



**Inclusive  
Research  
Network**

## **Support for Making Decisions - Handbook**

### **Part One: Before the interview**

This handbook was prepared by several members of the Inclusive Research Network.

The ethics forms were developed by Christina Burke, Brian Donohoe, Elaine Leonard and Helen O'Regan, with the support of Nicola Maxwell, Mary Barrett and Jackie Moran. This group met from August 2022 to May 2023 to develop these forms.

The interview questions were developed from November 2022 to May 2023, with input from everyone who attended monthly meetings and with the support of Eburne Garcia and Rob Hopkins.

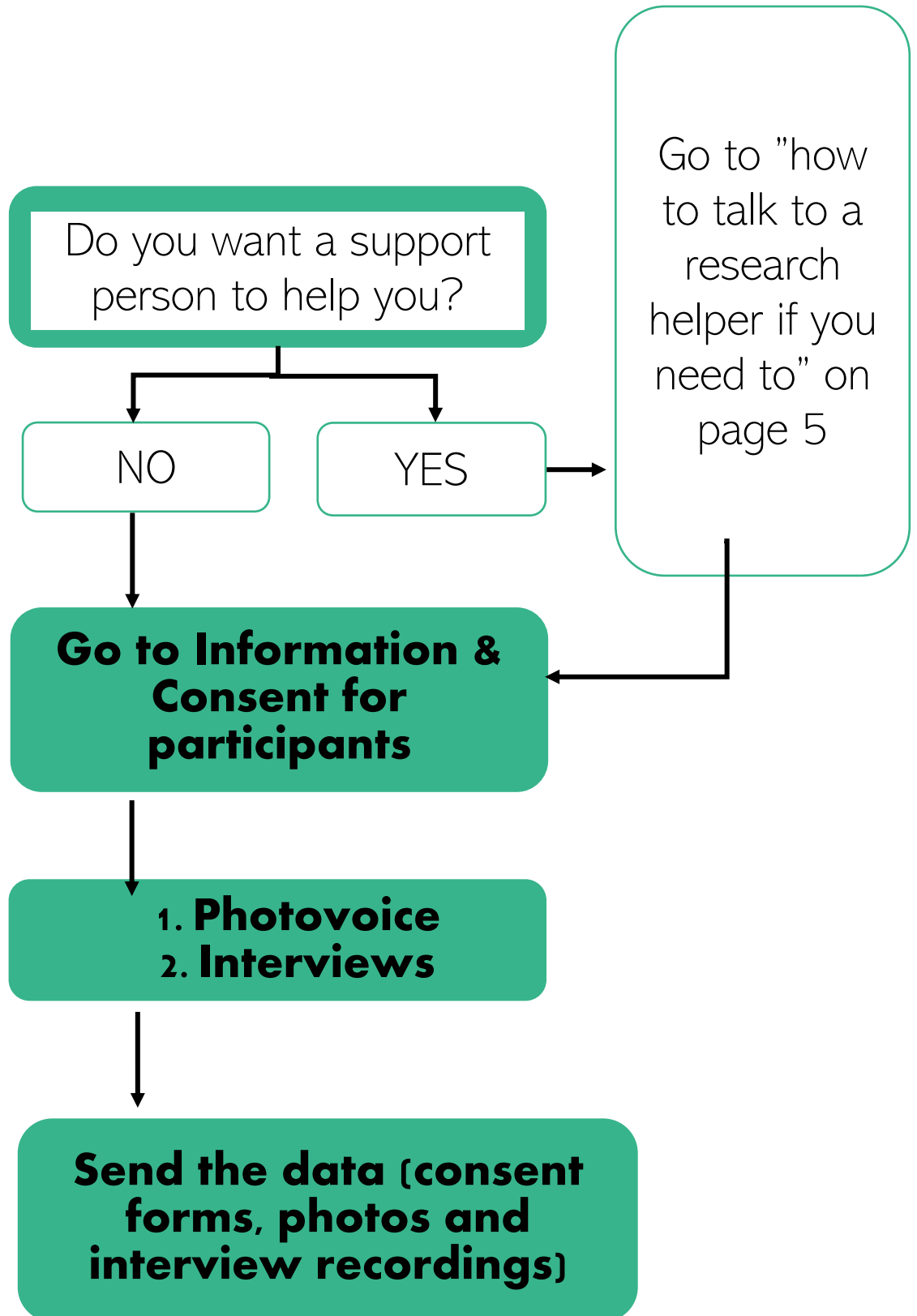
The handbook was put together by Maialen Beltran (TCD) and Ann Swift (TCD), with input from Brian Donohoe, Elaine Leonard, Kathleen McMeel and Helen O'Regan and with the support of Eburne Garcia.

# These are the steps to do the research

## Part One: Before the interview

	STEPS	PAGES
	1. How to talk to a research helper if you need to?	5 to 8
	2. How to run an information session?	9 to 11
	3. How to prepare for the interview?	12 to 13

# How to use this handbook?



## Who does the interviews?



IRN Researcher



**Supported by:**



IRN Research  
Helper  
(Optional)

## Who takes part in the interview?



Person with lived  
experience



**Supported by:**



Interview Assistant  
(Optional)



Supporter



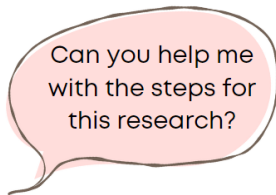
## 1. How to talk to a research helper if you need to?



- Give the information sheet to the IRN research helper (see page 31)



- Ask the IRN research helper to read about their role (page 6)



- Ask your research helper to:

- Help me go through the next steps



- Practice the next steps with me

This information is about the role of an IRN research helper – this person is there to help you (the IRN Researcher)- if you need it.

