

INCLUSIVE RESEARCH NETWORK



Share your ideas with other researchers.



Plan your own research.



Have an 'expert research buddy'



Get the support you need.



SUPPORTER HANDBOOK

RELATIONSHIPS AND SUPPORTS

STUDY

Handbook developed by
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National Institute for Intellectual Disability

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INSTRUCTIONS FOR SUPPORTERS OF IRN CO - RESEARCHERS

- By now you should have been approached by an IRN co – researcher for the study on relationships and supports.
- The co – researcher will follow the steps in the table below. Step 1 is about getting consent from you and you should sign the consent form before you start helping them.
- Support the co – researcher if they ask for support. Let the co – researcher ask you for support.
- Remind the co – researcher to

	1. Get a person to support me
	2. Talk to the organisation/advocacy group
	3. Find a good place for the focus group
	4. Give out information forms and flyers to people
	5. Do the focus group
	6. Send back recording, notes and all forms to the NIID

When you support the co – researcher you need to remember they are the ones doing the research.

- Try to support them only when they they ask you or they seem to need it to get back on track (i.e., if they forget one step) so they can continue independently.
- Try not to jump in and take over.

INSTRUCTIONS FOR SUPPORTERS OF IRN CO - RESEARCHERS

As well as supporting the co – researcher if they ask, supporters will always:

Step 1: Get a person to support me

- Check the co – researcher understands your role
- Read the information and consent form carefully before you agree to become involved
- Sign the consent form

Step 5: On the day of the focus group

- Ensure the co – researcher hands out the information forms (to focus group participants and their supporters) before the start of the focus group
- Check that focus group participants understand the information form.
- Check that focus group participants have a chance to ask questions
- Help the co – researcher distribute and collect consent forms
- Practice the steps involved in running the focus group with the co – researcher before the focus group
- Help the co – researcher check that participants have understood what the study is about
- During the focus group, write down ideas discussed on a flip chart
- Look out for discomfort or upset during the focus group
- Talk to the co – researcher about their experience afterwards – what went well, what went not so well and what they thought about what people said

Step 6: Send back recording, notes, and all forms to NIID

- **Help the co – researcher to gather all the materials to send back to NIID** (your consent form, consent form focus group participants / supporters, summary form, personal information forms, notes about the focus group, recording)

NOTES



1. GET A PERSON TO SUPPORT ME



Give the **information form** to the person who is going to support me

☐

(I can find this form on pages 25 and 26 of the handbook)



Get **consent** from the person who is going to support me

☐

(I can find the form on page 27 of this handbook)

☐ I agree to take part in this project.

Signed: _____

Printed name: _____

Date: _____



Make sure the person **signs the consent form**

☐

Ask my support person to

- **Help me** go through the next steps

☐

Can you help me with the steps for this research?

- **Practice** with my support person

☐



2. TALK TO THE ORGANISATION/ ADVOCACY GROUP



Make a list of people who I am
going to talk to about the study

☐

**LIST
PEOPLE I WILL TALK TO ABOUT THE STUDY**



2. TALK TO THE ORGANISATION/ ADVOCACY GROUP



Copy the flyer and information forms

for people with intellectual
disabilities, supporters,
organisations and family
members

☐

(I can find the flyer on page 28 of
this handbook)

(I can find the information forms in
pages 29 to 36 of this handbook)



Go to the organization / advocacy group

☐

Talk to the organization / advocacy group

- check if they are
interested in the study
- ask when would be a
good time and day to run
the focus group

☐☐

Talk to the social worker / key worker at the organization

- Make sure she / he is
available to talk to any focus
group participant in case the
focus group discussion
makes them feel upset

☐



2. TALK TO THE ORGANISATION/ ADVOCACY GROUP



Check with the managers of
The organization that it's ok to
run the focus group

☐

Ask if you can use one of their
rooms

☐

Check the room

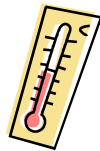
☐



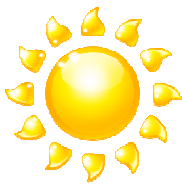
3. FIND A GOOD PLACE FOR THE FOCUS GROUP



