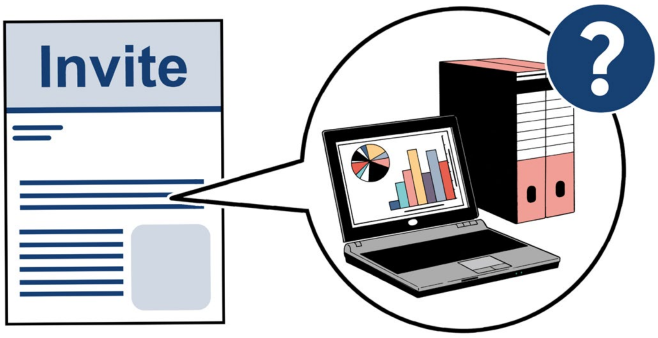
ReSPECT

Participant Information and Consent Form

Advisory Group

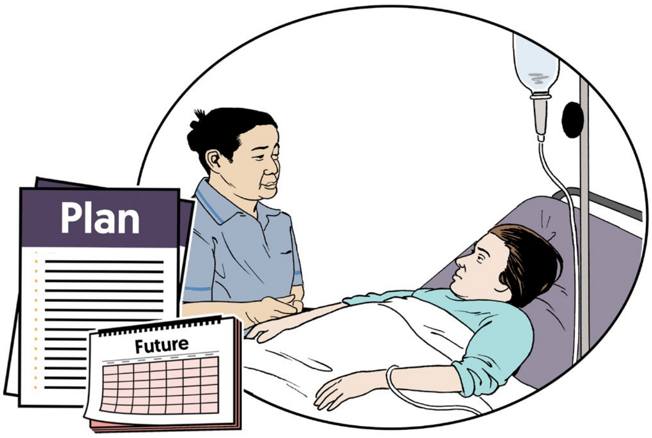


We would like to invite you to help us with our **research**.

Research is when people find out about how something works or how it could work better.

WARWICK
MEDICAL SCHOOL
UNIVERSITY OF LEEDS
FUNDED BY
NIHR | National Institute for Health and Care Research

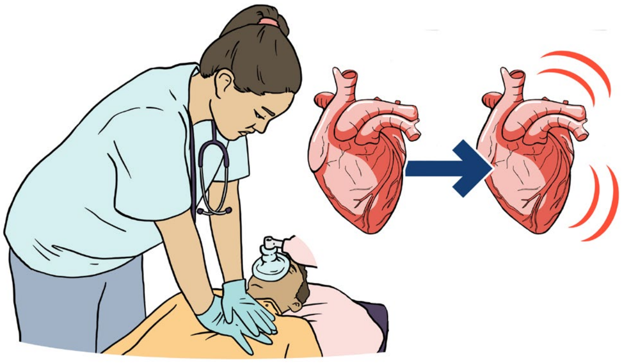
What is this research about?



This research is about planning for the future in case you become unwell.

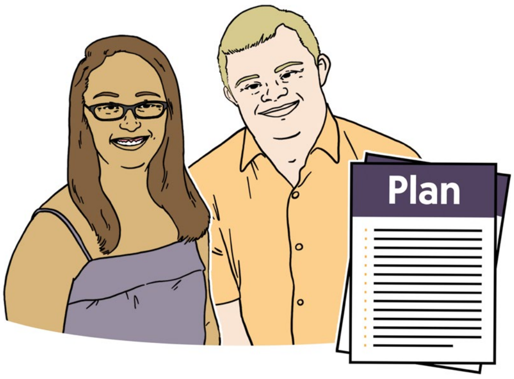
We are looking at a type of planning called the **ReSPECT** process. **ReSPECT** stands for **R**ecommended **S**ummary **P**lan for **E**mergency **C**are and **T**reatment.

A ReSPECT form is where you can write down which treatments doctors and nurses should give you, if you are in a health emergency in the future.



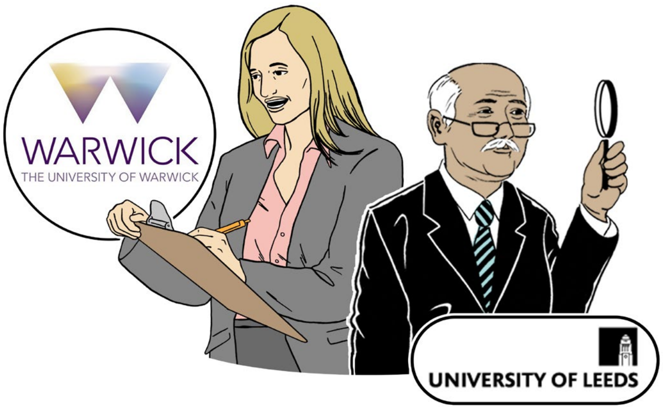
These can be things like giving you **CPR** if your heart stops. **CPR** is a process to try and start your heart beating again.

This is agreed between a person and their doctor or hospital doctor. Sometimes the agreement is made when a person goes into hospital.

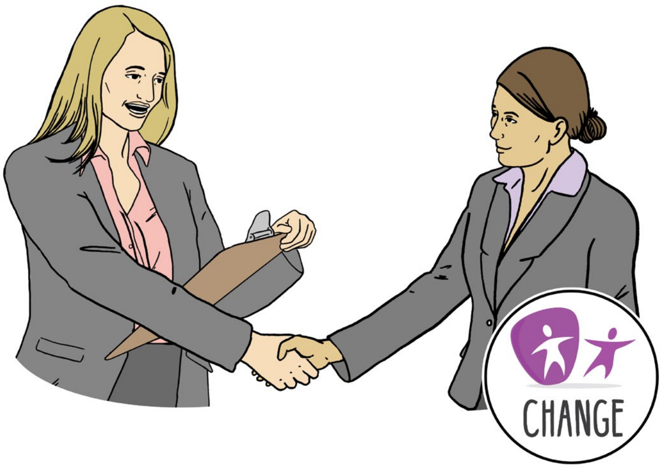


We want ideas about the best way to make these plans for people with a learning disability.

Who is doing this research?

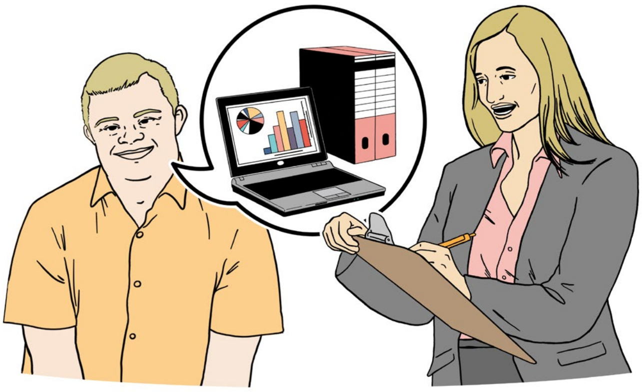


The research is being done by researchers at the University of Warwick and the University of Leeds.



They are working with CHANGE, an organisation led by disabled people.

Why are we asking you?



We would like people with a learning disability to help us decide how the research should be done.

We have asked people with a learning disability and carers to share this information, so that we can find people to take part.

We want to make an **Advisory Group** of people with a learning disability. This is a group of people who help us decide how to run our research.

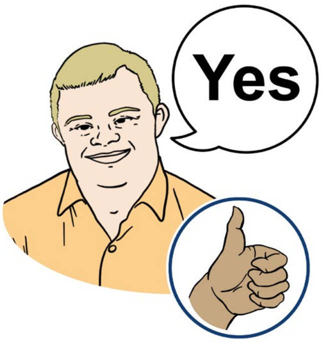
We think it is important for people with learning disabilities to be involved in decisions about their health care planning.

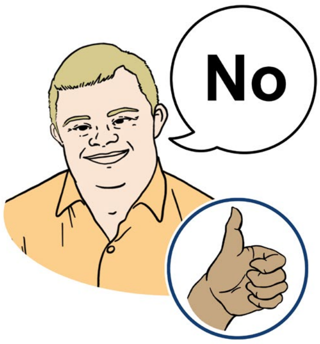
Why are we doing this research?

We want to know what people with a learning disability think about planning for their health in the future.

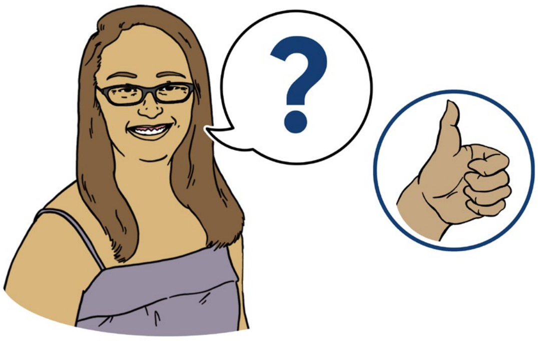
We want to find out if we can make using the ReSPECT process better for people with a learning disability.

Do I have to take part?





You can choose yes or no. It is your choice to take part or not.



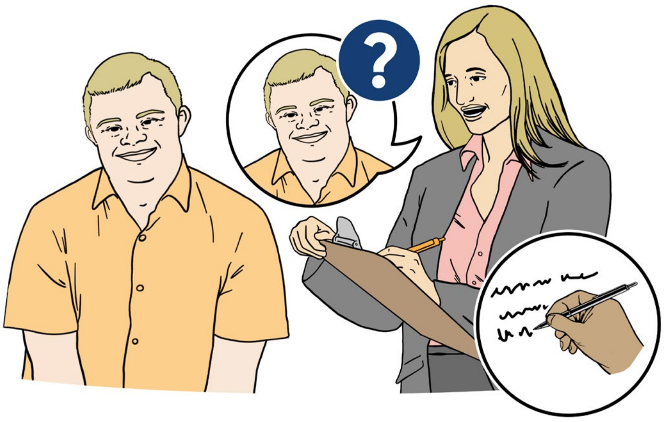
You can ask any questions you want before you choose.

No one will mind what you choose, and it will not affect your care or treatment.

