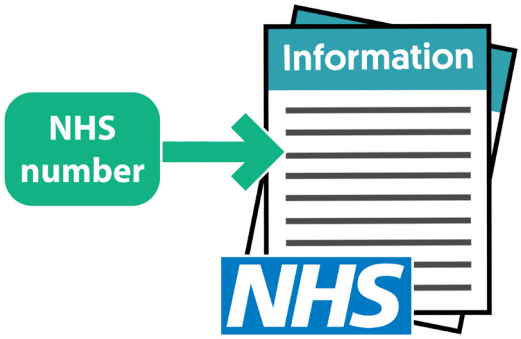


An **infection** is a health problem caused by germs. An **outbreak** is when lots of people get the same infection.

What are we doing?



We are collecting NHS numbers from **residents** in your relative's care home. This means people who live at the care home.

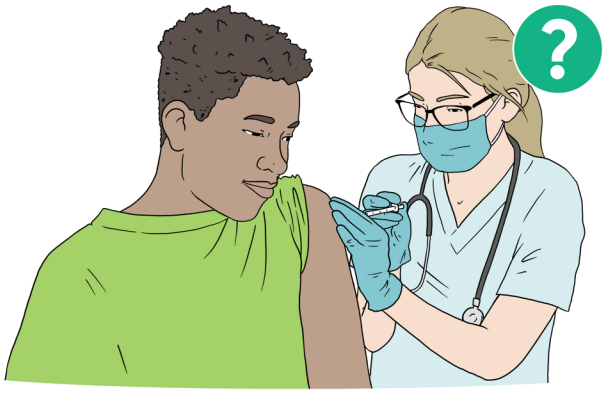


We will link these NHS numbers to other information that is already held by the NHS. This information is sometimes called **data**.

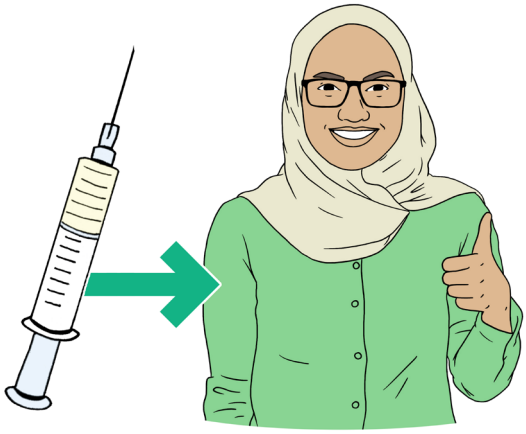
The research team, public health experts, care providers and people who live and work in care homes will work together to agree on the best way to use the data to measure infections and outbreaks.

They may measure:

- how many residents had a urine infection

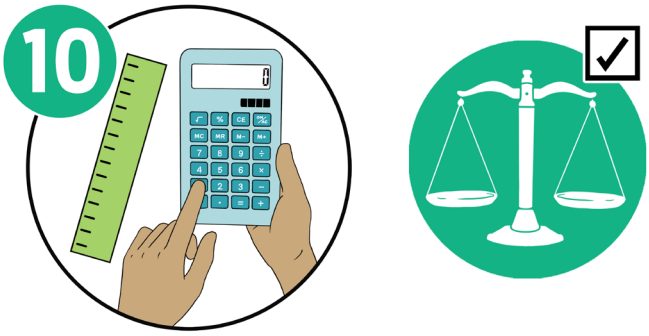


- how well **vaccines** are protecting residents from serious illness



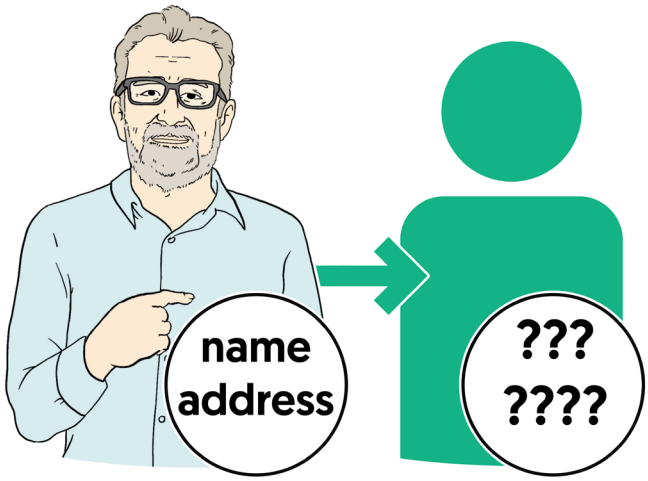
A **vaccine** is medicine that helps keep you safe from an illness.

