



Project Summary

Easy Read

Including adults with capacity and communication difficulties in safe and sound research





A project about including adults



with **capacity** and **communication difficulties**



in **research projects**



that are **safe and sound.**





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The images in this report are from Photosymbols:

<https://www.photosymbols.com>



The image for 'stroke' is taken from First Aid For Life:

<https://www.firstaidforlife.org.uk>





The Nuffield Foundation
gave us the money



for our project.



The date of this Report is
1st October 2021.



Thank you



Thank you to our **working group**.



They helped us with our project.



Thank you to the Broadland Art Group.



They made the drawings in this report.





Thank you to our **Advisory group**



They gave us help on our project



Thank you to our **Research Associates** who worked on the project



Oluseyi Jimoh
Hayley Ryan
Yvonne Plenderleith
Marcus Redley

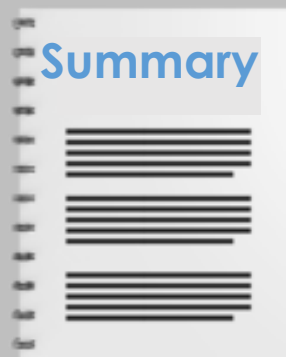




Illustrations by the
Broadland Clinic Art
Group

Project

assent

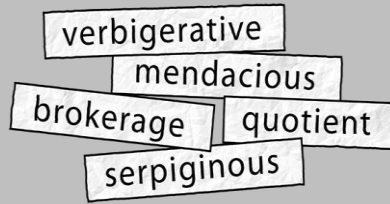


Project Summary





This report is in 3 parts.



Difficult words are explained separately.



This is part 1.



Project Summary



We carried out a project
called ASSENT



over 3 years.



Our team brings together
people who know about



the **law**





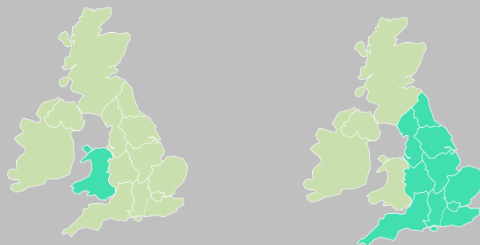
psychology



speech and language therapy



and **occupational therapy.**



Our project is about

taking part in research

in a safe and sound way

in England and Wales



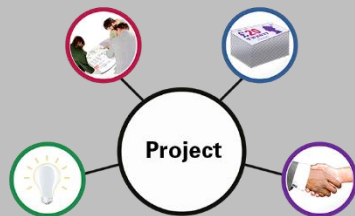
This report tells you



our project aims



the **methods**



the activities.



It tells you our findings



and what they mean.



You can get the full report at
<https://www.uea.ac.uk/groups-and-centres/assent/documents>



About the project



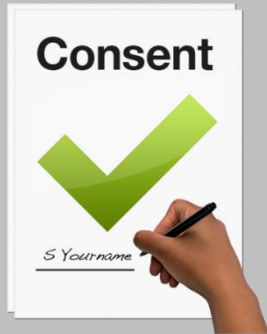
Taking part in research



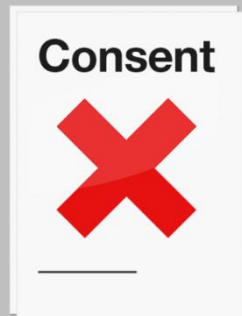
means making decisions for yourself



and understanding information about
a research project.



It means saying yes - you want to take part.



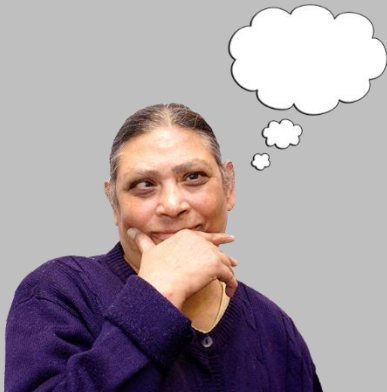
Or saying no - you don't want to take part.



Some people



have difficulties with understanding



and saying what they think.



Some people have difficulty speaking because they have:



learning disabilities,



autism,



mental health problems,



dementia,



had a stroke,



or a head injury.



People are living to an old age.