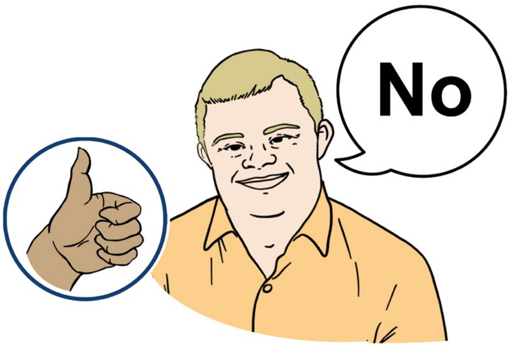
Choosing yes

If you would like to take part telephone us, or call us online, to talk to you.

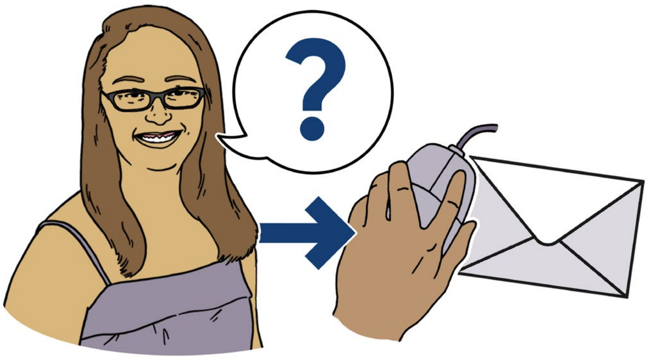
We will answer any questions you have about the research.



We will ask if you want to take part. If you say yes we will write this down and ask you a few questions about yourself.



You do not have to answer these questions if you do not want to. You can still be in the advisory group even if you do not answer.

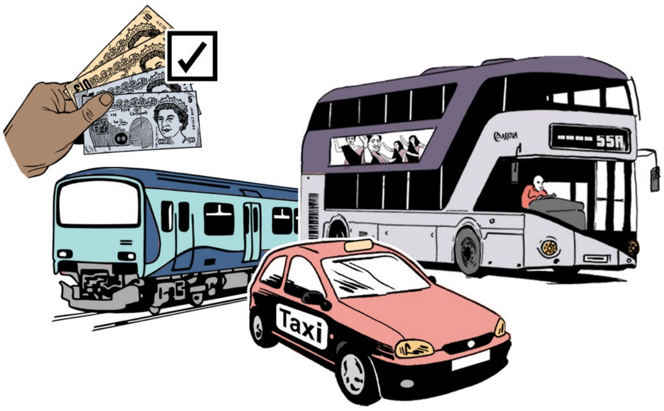


For more information, or if you want to take part, you can contact Dominique at CHANGE by email: **dominiqeb@changepeople.org**

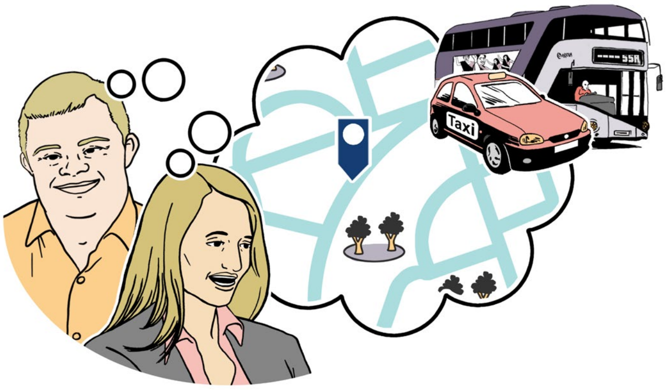
Or call:
0113 244 0606
and ask for Dominique.

Being part of the Advisory Group

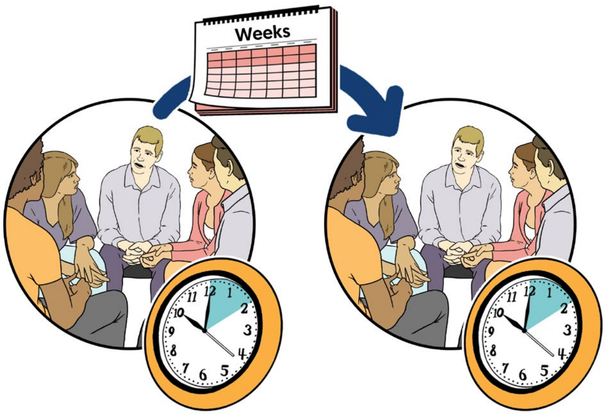
We will ask you to come to meet us in Leeds 8 times.



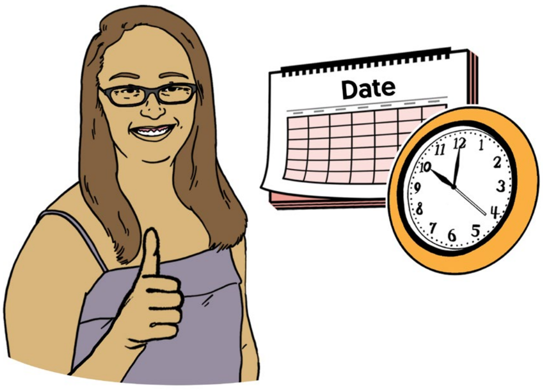
We will pay for your transport to and from Leeds if you need us to.



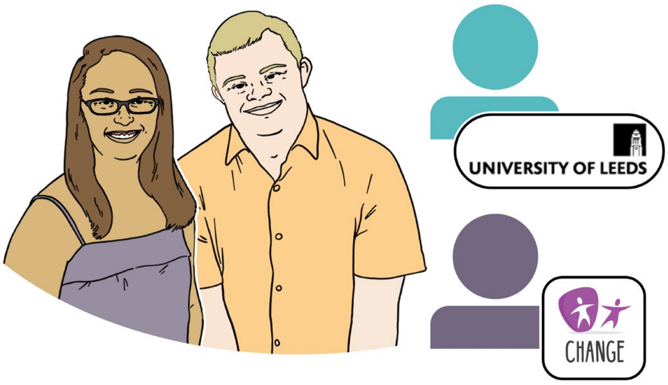
If you need help planning your journey we can help.



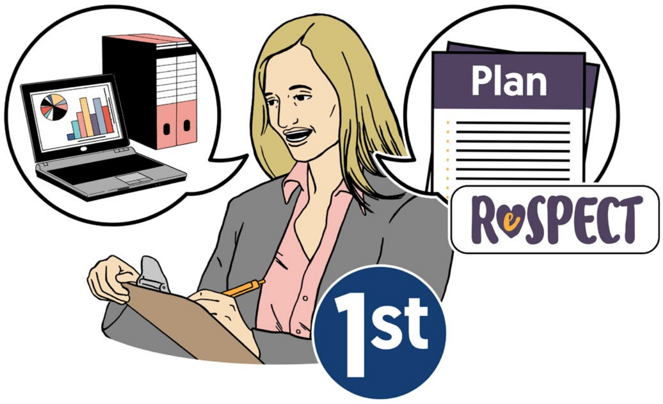
There will be a few weeks between meetings. Each meeting will last 2 hours.



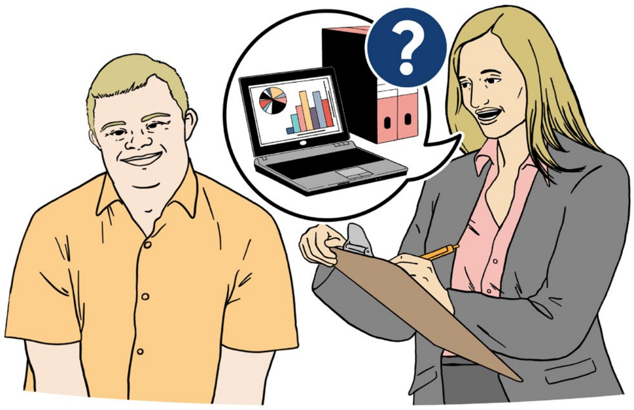
We will try to pick a time and date that you can make.



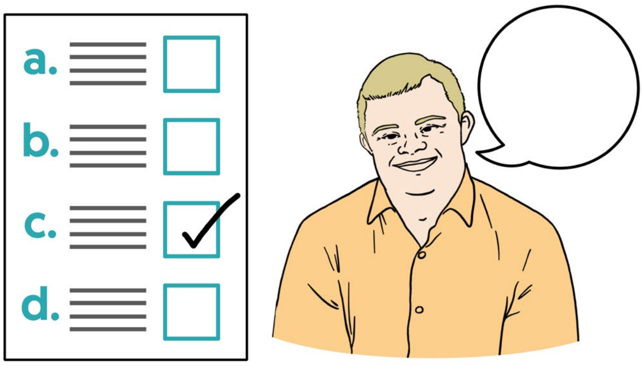
You would meet with people with a learning disability, Amy from the University of Leeds and Dominique who works at CHANGE.



At our first meeting we would talk about what research is and what our research is about.

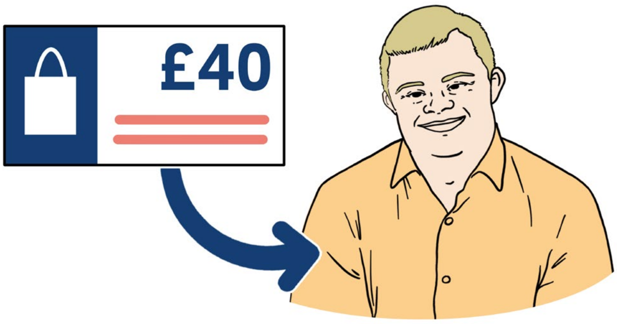


We would ask you how we should do our research.