Make sure that the room:



is comfortable (not too hot, not too cold)

☐

is bright

☐

is easy to get to

☐

Is close to **bathrooms** that everyone can use

☐

has **enough space** for 10 chairs

☐



4. GIVE OUT INFORMATION FORMS AND FLYERS



Ask people for a good time / day they can come to the focus group

☐

Organize the focus group at least one week after you have talked to the organization / advocacy group

☐

Book a room to run the focus group

☐

Add the **day, time and place** on the flyer

☐

Put up **flyer** with information....

(You can find the flyer on page 28 of this handbook)

☐

Give people **information forms**

(I can find the information forms on pages 29 to 36 of this handbook)

☐

Talk to people with intellectual disabilities and supporters about the study

☐

Answer any **questions** they have

☐



5. DO THE FOCUS GROUP

BEFORE PEOPLE ARRIVE



12:30

you arrive



1:00

group starts

Arrive about 30 minutes before group starts


☐

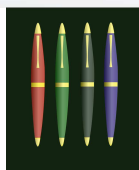
Check you have



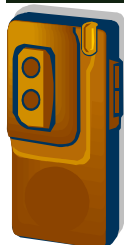
Flip chart, paper and stand

☐


Markers

☐


Pens for people taking part in the focus group

☐


Recorder and batteries

(You can borrow one from Edel or Edurne if you don't have one)

☐

<p>Relationships and Supports Study Participant Information Form</p>	
<p>My name is _____</p> <p>I am a member of the Inclusive Research Network which is looking at how people with disabilities can do research about issues that are important to them.</p> <p>You have decided to do some research about relationships and supports and we are asking you to take part because your views are important to them.</p> <p>Trinity College Dublin said I was OK to do this research because we are recording your rights as a person taking part in the research.</p>	
<p>RELATIONSHIPS AND SUPPORTS STUDY SUMMARY FORM TO BE COMPLETED BY CO-RESEARCHERS</p>	
<p>How many people attended the focus groups?</p>	<input type="text"/>
<p>How many men attended the focus groups?</p>	<input type="text"/>
<p>How many women attended the focus groups?</p>	<input type="text"/>
<p>How many men came with a supporter?</p>	<input type="text"/>
<p>How many women came with a supporter?</p>	<input type="text"/>

Consent, information and summary forms

☐

(You can find the consent forms on pages 37 to 45)

(You can find the information forms on pages 31 to 36)

(You can find the summary form on page 48)



5. DO THE FOCUS GROUP

What to do next



Put out the chairs in a circle
(leave spaces for wheelchair users)

☐

Put flip chart, paper and stand at
top of the circle

☐

Put drinks and snacks on table to
the side

☐

When you have all ready, you must wait for the people to come.

- When the people come, greet them. There are some tips at the end on how you can do that.



- Once you read the information form to the focus group participants you need to check that they understand the study *



- If they agree to take part in the study, they can sign the consent form.

Remember!

*You already gave the information form to them when you went to the organization.



5. DO THE FOCUS GROUP

WHEN PEOPLE ARRIVE



Meet people at the door, chat to them and make them feel comfortable.

You could say...

In your own words

Thanks for coming, how are you today?



Show them where the **drinks and snacks** are.

You could say...

Here is the tea and coffee. Please help yourself.



Ask the participants to **sit down**.

You could say...

There are lots of chairs. Please take a seat.





5. DO THE FOCUS GROUP



Introduce yourself. Ask the participants to introduce themselves.

You could say...

Hi, my name is _____. Could everybody say their name, one at a time. Who wants to start?



Explain what the study is about.

You could say...

We are here today to talk about relationships and supports



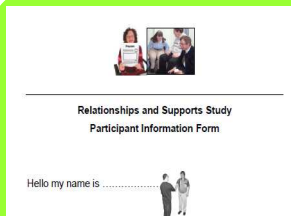
**NOW YOU ARE GOING TO GET CONSENT
FROM THE FOCUS GROUP PARTICIPANTS
AND THEIR SUPPORTERS**





5. DO THE FOCUS GROUP

GET CONSENT



Read information form out loud for everyone. Ask people if they have any questions.

