

Supplementary Material: Participant Information Sheet and Consent Form

Information about a Research Study

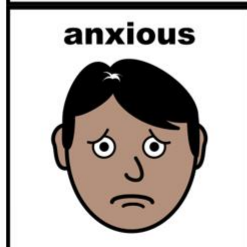
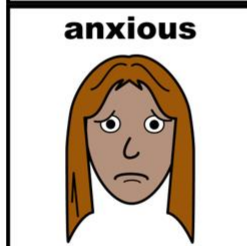
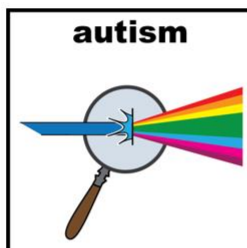


BEAMS-ID

Behavioural Interventions to Treat Anxiety in
Adults with Autism and Moderate to Severe
Intellectual Disabilities



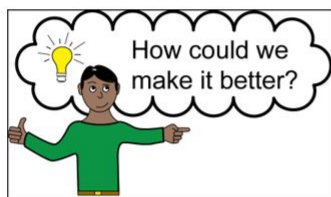
We are doing a
research study. It
is called
BEAMS-ID



Our research
study is about
autistic people
with learning
disabilities who
are anxious.



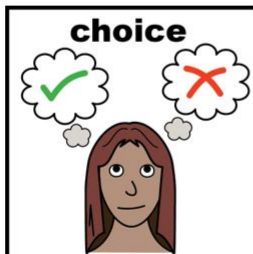
Our research study is about caring for people who are anxious.



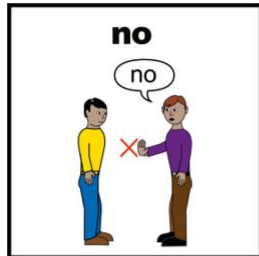
We want to find out how to help people better.



We want to know if you want to take part in our research study.



Taking part is your choice.



You do not have to talk to us. You can say no.



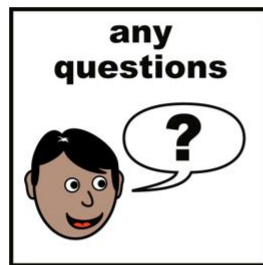
If you want, you can talk to your friends, carers, or family about this study.



If you have an advocate, you can talk to them about this study.

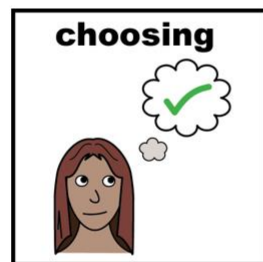


We want to tell you about the study before you make your decision.



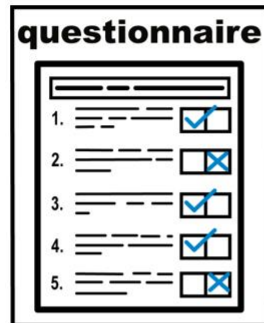
If you have any questions, just ask us, and we will answer them. Our contact details are at the end of this leaflet.

What will happen if I take part?



If you say yes to taking part, then the following 4 things will happen.

1. The first thing that will happen.



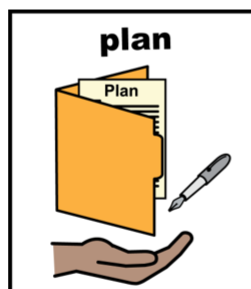
A researcher will fill out questionnaires about your feelings with you and your carer.

We will look in your medical records. We need your permission to do this first. You can say no.

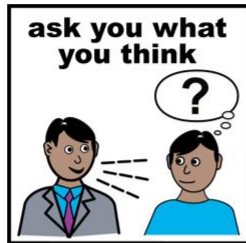
2. The second thing that will happen.



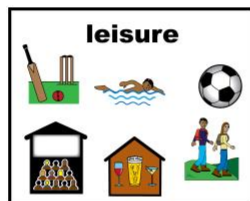
A therapist will come and talk to you and your carers. They will try to help you with your anxiety.



A therapist will make a plan to help you with your anxiety. We will do this with you and your carers.



We will ask you what you think about the plan.