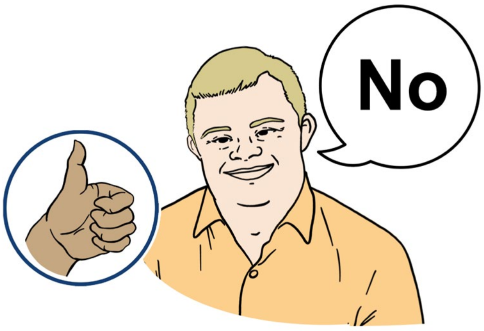
We will give you options to choose from and you can say what you think.

We would like to record the meetings so we can remember what you say and use it for our research.



At the end of each meeting we will give you a shopping voucher for £40 to say thank you for your help.

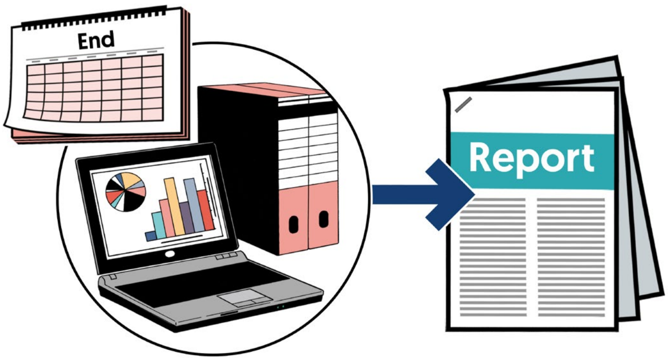
Choosing no



If you do not want to take part that is fine.

No one will mind, and it will not affect your care or treatment.

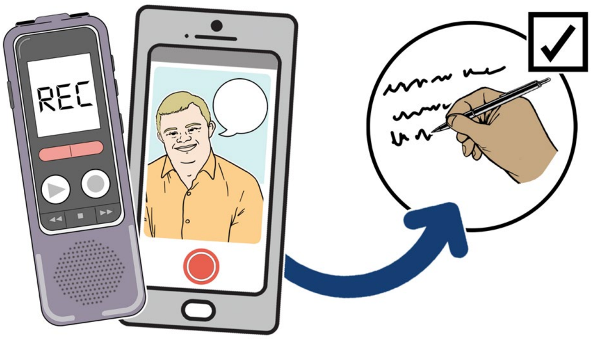
What happens after the research finishes?



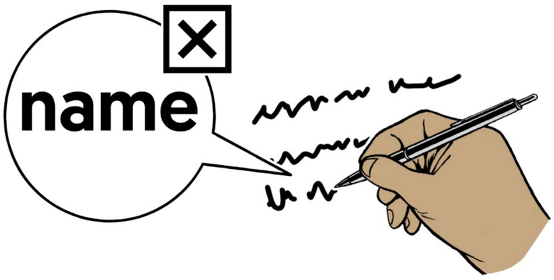
At the end of the research we will write a report to tell people what we found out.

We will write some new rules for doctors, nurses and carers to try out.

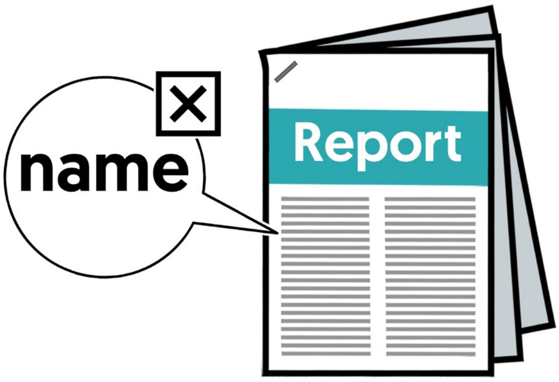
Keeping things private



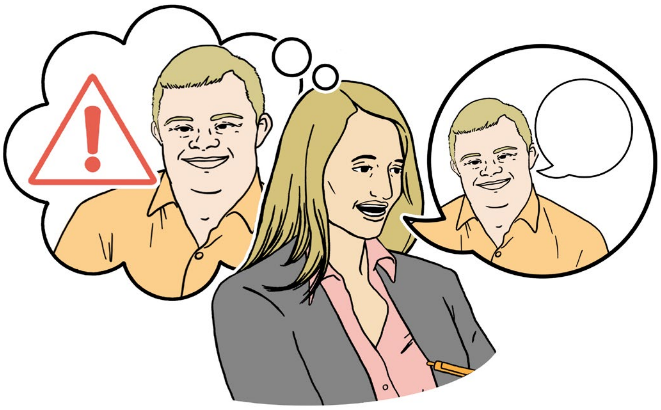
We will record the meetings you go to and use the recording to write down what you say.



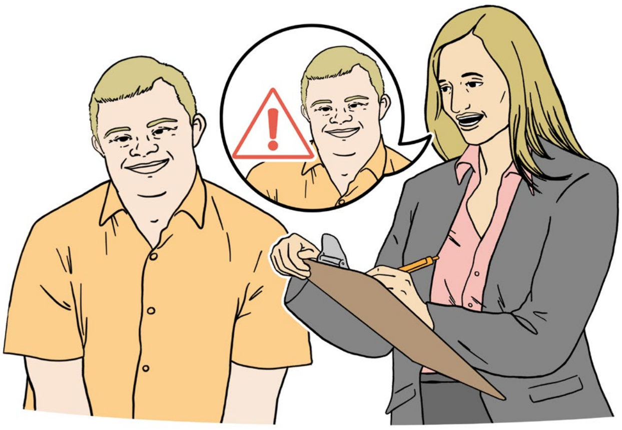
When we write down what you say we will not put your name on it.



If we write what you say in our report we will not put your name next to it.



The only time we might tell someone what you say in the meetings is if we were really worried you might get hurt, hurt someone else or hurt yourself.



If we were worried we would talk to you about it.

The University of Warwick is the **sponsor** for this Study.
This means that they will make sure your information is looked after and used properly.

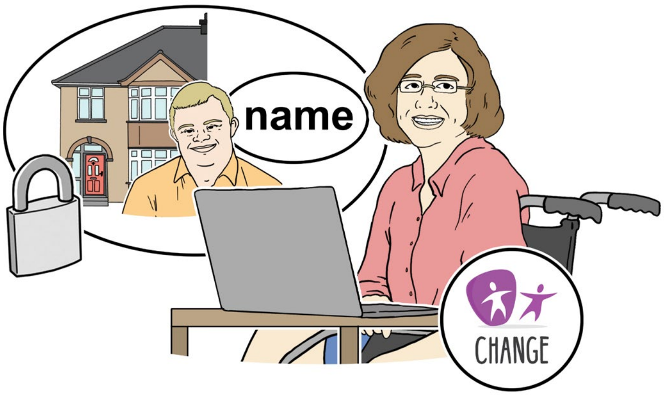
The information we will store about you will be:

- Your name

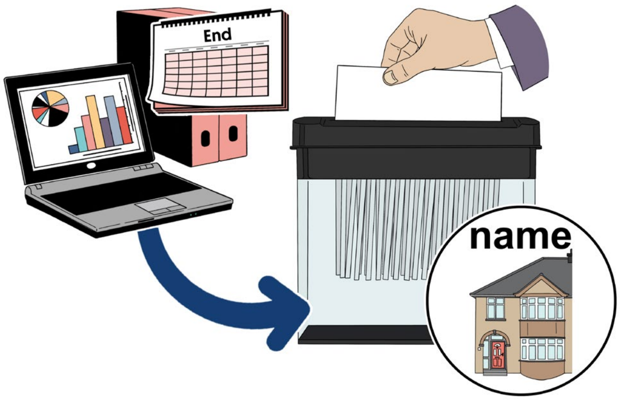
- Your home address

- Your phone number or email address.

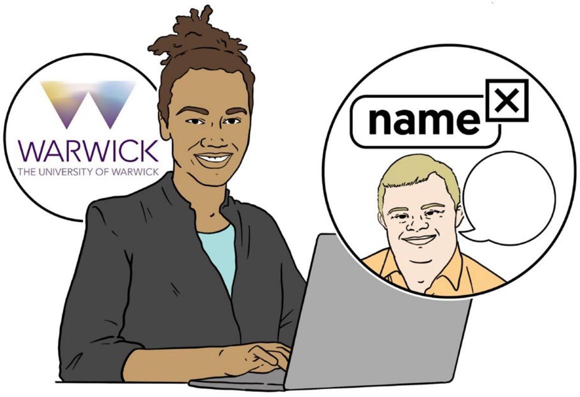
- Your opinions



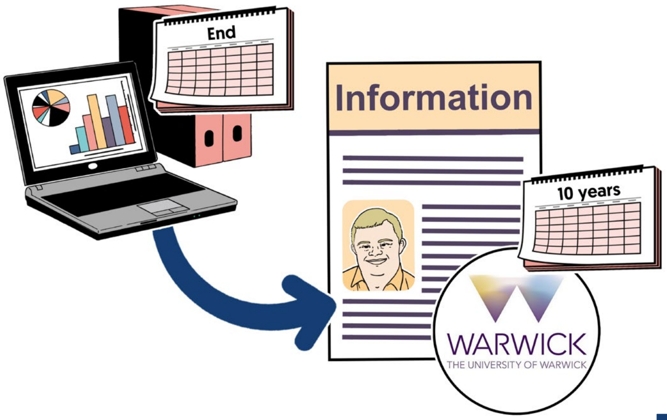
CHANGE will store your name and address so we can get in touch with you about the research. They will not share this information with anyone else.



At the end of the research CHANGE will remove your name and address from their records.



Warwick University will store the information that we write down about what you said. This will not have your name on it.



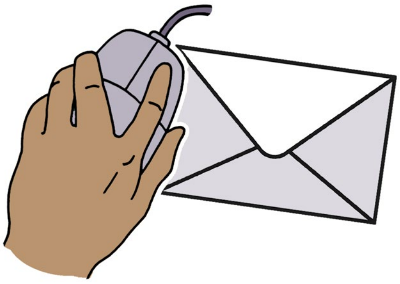
Warwick University will store this information in a safe place for 10 years after the research finishes.

If you want to know more or want to know what information we have about you, you can contact CHANGE’s Data Protection Officer.

