

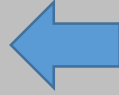


Part 3.

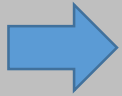
More Findings



Info



Some pictures were on the
right of the page

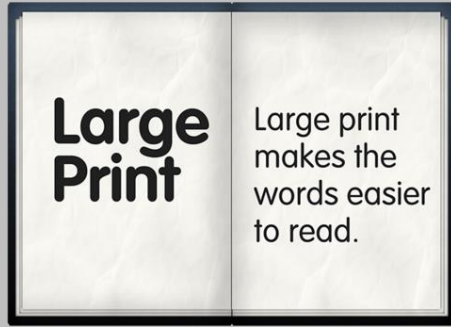


some on the left

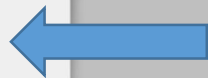
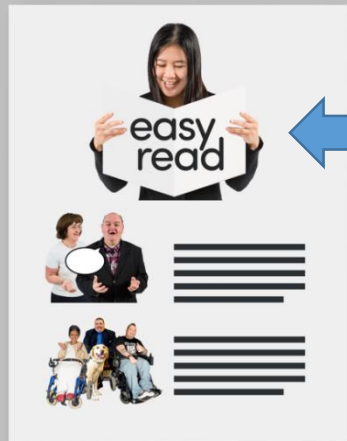


and some below the text.





Big print was used in over half of the sheets.



Most of the sheets had headings in them





About a quarter of the information sheets



used bullet points or numbers.



Most of the information sheets
used everyday words.



Some words were difficult to
understand.



Researchers



127 people filled out a **questionnaire**.



Over half of the people



worked with people with **capacity** and **communication difficulties** for more than 10 years.





Over half told us



they had done **research** for more than 10 years.



Most people said they knew a lot



about the **Mental Capacity Act**.





They included people with **capacity** and **communication difficulties**.



They used different ways of communicating.

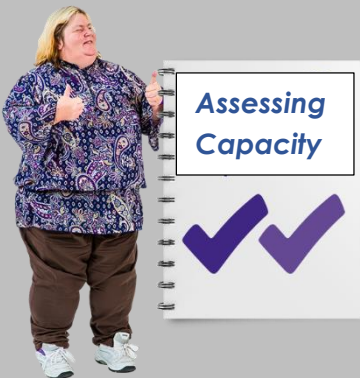




About a third of researchers said



they did not use **communication aids**.



Researchers felt good about **assessing capacity**.





There was some confusion about



using a **consultee**



and who should assess someone's
mental capacity.





Is it the **researcher**



or the **supporter?**

People interested in research



What did people say to us?



People with capacity and communication difficulties



think they should be included in **research**.



It helps researchers to understand what it means to have a disability.



It makes people feel useful.



It also gives a voice to people.



People did not like being left out.



But some people said **consultees** could help.



They said that the **consultee** should know the person well.



Some people think



a person with a **communication difficulty**



can't understand or communicate at all.



They become **invisible**.



Supporters



said it was wrong to leave people out of **research**.



Researchers need to make



project information easy and interesting.



They said some **research** did not give enough information.



Making communication easy



is important when you **assess capacity**.

Researchers and Research Ethics Committees



It is good to include



people with **capacity** and
communication difficulties.



The different people who can be a **consultee**



was confusing for some.



They agreed that information sheets should be



easier to read.



They thought there was too much attention



on printed information sheets.



Researchers thought there is need to support people with **capacity** and **communication difficulties**



to make their own decisions.



This is the case even when a **consultee** is giving advice.



Stage 3

Development of guidelines for the internet

Stages 1 and 2 The key messages were:



the researcher and person with capacity and communication difficulties need to work together;



people need to be helped to make their own decisions;



we need to use lots of different ways for giving information.

Development of guidelines



We worked with a media company.



We presented our findings to them.



They built our guidelines using colour, pictures and **animations.**

What do researchers think about the guidelines?



Questions

1. What do you think about it?

☐ Good

☐ Bad

☒ Not sure

31 people, mostly researchers, filled out a questionnaire about the **Guidelines**.



They looked at the guidelines on the Internet.



Most people thought they were very useful.



They liked the section on Adaptations and Accommodations the best.



Their ideas for how to make the guidelines better included:



- More examples of real people with capacity and communication difficulties;



- Buttons to help you move backwards as well as forwards through the information;



- Checking that the sound, text and pictures work together.



Our conclusions

The law and safe research



There is some confusion



about the **Mental Capacity Act**
and the **Code of Practice.**







There is not much about how we support people with **capacity** and **communication difficulties**.



There aren't many projects involving people who have **capacity and communication difficulties**.



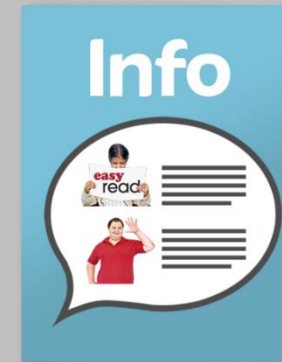
Research projects that include adults with capacity and communication difficulties



People are still left out of **research projects**.



Researchers use a lot of different materials to help people understand.



Information on paper is the main way information is given out.



When a **consultee** gives advice



it is not clear



how the **researcher** attends to the person's wishes and feelings.

Our recommendations

Working together: What is important?



Cooperation between the researcher and people taking part.



Checking the wishes and feelings of people.

Support for decision-making: What is important?



Guidance on helping people



to understand and express themselves.

Use of different ways of communicating: What is important?



Better information about the
communication methods



to help people take part in research.

ASSENT guidance is useful but could be improved by



including more case examples to help with decision-making.

This is the end of our
report of findings.

verbigerative
mendacious
brokerage quotient
serpiginous

Difficult words
are explained
next.