- the number of outbreaks in each care home.

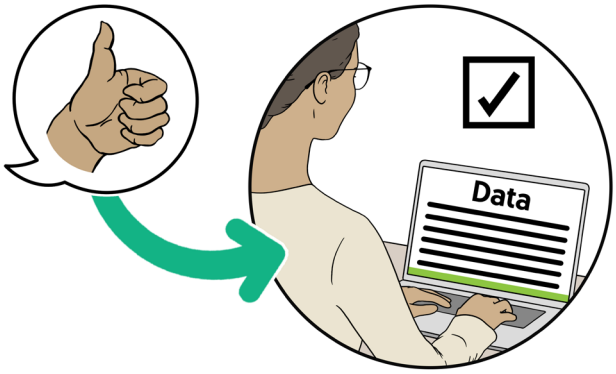


We want to have 10 different measures. We also want to make sure the measures we use are fair to all the care homes taking part.

We will also use the data we collect to make a research database that can be used by other researchers to find new ways to protect people living, working, and visiting care homes.

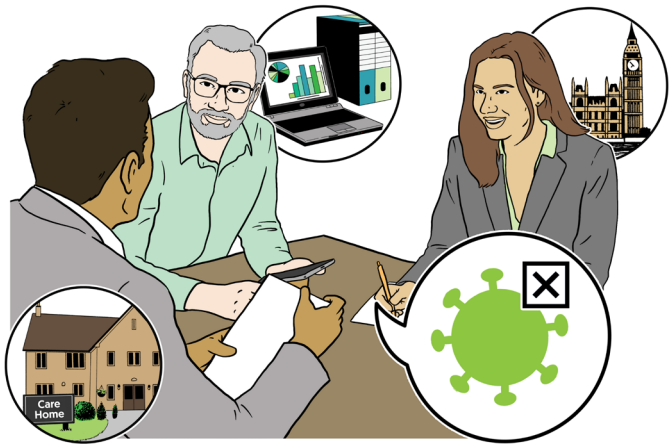


The data will be **anonymised**. This means it will not show anything that links back to your relative, like their name or address.

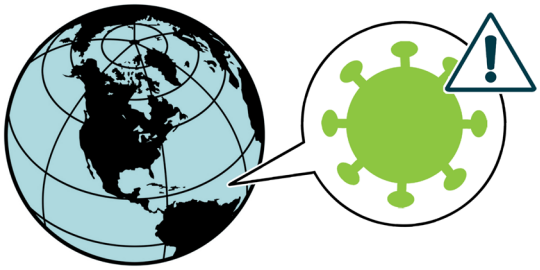


Only projects that have been approved by people who live and work in care homes will be allowed to use the research database.

Why are we doing this?



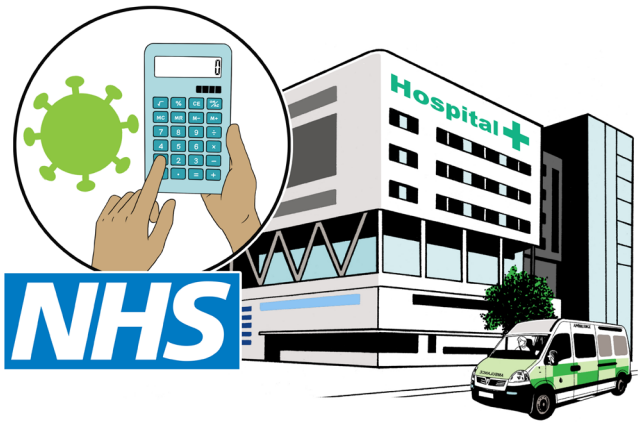
During the COVID-19 **pandemic**, people in care homes worked together with researchers and the Government to work out how to stop COVID-19.



A **pandemic** is when an illness spreads across the world.

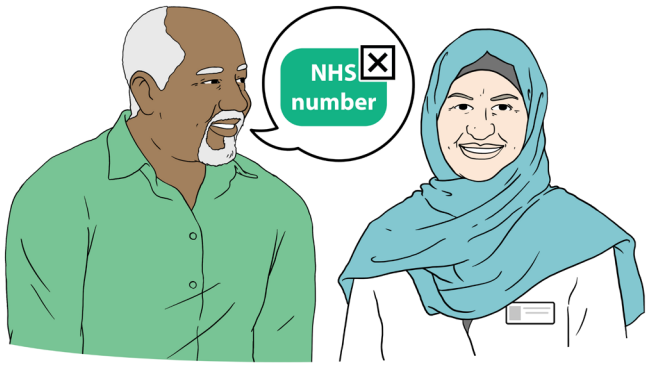
We want to use what we learned in the pandemic to reduce other infections and outbreaks, like flu.