Call:

0113 2440606

and ask for Linda Kelly.

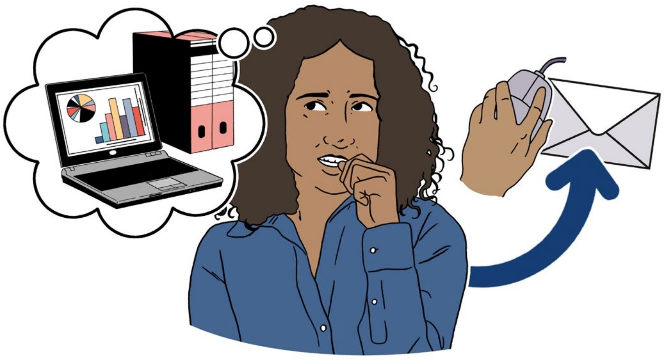


Or email:

Linda.kelly@advonet.org.uk

Or you can contact the University of Warwick Data Protection Officer by email:

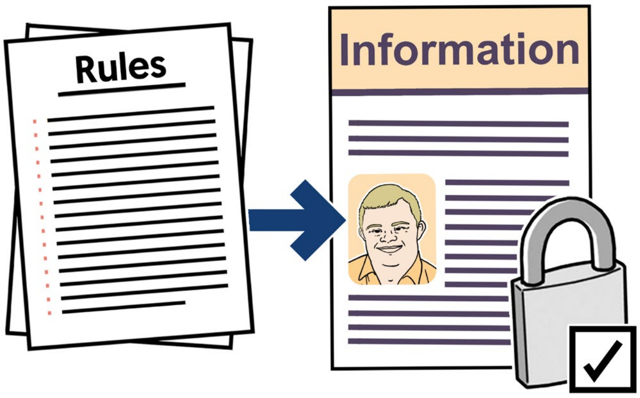
dpo@warwick.ac.uk



If you are worried about how this research is being done you can speak to the Advonet Quality and Performance manager by email:
Rosie.whitmore@advonet.org.uk

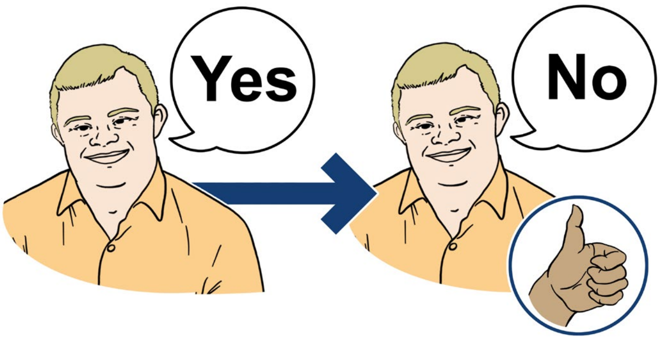
Or call:
0113 244 0606
and ask for Rosie Whitmore.

If they cannot help you, you can speak to the Head of Research from the University of Warwick.
By email:
researchgovernance@warwick.ac.uk



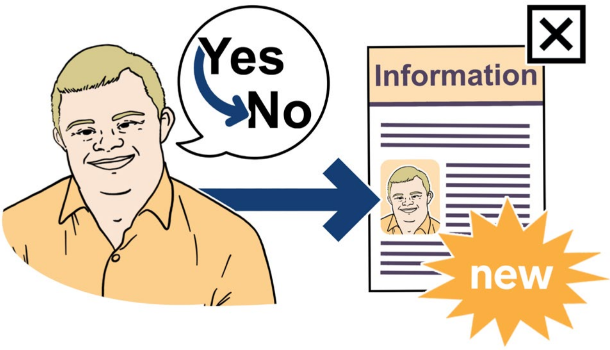
We will follow rules about how we look after your information. The rules are called **GDPR** which stands for **G**eneral **D**ata **P**rotection **R**egulation.

Changing your mind



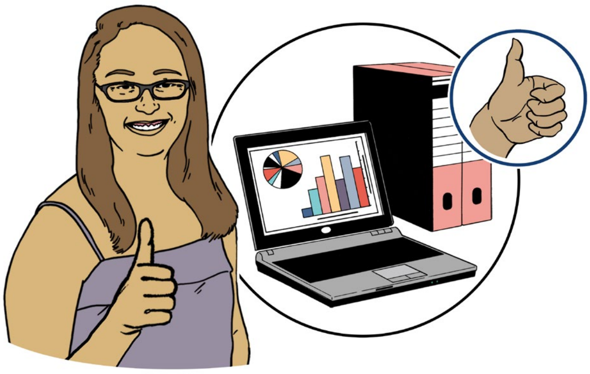
Even if you say yes to taking part you can change your mind at any time.

No one will mind, and it will not affect your care or treatment.

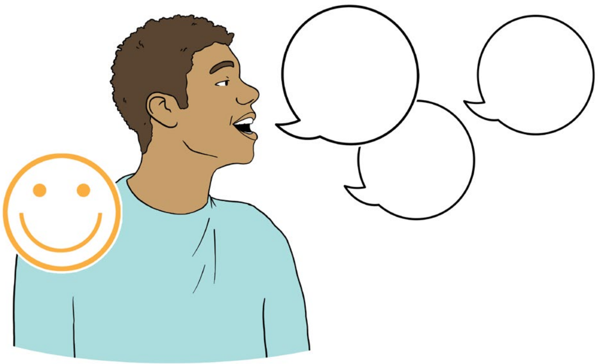


If you no longer want to take part then we would keep the information we have collected so far, but we would not collect anything new.

What might be good about taking part?



Some people like taking part in research.



Some people like talking about things and giving their opinion.

Some people like to know they have made a difference to research.

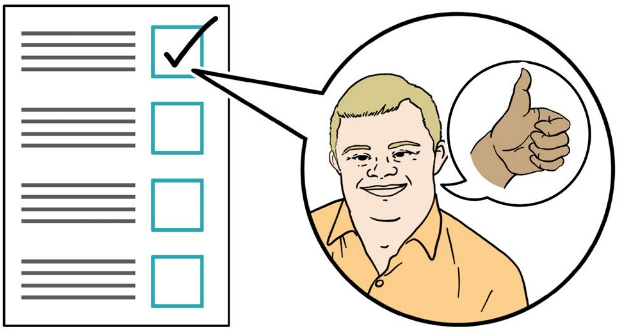
What might be bad about taking part?

Some people find talking about things a bit upsetting. If you are upset let us know.

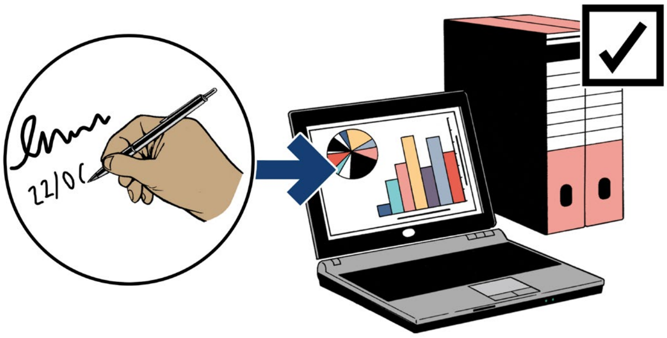
Being in the Advisory Group will take up some of your time so make sure you are ok with this.

☐

Consent form



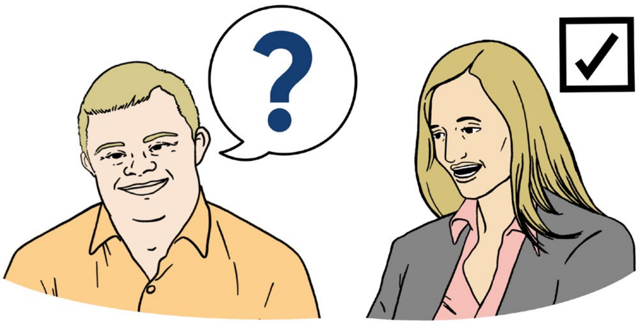
Read through or get help to look through the following points and put a tick next to them if you agree.



You will then write your name or make your mark at the bottom of this form to say that you agree to take part in this research.

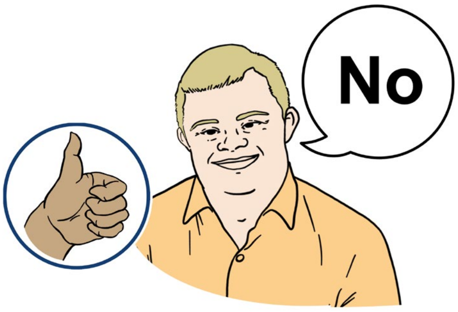
I understand what the participant information book says.

☐



I have had a chance to ask any questions I want about the research.

☐



I understand I can stop taking part at any time

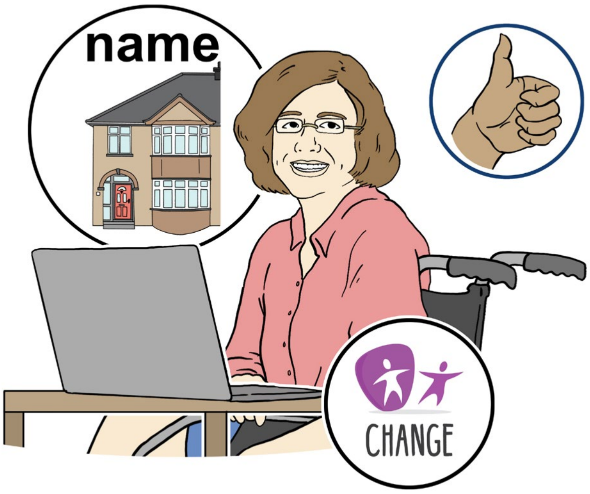
☐

I agree that the meetings can be recorded.

☐

I understand that my name will not be put on anything that is written about the research so no one will know if they are my words.

