



**Inclusive  
Research  
Network**

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

### **Part Two: During the interview and photovoice**

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 Edurne Garcia and Rob Hopkins.

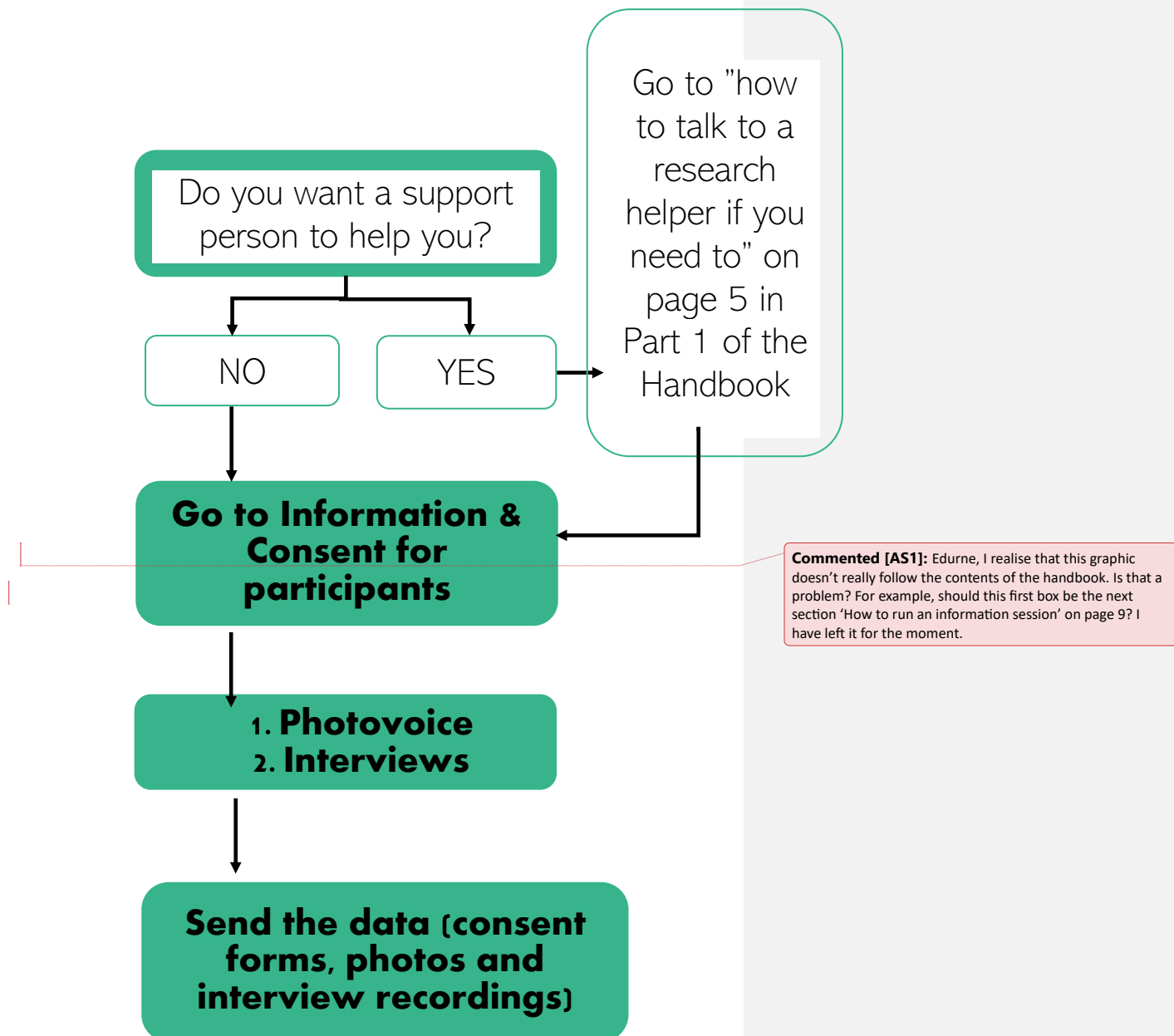
The handbook was put together by Maialen Beltran (TCD) and Ann Swift (TCD), with input from Brian Donohoe, Elaine Leonard, Kathleen McMeel and Helen O'Regan and with the support of Edurne Garcia.

# These are the steps to do the research

## Part Two: During the interview

	STEPS	PAGES
	1. How to do photovoice?	5 to 6
	2. How to do the interview? <ul style="list-style-type: none"><li>- Before people arrive</li><li>- Greet the participant</li><li>- Give the information form</li><li>- Get their consent</li><li>- Some tips to run the interview</li></ul>	7 to 16
	3. Forms.	18 to 66
	4. Interviews	67 to 91

## 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 do photovoice?

Give the **Instructions for Photovoice sheet (see page 38)** to the participant

Commented [AS2]: I have given this its current name.



- Photovoice takes place before the interview.



- Ask the participants to take at least 2 photographs and no more than 5 photographs about important decisions in their life.



- Give participants one week or 10 days to take the photographs and set up an interview.



- Ask them to follow the do's and don'ts of taking photographs (page 38). Check that photographs are Ok for the project.



- Participants can bring their photographs on their phone, tablet, camera or printed after 1 week / 10 days.



- Save the photographs in a computer or in a sealed envelope (to be sent to Edurne/Nicola, see part 3 of the handbook).



- Use the photographs for the interview.



## 2. How to do the interview?

### Before people arrive



- Arrive about 30 minutes before the interview starts

### Check that you have



- Pens and paper



- Audio recording device and batteries (You can borrow one if you don't have one, talk to Edurne or Nicola) or a work laptop with battery or charging cable.



- Information and consent information forms (see page 18)

### What to do next



- When you have all ready, you must wait for the participant and their interview assistant (if they have one) to come.

- When the participant comes, greet him or her.

**Here are some tips on the different steps of the interview:**

- Greet the participant when they arrive (pages 9 and 10).
- Give the Information Form (page 11).
- Get consent (pages 12 and 13).
- Carry out the interview (pages 14 to 16).
- What to do before the participant leaves (page 16 and 17).

**Commented [A53]:** Word 'out' added



## Greet the participant



**Meet the participant at the door**, chat to her or him and make them feel comfortable

**You could say...**

Thanks for coming,  
how are you today?

**In your own words...**



Ask the participants to **sit down**.

**You could say...**

Please, take a  
seat.



**Introduce** yourself and your IRN Research Helper (if you have one). Ask the participants to introduce themselves and their Interview Assistant (if they have one).

**You could say...**

Hi, my name is \_\_\_\_\_.  
This is my supporter \_\_\_\_\_.  
Can you tell me your name and the name of your supporter?

**In your own words...**



Read the information form

**You could say...**

We are here today to talk about decision making.

## Give the Information Form



**Read the information form out loud** (page) for the participant. Ask the participant if they have any questions.

### You could say...

Please ask any questions you have about this

### In your own words...



Check if everyone understands or ask my IRN Research Helper to do it.

### You could say...

Can you tell me what the study is about and what will you do if you take part?

### In your own words...



- Once you read the information leaflet to the person with lived experience (page 27) you need to check that he or she understands the study\*

\* You already gave the information leaflet to them when you met them.

**Commented [AS4]:** I have changed this word to leaflet, as that is how the document is listed. Same in a couple of other places.

## Get their consent



Read the consent forms and ask if they want to take part.

### You could say...

If you are happy taking part in the interview, please sign the consent form (page).

**In your own words...**



Ask if the participant is OK being recorded.  
Remind him or her that their participation is voluntary and they can stop taking part in the interview if they want to.

### You could say...

We want to record this so we don't forget what you say. Is this OK?

**In your own words...**

**The participant should know the following things before signing the consent form:**

- What the study is about.
- The parts of the study: photovoice and interview.
- That their participation is voluntary.
- That it is Ok to stop taking part.