You could say...

Please ask any questions you have about this.



Ask your supporter to check if everyone understands.

You could say...

___ is going to ask you four questions to see if I explained everything well to you.



Explain consent forms and ask if they want to sign them.

You could say...

If you are happy taking part in the focus group, please sign the consent form.





5. DO THE FOCUS GROUP



Ask if everyone is OK with being recorded. Remind them that their participation is voluntary and they can stop taking part in the focus group if they want to.

You could say...

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



5. DO THE FOCUS GROUP

RUN THE FOCUS GROUP



If everyone is ok with being recorded, put the recorder in the middle and **press record**. If somebody says “no”, ask my supporter to take notes.



Explain the **rules**.

Ask focus group participants to tell you the rules.

1. Have mobile phones switched off
2. One person talks at a time
3. Listen carefully to each other
4. There are no right or wrong answers
5. It is OK if somebody does not want to talk
6. We must respect everybody in the group
7. Any other rules?



5. DO THE FOCUS GROUP

SOME TIPS TO RUN THE FOCUS GROUP



Ask the questions.

1. What do you think makes a good friend?
2. What do you think about having a boyfriend / girlfriend?
3. What supports do you need to have friends and a boyfriend / girlfriend?



My supporter will **write down ideas** that people talk about **on the flip chart**.



Give people time to talk about each question.

You could say...

Does anyone else want to say something?



5. DO THE FOCUS GROUP



Listen carefully to what people are saying.



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



Stop others interrupting.

You could say...

Our rule is one person talking at a time



Ask the participants if they would like to say something else.

You could say...

Is there anything else you would like to say about this?



5. DO THE FOCUS GROUP

BEFORE PEOPLE LEAVE



Ask the participants how they are feeling after the focus group.

You could say...

How is everybody feeling now?



Thank them for coming to the focus group.

You could say...

Thanks for coming today and telling me what you think.



5. DO THE FOCUS GROUP



Tell participants the **next steps**.

- We are going to send these recordings to NIID.
- 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.



6. SEND BACK RECORDING, NOTES AND ALL FORMS BACK TO NIID



Play the recorder to make sure the sound is OK.
If the recorder didn't work, try to summarize all the responses in a new recording

☐

Talk to your supporter about how the group went:

- What was good about the focus group?
- What wasn't that good about the focus group?
- How do you think participants felt?

☐

Fill out the summary form

(You can find the summary form on page 48 of the handbook)