The first step to do this is to measure infections and outbreaks in each care home.

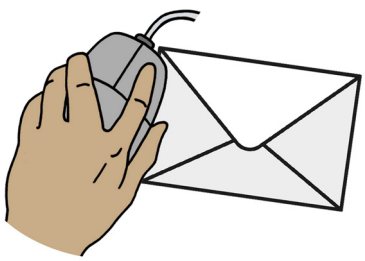


The NHS measures infection levels in hospitals, but no one is measuring infections in care homes.

What should I do if I do not want my relative to take part?

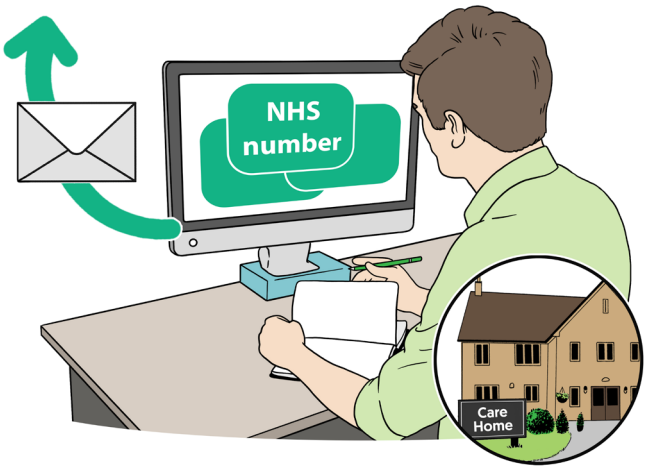


If you do not want your relative's data to be included, please tell someone who works in their care home. They will make sure the details are removed from the list.

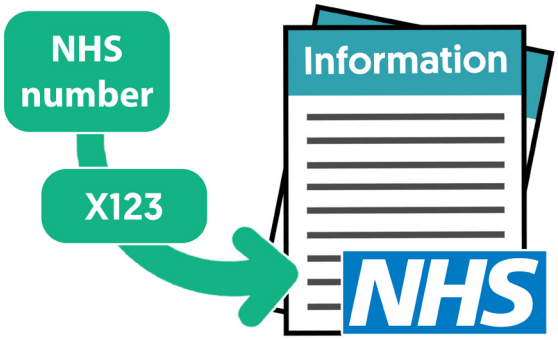


Or you can email:

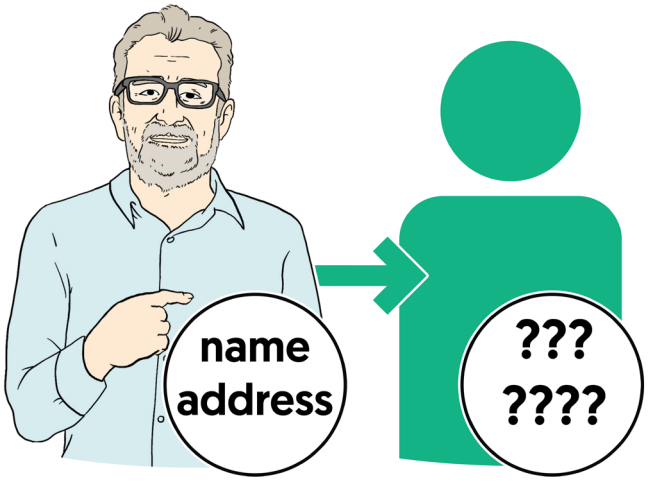
How are we collecting data?



The company that does electronic care records for your relative's care home will send NHS numbers for residents who are taking part to NHS England (NHSE).

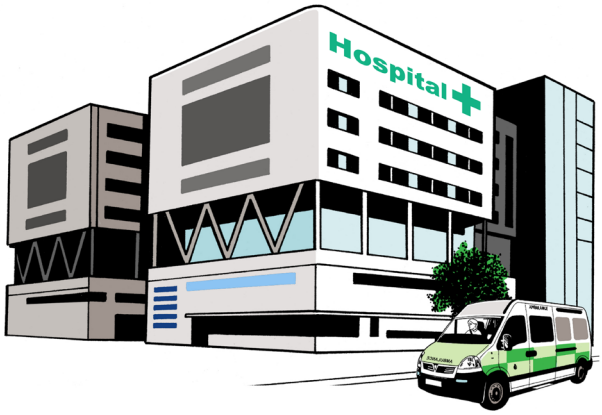


NHS England will change the NHS numbers into codes that can be linked to other data already held by the NHS.