If they understand all of it and agree to take part in the study, they can sign the consent form (or say that they agree to take part and that is audio-recorded).

**Remember!**

1. Have mobile phones switched off.
2. There are no right or wrong answers.
3. It is OK if the person does not want to answer a question.
4. Relax and smile.

## Some tips to run the interview



Ask the questions (the interview is at the end of this handbook, on pages 70-77 and 82-88)



If I have a supporter he or she will write down ideas that you talk about in a notebook.



Give the interview participant time to talk about each question.

### You could say...

Tell me more about...

**In your own words...**



Listen carefully to what the person you interview is saying.



Show the person you are listening. For example, nod your head and smile.



When you finish asking all the questions on the form, ask the participants if they would like to say something else.

### **You could say...**

Is there anything else you would like to say?

**In your own words...**

### **Tips for active listening and probing:**

- Listen to what the person is saying.
- Explore what they are saying.
- Ask further questions.
- Show interest.
- Give feedback to the interviewees.
- It is OK to ask if we don't understand something.
- Have your questions ready.
- The interviewee can ask you about your life.
- Share things about yourself (have something ready), so that it feels more equal, and the interviewee feels better.
- Ask 'is there anything you'd want to know about me?'
- As the interviewer, repeat back what you've been told (it shows interest).

- Encourage people to speak.
- Make eye contact.
- Think about the time of the day the interview is taking place.

## Before people leave



Tell the participants the next steps.

- We are going to send these recordings to Nicola Maxwell.
- You will get a copy of the transcript after the interview. We can support you to check the transcript.
- The findings of the study will be published as a report.
- We'll be happy to come and present the results of the study when we have the final report.



Make sure the room is tidy when you finish. Bring everything with you.





Ask the participants how they are feeling after the interview.

### **You could say...**

How are you feeling now?

**In your own words...**



Thank them for coming to the interview.





### **You could say...**

Thanks for coming today and telling me what you think.



## 7- Forms.

You will find the forms you will need for the study in the following pages:

IRN Research Helper (Optional)		<ul style="list-style-type: none"><li>• Participant Information Leaflet 19-25</li></ul>
Person with Lived Experience		<ul style="list-style-type: none"><li>• Participant Information Leaflet 26-32</li><li>• Consent Form 33-37</li><li>• Instructions for Photovoice 38-40</li></ul>
Interview Assistant (Optional)		<ul style="list-style-type: none"><li>• Participant Information Leaflet 41-47</li><li>• Consent Form 48-53</li></ul>
Supporter		<ul style="list-style-type: none"><li>• Participant Information Leaflet 54-60</li><li>• Consent Form 61-66</li></ul>

## FORMS FOR THE IRN RESEARCH HELPER






### 1. Participant Information Leaflet











## Participant Information Leaflet for the IRN Research Helper: “Support for Making Decisions” Study



Please note that not all the IRN Researchers might  
require an IRN Research Helper.

	<p>This project is about what kind of support people with lived experience of intellectual disability have to make decisions.</p>
	<p>You are asked to take part in this research if...</p> <ul style="list-style-type: none"> <li>• You are at least 18 years old.</li> <li>• You are a supporter of an IRN Researcher (Research Helper)</li> </ul>
	<p>The IRN ask that participants bring 2 to 5 photographs to the interview. The questions can be used to find out about support for the steps of making the decision.</p>
	<p>The IRN would like the Person with Lived Experience of Intellectual Disability and Supporters to take 2 to 5 photos of places or things that are about decisions they have made (people with lived experience of ID) or have supported (supporters).</p>

	<p>Please read the Photovoice Information Sheet. That explains what you need to know about the process.</p>
	<p>The IRN Researcher will ask questions in an interview about the photos the Person with Lived Experience of Intellectual Disability and Supporters have taken.</p> <p>We will not say that they took the photos to protect their identities.</p> <p>You should know, however, that people may be able to guess their identities from their choice of places or things to photograph.</p> <p>We have some tips on how to take photographs to protect someone's identity.</p>
	<p>In the interview, the IRN Researcher will ask questions about:</p> <ul style="list-style-type: none"> <li>• The photos the interviewees have taken.</li> <li>• Important decisions they have made or supported.</li> <li>• How these decisions were supported.</li> </ul>
<p><b>1</b></p> 	<p>The interview will last about 1 hour.</p>

	<p>Interviewees will be asked to only talk about things they don't mind saying in an interview.</p>
	<p>If an interviewee does not want to answer any of the questions in the interview, they don't have to.</p>
 	<p>All interviews will be recorded. Having the recording helps us to keep all the things the interviewees said and type up the information.</p> <p>When the interview is over, it will be typed up. This is called a transcript.</p> <p>In the transcript the names and details will all be taken out.</p> <p>The interviewees will get a copy of the transcript after the interview.</p> <p>They will have 1 month to check the transcript.</p> <p>They can decide if they are happy that their exact words are in the transcript and can be used in IRN talks and reports. They can have up until this moment to withdraw from the study.</p> <p>We can support them to check the transcript.</p>

	<p>Once the recording of the interview is typed up, then the recording is deleted.</p>
 <p><b>CONFIDENTIAL</b></p>   	<p>Will taking part be confidential?</p> <ul style="list-style-type: none"> <li>• We will keep written versions of what they say without their names (anonymised transcript) for 5 years and then give them to the TCD library.</li> <li>• Only the IRN Researchers will be able to listen to the recordings. Participants can also ask for their personal files anytime up until one month after the interview.</li> <li>• If we think someone has been harmed or is in danger, or if a crime has been committed, we will have to let the relevant authorities know about it. We will tell the interviewee first, about who we will talk to.</li> </ul> <p>The information they give us will be stored as follows:</p> <ul style="list-style-type: none"> <li>• All the information will be stored in SharePoint. This cloud is password protected and only the IRN researchers will have access to it.</li> <li>• The scanned consent form and audio recordings will be deleted once the transcript is ready and checked.</li> <li>• These anonymised transcripts will be kept in the TCD cloud and only the IRN researchers will have access to them.</li> </ul>

	<ul style="list-style-type: none"> <li>• Under freedom of information and data protection legislation the interviewees have the right to access their information. They have up until one month after their interview to ask for this.</li> </ul>
	<p>The photovoice photographs may be used in the final IRN report and whatever future presentations, photograph exhibitions, journal articles, submissions and other chances for discussing the research that the IRN agree to.</p>
	<p>What can participants gain from taking part?</p> <ul style="list-style-type: none"> <li>• We hope people will understand what support people with intellectual disabilities need to make their own decisions.</li> <li>• Their stories can be of help to others.</li> </ul>



## DATA PROTECTION INFORMATION

Data Controller	Trinity College Dublin, University College Cork and National Federation of Voluntary Service Providers.
Data Protection Officer	Data Protection Officer Secretary's Office Trinity College Dublin Dublin 2 <b>Email:</b> <a href="mailto:dataprotection@tcd.ie">dataprotection@tcd.ie</a> <b>Website:</b> <a href="http://www.tcd.ie/privacy">www.tcd.ie/privacy</a>

What are the interviewees' rights in relation to the use of their personal data?



The interviewees are entitled to:

- Access to their data and receive a copy of it.
- Say NO to the use of their data.
- Correct information about them.
- Have information about them that is not correct deleted
- Get their data in a portable format.
- Have their data sent to another data controller.
- Ask for their data to be deleted.



If they want to do any of the above:



- They can contact Edurne Garcia Iriarte at [iriartee@tcd.ie](mailto:iriartee@tcd.ie)
- The Trinity College Data Protection Officer (contact details above).

If their data is anonymous (does not give their names), we will not be able to access or delete it, as we will have no way of being able to link the data to them.

