



Participant Information Sheet for Service Users

A trial of one to one befriending in people with learning disabilities



My name is Emma



I am a researcher



I am writing to ask if you want to take part



To help you understand this letter you can



ask someone to read it for you

• talk to your carer about it

you can ask me questions

What is my work about?



I want to find out if befriending may help people with learning disabilities



befriending is when someone spends time with you but they are not paid to do this this person may help you to go outside and do activities with you



I want to find out

 if befriending can help people who are feeling lonely or who cannot go out much



 I want to find out if befriending can help people feel happier and better about themselves



I am looking for 50 people to take part

Why do I want to see you?

I want to see you because



- you have said that you would like a befriender
- you have been referred to a befriending service



 you have a mild or moderate learning disability



 the information you give may help to make things better for other people who are feeling lonely or sad

What will happen to me if I take part?



You do not have to take part

It is up to you



If you say Yes to taking part



I will ask you some questions about your mood and carry out an a short test of your abilities



To take part, you will need to have some symptoms of depression (low mood)





You will be put in one of two groups



You will not choose which group you will be in. That will be decided by chance, like a lucky dip



Half the people who take part will be in the group that will get a **befriender**



The other half will carry on with the things that they usually do (usual care group)



If you are in the group that will get a befriender



We will try to match you with someone who likes the same things as you



The volunteering coordinator will introduce you to your befriender



If you get along with each other, you will meet each other **once a** week for 6 months



The befriender may meet with you during the day, at weekends or in the evening.



You and the befriender will plan activities that you would like to do with each other



You will both be given some information about activities in the local area



You will both me asked to keep a diary of things that you do together



The volunteer coordinator will meet with you both 6 weeks after your first meeting



They will call you once a month to find out how you are doing



If your befriender can no longer visit you, we will try to match you with some one else



You will both meet the volunteer coordinator again at the end of the six months.



At the end of the six months, you and your befriender can decide if you want to carry on meeting up



If you are in the **usual care group**, you **will not** have a befriender

you will carry on with your usual activities



At the end of 6 months, you will be matched to a befriender but you may have to wait.



We will ask **everyone** in the study some questions



We will ask you some questions at the start of the study and again at six months



and 12 months into the study



These questions will be about

- your mood and how you feel about your self
- if you feel lonely



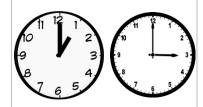
your quality of life



- the help and support you get
- what activities you do outside of the home



 I will also ask your carer some questions about your appointments with health staff



The questions may take up to two hours to do



At the end of the study we may invite you to take part in a short interview about the study

- This will be recorded
- You do not have to take part in this

Do you have to take part?



No, you do not have to take part

You can tell me Yes if you want to take part



You can tell me No if you do not want to take part

If you say No it will not change the care you get



If you say **Yes**, I will ask you to sign a consent form



You can stop taking part at any time



You do not have to give a reason and this will not change the care you get



If something happens and you can't give consent anymore, you will no longer be included in the study

But we will keep the information we already have unless you tell us not to.

What happens after you have seen me?



If you agree to take part in this research



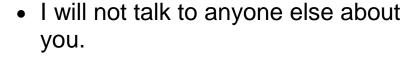
To thank you for your time, we will give you a £15 gift voucher after answering the questions at 6 months and 12 months (£30 in total)

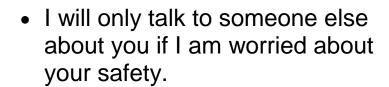


I will let your GP (doctor) know you are taking part



 the information you give will be confidential (private)







 the recordings form the interview will be put on a computer and erased from the digital recorder



 I will not use any information with your name and address

Privacy notice



- UCL is the sponsor for this study.
- We are the data controllers this means that we have to make sure your data is used in the right way



 Your data may be looked at by people at UCL to make sure we are doing things right



 We will keep information about you up to 1 year after the study has ended You can find out more about how we use your information at data-protection@ucl.ac.uk.

If you want to talk to me



 You can call me if you have any questions about the study



 You can call me if you are not happy with the study or if anything happens in the study that you feel uncomfortable about.



My phone number is 078 7984 3542

Befriending in people with ID (BID study) Participant Information sheet Version 4; 30/04/2019 IRAS number: 240552

Name: Emma Mckenzie Research Assistant Division of Psychiatry University College London 6th Floor, Maple House 149 Tottenham Court Road London W1T 7NF

Tel: 0300 555 1200 Ext. 54997

Mob: 078 7984 3542

Email: emma.mckenzie@nelft.nhs.uk

Name: Dr Afia Ali
Chief Investigator
Consultant Psychiatrist and Senior Clinical Lecturer
University College London
6th Floor, Maple House
149 Tottenham Court Road
London W1T 7NF

Tel: 0208 928 8300

Email: afia.ali@nelft.nhs.uk; afia.ali@ucl.ac.uk

Thank you for looking at this

Befriending in people with ID (BID study) Participant Information sheet Version 4; 30/04/2019 IRAS number: 240552

This research project has been reviewed by the London- City & East Research Ethics Committee who are there to make sure you are treated well.