They will then delete the NHS numbers and remove any personal information like their name or address.

NHS England will follow laws about how to keep information safe. These are called the General Data Protection Regulations (**GDPR**).



The data that we will link the NHS number to includes:

- **Hospital admission**
  The dates and the reason for going to the hospital.

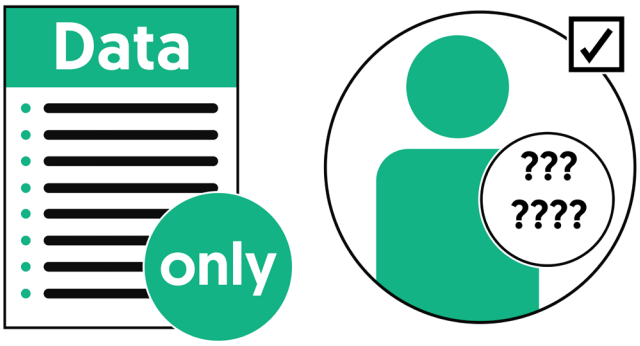
- **A&E attendance**
  The dates and the reason for going to accident and emergency (A&E).

- **Vaccination records**
  The dates and the type of vaccine.

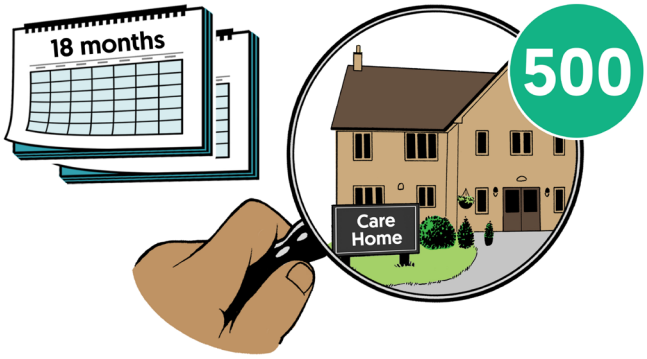
- **Death records**
  The date and cause of death.

- **Lab test results for infection**
  The dates, the type of test and what the test said.

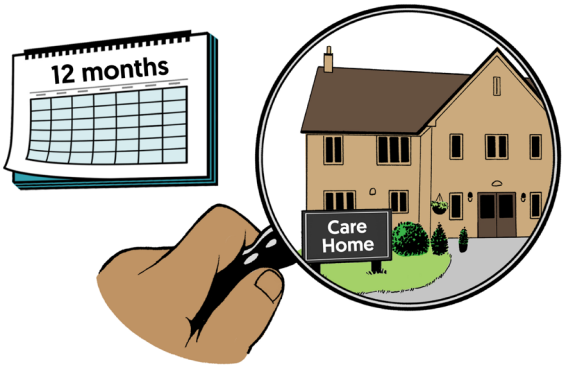
- **Antibiotic prescriptions**
  The dates and the type of antibiotic. An **antibiotic** is a type of medicine that helps fight infection.



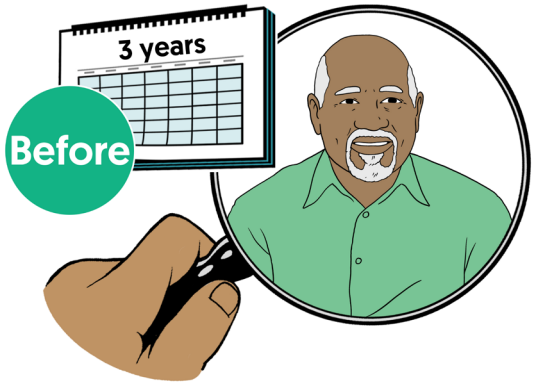
No other data will be accessed and all information that links to your relative, like their name, will be removed before it is shared with the project team.