**Commented [A55]:** Is this 'Correct any mistakes in information about them?'

**Commented [EG16R5]:** It can also be incomplete information. These have been reviewed by the DPO and they were approved. I suggest we leave the wording as it is.

FORMS FOR THE PERSON WITH LIVED EXPERIENCE  
OF INTELLECTUAL DISABILITY











1. Participant Information Leaflet
2. Consent Form
3. Instructions for Photovoice



## Participant Information Leaflet for the Person with Lived Experience of Intellectual Disability: “Support for Making Decisions” Study

	<p>This project is about what kind of support people with lived experience of intellectual disability have to make decisions.</p>
	<p>You are asked to take part in this research if...</p> <ul style="list-style-type: none"> <li>• You are at least 18 years old.</li> <li>• You are a person with an intellectual disability or a learning difficulty.</li> <li>• You are happy to take photos about:             <ul style="list-style-type: none"> <li>➤ decisions that are important to you and</li> <li>➤ the support you have to make decisions.</li> </ul> </li> <li>• You are willing to take part in an interview to talk about the photos you take.</li> </ul>
	<p>The IRN ask that you bring 2 to 5 photographs to the interview. The photographs can be used to find out about support for the steps of making the decision.</p>

	<p>The IRN would like you to take 2 to 5 photos of places or things that are about decisions you have made.</p> <p>Please read the Photovoice Information Sheet. That explains what you need to do when taking the photographs</p>
	<p>We would like to ask you questions in an interview about the photos you take.</p> <p>We will not say that it was you who took the photos to protect your identity. You should know, however, that people may be able to guess your identity from your choice of places or things to photograph. We have some tips on how to take photographs to protect your identity.</p>
	<p>In the interview you will be asked questions about:</p> <ul style="list-style-type: none"> <li>• The photos you have taken.</li> <li>• Important decisions you have made.</li> <li>• The support you had to make decisions.</li> </ul>
	<p>The interview will last about 1 hour.</p>

	<p>Only talk about things you won't mind saying in an interview.</p>
	<p>If you do not want to answer any of the questions in the interview you don't have to.</p>
	<p>All interviews will be recorded. Having the recording helps us keep all the things you said and type up the information.</p> <p>When the interview is over, it will be typed up. This is called a transcript.</p>
	<p>In the transcript your name and details will all be taken out. No one will know that it was you who said what you said.</p> <p>You will get a copy of the transcript after the interview.</p> <p>You will have 1 month to check the transcript.</p> <p>You can decide if you are happy that your exact words are in the transcript and can be used in IRN talks and reports. You can have up until this moment to withdraw from the study.</p> <p>We can support you to check the transcript.</p>



Once the recording of the interview is typed up, then the recording is deleted.



Will taking part be confidential?




- We will keep written versions of what you say without your name (this is called anonymised transcript) for 5 years and then give it to the TCD Library.
- Only the IRN Researchers will be able to listen to the recordings. You can also ask for your personal files anytime up until one month after the interview.
- If we think you or someone else has been harmed or is in danger, or if a crime has been committed, we will have to let the relevant authorities know about it. We will tell you first, about who we will talk to.



The information you give us will be stored as follows:

- All the information will be stored in SharePoint. This cloud is password protected and only the IRN researchers will have access to it.
- The scanned consent form and audio recordings will be deleted once the transcript is ready and checked.
- The anonymised transcripts will be kept in the TCD cloud and only the IRN researchers will have access to them.
- Under freedom of information and data protection legislation you have the right to



	<p>access the information. You have up until one month after your interview.</p> <ul style="list-style-type: none"> <li>• We will not include your name when we type out what you said in the report.</li> <li>• If we think you or someone else has been harmed or is in danger, or if a crime has been committed, we will have to let the relevant authorities know about it. We will tell you first, about who we will talk to.</li> </ul>
	<p>The photovoice photographs may be used in the final IRN report and whatever future presentations, photograph exhibitions, journal articles, submissions and other chances for discussing the research that the IRN agree to.</p>
	<p>What can you gain from taking part?</p> <ul style="list-style-type: none"> <li>• We hope people will understand what support people with intellectual disabilities need to make their own decisions.</li> <li>• Your story can be of help to others.</li> </ul>

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Data Protection Officer	Data Protection Officer Secretary's Office Trinity College Dublin Dublin 2 Email: <a href="mailto:dataprotection@tcd.ie">dataprotection@tcd.ie</a> Website: <a href="http://www.tcd.ie/privacy">www.tcd.ie/privacy</a>

What are your rights in relation to the use of your personal data?

You are entitled to:



- Access your data and receive a copy of it.
- Say NO to the use of your data.
- Correct information about you.
- Ask for your data to be deleted.

If you want to do any of the above:







- You can contact Edurne Garcia Iriarte at [iriartee@tcd.ie](mailto:iriartee@tcd.ie) or
- The Trinity College Data Protection Officer (contact details above).

If your data is anonymous (does not give your name), we will not be able to access or delete it, as we will have no way of being able to link the data to you.








## Consent Form for the Person with Lived Experience of Intellectual Disability: “Support for Making Decisions” Study

		For YES
	I know what this study is about. I read the letter about this study. All my questions were answered.	✓
	I know that I will take photos of decisions that are important for me.	
	I know that I will take part in an interview to talk about: <ul style="list-style-type: none"> <li>• The photos that I take about decisions.</li> <li>• The support I had to make decisions.</li> <li>• The interview will last about 1 hour.</li> </ul>	
	I know that the interview about the photos and my experience of support to make decisions will be audio recorded. I know that only the researchers from the Inclusive Research Network will be able to listen to the recordings.	

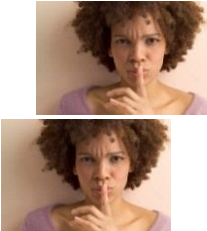





## Consent Form for the Person with Lived Experience of Intellectual Disability: "Support for Making Decisions" Study

		For YES
	<p>I know that I can stop talking any time I want. I don't have to answer any questions that I don't want to answer.</p>	<input checked="" type="checkbox"/>
	<p>I know that I will get a copy of the transcript after the interview.</p> <p>I know that I have 1 month to check the transcript and withdraw from the study.</p> <p>I know that I can decide if I am happy that my exact words are in the transcript and can be used in IRN talks and reports.</p>	<input type="checkbox"/>
	<p>I know the photovoice photographs may be used in the final IRN report and whatever future presentations, photograph exhibitions, journal articles, submissions and other chances for discussing the research that the IRN agree to.</p>	<input type="checkbox"/>



Consent Form for the Person with Lived Experience of Intellectual Disability:  
“Support for Making Decisions” Study

		For YES
	<p>I know that I will not be named in any reports or talks about this study.</p> <p>It might be possible for someone to guess that I have given information because of my words. The researchers will try to make sure this does not happen.</p>	<input checked="" type="checkbox"/>
	<p>I agree that things I say in the interview can be included in talks or papers about the study.</p>	<input type="checkbox"/>
	<p>I agree that future students working with the research team can look at the interview transcripts without my name on them.</p>	<input type="checkbox"/>
	<p>I was given a copy of the project details.</p> <p>If I take part in the study, I will get a copy of the consent form.</p>	<input type="checkbox"/>



Consent Form for the Person with Lived Experience of Intellectual Disability: "Support for Making Decisions" Study

		For YES
	<p>I want to get a copy of the project report. Please send it by post or email to: _____@_____</p>	
	<p>I want to be invited to a talk the IRN will do about the project findings. Contact me this way (phone, email, post): (say which below)</p>	
	<p>I want to be involved in an exhibition of the photographs where I can talk about them with people with intellectual disability, policy makers, staff from disability organisations, researchers. Contact me this way (phone, email, post) (say which below):</p>	

Brian Donohoe, Inclusion Research Network

Eduerne Garcia, Trinity College Dublin

Nicola Maxwell, University College Cork

\_\_\_\_\_  
Participant's Signature    Date    Researcher's Signature    Date



If the person prefers not to sign their name but has consented to take part in the research, a person assisting them may sign here with the agreement of the person or consent may be audio recorded.