The plan will involve doing new activities. Some of these might take place in the community.



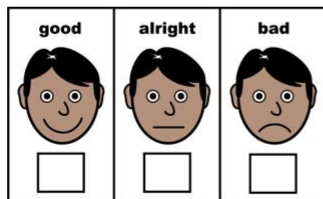
This means that you might go outside and do some new things.



The therapist will talk to you and your carer about how you have been feeling. This is like counselling.

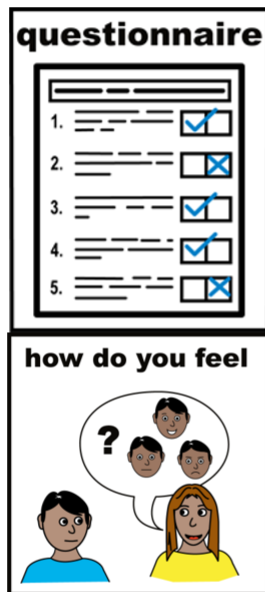


The therapist will come and see you and your carer up to 12 times in total. Each time will last about 1 and a half hours.



The therapist and your carer will ask you how you are feeling to make sure you are ok.

3. The third thing that will happen.

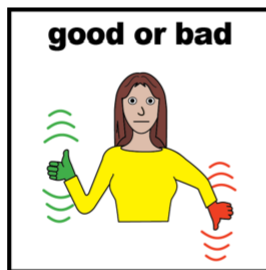


We will fill out
some
questionnaires
about your
feelings with you
and your carer
again.

4. The fourth thing that will happen.



When all your appointments are over, we would like to interview you and your carer.



We will ask you about the good and bad things about the treatment plan.



We need to record the interview to play it back later.

Good and bad things about taking part

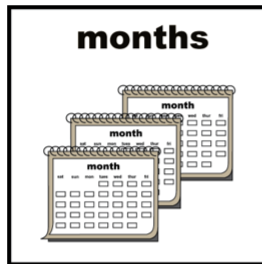


You will help us to work out how to help people with autism and learning disabilities who are anxious. It will also help us decide whether to do a bigger study.



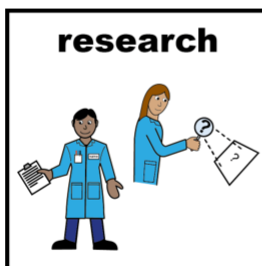
When doing your plan, you might feel more anxious sometimes. But we will work with you and your carer to help you.

How long does the study last?

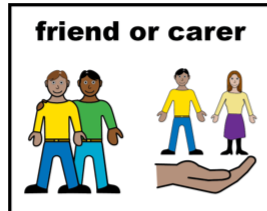


Our study will last over a year. If you say yes to taking part, you will take part for up to six months. This is half of a year.

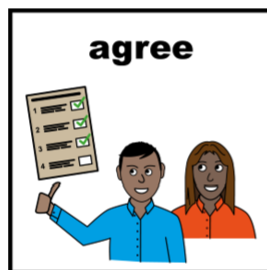
Who will know about me if I take part?



We will know that you said yes, and we will tell some other people. But we will keep your information private.



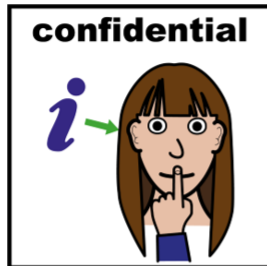
But we will tell your carer. We also want them to be part of our study.



We need your permission to talk to your carer. We will ask your carer to be in our study with you. Your carer might be a family member. Or it could be someone else who helps you.



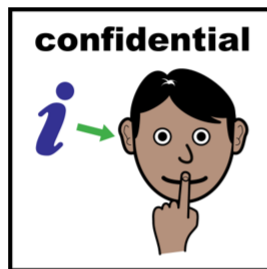
We will also tell the community learning disabilities team. You may already know them.



We will keep all the information we have about you confidential. This means it is private. We will not tell other people about you.



We will only ask for information we need for the study. We will record your name, address, and telephone number. We will keep this confidential.