This means there are more people



who have dementia



or have strokes



Good hospitals mean that



very small babies live



but some grow up with disabilities.



Is it safe for adults with disabilities



to take part in research?



There are concerns



about people with **capacity and communication difficulties**



Some people think



that it might be safer
to leave them out



for their own **protection.**



If we leave people out



we won't know about their difficulties
and how best to help them.



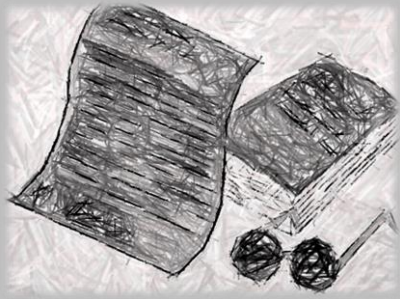
We wanted to find a way



to include adults with **capacity**
and **communication difficulties**



in safe research.



About our methods



We carried out our project



in 3 stages.



Stage 1

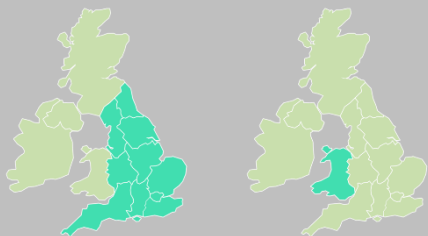
The law and safe research



Mental Capacity Act (2005)



We looked at research



in England and Wales.



We looked at the
Mental Capacity Act



and the **Code of Practice.**



We read the reports



about the **Mental Capacity Act.**



Research advice



We looked at the advice of the
Health Research Authority.



Research articles



We read lots of **journal articles**



about people with **capacity** and
communication difficulties



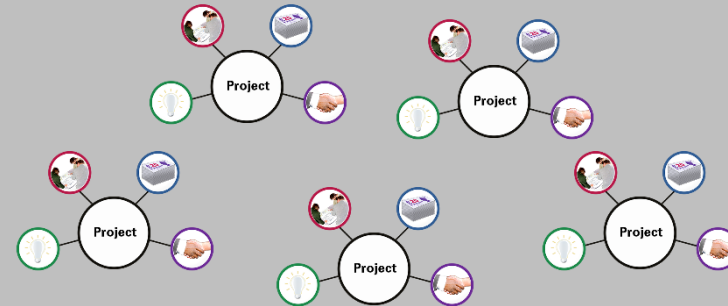
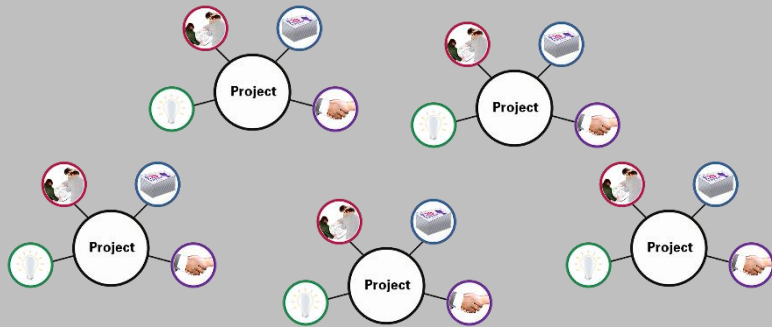
taking part in **research.**



Stage 2: Surveys



We looked at



Lots of **research projects**
from the **past**.

Lots of **research projects**
In **1 year**





Information about projects



We looked at the different information



given to people with **capacity** and
communication difficulties,



Researchers



We asked researchers



about including adults with **capacity** and
communication difficulties



in their **research.**



People interested in research



We asked different people



about safe **research projects.**





We asked people with
**capacity and
communication difficulties.**



We asked the
people who
give support.



We asked researchers.



We asked members
of **Research Ethics
Committees.**



Stage 3

Development of guidelines for the internet



Stages 1 and 2



We looked at all our findings.



Development of guidelines

1.



We wrote some information



for researchers

2.



A company made our **guidelines**



for the **Internet.**

What do researchers think about our guidelines?



We asked researchers



to look at the guidelines.

Tell us what you think



1. Do you think the idea is a good one?

☐ Yes

☒ No

☐ Not sure



They told us what they think about them.



Go to Part 2 for more findings.