☐



I agree that CHANGE can keep my contact details so that they can get in touch with me during the research.

☐

I would like to be part of the Advisory Group. ☐

Name of person taking part:

Date they said yes:

Verbal consent obtained by:

Job:

Date:

ReSPECT

WARWICK
MEDICAL SCHOOL

UNIVERSITY OF LEEDS

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CHANGE

RESPECT

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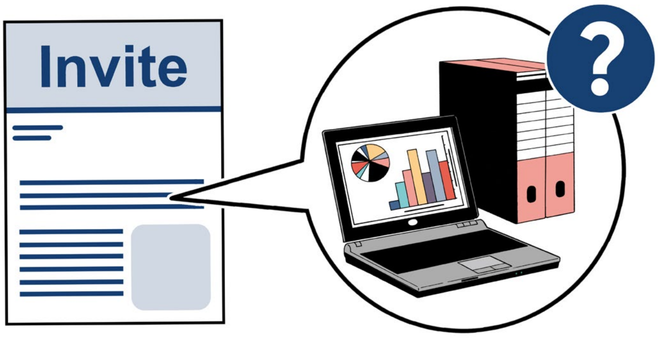
Workshops



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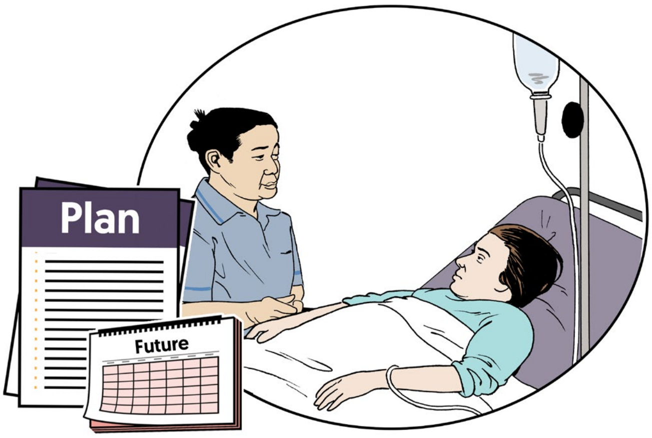

This research is about planning for the future in case you become unwell.

We are looking at a type of planning called the **ReSPECT** process. **ReSPECT** stands for **R**ecommended **S**ummary **P**lan for **E**mergency **C**are and **T**reatment.

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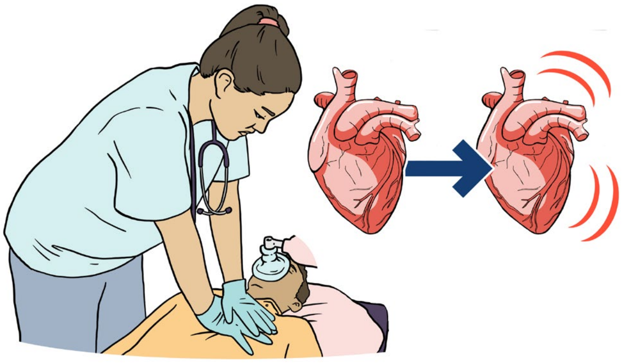

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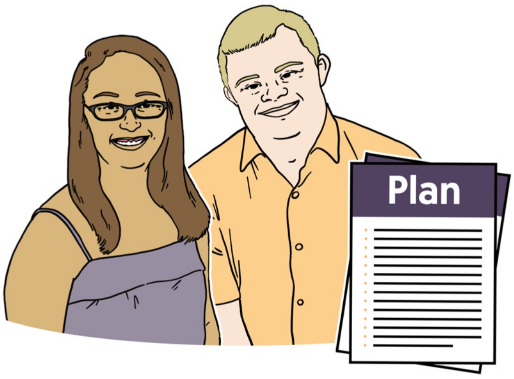
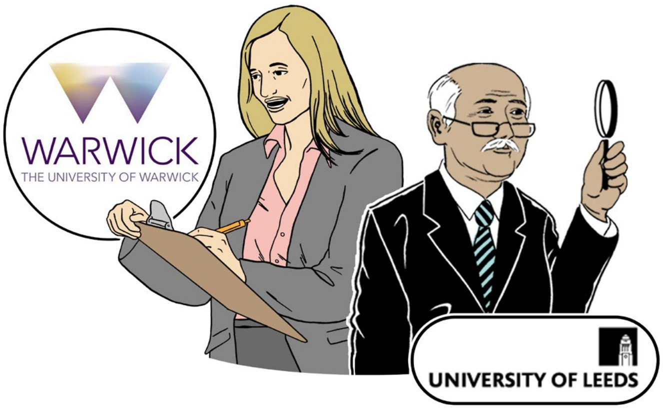


We want ideas about the best way to make these plans for people with a learning disability.

Who is doing this research?



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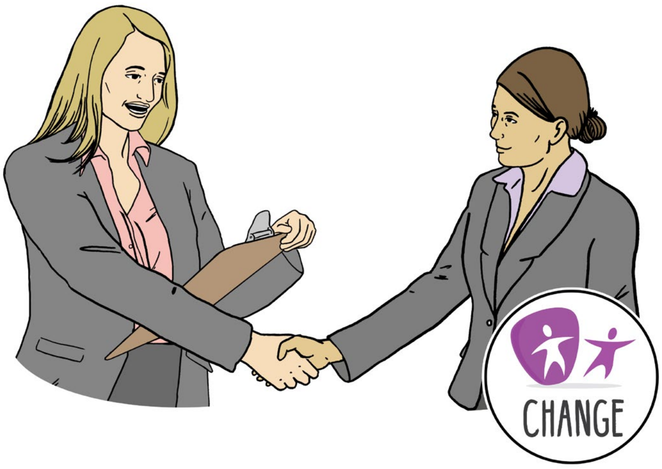

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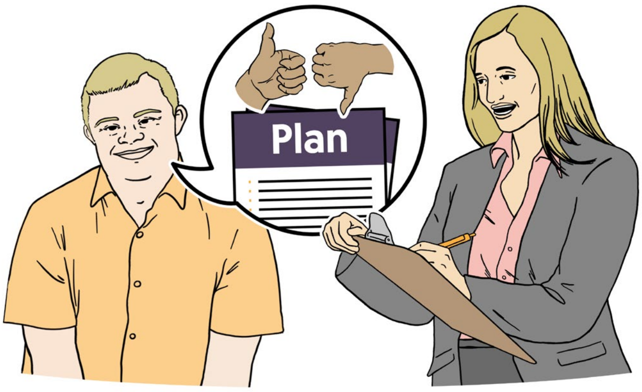
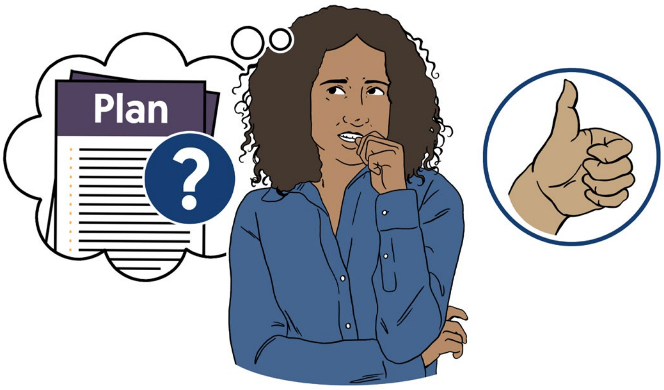
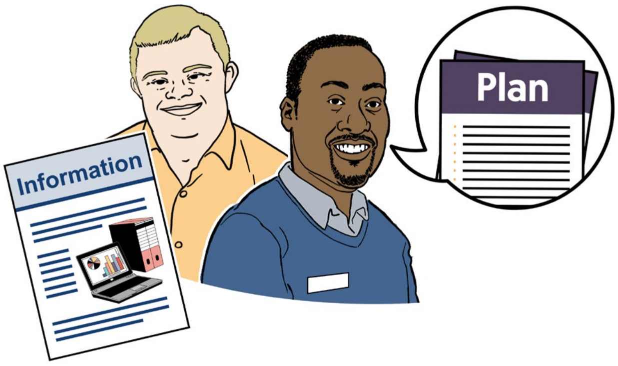


We would like people with a learning disability to tell us what they think about the ReSPECT process.



It is ok if you do not know anything about the ReSPECT process yet.



We have asked people with a learning disability and carers to share this information, so that we can find people to take part.

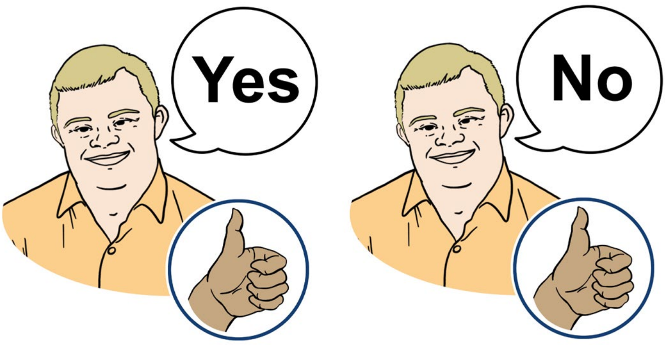
We think it is important for people with learning disabilities to be involved in decisions about their health care planning.

Why are we doing this research?

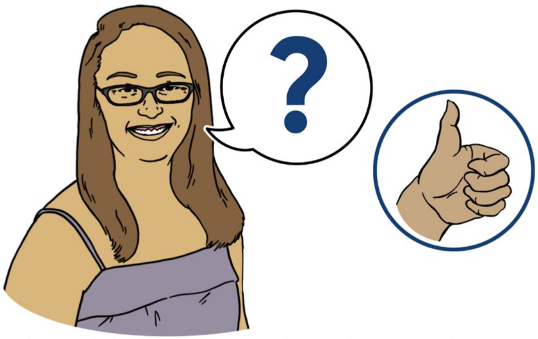
We want to know what people with a learning disability think about planning for their health in the future.