Thanks for agreeing to be my Research Helper when I do the IRN project Support for Making Decisions.

When you support me, you need to remember that I am the one doing the research.

Do your best not to jump in and take over.

During the research, please follow my lead and support me if I ask for help or if I need to get things back on track. If I forget a step remind me of what I skipped.

Don't speak for me and please respect my expertise.

In the next page, you can see all the steps I will follow with your support.

### **Step 1: Be clear about your role with me / Make your role in the interview clear:**

- Check that I understand that **you are there to support me** but not to tell participants about photovoice and not to do the interview yourself.
- **Practice the steps involved in the research with me** before we meet with participants.

### **Step 2: Help me give information about the study:**

- Help me organise an information session (pages 9-11).
- Put up flyer with information (page 11).
- Give people information forms (see page 31).
- Talk to people with intellectual disabilities and supporters about the study.
- Answer any questions they might have.

### **Step 3: Give the participants photovoice instructions:**

- Make sure I give the **information forms** to participants with lived experience (see page 31;) and (if they have one) to their interview assistant (see page 31) before they start with photovoice.
- Help me check **that participants understand what the study is about**. If they don't, **help me explain the study** again.
- Make sure **participants have a chance to ask questions**.
- Help me give out and collect signed **consent forms** (see page 31).
- Help me give them **instructions for doing photovoice** (pages 50-52).

#### Step 4: Do the interviews:

- Before the interview, **help me check and save the photos** participants bring to the interview (about good decisions and about decisions that didn't work). See pages 27-30 for instructions on saving the photos.
- During the interview, **write down the key ideas** discussed in a notebook.
- During the interview, remind me to **listen and to ask for more information**.
- Look out for **signs that the participant is uncomfortable** or is getting upset during the interview.
- We will **take some time to talk about the interview** when it is done – key things the participants said, what went well, anything that happened that wasn't planned.

#### Step 5: Save research materials:

- Help me gather all the data to: 1) save it to SharePoint; 2) send back to Edurne Garcia or Nicola Maxwell (see page 27-30 for sending data).
- Once the data has been received safely by Edurne or Nicola, help me delete it (see pages 27-30 for instructions on deleting information).

As well as supporting me when I ask you, you will help me with all research phases (2 – 8).





## 2. How to run an information session

In an information session, IRN researchers tell people with an interest in the study about:

- what they are asked to do if they take part
- what their rights are if they take part.



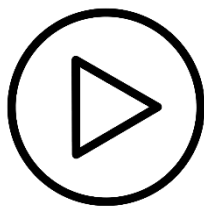
- Book a room in a service organisation/community centre for about 1 hour.
- If it is easier, you can also run the session online, via zoom or Microsoft Teams.



- Put up flyer with details about the information session (date, time, place) (see page 11)



- Have information and consent forms ready to give out.



- Play the video about the study.
  - You can play it all and then ask if people have questions.
  - You can also play it and stop after each key message to see if people have questions.





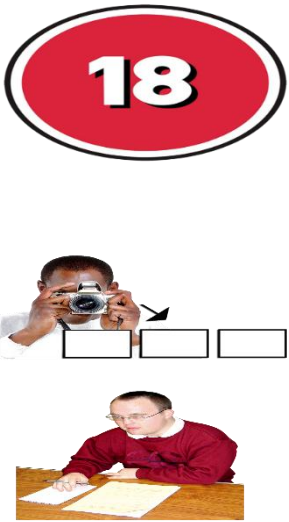


- Ask people to take a week to think about taking part in the study.

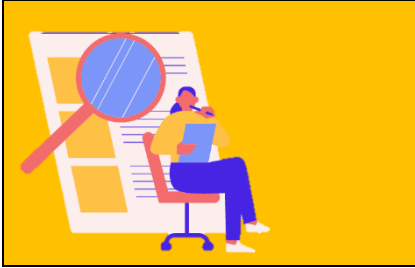


- After one week, and if they are happy to take part, they can contact you. Give your contact information to people in the information session:
  - Your name
  - Your phone number
  - Your email address
  - \*you can also give your supporter's contact information.

# Support for Making Decisions: People with Lived Experience of Intellectual Disability (ID)

## Research Flyer

	<p>The Inclusive Research Network is a group of people with disabilities and supporters.</p>
	<ul style="list-style-type: none"> <li>• We are doing a research project called Support for Making Decisions.</li> <li>• We want to find out what support people with lived experience of intellectual disability have and need to make decisions.</li> </ul>
	<p>To take part, you must be:</p> <ul style="list-style-type: none"> <li>• Over 18 years old</li> <li>• A person with an intellectual disability</li> <li>• A person supporting someone with intellectual disability to make decisions</li> </ul> <p>If you take part, you will be asked to:</p> <ul style="list-style-type: none"> <li>• take photos about decisions you have made/supported to make</li> <li>• take part in an interview to talk about the photos and the support to make the decisions.</li> </ul>
	<p>If you want to learn more about this study please contact:</p>
	<p>We are running an information session on:          Date: _____          Time: _____          Place: _____          You are welcome to attend!</p>



### 3. How to prepare for the interview?



- Ask people for a good time / day they can come for the interview when you give them the information form.



- Organize the interview at least one week after you have given the participants the instructions.



- Tell the day, time and place to the participant.
- Ask people to bring the consent form signed to the interview. Participants can also audio record their consent to take part at the start of the interview.



- Book a room to do the interview.

## Make sure that the room:



- Is comfortable (not too hot, not too cold)



- Is bright



- Is easy to get to



- Is close to the bathrooms that everyone can use



- Has enough space for up to 4 people