I \_\_\_\_\_ confirm  
that \_\_\_\_\_ has agreed that I  
may sign this consent form on their behalf.


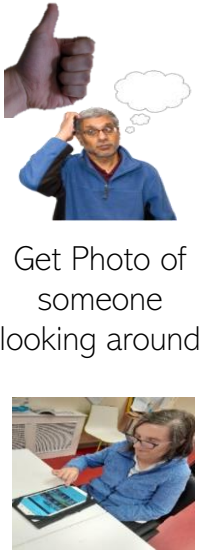

Signature: \_\_\_\_\_

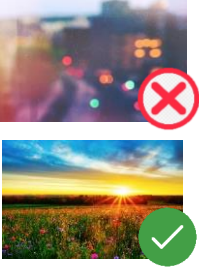




Date: \_\_\_\_\_



## Instructions for Photovoice (these instructions are for all participants): “Support for Making Decisions” Study

	<p>Think about:</p> <ul style="list-style-type: none"> <li>• Decisions you have made that are important to you.</li> <li>• About the support you have to make decisions.</li> </ul> <p>For Supporters, think about;</p> <ul style="list-style-type: none"> <li>• Decisions that someone you support with lived experience of intellectual disability made that are important to them.</li> <li>• How you provided the person with support to make the decision(s).</li> </ul>
<p>Take 2 to 5 photographs</p> 	<p>Take photographs that show good decisions and decisions that didn't go as you wanted/decisions that you have supported.</p> <p>Photographs have to be about “important decisions” for example, buying something like a phone, going on a trip, signing up for a new activity/course, changing support.</p> <p>You should take photographs of good decisions and decisions that did not work out well:</p> <ul style="list-style-type: none"> <li>• GOOD decisions are decisions that worked out well for you.</li> <li>• Decisions that didn't work out well are decisions where there was no support, or the support was</li> </ul>

	<p>not good, the decision was not put into action, there were challenges or obstacles.</p>
	<p>You can use your phone or iPad or a camera.</p>
 <p>Get Photo of someone looking around</p>	<p>Do's</p> <ul style="list-style-type: none"> <li>• Think about the things you need to photograph. For example, mobile phones, holiday brochures, a street, well-known shops and supermarkets, post-office, cars or car keys, parks and public areas, keys, public transport, documents like job applications. If you are not sure, let us know.</li> <li>• Look around for things you can photograph about important decisions that you have made/supported to make.</li> <li>• Make sure your photo tells your story about decisions you have made.</li> <li>• Check that each photograph is about a decision that is important to you/the person you support.</li> </ul>
	<p>Don'ts</p> <ul style="list-style-type: none"> <li>• Do not take photographs of yourself, your family, your friends, or anyone else.</li> <li>• Do not include any details that could identify people. Examples include: <ul style="list-style-type: none"> <li>○ Car registrations.</li> <li>○ NCT, tax and insurance details on cars.</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>○ Street names.</li> <li>○ House numbers.</li> </ul> <ul style="list-style-type: none"> <li>• Do not take photos of things like Garda squad cars, army vehicles or any official vehicle.</li> </ul>
	<ul style="list-style-type: none"> <li>• Make sure the photographs are not blurred.</li> <li>• Make sure there is good lighting.</li> <li>• Make sure there is no glare or shadows.</li> </ul>
	<p>Bring your photographs to the interview. You can bring them in your iPhone, iPad, computer or print them out.</p>
	<ul style="list-style-type: none"> <li>• We will keep your photos in a secure folder that no-one else has access to.</li> <li>• Make sure that anything that can identify you as the person who took the photographs is removed.</li> </ul>
	<p>We will use your photograph during the interviews about support for making decisions.</p>
	<p>The photovoice photographs may be used in the final IRN report and whatever future presentations, photograph exhibitions, journal articles, submissions and other chances for discussing the research that the IRN agree to.</p>



## FORMS FOR THE INTERVIEW ASSISTANT







1. Participant Information Leaflet
2. Consent Form




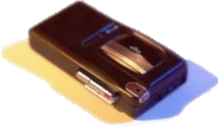



## Participant Information Leaflet for the Interview Assistant: “Support for Making Decisions” Study

Please note that not every Person with Lived Experience of Intellectual Disability might require an Interview Assistant.

	<p>This project is about what kind of support people with lived experience of intellectual disability have to make decisions.</p>
	<p>The person you assist is asked to take part in this research if...</p> <ul style="list-style-type: none"> <li>• They are at least 18 years old.</li> <li>• They are a person with an intellectual disability or a learning difficulty.</li> <li>• They are happy to take photos about:             <ul style="list-style-type: none"> <li>➤ decisions that are important to them and</li> <li>➤ the support they have to make decisions.</li> </ul> </li> <li>• They are willing to take part in an interview to talk about the photos they take.</li> </ul>

	<p>The Ethics Group ask that people bring from 2 to 5 photographs to the interview. The photographs can be used to find out about support for the steps of making the decision.</p>
	<p>The IRN would like them to take between 2 and 5 photos of places or things that are about decisions they have made.</p> <p>Please read the Photovoice Information Sheet. That explains what they need to do when taking the photographs</p>
	<p>We would like to ask them questions in an interview about the photos they take.</p> <p>We will not say that it was them who took the photos to protect their identity.</p> <p>You and they should know, however, that people may be able to guess their identity from their choice of places or things to photograph. We have some tips on how to take photographs to protect their identity.</p>
	<p>In the interview people will be asked questions about:</p> <ul style="list-style-type: none"> <li>• The photos they have taken.</li> <li>• Important decisions they have made.</li> <li>• The support they had to make decisions.</li> </ul>

	<p>The interview will last about 1 hour.</p>
	<p>The person you assist will be asked to only talk about things they don't mind saying in an interview.</p>
	<p>If they do not want to answer any of the questions in the interview they don't have to.</p>
	<p>All interviews will be recorded. Having the recording helps us keep all the things they say and type up the information.</p> <p>When the interview is over, it will be typed up. This is called a transcript.</p>
	<p>In the transcript their name and details will all be taken out. No one will know that it was them who said what they said.</p> <p>They will get a copy of the transcript after the interview.</p> <p>They will have 1 month to check the transcript.</p> <p>They can decide if they are happy that their exact words are in the transcript and can be used in IRN talks and reports. They can have up until this moment to withdraw from the study.</p> <p>We can support them to check the transcript.</p>



Once the recording of the interview is typed up, then the recording is deleted.



Will taking part be confidential?

- We will keep written versions of what they say without their name (this is called an anonymised transcript) for 5 years and then give them to the TCD library.
- Only the IRN Researchers will be able to listen to the recordings. The person you assist can also ask for their personal files anytime up until one month after the interview.
- If we think the person you assist or someone else has been harmed or is in danger, or if a crime has been committed, we will have to let the relevant authorities know about it. We will tell them first, about who we will talk to.

The information the person you assist gives us will be stored as follows:



- All the information will be stored in SharePoint. This cloud is password protected and only the IRN researchers will have access to it.
- The scanned consent form and audio recordings will be deleted once the transcript is ready and checked.