☐

Gather consent forms. Put notes from flipchart in the envelope

☐

Put the forms in an envelope

☐

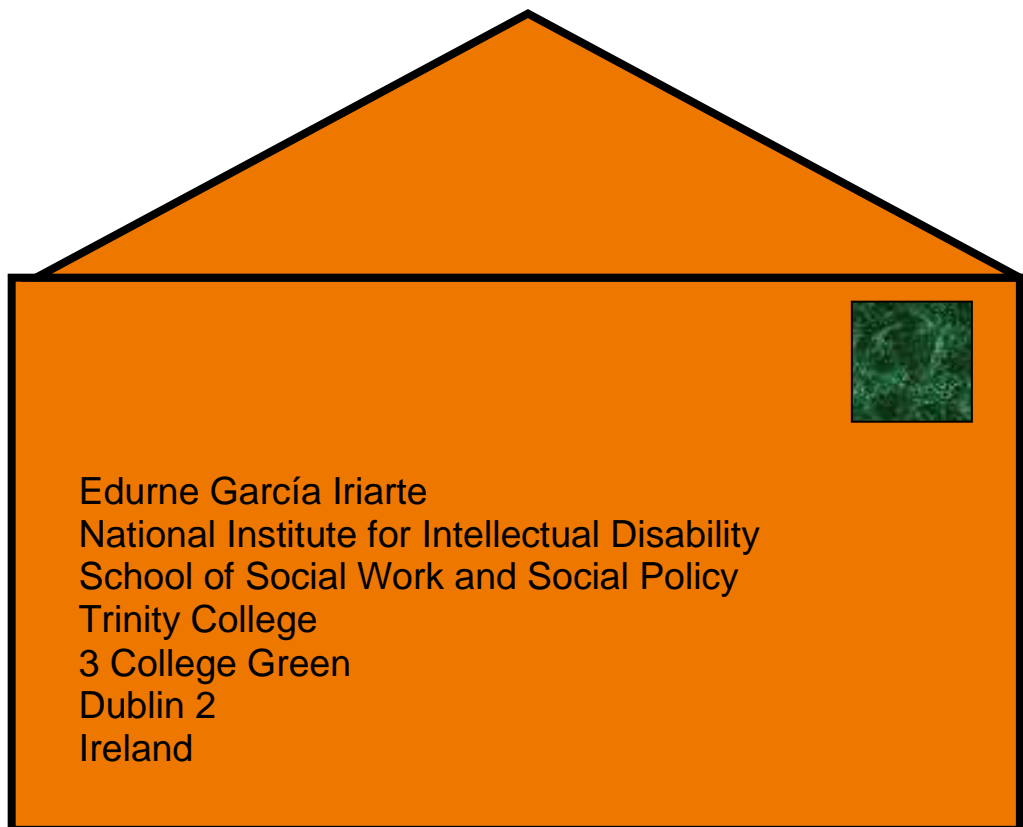
Put the recorder in an envelope

☐



6. SEND BACK RECORDING, NOTES AND ALL FORMS BACK TO NIID

Send the forms, notes and recording back to NIID



FORMS

Supporters of co - researchers



Information form

25 – 26



Consent form

27

Focus group flyer

28

Organizations and family members



Information form

29 – 30

Focus group participants



Information form

31 – 34

Supporters of focus group participants



Information form

35 – 36



Consent form

37

FORMS

Focus group participants



Pre – consent form 38 – 43



Consent form 44 – 45



Personal information form 46 – 47

To be completed by co - researchers



Summary form 48



RELATIONSHIPS AND SUPPORTS STUDY INFORMATION FORM FOR SUPPORT PERSONS OF IRN CO – RESEARCHERS

The proposed research plans to conduct focus groups with people with intellectual disabilities about relationships and supports. This will be one of the few opportunities in which people with intellectual disabilities have been asked to express an opinion about relationships and supports. This research study received ethical approval from Trinity College Dublin in May 2010. This research aims at answering the following questions:

- What makes a good friend?
- What do you think about having a boyfriend / girlfriend?
- What supports do you need to have friends and a boyfriend / girlfriend?

Information forms and flyers about the research will be distributed to organisations and advocacy agencies as well as other people with intellectual disabilities. Focus group participants will have the opportunity to ask questions about the research project and will join the focus group voluntarily upon signing the consent form.

Each focus group will last from 45 minutes to 1 hour. Members of the IRN who have been trained in this methodology will facilitate the focus groups. Members of the IRN will record the main points of the discussion on a flip chart and the focus group's discussion will be recorded with the agreement and signed consent of all participants.



As a support person of the IRN co – researchers, your involvement in the study will include:

1. Supporting the IRN co – researcher through all the steps in the research process, including:
 - recruitment of research participants
 - making arrangements for the focus groups
 - running the focus groups
 - collecting the data
2. Tasks specific to the support person of IRN co – researcher, which are described in the *Supporter Handbook*.

This can be an emotional and sensitive topic for some people and during the course of running the focus groups it is possible that a person may become upset or reveal personal difficulties.

If we hear from any of the research participants anything that would suggest he or she is unsafe, the necessary authorities may need to be contacted after the person has had the opportunity to discuss the issues with a third party.

When the research is completed, a research report will be developed and available at the NIID and NFVB websites. A major purpose of this research is to hear the voice of citizens with intellectual disabilities so that their needs and wishes regarding relationships and supports can be better addressed.

If you have any questions about this research please contact Edel Tierney at (091) 792316 or Edurne Garcia at (01) 896220. Thank you.



