



How we will work together

Our Terms of Reference

Who are We?

What are We Doing?

How Are We Doing It?



How we will work together: Our Terms of Reference

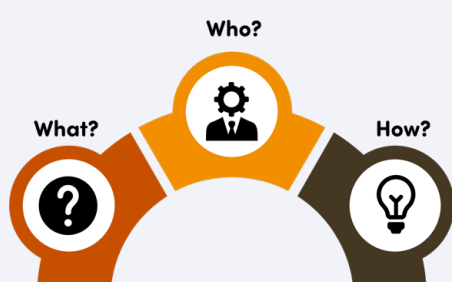


**No Research
About Us
Without Us**

**'No Research About Us, Without Us'
is a health research project.**



This easy-read booklet tells you:



1

Who We Are

2

What We Are Doing

3

How Are Doing It



This is called Our Terms of Reference.

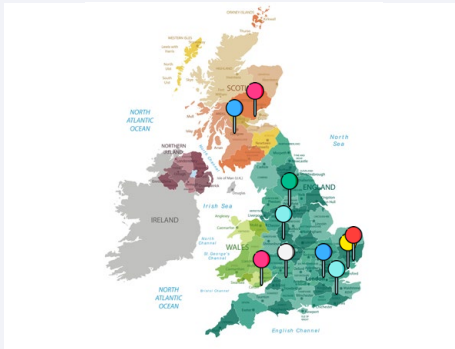


**No Research
About Us
Without Us**

Section 1

Who We Are

Who We Are: Our Terms of Reference



We are a group of people from around the UK.



We are working together as a health research partnership.

We are:



People with a learning disability



Learning disability organisations

Who We Are: Our Terms of Reference





Section 2

What We

Are Doing

What We Are Doing: Our Terms of Reference



In our project we plan to:



Find out how to share power and leadership in a research project.



Look at the barriers to research for people with a learning disability.



Look at ways of overcoming some of the barriers.

What We Are Doing: Our Terms of Reference



**Make recommendations for
future research.**



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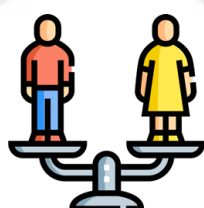
Section 3

How We Are Doing It

How We Are Doing It: Our Terms of Reference



We will work together to support everyone to understand and take part in our research project:



As equal partners



With equal access to meetings



With equal opportunity to take part



With a fair share of the work



With adjustments allowing each one of us to do this

How We Are Doing It: Our Terms of Reference



This means:



Our project will have 2 people leading the project. One is a self-advocate with a learning disability and one is a researcher without a learning disability.



Each one of us will make sure that self-advocates are supported well at every stage of the project.



Basecamp

We will use Basecamp as an online place for holding our documents and having short discussions.

How We Are Doing It: Our Terms of Reference



All members will:



Make a one-page profile to allow us to get to know one another.



Make sure we feedback about how we feel the project is going.



Make sure self-advocates are supported to speak at meetings and events.

How We Are Doing It: Our Terms of Reference



Advise on the format of meetings to make sure they work well for everyone.



Make sure that we are all following our own Terms of Reference.



Some members will lead on:

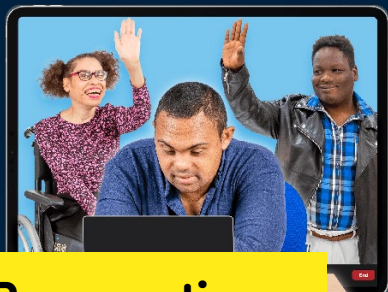


Making shared documents in easy-read - such as agendas and meeting notes.

How We Are Doing It: Our Terms of Reference



Making easy-read summaries of important documents and an accessible video to explain what our project is doing.



Pre-meetings

Supporting self-advocates to prepare for a discussion or face to face activities.



Amy and Gary will meet before the team meeting to plan what happens in our meetings.



Gary will take the plan for the meeting to a pre-meeting of all of the self-advocates where they can comment on the plan and how the project is going.

How We Are Doing It: Our Terms of Reference



Gary's personal assistant will take notes at the pre-meeting and send them to Amy to help her and Gary make the project better and more inclusive.



We will make sure our meetings work for everyone in the group.

We will:



Send out an easy-read agenda 1 week before the meeting



**Introduce ourselves at meetings and talk about how we are feeling at the start
(by rating our mood to pictures of animals)**

How We Are Doing It: Our Terms of Reference



Make easy-read presentations for our meetings.

We will send the presentation to each group member before each meeting.

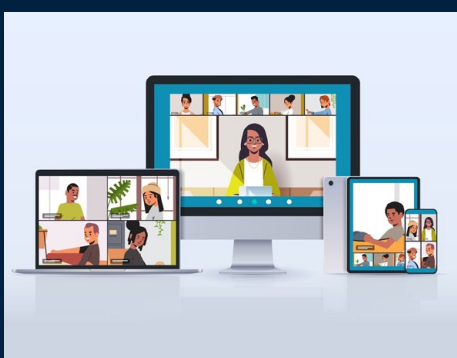
What's happened?



We will start each meeting with a recap of the project and what has happened since we last met.



Put hands up on Zoom to take turns to speak.



Use breakout rooms for discussions so voices are not lost in the big meeting.

How We Are Doing It: Our Terms of Reference



Use Mentimeter for voting.



We will not use jargon or acronyms.



We will take a 10 minute break in the middle of 2 hour meetings.



Not set times for questions. Some people may have something they want to say quickly, before they forget. This is OK!

How We Are Doing It: Our Terms of Reference



Make a record of actions and decisions rather than long minutes.



We will check if we are doing what we said we would do by:



1. Ask team members evaluation questions to check how inclusive the project is.

People can record of what was important to them – by video or voice recording.



Workshop

2. Half way through the project we will have a face to face workshop. We will use arts-based activities to show how we feel about the project.

How We Are Doing It: Our Terms of Reference



3. At their meetings Amy and Gary will look at the evaluation answers and what we made in the workshop to see what needs to change.



4. They will challenge anyone who is not being inclusive.



5. They will change the Terms of Reference and way the project works if they need to.

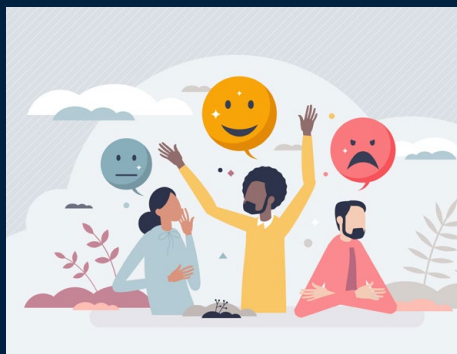


6. Every 6 months the team will look at the Terms of Reference to check we are doing what we said.

How We Are Doing It: Our Terms of Reference



7. We will ask an Advisory Group to look at our Terms of Reference.



We will ask them to tell us if we are doing what we said we would and if we are being inclusive.



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This document was created by the 'No Research About Us, Without Us' project team to support our working. They are shared to support other teams to work together with people with a learning disability as equal team members.

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