- The anonymised transcripts will be kept in the TCD cloud and only the IRN researchers will have access to them.
- Under freedom of information legislation the person you assist has the right to access the

	<p>information. They have up until one month after their interview to ask for it.</p> <ul style="list-style-type: none"> <li>• We will not include their name (or yours) when we type out what they said in the report.</li> <li>• If we think the person you assist or someone else has been harmed or is in danger, or if a crime has been committed, we will have to let the relevant authorities know about it. We will tell the person first, about who we will talk to.</li> </ul>
	<p>The photovoice photographs may be used in the final IRN report and whatever future presentations, photograph exhibitions, journal articles, submissions and other chances for discussing the research that the IRN agree.</p>
	<p>What can the person you assist gain from taking part?</p> <ul style="list-style-type: none"> <li>• We hope people will understand what support people with intellectual disabilities need to make their own decisions.</li> <li>• Their stories can be of help to others.</li> </ul>

## DATA PROTECTION INFORMATION

Data Controller	Trinity College Dublin, University College Cork & National Federation of Voluntary Bodies
Data Protection Officer	Data Protection Officer Secretary's Office Trinity College Dublin Dublin 2 Email: <a href="mailto:dataprotection@tcd.ie">dataprotection@tcd.ie</a> Website: <a href="http://www.tcd.ie/privacy">www.tcd.ie/privacy</a>

What are the interviewees' rights in relation to the use of their personal data?



The interviewees are entitled to:

- Access to their data and receive a copy of it.
- Say NO to the use of their data.
- Correct information about them.
- Delete information about them that is not correct.
- Get their data in a portable format.
- Have their data sent to another data controller.
- Ask for their data to be deleted.



If they want to do any of the above:





- They can contact Edurne Garcia Iriarte at [iriartee@tcd.ie](mailto:iriartee@tcd.ie) or
- The Trinity College Data Protection Officer (contact details above).








If their data is anonymous (does not have their names), we will not be able to access or delete it, as we will have no way of being able to link the data to them.







## Consent Form for the Interview Assistant: “Support for Making Decisions” Study


		For YES 
	<p>I have read the information form about this research.</p> <p>I know that this research is about people with intellectual disabilities (ID) experience of support with making decisions.</p>	<input type="checkbox"/>
	<p>I know that taking part in this research means that the person I am assisting will:</p> <ul style="list-style-type: none"> <li>• Take photos of decisions that they have made.</li> <li>• Take part in an interview to talk about decisions and their experience of support for making decisions.</li> </ul>	<input type="checkbox"/>
	<p>I know that my role is to assist the person communicate their views and decisions (and not my own views and decisions).</p>	<input type="checkbox"/>











		For YES 
	<p>Before the interview:</p> <ul style="list-style-type: none"> <li>• I will make sure I understand how the person wants me to assist them in the interview.</li> <li>• I will work with the person to make sure they get their points across.</li> </ul>	
	<p>In the interview:</p> <ul style="list-style-type: none"> <li>• I agree not to speak on behalf of the person.</li> <li>• I will help the person to get their points across only if the person makes it clear that they want my assistance.</li> <li>• I agree that this will be made clear at the start of the interview.</li> </ul>	
	All my questions have been answered.	
	I know that the person I assist can stop taking part in this study at any time up to one month after the interview takes place. This is his/her decision and not mine.	

		For YES 
	I know that there are no benefits from taking part in this study.	
	I know that what is said in the interview will be treated confidentially.  I know that I must treat everything that is said in the interview confidentially.	
	I know that if the person I assist or someone else is at risk of harm, the researcher will talk to the relevant authorities. They will let the person I assist know this first.	
 	I know that: <ul style="list-style-type: none"> <li>• Anonymised transcripts will be kept for 5 years and then given to the TCD library.</li> <li>• Only the researchers from the Inclusive Research Network will be able to listen to the recordings.</li> <li>• The person I assist can also ask for the recordings or personal files anytime up until one month after the interview</li> </ul>	



	<p>when they are contacted about the transcript.</p> <ul style="list-style-type: none"><li>• Their names will not be included in the report.</li><li>◦ It might be possible for someone to guess that they have given information because of their words. The researchers will try this does not happen.</li><li>• If the IRN researchers learn that someone has been harmed or is in danger, or if a crime has been committed, they will have to let the relevant authorities know about it. They will tell the person I assist first and who they are going to talk to.</li><li>• The consent form, photographs and audio recordings will be stored in a password protected online server at Trinity College Dublin (TCD).</li><li>• This cloud is password protected and only the IRN</li></ul>	For YES 
--	--	---

	<p>researchers will have access to it.</p> <ul style="list-style-type: none"> <li>• When what the person I assist says is typed out their name and any other personal information that can identify them will be deleted. These transcripts will be kept in the TCD cloud and only the IRN researchers will have access to them.</li> <li>• Under freedom of information legislation they have the right to access the information. They have up until one month after they do the interview.</li> </ul>	<p>For YES</p> 
	<p>I know the photovoice photographs may be used in the final IRN report and whatever future presentations, photograph exhibitions, journal articles, submissions and other chances for discussing the research that the IRN agree to.</p>	
	<p>The person I assist can agree that future students working with the research team can access the interview transcripts once their details are taken out.</p>	

		For YES 
	I know that my consent form will be kept until the report is published and data is analysed on TCD password protected computers.	
	I know that I can contact any of the people involved in the research to learn more about the study.	
	I agree to provide assistance to the person to take part in the study.	

Brian Donohoe, Inclusion Research Network

Eduarne Garcia, Trinity College Dublin

Nicola Maxwell, University College Cork

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Participant's Signature \_\_\_\_\_ Date \_\_\_\_\_

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Researcher's Signature \_\_\_\_\_ Date \_\_\_\_\_

## FORMS FOR THE SUPPORTER







1. Participant Information Leaflet
2. Consent Form




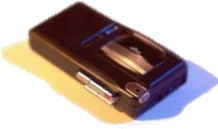



## Consent Form for the Supporter: “Support for Making Decisions” Study

Commented [AS7]: Should this be 'Information Leaflet'?

	<p>This project is about what kind of support people with lived experience of intellectual disability have to make decisions.</p>
	<p>You are asked to take part in this research if...</p> <ul style="list-style-type: none"> <li>• You are at least 18 years old.</li> <li>• You are a person who supports or has supported a person with an intellectual disability or a learning difficulty.</li> <li>• You are happy to take photos about:             <ul style="list-style-type: none"> <li>➤ decisions that are important to the person you support and</li> <li>➤ the support you have provided to make decisions.</li> </ul> </li> <li>• You are willing to take part in an interview to talk about the photos you take.</li> </ul>
	<p>The IRN ask that people bring between 2 and 5 photographs to the interview. The photographs can be used to find out about support for the steps of decision making.</p>

	<p>The IRN would like you to take between 2 and 5 photos of places or things that are about decisions you have supported someone else to make.</p> <p>Please read the Photovoice Information Sheet. That explains what you need to do when taking the photographs</p>
	<p>We would like to ask you questions in an interview about the photos you take.</p> <p>We will not say that it was you who took the photos to protect your identity. You should know, however, that people may be able to guess your identity from your choice of places or things to photograph. We have some tips on how to take photographs to protect your identity.</p>
	<p>In the interview, you will be asked questions about:</p> <ul style="list-style-type: none"> <li>• The photos you have taken.</li> <li>• Important decisions you have supported someone else to make.</li> <li>• The support you provided for someone else to make decisions.</li> </ul>
	<p>The interview will last about 1 hour.</p>
	<p>Only talk about things you won't mind saying in an interview.</p>



	<p>If you do not want to answer any of the questions in the interview you don't have to do it.</p>
	<p>All interviews will be recorded. Having the recording helps us keep all the things that were said and type up the information.</p> <p>When the interview is over, it will be typed up. This is called a transcript.</p>
	<p>In the transcript your name and details will all be taken out. No one will know that it was you who said what you said.</p> <p>You will get a copy of the transcript after the interview.</p> <p>You will have 1 month to check the transcript.</p> <p>You can decide if you are happy that your exact words are in the transcript and can be used in IRN talks and reports. You can have up until this moment to withdraw from the study.</p> <p>We can support you to check the transcript.</p>
	<p>Once the recording of the interview is typed up, then the recording is deleted.</p>
	<p>Will taking part be confidential?</p> <ul style="list-style-type: none"> <li>• We will keep written versions of what you say without your name (this is called anonymised)</li> </ul>



transcript) for 5 years and then give them to the TCD library.