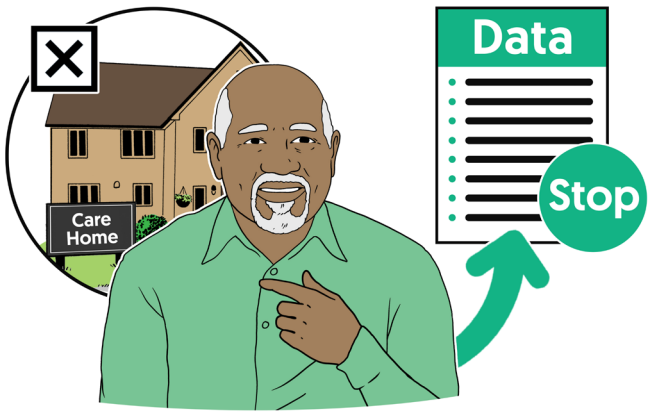
We are planning to collect data from around 500 care homes over 18 months.



We will only collect data from each care home for a maximum of 12 months.



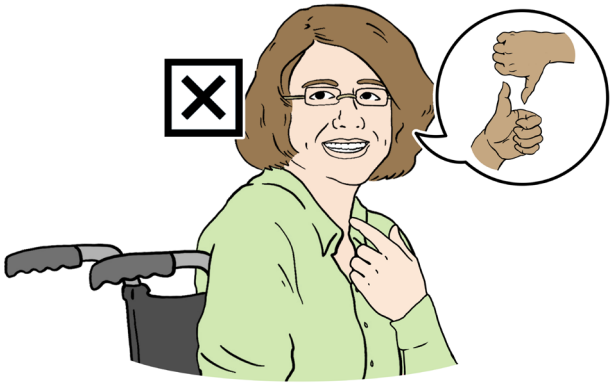
We will also look at data about your relative from the three years before we start collecting data for this project.



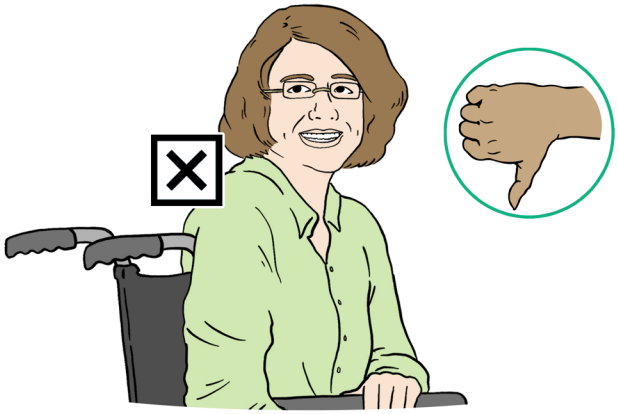
Once your relative leaves the care home, we will stop collecting data about them.

Why are we collecting data without consent?

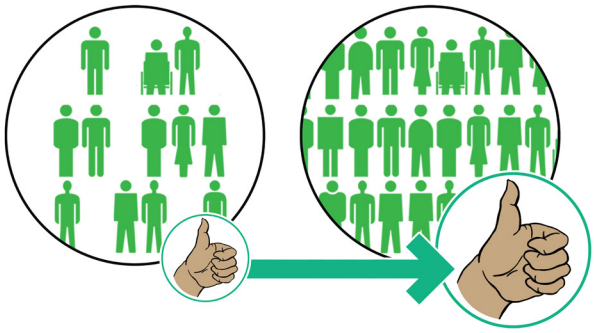
Normally in research studies people **consent** to take part and sign a form. **Consent** means that you have said it is ok.



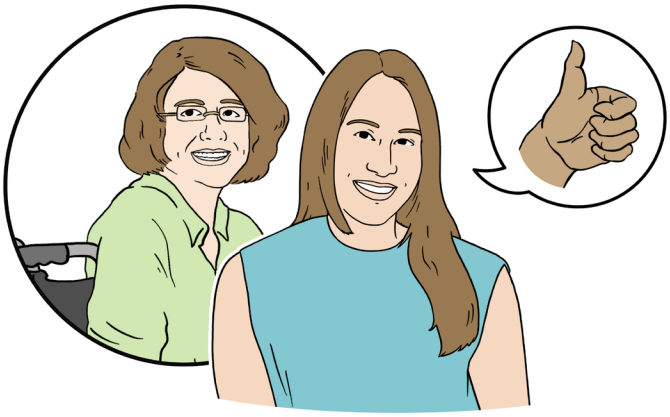
But many people in care homes can not give consent. For example, people who **lack capacity**. This means someone who can not make decisions for themselves.



We think it is not fair to leave these residents out. And it may mean that what we learn in the study does not help them.