We want to find out if we can make using the ReSPECT process better for people with a learning disability.

Do I have to take part?



You can choose yes or no. It is your choice to take part or not.



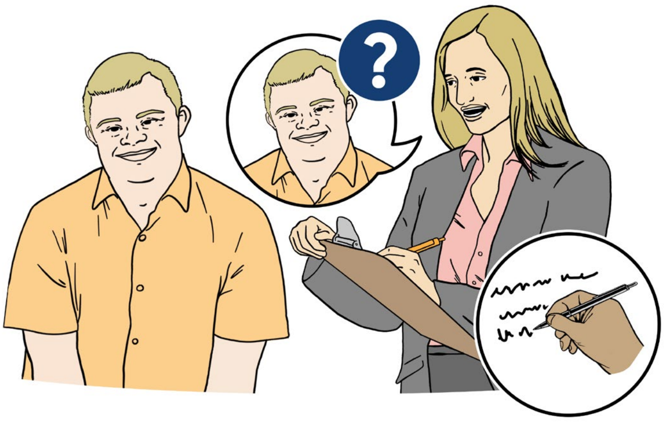
You can ask any questions you want before you choose.

No one will mind what you choose, and it will not affect your care or treatment.

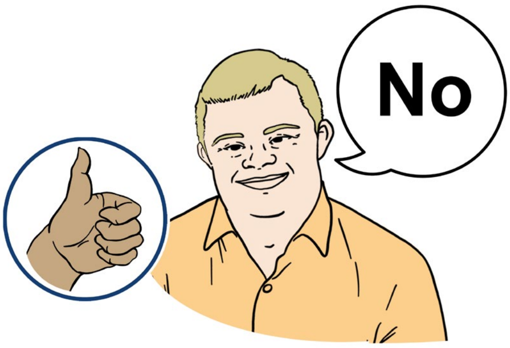
Choosing yes

If you would like to take part telephone us or call us online to talk to you.

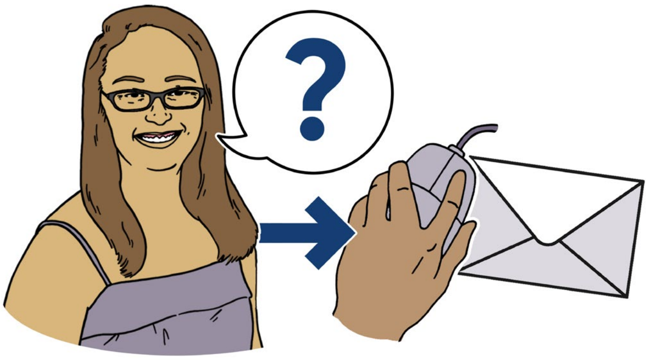
We will answer any questions you have about the research.



We will ask if you want to take part. If you say yes we will write this down and ask you a few questions about yourself.



You do not have to answer these questions if you do not want to. You can still be in the workshops even if you do not answer.

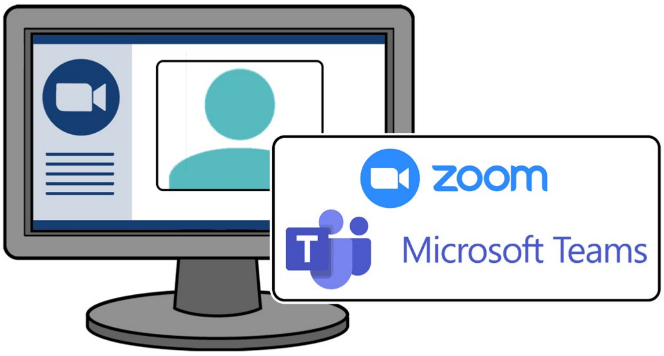


For more information, or if you want to take part, you can contact Dominique at CHANGE by email: **dominiqeb@changepeople.org**

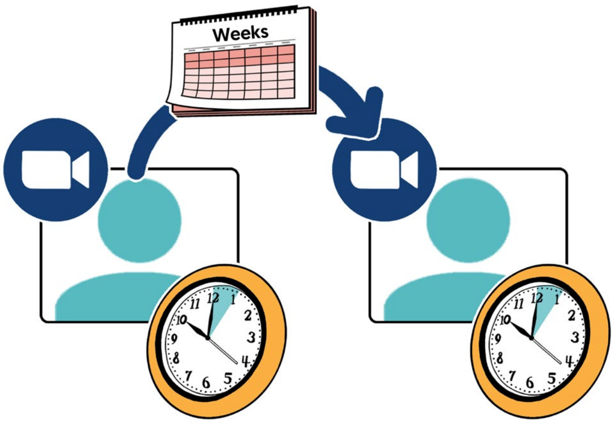
Or call:
0113 244 0606
and ask for Dominique.

Taking part in a workshop

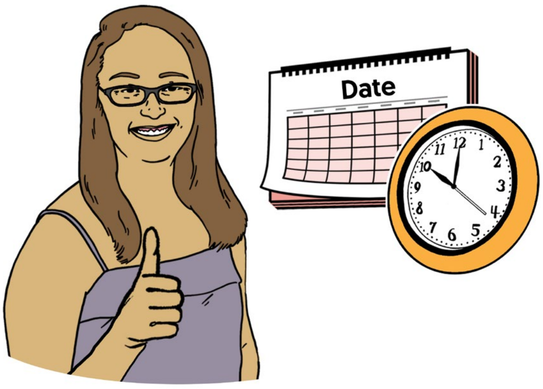
We will ask you to meet us online 5 times, in a group of 8 people.



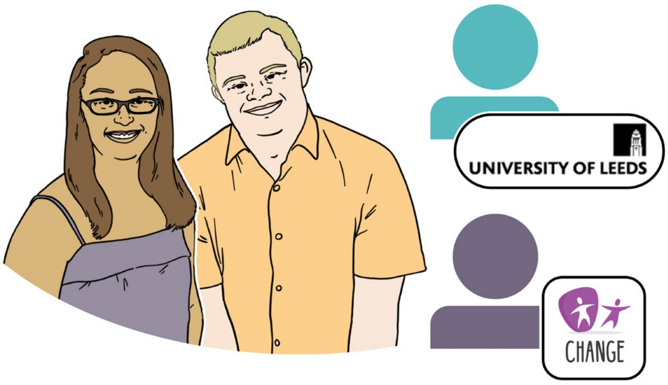
We would meet online using video chat programmes, like Zoom or Microsoft Teams.



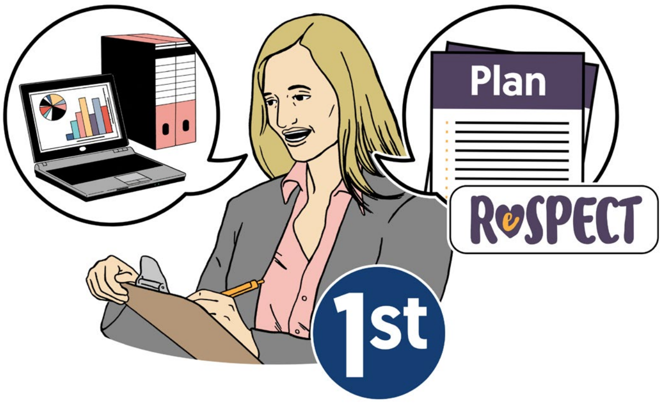
There will be a few weeks between meetings. Each meeting will last about 1 hour.



We will try to pick a time and date that you can make.



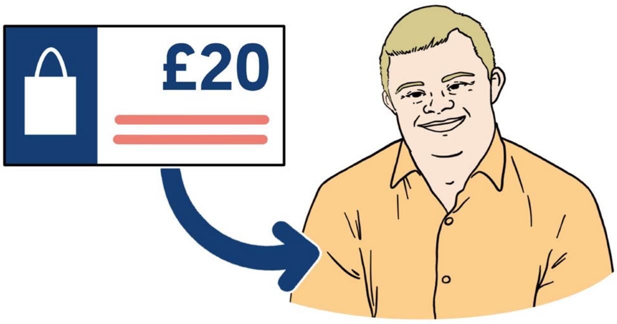
You would meet with people with a learning disability, Amy from the University of Leeds and Dominique who works at CHANGE.



At our first meeting we would talk about what research is and what our research is about.

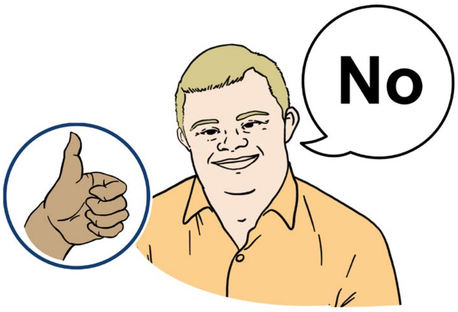
We would explain what the ReSPECT process is and ask you for your opinion. We will try to make it fun.

We would like to record the meetings so we can remember what you say and use it for our research.



At the end of each of the workshops we will give you a shopping voucher for £20 to say thank you for your help.

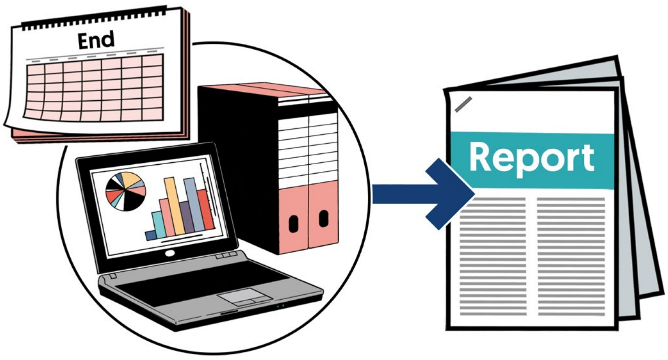
Choosing no



If you do not want to take part that is fine.

No one will mind, and it will not affect your care or treatment.