- Only the IRN Researchers will be able to listen to the recordings. You can also ask for your personal files anytime up until one month after the interview.

The information you give us will be stored as follows:

- All the information will be stored in SharePoint. This TCD cloud is password protected and only the IRN researchers will have access to it.
- The scanned consent form and audio recordings will be deleted once the transcript is ready and checked.
- The anonymised transcripts will be kept in the TCD cloud and only the IRN researchers will have access to them.
- Under freedom of information and data protection legislation you have the right to access the information. You have up until one month after your interview.
- We will not include your name when we type out what you said in the report.
- If we think you or someone else has been harmed or is in danger, or if a crime has been committed, we will have to let the relevant authorities know about it. We will tell you first, about who we will talk to.





The photovoice photographs may be used in the final IRN report and whatever future presentations, photograph exhibitions, journal articles, photograph exhibitions, submissions and other chances for discussing the research that the IRN agree to.



What can you gain from taking part?

- We hope people will understand what support people with intellectual disabilities need to make their own decisions.
- Your story can be of help to others.

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- Say NO to the use of your data.
- Correct information about you.
- Ask for your data to be deleted

If you want to do any of the above:













- You can contact Edurne Garcia Iriarte at [iriartee@tcd.ie](mailto:iriartee@tcd.ie) or
- The Trinity College Data Protection Officer (contact details above).






If your data is anonymous (does not have your names), we will not be able to access or delete it, as we will have no way of being able to link the data to you.



## Consent Form for the Supporter: “Support for Making Decisions” Study

		For YES 
	I know what this study is about. I read the letter about this study. All my questions were answered.	<input checked="" type="checkbox"/>
	I know that I will not be named in any reports or talks about this study.	<input type="checkbox"/>
	I know that I will take photos of decisions that I have supported people with ID to make.	<input type="checkbox"/>
	I know that I will take part in an interview to talk about: <ul style="list-style-type: none"> <li>• The photos that I take about decisions.</li> <li>• The support I provided to make decisions.</li> <li>• The interview will last about 1 hour.</li> </ul>	<input type="checkbox"/>

		For YES ✓
	<p>I know that the interview about the photos and my experience of support to people with ID to make decisions will be audio recorded.</p>	
	<p>I know that I can stop talking any time I want. I don't have to answer any questions that I don't want to answer.</p>	
	<p>I agree that things I say in the interview can be included in talks or papers about the study.</p>	
 	<p>I know that I will get a copy of the anonymised transcript after the interview.</p> <p>I know that my name and details will be taken out of the transcript.</p> <p>I know that I have 1 month to check the transcript and withdraw from the study.</p> <p>I know that I can decide if I am happy that my exact words are in the transcript and can be used in IRN talks and reports.</p>	




		For YES ✓
	<p>I know that I can change my mind about having my exact words used in talks or reports up until 1 month after the interview.</p>	
	<p>I agree that future students working with the research team can access the interview transcripts once my details are taken out.</p>	
	<p>I was given a copy of the project details. If I sign the consent form, I will get a copy.</p>	
  	<p>I know that:</p> <ul style="list-style-type: none"> <li>• Written versions of what I say without my name will be kept for 5 years and then given to the TCD library.</li> <li>• Only the researchers from the Inclusive Research Network will be able to listen to the recordings.</li> <li>• I can also ask for my recordings or personal files anytime up until one month after the interview when I am contacted about the transcript.</li> </ul>	



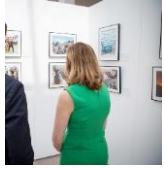
For YES



- My name will not be included in the report.
  - It might be possible for someone to guess that I have given information because of my words. The researchers will try to make sure this does not happen.
- If the IRN researchers think I or someone else has been harmed or is in danger, or if a crime has been committed, they will have to let the relevant authorities know about it. They will tell me first about who they are going to talk to.
- The consent form, photographs and audio recordings will be stored in a password protected online server at TCD.
- This cloud is password protected and only the IRN researchers will have access to it.



		For YES 
	<ul style="list-style-type: none"> <li>• When what I say is typed out my name and any other personal information that can identify me will be deleted. These transcripts will be kept in the TCD cloud and only the IRN researchers will have access to them.</li> <li>• Under freedom of information legislation I have the right to access the information. I have up until one month after I do the interview to access it.</li> </ul>	
	I know the photovoice photographs may be used in the final IRN report and whatever future presentations, photograph exhibitions, journal articles, submissions and other chances for discussing the research that the IRN agree to.	
	I want to get a copy of the project report. Please send it by post or email to (say below where to send it):	

	<p>I want to be invited to a talk the IRN will do about the project findings.</p> <p>Contact me this way (phone, email, post):</p> <p>_____</p> <p>@_____</p>	<p>For YES</p> 
	<p>I want to be involved in an exhibition of the photographs where I can talk about them with people with intellectual disability, policy makers, staff from disability organisations, researchers.</p> <p>Contact me this way (phone, email, post):</p> <p>_____</p>	

Brian Donohoe, Inclusion Research Network

Edurne Garcia, Trinity College Dublin

Nicola Maxwell, University College Cork

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Participant's Signature

Date

---



Researcher's Signature

Date



## 8. Interviews

You will find the following information in the following pages:

Person & Supporter	• Details of People Taking Part	68-69
Person with Lived Experience 	• Interview Questions for People with Lived Experience of Intellectual Disability • Advice by the IRN	70-77 78-81
Supporter 	• Interview Questions for Supporters	82-88
Person & Supporter	• Information and Contacts for Participants in Distress Protocol	89-91

## Decision Making study Details of People Taking Part



This paper will be shredded once the details are typed into a file. These details will only be stored in a locked file on SharePoint. Your name and age will not be used when the IRN tells people about the project.

My name is...

I am a.... (please circle)

Woman



Man



Non-binary (neither a man nor a woman)

I prefer not to say

My age is...



\_\_\_\_\_ YEARS

I was born in Ireland... (circle)

YES



NO



If not, I was born in...







I attend a disability service on a regular basis...

YES



NO



I live in a...	<input type="checkbox"/> Group home <input type="checkbox"/> An apartment shared with other persons with ID <input type="checkbox"/> Family home <input type="checkbox"/> An apartment of my own <input type="checkbox"/> Other
I have a key worker...	YES  NO 
I am supported by a team...	YES  NO 
I have a personal budget...	YES  NO 
This person can be called if I need support during the interview	Name: _____ Contact Number: _____



## Interview with Person with Lived Experience of Intellectual Disability: “Support for Making Decisions” Study

### Introduction

Hello and thank you for taking part in this study.

My name is \_\_\_\_\_ and I am a member of the Inclusive Research Network.

The Inclusive Research Network is a group of researchers with lived experience of intellectual disability, their supporters and university researchers from all over Ireland. We do research about issues important to us.

This study is about support making decisions. This is because the law has changed in Ireland. With the new law, we hope that more people with lived experience of intellectual disability will be supported to make decisions and we want to know more about what support works well.

To start the interview




I'm going to ask you questions about some decisions you have made:

- BIG decisions such as buying something with your own money, like a phone, going on a trip, signing up for a new activity/course, changing your support.