RELATIONSHIPS AND SUPPORTS STUDY

CONSENT FORM FOR

SUPPORT PERSONS OF IRN CO – RESEARCHERS

Please tick

- ☐ I have had this research explained to me.
- ☐ I have been able to ask questions and have them answered.
- ☐ I understand what is expected of me as a support person of the IRN co – researcher.
- ☐ I will support the IRN co - researcher through the different research steps:
 - recruitment of research participants
 - making arrangements for the focus groups
 - running the focus groups
 - collecting the data
- ☐ I will not speak for the researcher unless invited to do so by them.
- ☐ I understand that the focus group will be recorded using audio equipment.
- ☐ I will not speak for the focus group participants taking part.
- ☐ I will not talk about what goes on in the focus group to other people.
- ☐ I agree to take part in this project.

Signed: _____

Printed name: _____

Date: _____

Focus Group Invitation

The Inclusive Research Network is pleased to invite you to talk about supports and relationships in a focus group.

We are inviting you because we think your views are important.

We will ask you questions about



What makes a good friend?



What do you think about having a boyfriend / girlfriend?



What supports do you need to have a good friend, a boyfriend, and a girlfriend?

The research will not change how many people help and support you or your relationships, but will help us know more about what needs to be done to help you live a good life.

We will meet:

Where? _____



When? _____



What time? _____



There will be snacks.

Your organisation has a copy of this flyer.



If you have any questions, please contact the Inclusive Research Network (IRN) on



(091)792316 or email



irn@fedvol.ie



RELATIONSHIPS AND SUPPORTS STUDY

INFORMATION FORM FOR

ORGANISATIONS AND FAMILY MEMBERS.

The proposed research plans to conduct focus groups with people with intellectual disabilities about relationships and supports. This will be one of the few opportunities in which people with intellectual disabilities have been asked to express an opinion about relationships and supports. This research study received ethical approval from Trinity College Dublin in May 2010. This research aims at answering the following questions:

- What makes a good friend?
- What do you think about having a boyfriend / girlfriend?
- What supports do you need to have friends and a boyfriend / girlfriend?

Information forms and flyers about the research will be distributed to organisations and advocacy agencies as well as other people with intellectual disabilities. Focus group participants will have the opportunity to ask questions about the research project and will join the focus group voluntarily upon signing the consent form.

Each focus group will last from 45 minutes to 1 hour. Members of the IRN, co – researchers with intellectual disabilities and their supporters, who have been trained in this methodology, will facilitate the focus groups. Members of the IRN will record the main points of the discussion on a flip chart and the focus group's discussion will be recorded with the agreement and signed consent of all participants.



If we hear from any of the research participants anything that would suggest he or she is unsafe, the necessary authorities may need to be contacted after the person has had the opportunity to discuss the issues with a third party.

This can be an emotional and sensitive topic for some people and during the course of running the focus groups it is possible that a person may become upset or reveal personal difficulties.

We have asked supporters of the co – researchers to be aware of this and to take the necessary steps in supporting the co – researchers and focus group participants to talk about this topic. This may mean referring the person(s) to a third party for further ongoing discussion or support.

When the research is completed, a research report will be developed and available at the NIID and NFVB websites. A major purpose of this research is to hear the voice of citizens with intellectual disabilities so that their needs and wishes regarding relationships and supports can be better addressed.

If you have any questions about this research please contact Edel Tierney at (091) 792316 or Edurne Garcia at (01) 896220. Thank you.



Relationships and Supports Study

Participant Information Form

Hello my name is



I am a member of the Inclusive Research Network which is looking at how people with disabilities can do research about issues that are important to them.



We have decided to do some research about **friends, boyfriends and girlfriends.**



We are asking you to take part because your ideas are important to us.



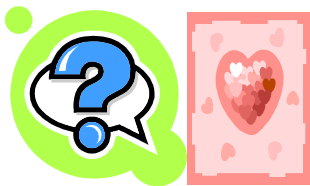
Trinity College Dublin said it is OK to do this research.