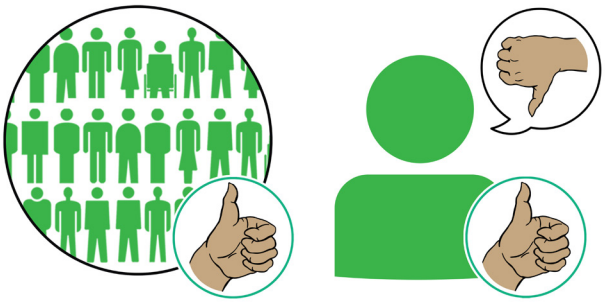
The more people we can include in our research the better. If everyone is included then they may all be helped by what we learn.



One way of including residents who can not consent is to get consent from their family.

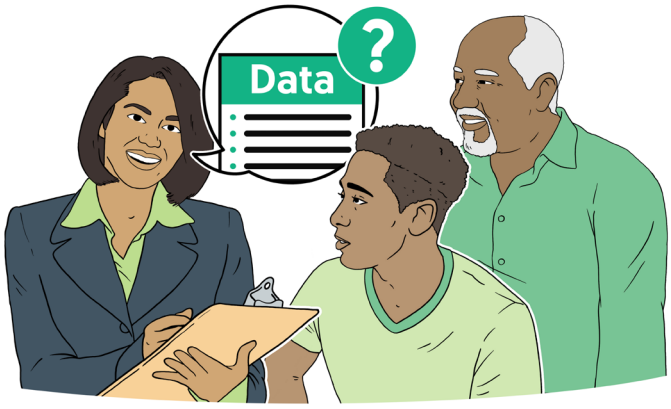
This might work in some homes, but would be a lot of work for teams to phone every family to see if they are happy for their relative to take part.

We have talked to residents, family members, care home staff, and care providers about how to include residents who can not give consent.



And we think it is fair to let everyone take part, but give the chance to ask to not take part.

This is a **pilot study**, this means this is the first time we are trying this way of working. We are trying to learn if this works and is good for residents and families.

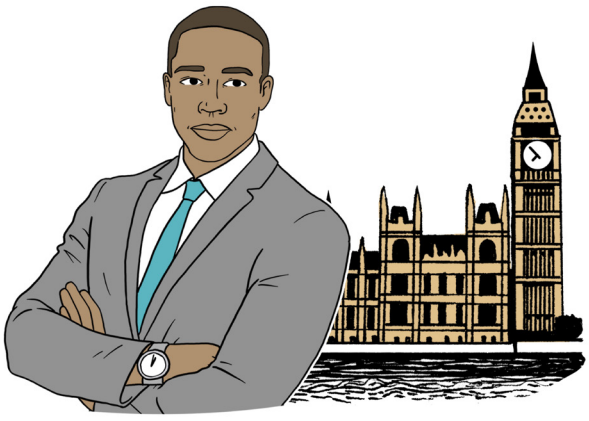


Throughout the project, we will talk to residents and family members to find out what they think about how we are using the data.

Who has approved this project?

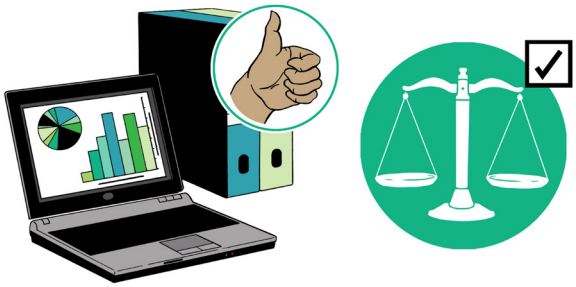
This project was approved by:

- **The Health Research Authority**
  This is an organisation that protects patients and the public in health and social care research.

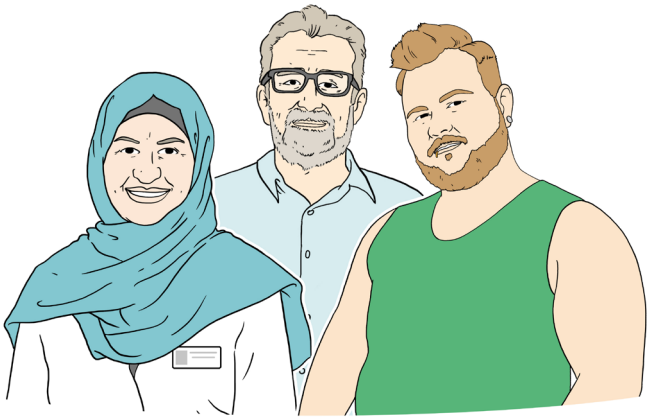


- **Secretary of State for Health and Social Care**
  This is the person in charge of the government health and social care department.

