



Accessible participant information leaflet (WP3 & WP4)



**Developing guidelines for support after a
dementia diagnosis**

**PARTICIPANT
INFORMATION BOOKLET**

This study is being carried out by Trinity College Dublin

Dear Participant (and/or support person),

This booklet is to tell you about our research.

We are researching supports for people with intellectual disability when they get a diagnosis of dementia.

1. What is this study about?



This study is about people with an intellectual disability and dementia.

Trinity College Dublin is doing this study.



Dementia is a condition that affects how people think and remember things.

It makes it more difficult for people to take care of themselves.



This study will help us to understand what is important to people with an intellectual disability when they get a diagnosis of dementia.



We want to understand what supports are important when living with dementia.

We also want to understand what it is like using these supports.

2. Who is taking part in the study?



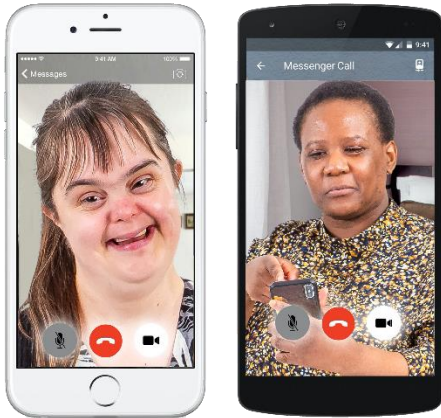
People with an intellectual disability and a diagnosis of dementia.



People from all over Ireland are taking part in the study.

We are recruiting people from the National Intellectual Disability Memory Service and other services.

3. What will I do if I take part?



You will talk with a researcher.

You can ask someone to support you for this.



You could bring a photograph, an object or something that is important to you with you to the interview to tell us what living with dementia is like.

You can use this to tell us about what kind of support you get.

This might be helpful if it is difficult for you to put your answers into words.

4. What will you be asked?

You will be asked questions about:



What kind of supports you got after being diagnosed with dementia



What you liked or did not like about the supports you got



What kind of supports you would like to have in the future

You can choose someone to help you answer questions



If you wish, someone you know can help you answer the questions

6. Who will speak with you?



A researcher from Trinity College will call to speak to you.

7. How will they collect the information?



The researcher will put your answers into a computer.




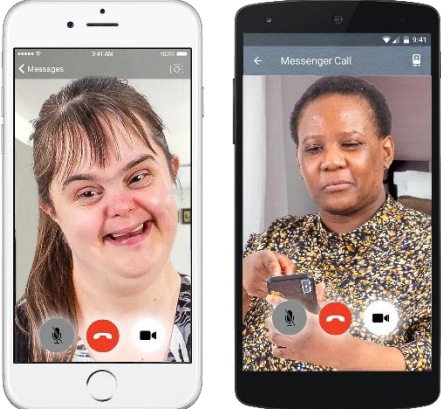
All of your information will be kept safe and private.

8. How long will it take?




The interview will last for around 1 hour.

	<p>If the interview is too long, you can take a break.</p>
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	<p>The researcher can also call back a second time to finish the interview.</p>
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9. Do you have to take part?

	<p>No.</p> <p>It is your choice to take part in the study.</p> <p>You can also change your mind and stop taking part at any time.</p> <p>Your decision will not affect the support you receive.</p>
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10. Are there any risks or benefits involved?



Some of the things we talk about in the interviews might be upsetting.

Please let us know if you are finding it difficult to continue with the interview.

Remember: you are free to stop participation at any point if you wish to.



Let us know if there is anything you want to talk about afterwards.

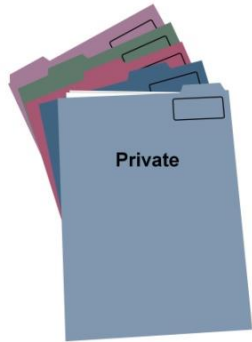
You may want to talk to your key worker or service after the interview, or you can ask us to talk to them.

If you wish, you may want to talk to Samaritans. They listen to people who want to talk about difficult feelings.

You can call Samaritans at 116 123.

You can email Samaritans at jo@samaritans.ie

11. Will anyone else know what you tell us?



No.

We will keep all your personal information private.

Your name will not be in any report.

12. What should you do next?



A researcher will be in contact with you soon to agree a time for you to take part.

13. Is there anything else you need to think about?



Yes – you need to think about:

- When is a good time to meet for the interview?
- Do you want someone to support you with the interview?

14. Who do you contact if you have any questions?



If you have any questions, please contact:



Andrew P. Allen
Research Fellow
Phone: 089-9526518
Email: apallen@tcd.ie