This means we would like you to come to a group and talk about:



- What makes a good friend?



- What do you think about having a boyfriend / girlfriend?



- What supports do you need to have friends and a boyfriend / girlfriend?



What you say in the group will be kept private. People outside the room will not know anything you say.



The research will not change how many people help and support you. It will not change how many friends, boyfriends or girlfriends you have, but will help us know more about what needs to be done to help you live a good life.



We will write a report about what everyone says. This will be available on the Internet (NFVB and NIID websites).



Please think if you want to take part in this research and ask me any questions you have about it.

If you don't want to take part in the research, that's fine.



If you decide to take part in this research, I will ask you to sign the consent form.



If you decide to take part in this research, it is OK to stop at any time.



This can be an emotional and sensitive topic for some people. If you become upset, we will ask you if you want to stop taking part in the focus group. The social worker / key worker at your organization will be happy to talk to you about it too.

If we hear some things that make us think that people are unsafe, then we would ask you to meet with another person to talk to them about what has happened and to support you to decide what to do next.



If you have any questions later on, please contact Edel Tierney at (091) 792316 or Edurne Garcia at (01) 896220.

Thank you!



RELATIONSHIPS AND SUPPORTS STUDY

INFORMATION FORM FOR

SUPPORTERS OF FOCUS GROUP PARTICIPANTS

The proposed research plans to conduct focus groups with people with intellectual disabilities about relationships and supports. This will be one of the few opportunities in which people with intellectual disabilities have been asked to express an opinion about relationships and supports. This research study received ethical approval from Trinity College Dublin in May 2010. This research aims at answering the following questions:

- What makes a good friend?
- What do you think about having a boyfriend / girlfriend?
- What supports do you need to have friends and a boyfriend / girlfriend?

Information forms and flyers about the research will be distributed to organisations and advocacy agencies as well as other people with intellectual disabilities. Focus group participants will have the opportunity to ask questions about the research project and will join the focus group voluntarily upon signing the consent form.

Each focus group will last from 45 minutes to 1 hour. Members of the IRN who have been trained in this methodology will facilitate the focus groups. Members of the IRN will record the main points of the discussion on a flip chart and the focus group's discussion will be recorded with the agreement and signed consent of all participants.



As a supporter of a person with an intellectual disability you will be asked to help the person communicate his / her views in the focus group by asking questions e.g. 'What do you think?' or prompting e.g. 'Do you want to say anything about that?'.

If we hear from any of the research participants anything that would suggest he or she is unsafe, the necessary authorities may need to be contacted after the person has had the opportunity to discuss the issues with a third party.

When the research is completed, a research report will be developed and available at the NIID and NFVB websites. A major purpose of this research is to hear the voice of citizens with intellectual disabilities so that their needs and wishes regarding relationships and supports can be better addressed.

If you have any questions about this research please contact Edel Tierney at (091) 792316 or Edurne Garcia at (01) 896220. Thank you.



RELATIONSHIPS AND SUPPORTS STUDY CONSENT FORM FOR SUPPORT PERSONS OF FOCUS GROUP PARTICIPANTS

Please tick

- ☐ I have had this research explained to me.
- ☐ I have been able to ask questions and have them answered.
- ☐ I understand what is expected of me as a support person of the focus group participant (help him / her express their own views).
- ☐ I will support the focus group participant to speak up at the focus group.
- ☐ I will not speak for the focus group participant I support unless invited to do so by him / her.
- ☐ I will not speak for the other focus group participants and the IRN co – researcher.
- ☐ I understand that the focus group will be recorded using audio equipment.
- ☐ I will not talk about what goes on in the meeting to other people.
- ☐ I agree to take part in this project.

Signed: _____

Printed name: _____

Date: _____



Now check that the person you are going to take part in the focus group understands

- **what she or he is going to do and**
- **what the study is about.**

You can say:

I am going to ask you four questions to see if I explained everything well to you.