- **Confidentiality Advisory Group**
  This is an organisation that reviews plans for research in health and social care that use data that has been collected without consent.

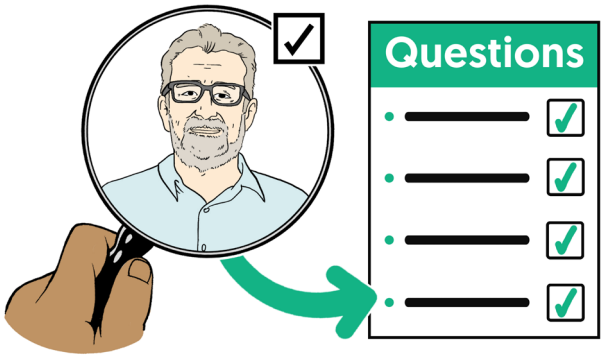


They make sure the research is safe and fair.



- **Oversight group**
  This is a group of people that includes residents, family members, and care home staff.

What are the benefits of taking part?

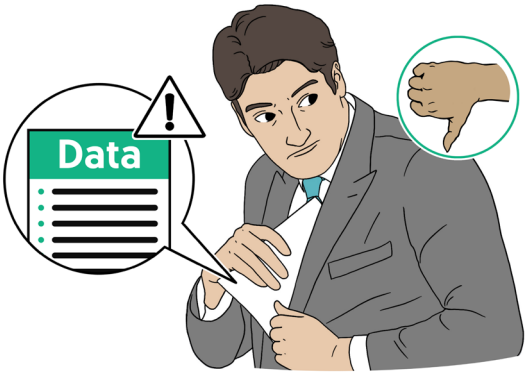


By taking part, your relative can help us answer important questions about infections and outbreaks.

This could help us reduce infections, hospital treatment, and death in care homes.

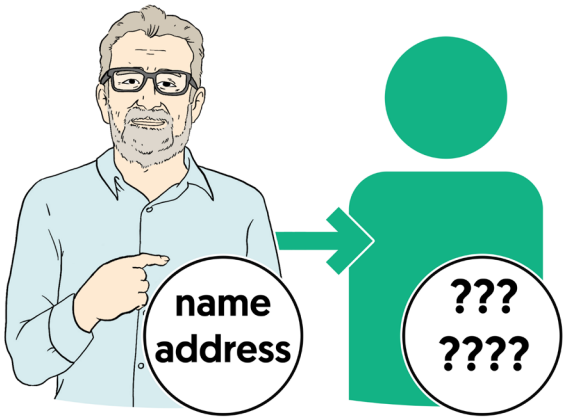
It can also help us to reduce outbreaks which sometimes close care homes, and stop family members from visiting.

What are the risks of taking part?



The only risk is that someone who does not have permission is able to see your relative's data.

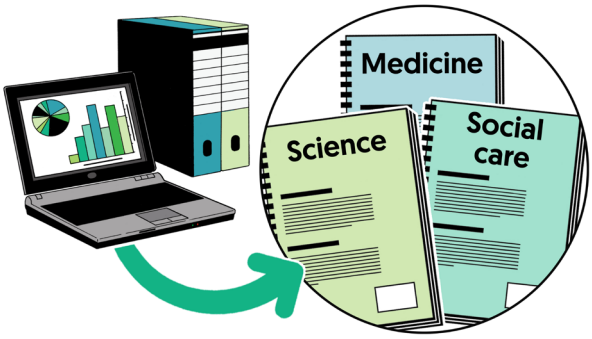
This risk is very low because we are only collecting one piece of information that links to your relative, their NHS number.



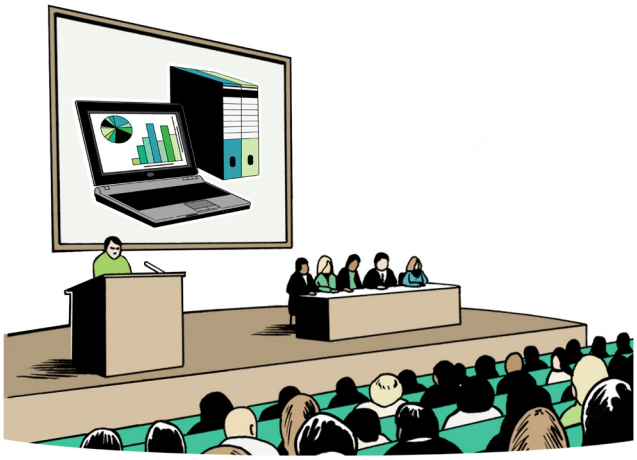
The NHS will be in charge of linking the NHS number with their data. They will remove any information linking back to your relative, like their name or address, before it is shared with the project team.