	<ul style="list-style-type: none"> <li>• We want to hear from you about: <ul style="list-style-type: none"> <li>○ GOOD decisions, decisions that worked out well for you.</li> <li>○ Decisions that didn't work out well for you, there was no support or the support was not good, the decision was not put into action, there were challenges or obstacles.</li> </ul> </li> </ul> <p>We will look at one photograph at a time and talk about the decision that the photograph shows. Can you please pick one photo that you would like to talk about?</p> <p>(Let the person pick a photo and ask the next questions about it)</p>
--	---

### Checking the support for the interview


	<p>If the participant is with an interview assistant to support them during the interview, ask the interview assistant to leave the room and ask the participant <u>privately</u>:</p> <ul style="list-style-type: none"> <li>• Did you choose this person to support you to do this interview? YES NO</li> <li>• Does this person have experience supporting you? YES NO</li> </ul>
---	--

	<ul style="list-style-type: none"> <li>• Do you get on well with this person? YES NO</li> <li>• Are you happy for this person to support you? YES NO</li> </ul> <p>If the participant answers YES to these questions, continue the interview.</p> <p>If the participant answers NO to one of the questions, stop and ask the participant if they would like to have someone else supporting them to do the interview.</p>
--	---

Making a decision is about thinking about the options, making your mind about it and saying it to others (Brown & Brown, 2009).

This is similar to the steps outlined in the Assisted Decision Making (Capacity) Act (2015): understand relevant information and facts, use or weigh that information, communicate the decision by any means, including by assistive technology.


1. Can you tell me about this photograph?

	<p>Can you please pick one photo from the photos you have brought that you would like to talk about?</p> <p>(Let the person pick a photo and ask the next questions about it)</p> <p>Let the person talk about the photograph and the decision.</p>
---	---




	<p>You can ask the next questions to help them talk:</p> <ul style="list-style-type: none"> <li>• What was the decision?</li> <li>• Why did you make that decision?</li> </ul>
--	--


2. How did you feel when you made this decision?

	
---	--

3. Did you have ideas about the decision you were making?


	<ul style="list-style-type: none"> <li>• What ideas did you have?</li> </ul>
---	--

4. Was the decision put into action? (for example, if the participant wanted to buy a car, did the participant buy the car?)


	<p>YES</p> <p>If the person answers "yes", ask:</p>	<p>NO</p> <p>If the person answers "no", ask:</p>
	<ul style="list-style-type: none"> <li>• How was the decision put into action?</li> </ul>	<ul style="list-style-type: none"> <li>• What happened?</li> </ul>

	<ul style="list-style-type: none"> <li>• What has happened as a result?</li> </ul>	<ul style="list-style-type: none"> <li>• Are you still working on it?</li> <li>• Did anyone try to stop you making a decision?</li> </ul>
--	--	---


5. If you had to make this decision again, would you do anything different?

	<ul style="list-style-type: none"> <li>• What would that be?</li> </ul>
---	---


6. Do you think it was your decision in the end?

	<ul style="list-style-type: none"> <li>• Why do you think that?</li> </ul>
---	--





7. Did you need support to make the decision?

	<p>YES</p> <p>If the person answers "yes", ask the next questions:</p> <ul style="list-style-type: none"> <li>• What support did you need?</li> <li>• Did you get that support?</li> </ul>	<p>NO</p> <p>Even if the person answers "no", go to question 8.</p>
---	--	---


8. Did anyone support/help you to make the decision?

	<p>YES</p> <p>If the person answers “yes”, ask the next questions:</p> <ul style="list-style-type: none"> <li>• Who supported/helped you?</li> <li>• If the person supporting the decision is the same as the person supporting the interview, ask them to leave at this point (for questions 8 and 9)</li> <li>• How do you get on with this person/people?</li> <li>• Were you involved in choosing your supporter?</li> <li>• Do you have enough choice about the support person?</li> </ul>	<p>NO</p> <p>If the person answers “no”, go to question 10.</p>
---	---	---


9. What did the support person/people do to help you? (First, let the person talk about the support. You can ask the next questions if they have not talked about it.)

	<ul style="list-style-type: none"> <li>• Did you talk about...             <ul style="list-style-type: none"> <li>• All the different choices available to you when making the decision?</li> <li>• What you wanted</li> <li>• What would happen in the future if you went through with your decision</li> </ul> </li> <li>• Did they talk to someone else about this decision?</li> </ul>
	<ul style="list-style-type: none"> <li>• Did they give you information that was easy to understand? For example, easy to read information.</li> </ul>
	<ul style="list-style-type: none"> <li>• Did your supporter come with any ideas of theirs to support you to make your decision?</li> </ul>
	<ul style="list-style-type: none"> <li>• Did they do anything else?</li> </ul>
	<ul style="list-style-type: none"> <li>• What did the supporter do well?</li> <li>• Could they have done better?</li> </ul>


10. Do you want to say something else about this photo or the decision you made?
11. Now you can pick another of your photos and I will ask the same questions about the decision you made. Would you like to do that?

	<p>YES If the person answers "yes", repeat questions 1-10.</p>	<p>NO If the person answers "no", go to question 12.</p>
---	--	--

12. Is there anything else you would like to tell us?


	<ul style="list-style-type: none"> <li>o About the photos you have taken?</li> <li>o About making your own decisions?</li> </ul>
--	--


To end the interview

	<p>Thank you very much for taking part in this study. We really appreciate it. We will contact you with a copy of what you said in the interview (that is called a transcript). We would like to know if you are happy with what you have said in this interview.</p> <p>If you want to hear about the results of this study, you can give me your email address and we will send them to you.</p>
---	--




This is some advice by the Inclusive Research Network about making decisions.

## The Assisted Decision-Making (Capacity) Act 2015


 <p>Number 64 of 2015</p> <p>Assisted Decision-Making (Capacity) Act 2015</p>	<p>The Assisted Decision-Making (Capacity) Act 2015 is a new law about people making their own decisions and what supports they can use.</p>
	<p>There are rules in the Act about who can help you make decisions and when people can stop you.</p> <p>Here are some of the important ones for you to know.</p>
	<p>We have to start by thinking everyone can make their own decisions.</p>
	<p>If you want to make a decision that other people think is unwise or a mistake this does not mean they can stop you.</p>
	<p>If you need help to make decisions you can choose who helps you.</p>

	<p>When other people make decisions for you, they have to respect your will and preferences.</p> <p>Will and preferences means what your idea of a good life is, what you like and do not like.</p>
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**What sorts of decisions can you get support with under the new law?**

	<p>Property, for example, if you need to buy, sell, or rent a house</p>
	<p>How you spend your money, paying your bills and applying for benefits</p>
	<p>Your health, for example, going to the doctor, what medications or treatments you should have</p>

**What are the new roles under the Act?**

	<p>There are 3 new roles or jobs under the Act,</p>
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A **decision making assistant** is someone who helps you to make decision.

They could help you find out more about the decision,



A **co-decision maker** makes the decision with you.

They can stop you if they think it might hurt you or cause 'serious harm'.








A **decision making representative** is someone the court says is allowed to decide for you.

They have to ask you what you think and decide based on what your will and preferences or what you want.



## How can I find out more?

 <p>seirbhís tacaíochta cinn-teoireachta decision support service</p>	<p>The Decision Support Service was set up to help run the new law and make sure people were following it properly.</p>
   	<p>To find out more about the Decision Support Service and the new law, you can contact them then using the details below.</p> <p><b>Website:</b> <a href="http://www.decisionsupportservice.ie">www.decisionsupportservice.ie</a></p> <p><b>Phone number:</b> 01 2119750</p> <p><b>Email:</b> <a href="mailto:queries@decisionsupportservice.ie">queries@decisionsupportservice.ie</a></p> <p><b>Write to:</b> Decision Support Service, Waterloo Exchange, Waterloo Road, Dublin 4 DO4 E5W7.</p>



## Interview with Supporters of People with Lived Experience of Intellectual Disability: “Support for Making Decisions” Study

### Introduction

Hello and thank you for taking part in this study.

My name is \_\_\_\_\_ and I am a member of the Inclusive Research Network.