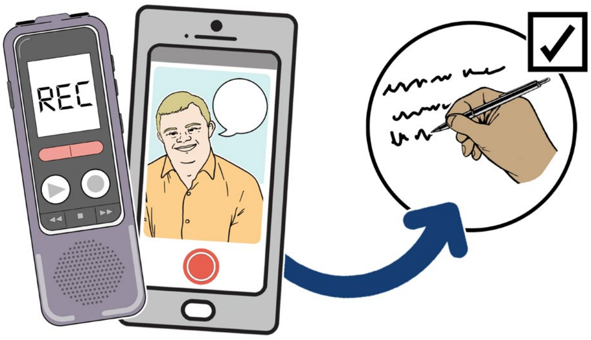
What happens after the research finishes?



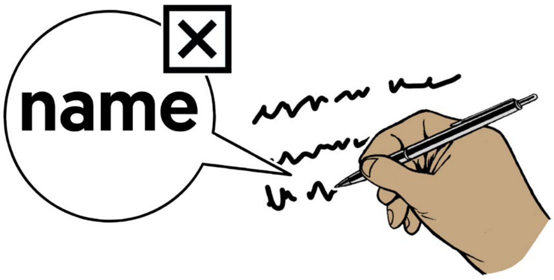
At the end of the research we will write a report to tell people what we found out.

We will write some new rules for doctors, nurses and carers to try out.

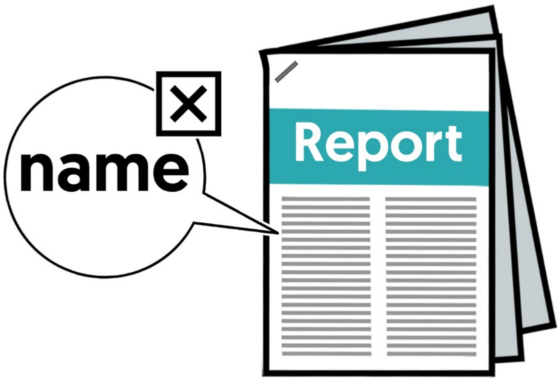
Keeping things private



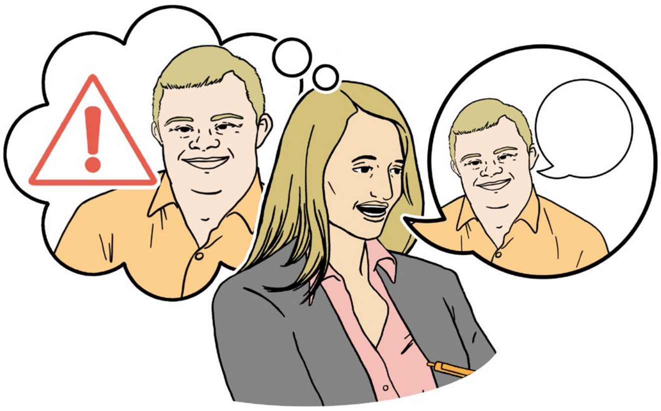
We will record the workshops you go to and use the recording to write down what you say.



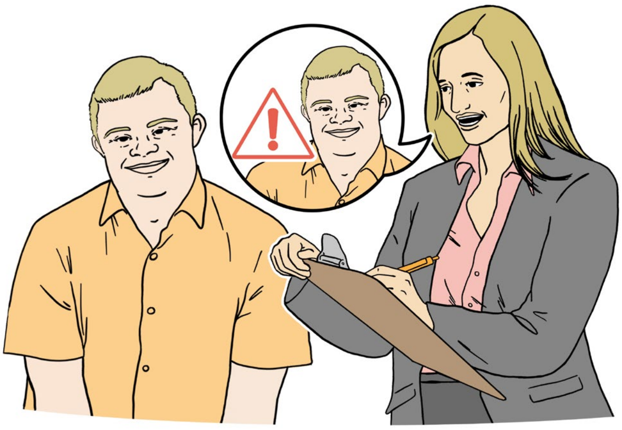
When we write down what you say we will not put your name on it.



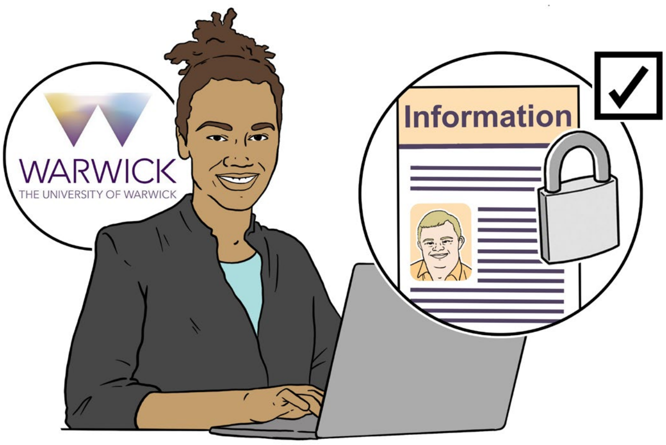
If we write what you say in our report we will not put your name next to it.



The only time we might tell someone what you say in the workshops is if we were really worried you might get hurt, hurt someone else or hurt yourself.



If we were worried we would talk to you about it.



The University of Warwick is the **sponsor** for this Study.
This means that they will make sure your information is looked after and used properly.

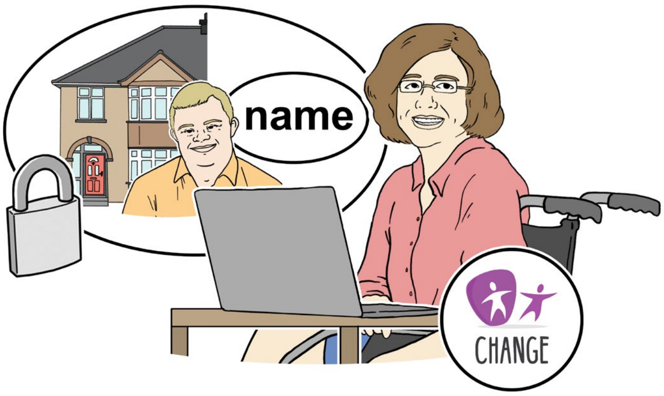
The information we will store about you will be:

- Your name

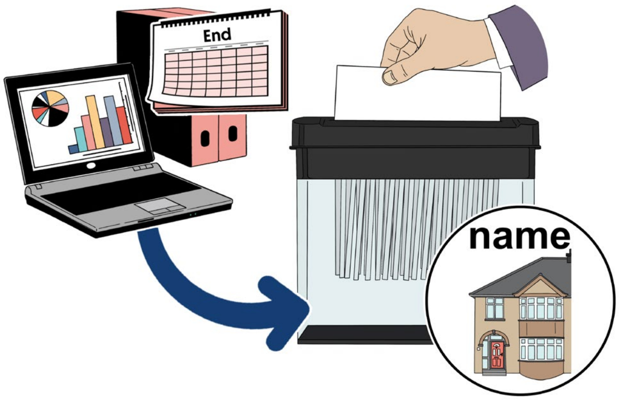
- Your home address

- Your phone number or email address.

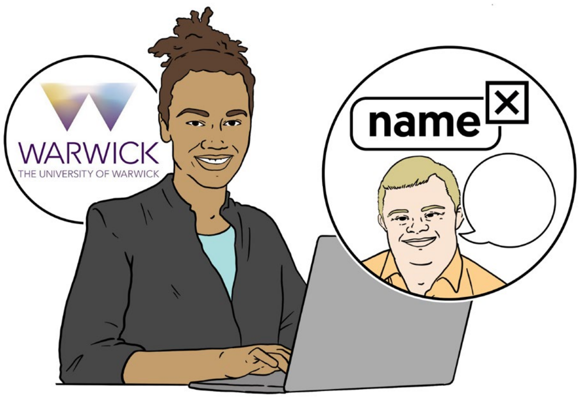
- Your opinions



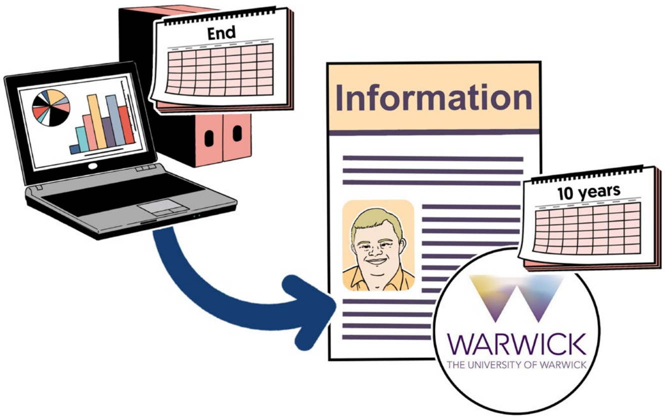
CHANGE will store your name and address so we can get in touch with you about the research. They will not share this information with anyone else.



At the end of the research CHANGE will remove your name and address from their records.



Warwick University will store the information that we write down about what you said. This will not have your name on it.



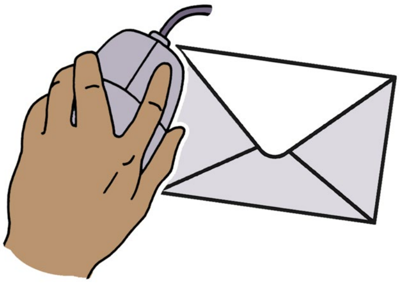
Warwick University will store this information in a safe place for 10 years after the research finishes.

If you want to know more or want to know what information we have about you, you can contact CHANGE’s Data Protection Officer.

Call:

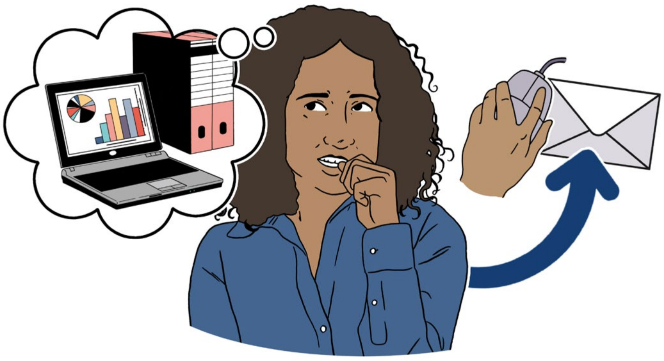
0113 2440606

and ask for Linda Kelly.