The NHS will follow the GDPR rules to keep information safe.

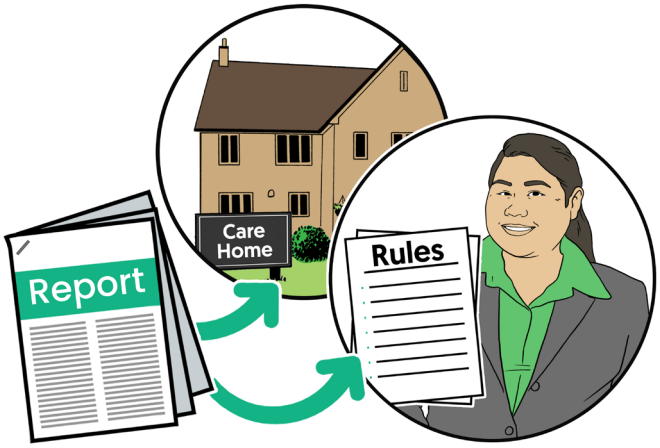
What will happen with the results?



The results from the research will be published in scientific, medical, and social care journals.

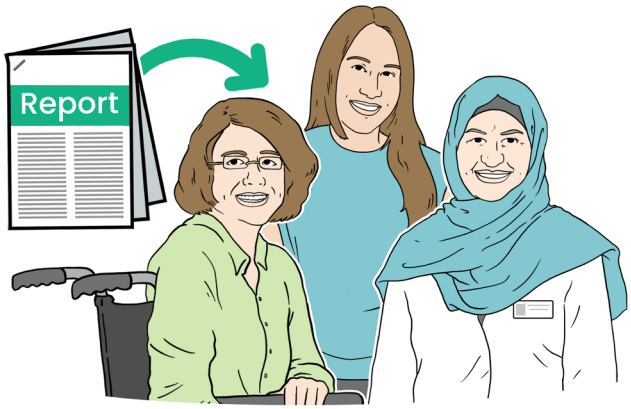


They will be presented at conferences for professionals.

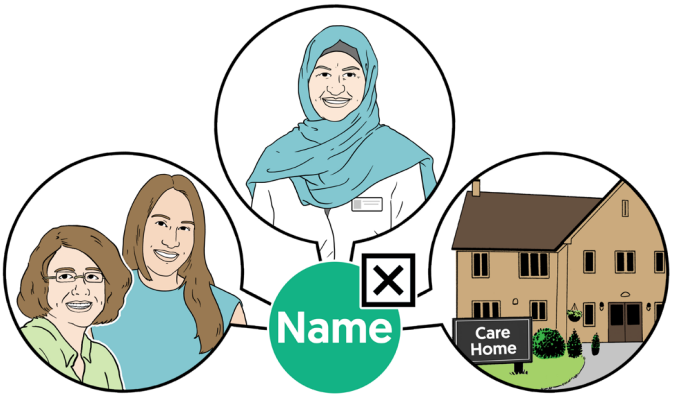


Reports will be shared with care homes and people who make rules and guidelines for social care.

This is so we can look at how to improve care.



We will also share the results with residents and their family, as well as the staff working in the care home.

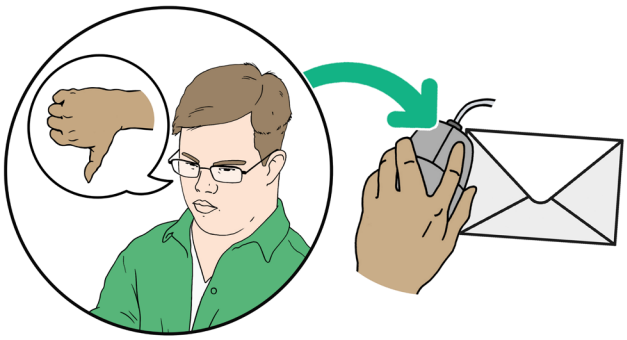


No resident, family member, staff member or care home will be named.

What if something goes wrong?

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

info@vivaldisocialcare.co.uk



If you want to make a complaint, please contact the UCL research complaints team:

research-incidents@ucl.ac.uk

More information and contact details

To find out more about the VIVALDI Social Care project you can email:

info@vivaldisocialcare.co.uk

To find out more about the Outstanding Society visit their website:

www.theoutstandingsociety.co.uk

To find out more about Care England visit their website:

www.careengland.org.uk

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