RHAPSODY (Research to Assess Policies and Strategies for Dementia in the Young)

Informed consent form for carers of adults with young onset dementia

Before reading further, please review the Participant Information Sheet.

You do not have to decide today whether or not you will participate in the study. Before you decide you may wish to talk about the research with anyone you feel comfortable with.

If there is information you do not understand, please feel free to ask any of the researchers.

Please note that our deadline for recruiting volunteers is still open.

Contact

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CONSENT FORM

A pilot study of an online information and support program for informal carers (that is, family or friends rather than paid or professional carers) of adults with young onset dementia (YOD).

Please initial each box

I have read the document 'Participant Information Sheet' about the Rhapsody study, which will evaluate an online program developed for carers of adults with young onset Alzheimer's disease or Frontotemporal Dementia. I have had the opportunity to ask the research team questions, and my questions have been answered to my satisfaction. I have been given enough time to think about participating.	
I understand that I will be asked to take part in three appointments and that these appointments can be by telephone, or skype, or in person at the University, according to my choice.	
I understand that taking part in the study involves using an online program on a computer or tablet over a period of up to 6 weeks. I will have a personal user log in to access the program, and how I use the program online will be monitored.	
I understand that after having used the program, I will be asked to answer questions about my experience of using it. My feedback will be used to improve the online program before it is used more widely.	
I understand that I will be allocated by a random procedure to one of two groups of participants. If I am allocated to group A, I will have access to the program as soon as the study starts. If I am allocated to group B, I will be able to use the program 6 weeks later.	
I understand that I have the right to stop participating in the study at any time, without stating reasons and without any consequences for the care received by myself or the person with YOD.	
I give permission for my data to be stored securely for 15 years, and to be shared only with the relevant entities/organisations involved in this study. I understand that my personal data will be treated as confidential and handled in accordance with the Data Protection Act 1998. It will not be possible to identify me in any information published about this study.	
I consent voluntarily to be a participant in this study.	

Name of participant: _____

Signature of participant: _____ Date: _____

***Statement by the researcher/person taking consent**:*

I state that the above mentioned participant was informed about the study. I confirm that the participant was given an opportunity to ask questions about the study, and all their questions have been answered to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

Name: _____ Function: _____

Signature (researcher):_____ Date: _____