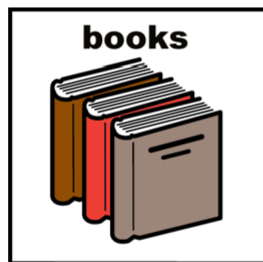
To keep information private, we make it anonymous. This means we will use a special number rather than your name when we write about you. This is to keep your name secret. We might share anonymous information with others. Nobody will be able to tell who you are.



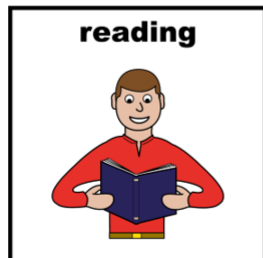
If we think someone is hurting you, or someone you know is being hurt, we will have to tell someone

else about you. This might be a social worker. We would do this to keep people safe.

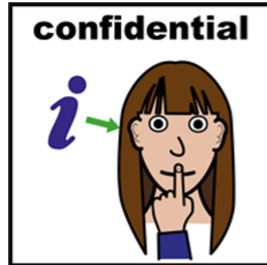
What happens at the end of the study?



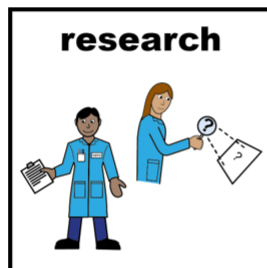
We will write about what we have found out and share it. You can have a copy.



This is so other people can read about the study and learn from it.



We will not write your name. You taking part remains confidential



We might do a bigger study.

Payment

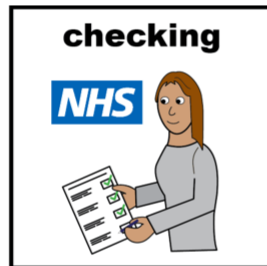


We will pay you £10 each time you do an assessment.

Who has checked this study?



A group of people called Wales Research Ethics Committee 6 (IRAS project ID: 292402). have checked this study.



People from the NHS may also check our study. This is to make sure that the researchers are following the rules.



We will follow rules and laws that protect what you tell us. They are called General Data Protection Regulation (GDPR) and the Data Protection Act.

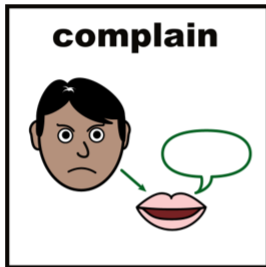
Who is paying for this study?



The National Institute for Health Research pay for this study. They pay for studies that are about making care better in the NHS.

Complaints

complain



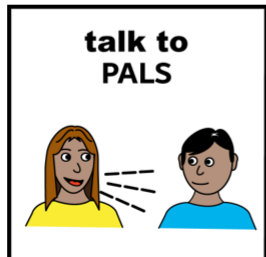
If you are not happy about something, you can ask us to talk to you about it.

talk to keyworker



You might not want to talk to us. Instead, you can talk to your keyworker.

talk to PALS



You can also talk to *PALS* who will help you. *PALS* stands for *Patient Advice and*

Liaison Service. They help with complaints.



PALS can be reached by calling 0800 212 445 or by emailing PALS@covwarkpt.nhs.uk or you can write to them: PALS and Complaints Team, Wayside House, Wilsons Lane, Coventry, CV6 6NY



If you are not happy with how we used your information, you can contact our Data Protection Officer. Her name is Becky Keough and her email address is:

Becky.Keough@covwarkpt.nhs.uk



Coventry and Warwickshire Partnership NHS Trust are the sponsor of this study. This means that they are keeping an eye on things to make sure the study goes to plan.

Who is doing this study?



Professor Peter Langdon oversees the study. He is a clinical psychologist.



There are people from the National Autistic Society helping with the study



People from the Universities of Glasgow, East Anglia, Bristol, and the NHS are helping.