The Inclusive Research Network is a group of researchers with lived experience of intellectual disability, their supporters and university researchers from all over Ireland. We do research about issues important to us.

This study is about support making decisions. This is because the law has changed in Ireland. With the new law, we hope that more people with lived experience of intellectual disability will be supported to make decisions and we want to know more about what support works well.

To start the interview



Hello, and thank you for taking part in this study.  
I'm going to ask you questions about how you work with people to help them make decisions.  
I'm going to ask you questions about some decisions you have supported to make:


- BIG decisions such as buying something with people's own money, like a phone, going on a

	<p>trip, signing up for a new activity/course, changing their support.</p> <ul style="list-style-type: none"> <li>• We want to hear from you about: <ul style="list-style-type: none"> <li>○ GOOD decisions, decisions that worked out well for the person you supported</li> <li>○ BAD decisions, decisions that didn't work out well for the person, the decision was not put into action, there were challenges or obstacles.</li> </ul> </li> </ul> <p>We will look at one photograph at a time and talk about the decision that the photograph shows.</p>
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Making a decision is about thinking about the options, making your mind about it and saying it to others (Brown & Brown, 2009).


The definition above is similar to the steps outlined in the Assisted Decision Making (Capacity) Act (2015): understand relevant information and facts, use or weigh that information, communicate the decision by any means, including by assistive technology.

1. Can you tell me about this photo?





	<p>Can you please pick one photo from the photos you have brought that you would like to talk about?</p> <p>(Let the person pick a photo and ask the next questions about it)</p>
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	<p>First, <u>let the person talk about the photo and the decision.</u></p> <p>You can ask the next questions to help them talk:</p> <ul style="list-style-type: none"> <li>• What was the decision?</li> <li>• Why was the person making the decision?</li> </ul>
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2. Did you support/help the person with a lived experience of disability to make the decision?


	<p>YES</p> <p>If the person answers “yes”, ask the next questions:</p> <ul style="list-style-type: none"> <li>• Can you tell me about your relationship with this person?</li> <li>• Were you chosen by the person with lived experience of disability?</li> <li>• Were there other options of supporters to choose from?</li> </ul>	<p>NO</p> <p>If the person answers “no”, ask:</p> <ul style="list-style-type: none"> <li>• Did the person make the decision on their own?</li> <li>• Did you support the person to follow through on their decision?</li> </ul> <p>If the person answers “yes” to this question, go to question 3. If the person answers “no” ask the person to choose another photo of a decision they supported to make or supported to follow through.</p>
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3. What was the support you gave? First, let the person talk about the support. You can ask these questions to help them talk about it.


	<ul style="list-style-type: none"> <li>• Did you talk about...             <ul style="list-style-type: none"> <li>○ All the different choices available to the person when making the decision/following it through?</li> <li>○ What the person wanted?</li> <li>○ What might happen in the future if they went through with their decision?</li> </ul> </li> <li>• Did you look for other opinions to help the person make the decision/follow it through?</li> </ul>
	<ul style="list-style-type: none"> <li>• Did you give information that was easy to understand? For example, easy to read information</li> </ul>
	<ul style="list-style-type: none"> <li>• Did you come up with any ideas of your own to support the decision?</li> </ul>
	<ul style="list-style-type: none"> <li>• Did you do anything else?</li> </ul>

	<ul style="list-style-type: none"> <li>• What did you feel you did well?</li> <li>• Could you have done better?</li> </ul>
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4. How did you feel about the support you gave to the decision maker?

	
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5. Did you have different ideas (from the person's ideas) about the decision you have supported?


	<ul style="list-style-type: none"> <li>• What ideas did you have?</li> </ul>
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6. Was the decision you supported put into action?


	<p>YES If the person answers "yes", ask:</p> <ul style="list-style-type: none"> <li>• How was the decision put into action?</li> <li>• What has happened as a result?</li> </ul>	<p>NO If the person answers "no", ask:</p> <ul style="list-style-type: none"> <li>• What happened?</li> <li>• Is the person still working on it?</li> </ul>
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	<ul style="list-style-type: none"> <li>• What did you do to support the decision being put into action?</li> </ul>	<ul style="list-style-type: none"> <li>• What did you do to support the decision being put into action (even if it was not put into action)?</li> </ul>
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7. If you had to support this decision again, would you do anything different?


	<ul style="list-style-type: none"> <li>• What would that be?</li> </ul>
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8. Do you think you influenced the decision in the end?


	<ul style="list-style-type: none"> <li>• Why do you think that?</li> </ul>
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9. Do you want to say something else about this photo or the decision you helped the person make?


10. Now you can pick another of your photos and I will ask the same questions about the decision you helped the person to make. Would you like to do that?

	<p>YES If the person answers "yes", repeat questions 1-9.</p>	<p>NO If the person answers "no", go to question 11.</p>
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11. Is there anything else you would like to tell us?

	<ul style="list-style-type: none"> <li>o About the photos you have taken?</li> <li>o About supporting people with lived experience of disability to make decisions (making your own decisions)</li> </ul>
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To end the interview

	<p>Thank you very much for taking part in this study. We really appreciate it. We will contact you with a the write up of this interview (that is called a transcript). We would like to know if you are happy with what have said in this interview. If you want to hear about the results of this study, you can give me your email address and we will send them to you.</p>
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This is some advice by the Inclusive Research Network about support making decisions (please see pages 78-81).



### Information and Contacts for Participants in Distress Protocol

The research plan says that only adults who understand and voluntarily consent to participate in the research will be interviewed.

While we do not think there will be any distress due to taking part in the research, if distress does occur, the following steps will be followed.

1. In an interview situation, turn off recording equipment and ask if the person if they wish to take a break. Where upset/distress continues, ask if they would like to end the interview and call someone to support the person (family member, support worker, counselling service).
2. Ask the person(s) if they wish to have the researcher or a trusted support person to call them later to ensure they have recovered from the distress/upset.
3. If it is not likely to cause additional upset, ask the affected person(s) if they wish to have information on relevant information or counselling services.

Participants will be free to end their participation in the process at any time and to refuse to engage in the research or answer questions in interview settings.

Participants are free to withdraw from the research at any point up to a month after their participation in the study. Participants will be asked regularly if they wish to have any further information.

Organisations & Contact Details (for distressed participants):

Citizens' Advice Information:

<http://www.citizensinformation.ie/en/> (details of nearest office here)

Health Information and Quality

Authority: <https://www.hiqa.ie/> Unit 1301, City Gate, Mahon, Cork, T12 Y2XT.

General information (Head office reception) Tel 021 240 9300 / Email: [info@hiqa.ie](mailto:info@hiqa.ie)

Inclusion Ireland (national rights-based advocacy organisation that is committed to the promotion of the rights of people with an intellectual disability and their families) Unit C2, The Steelworks, Foley Street, Dublin 1. Tel: 01 8559891 / Email: [info@inclusionireland.ie](mailto:info@inclusionireland.ie)

Irish Human Rights and Equality Commission

<https://www.ihrec.ie/> 16-22 Green Street, Dublin 7, D07 CR20Lo-call: 1 890 245545/ Tel: + 353 (0) 1 8589601 / Email: [info@ihrec.ie](mailto:info@ihrec.ie)

National Employment Rights Authority (NERA),

<https://employmentrights.ie> Government Buildings, O'Brien Road, Carlow /Tel 059 917 8800/ Lo-call 1890 808 090

## Disclosure of abuse

If an interviewee discloses experience of abuse, the following steps will be taken:

- a) Refer to the Health Service Executive (HSE) policy and steps for Safeguarding Vulnerable Persons at Risk of Abuse: National Policy and Procedures (2014);
- b) Communicate procedures for reporting abuse to the person concerned;
- c) Observe confidentiality and communicate information only with the consent of the person;
- d) Respond to a disclosure in accordance with the Stage 1 steps outlined in the HSE policy.