1. If you decide to take part in this research, what are we going to talk about? (Please pick one of these two options)

- ... relationships and supports? ☐



OR

- ... arts and crafts? ☐





2. If you decide to take part in this research, what will you be doing? (please pick one)

- Going bowling ☐



OR

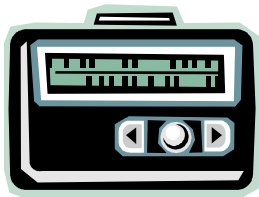
- Coming to a group to talk and answer questions ☐





3. If you take part in this group...

- More people will know what you are telling me ☐



- Outside the focus group, nobody will know about what you tell me. Whatever we say in the room stays in the room ☐



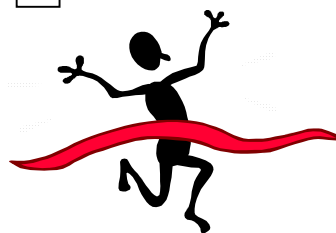


4. If you don't want to keep answering the questions...

- You can stop answering the questions at any time ☐



- You have to answer every question. You are not allowed to stop ☐





Now check the answers:

If all the answers are correct, ask the person to sign the consent form.

“You have answered all the questions and now I will fill in a consent form with you.”

If one or more of the answers are incorrect, explain the information form again to them and repeat the questions.

If one or more of the answers are still incorrect, explain to the person that they can't take part in the study.



RELATIONSHIPS AND SUPPORTS STUDY CONSENT FORM FOR RESEARCH PARTICIPANTS

Please tick if you agree

☐ The researcher has talked about the research to me.

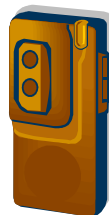


☐ I have been able to ask questions about the research.



☐ I understand that I will join a group of people and I will talk about friends, boyfriends and girlfriends with them.

☐ I agree to have what I say recorded.





☐ I can stop being involved at any time on this project.



☐ My answers will be kept confidential.



☐ I would be happy to talk to another person if I am unhappy about anything in this focus group.



☐ I agree to take part in this project.



Signed:

Printed name

Date: _____

Signature of witness:

Printed name:

Date: _____




RELATIONSHIPS AND SUPPORTS STUDY

PERSONAL INFORMATION FORM FOR FOCUS GROUP PARTICIPANTS

Please tick one box for each question or write your answer. You don't have to answer the questions if you do not want to. This information is private. Nobody will know it was you who wrote this.

	What age are you?	
	Are you a man or a woman?	Man..... <input type="checkbox"/> Woman..... <input type="checkbox"/>
	Where do you live?	with family..... <input type="checkbox"/> in a group home..... <input type="checkbox"/> in a semi – independent apartment..... <input type="checkbox"/> other _____
	What do you do during the day? (you can choose more than one)	Home based..... <input type="checkbox"/> Day / Training centre..... <input type="checkbox"/> Sheltered workshop..... <input type="checkbox"/> Regular paid employment.... <input type="checkbox"/> Regular unpaid employment.. <input type="checkbox"/> Supported employment..... <input type="checkbox"/> Mainstream school..... <input type="checkbox"/> Special school..... <input type="checkbox"/> College / University..... <input type="checkbox"/> Other _____ No day activities..... <input type="checkbox"/>
	Are you in a self – advocacy group?	yes..... <input type="checkbox"/> no..... <input type="checkbox"/>
	Are you ?	married..... <input type="checkbox"/> single..... <input type="checkbox"/> divorced..... <input type="checkbox"/> widowed..... <input type="checkbox"/>








	<p>Are you or have you been in a romantic relationship?</p>	<p>Yes, I have been..... <input type="checkbox"/></p> <p>No, I haven't been..... <input type="checkbox"/></p> <p>Yes I am..... <input type="checkbox"/></p> <p>No I am not..... <input type="checkbox"/></p>
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RELATIONSHIPS AND SUPPORTS STUDY

SUMMARY FORM TO BE COMPLETED BY CO-RESEARCHERS

	How many people attended the focus groups?	
	How many men attended the focus groups?	
	How many women attended the focus groups?	
	How many men came with a supporter ?	
	How many women came with a supporter ?	