You can contact Peter by calling 02476 522912, or emailing him:

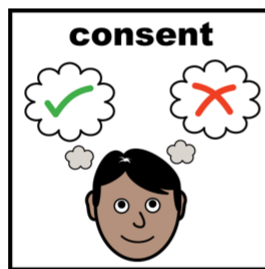
Peter.Langdon@warwick.ac.uk or

write to him at CEDAR, University of Warwick, Coventry, CV4 7AL

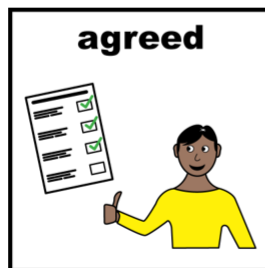
What happens next?



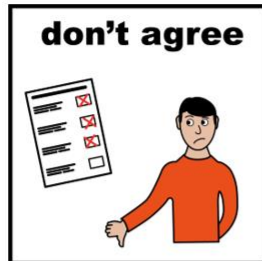
You make a choice about whether you want to take part in our study.



This is called getting your consent. You choose yes or no.



If you want to take part, we will ask you to sign a consent form. This form is at the end of this leaflet.



If you do not want to take part in our study. This is ok. It is your choice.



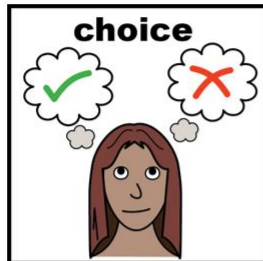
Take some time to make a choice. Talk to others, like a friend, carer, or family member.



If you have any questions, ask them.



When you make your decision, tell us.



If you decide to take part, you can change your mind later. You do not have to give us a reason. It's your choice.

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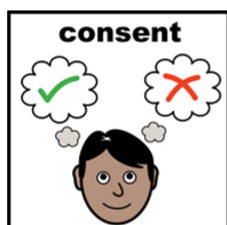
Tear off the Consent Form and return to the BEAMS-ID team.
Leave the Information Leaflet for your record.



CONSENT FORM

(Version 3.0 – 3 February 2021)

Participant Identification Number



This is a consent form. You should complete this form if you want to be in our study.



You need to read each part and tick to show you agree. Then sign your name. We will read this with you.

Please tick

Yes No

I understand the information about the BEAMS-ID study (Version 3.0 – 3 February 2021).

<input type="checkbox"/>	<input type="checkbox"/>
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Yes No

I have spoken to the research team, and asked questions, if I wanted. They answered any questions I asked.

<input type="checkbox"/>	<input type="checkbox"/>
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Yes No

I understand that taking part is my choice. I can change my mind in the future and say that I no longer want to be in the study. I do not have to tell the researchers why.

<input type="checkbox"/>	<input type="checkbox"/>
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Yes No

I understand that if I stop taking part in this study in the future, it will not affect my care or treatment.

<input type="checkbox"/>	<input type="checkbox"/>
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Yes No

I understand that a therapist will come and see me and make a plan to help me with anxiety.

<input type="checkbox"/>	<input type="checkbox"/>
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Yes No

The research team and therapist will speak to and work with my carers. I agree to this. The name of my carer is:

<input type="checkbox"/>	<input type="checkbox"/>
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Yes No

I agree that the research team can look at my medical records.

<input type="checkbox"/>	<input type="checkbox"/>
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Yes No

When my plan is completed, the research team may interview me. I agree that this interview can be recorded.

<input type="checkbox"/>	<input type="checkbox"/>
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Yes No

I understand that people from the NHS may look at the information collected during the study to check that the researchers are following the rules. I agree to this.

<input type="checkbox"/>	<input type="checkbox"/>
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Yes No

I understand that the information collected about me will be made anonymous. This anonymous data may be shared with other researchers. I agree to this.

<input type="checkbox"/>	<input type="checkbox"/>
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Yes No

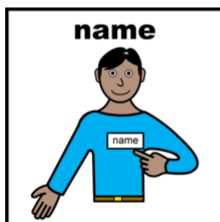
I understand that if I change my mind in the future and no longer want to be in the study, the researchers will ask to keep my information. I can say no if I want.

<input type="checkbox"/>	<input type="checkbox"/>
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Yes No

I agree to be in the study.

<input type="checkbox"/>	<input type="checkbox"/>
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What is your name?



What is your phone number?



What is your address?



Your signature



Today's date

**Name of the Person
taking consent:**

Signature:

Date:

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