Or email:
Linda.kelly@advonet.org.uk

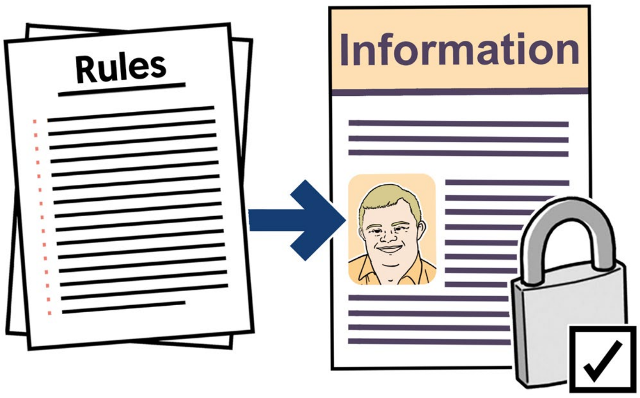
Or you can contact the University of Warwick Data Protection Officer by email:
dpo@warwick.ac.uk



If you are worried about how this research is being done you can speak to the Advonet Quality and Performance manager by email:
Rosie.whitmore@advonet.org.uk

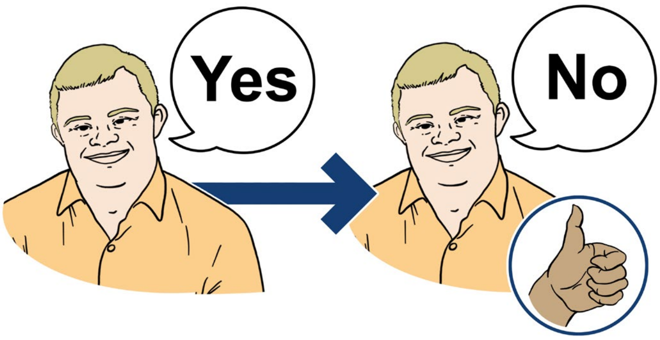
Or call:
0113 244 0606
and ask for Rosie Whitmore.

If they cannot help you, you can speak to the Head of Research from the University of Warwick. By email: **researchgovernance@warwick.ac.uk**



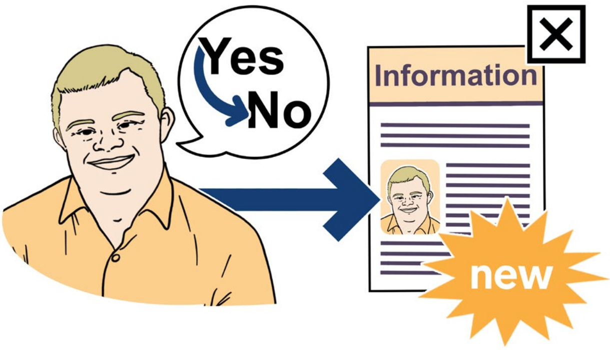
We will follow rules about how we look after your information. The rules are called **GDPR** which stands for **G**eneral **D**ata **P**rotection **R**egulation.

Changing your mind



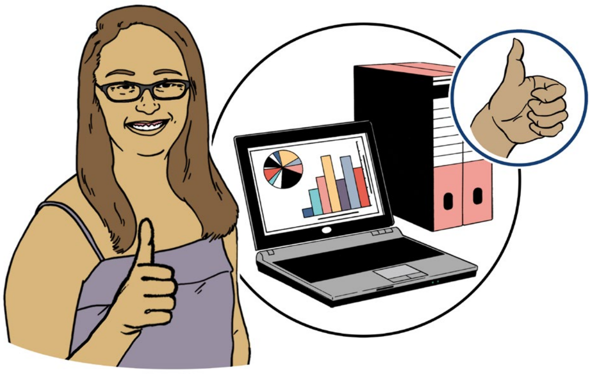
Even if you say yes to taking part you can change your mind at any time.

No one will mind, and it will not affect your care or treatment.

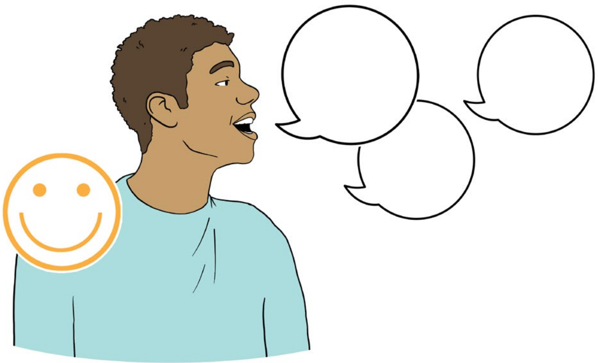


If you no longer want to take part then we would keep the information we have collected so far, but we would not collect anything new.

What might be good about taking part?



Some people like taking part in research.



Some people like talking about things and giving their opinion.

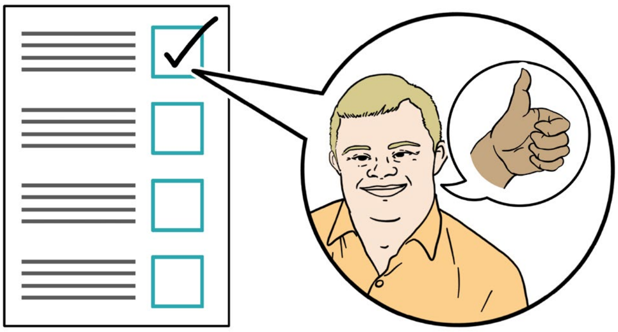
Some people like to know they have made a difference to research.

What might be bad about taking part?

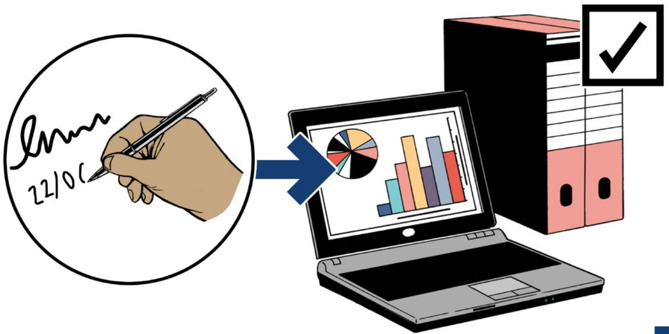
Some people find talking about things a bit upsetting. If you are upset let us know.

Taking part in the workshops will take up some of your time so make sure you are ok with this.

Consent form



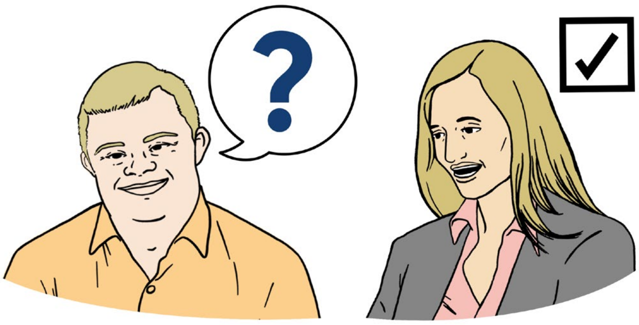
Read through or get help to look through the following points and put a tick next to them if you agree.



You will then write your name or make your mark at the bottom of this form to say that you agree to take part in this research.

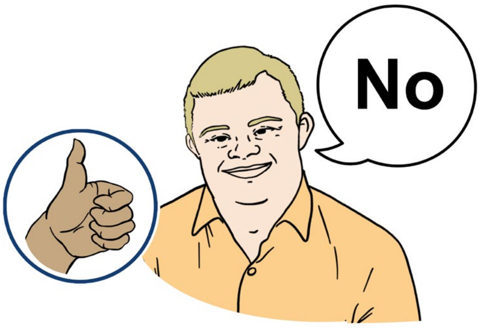
I understand what the participant information book says.

☐



I have had a chance to ask any questions I want about the research.

☐



I understand I can stop taking part at any time.

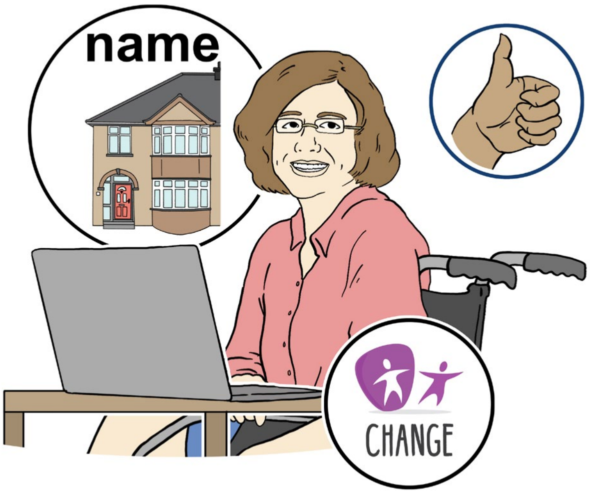
☐

I agree that the meetings can be recorded.

☐

I understand that my name will not be put on anything that is written about the research so no one will know if they are my words.

☐



I agree that CHANGE can keep my contact details so that they can get in touch with me during the research.

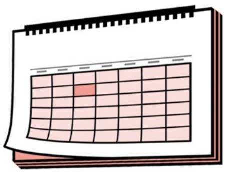
☐

I would like to take part in the workshops.

☐

Name of person taking part:

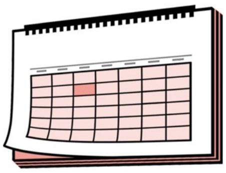
Date they said yes:



Verbal consent obtained by:

Role:

Date:



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