

# Participant information Sheet (Young People)

## Research Project Title

Mechanisms of change in intensive group intervention for teenagers who stammer.

## Invitation

You are being invited to take part in this research project. Before you decide to do so, it is important you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

## What is the project's purpose?

This research project aims to find out how taking part in the Talking Out Residential can lead to you feeling differently about stammering.

The project is being carried out by Ben Bolton-Grant. Ben is a speech and language therapist and a PHD student at Leeds Beckett University. This project is being carried out as part of Ben's PHD.

## Why have I been asked to take part?

You have been asked to take because you are going to be going on the Talking Out Residential and we are interested in finding out about what taking part in the residential is like.

## What do I have to do?

If you choose to take part in this research, there are different ways to take part.

1. Ben is one of the speech and language therapy team who run the residential. During the residential, he will make notes about what he notices. He won't use your name or anything else that could be used to identify who you are in the notes. This means you don't need to do anything extra.
2. Ben will be given a copy of the assessments you fill in during the residential. These are a normal part of the residential and you will be asked to fill them in even if you don't want to be part of the research project. This means that you don't need to do anything extra.
3. Take part in online focus groups after the residential has finished. A focus group is a small group discussion during which Ben will ask the group questions about what the residential has been like. They will last no more than 1 hour and you can choose whether or not you want to take part. The conversation will be recorded so that Ben can listen back to it later to analyse what everyone said to help work out how the residential works. These recordings will be kept secure and not shown to anyone else.
4. Photographs and videos will be taken during the residential (if you have agreed to this on the referral form). You might be asked to look at them during the focus group to help everyone remember what happened during the day.

## Do I have to take part?

No.

It is up to you to decide whether or not to take part and any part of this research. If you want to just volunteer for some parts and not others, that's fine too.

## Can I still go on the residential if I don't want to take part in the research?

Yes. You can still go on the residential if you don't want to take part in the research. Your place on the residential and the activities and support you receive during it will not change if you do not wish to be part of the research.

## Can I change my mind?

Yes, you can change your mind and opt out of the research. You can do this up until 10 days after the focus group has happened. After this point your data will have been combined with other people's data and it will not be possible to remove it from the analysis.

## What are the possible disadvantages and risks of taking part?

Taking part in the research probably won't feel very different from taking part in the residential. However, if you choose to join in with the focus groups this will mean doing extra online sessions once you get back home after the residential. You might feel too tired sometimes, or feel that you don't want to talk about stammering anymore. It's ok to not join in if you feel that way.

Taking part in the research will not affect the activities and support you receive on the residential in anyway. You can give your honest opinions about what the residential has been like and these won't change how you are treated or the support you are given during the week.

## What are the possible benefits of taking part?

Taking part in the research will help Ben and the Talking Out team understand what it is like to take part in the residential, which might lead to improvements in the future. This may be helpful to other people who stammer.

Focus groups can be fun and it might be helpful to think about what you have done on the residential and how this has helped you to feel differently about stammering.

## What if something goes wrong?

If you have any complaints about the project then you can talk to Ben or one of the team at the residential. If you feel your complaint has not been handled to your satisfaction you or your parents can contact the Leeds Beckett University using the details below.

## Will my taking part in this project be kept confidential?

Yes. All the information that we collect about you during the course of the research will be kept strictly confidential. This means that you will not be able to be identified or identifiable in any reports or publications. Any data collected about you the assessments, or recordings of the focus groups will be stored online in a safe server and will be protected by a password.

What you say in focus groups will be kept private and won't be shared with the other residential staff.

Data collected may be shared in an anonymised form to allow reuse by the research team and other third parties. No information about who you are will be shared with anybody.

The only time we will share information is if you share something that raises concerns about your or somebody else's safety. We will talk to you if this happens.

## How will the focus groups happen?

Focus groups will run online using Microsoft Teams. A link will be sent to you and ahead of the group.

## Will I be recorded, and how will the recorded media be used?

Yes, if you take part in the focus groups these will be video recorded. These recordings will be used by Ben to look back on so he can use what you say to help him understand what being part of the residential is like. The videos will be kept in a secure file online and protected by a password. Nobody else will be able to see them. The videos will be deleted once the research project has finished.

## What will I be asked about and why will this help the research project?

1. Ben will join in with all the activities on the residential and make notes on what he notices happening. He won't use your name in these notes, and if you have not volunteered for this part of the study he will not include any notes about you at all.
2. The assessments that you will complete as part of the residential will be shared with Ben who will use these to help find out what changes you have noticed during and after the residential.
3. In the focus groups Ben will ask questions about what has happened during the residential. These questions will ask about what things you have enjoyed, which things you didn't like, what was helpful, what wasn't helpful and if there is anything about the residential you would change. This will be kept private and you can be as honest as you like. This information will help Ben to understand how going on the residential might help you to feel differently about stammering.

## What will happen to the results of the research project?

Results of the research will be written up as a thesis. This is a big report that describes the research project and what the results were. This will be submitted to Leeds Beckett University to be marked as part of Ben's PHD.

The results from the research may also be published as an article in a research journal, talked about at a conference or a professional meeting. You will not be identified in any report or publication.

## Who is organising and funding the research?

The project is being organised and carried out by Ben Bolton-Grant. Ben is a speech and language therapist and a PHD student at Leeds Beckett University. This project will be written up and submitted as part of his PHD. The study is being supervised by Dr Sarah James and Dr Trish Holch from Leeds Beckett University.

## Ethical approval

This design and plan for this project has received ethical approval from Leeds Beckett University.

## Contacts for further information

If you have any questions or would like to discuss any of this information, or any elements of the project, please contact Ben in the first instance.

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