



ASSSIST2 QUALITATIVE INTERVIEWS PARTICIPANT INFORMATION SHEET: PARENTS/CARERS

Study title: Autism Spectrum Social Stories™ in Schools Trial 2 (ASSSIST2)

This leaflet lets you know about our qualitative research study linked to the ASSSIST2 trial. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it will involve.

Please take some time to read through the following information carefully and discuss it with others if you would like to. If there is anything that is not clear or you would like more information please contact us using the details at the end of this leaflet. Take time to decide whether or not you want to take part.

What is the purpose of the study?

As you are aware, the ASSSIST2 trial aims to establish whether Social Stories™ can be used to help primary school children with Autism Spectrum Disorder (ASD) by reducing challenging behaviour and improving social interaction, communication and emotional health. The study aims to see if Social Stories™ are clinically effective in helping children with ASD and also if they are cost effective.

As part of this research we would like to explore parents' experiences of their child using Social Stories™, and parents' experiences of receiving training on Social Stories™ (if you attended a training session).

We would also like to use the information we gather from interviews to put together a Frequently Asked Questions (FAQ) document about Social Stories™. Any information that we use from your interview will be completely anonymised before it is included in this FAQ document.

Why am I being asked to take part?

You have been invited to be interviewed because your child used Social Stories™ as part of the trial and because you received training on Social Stories™.

What will happen if I decide to take part?

If you do decide to take part you will be asked to sign a consent form that states you are willing to be interviewed.

A researcher will arrange a time with you to conduct the interview. Interviews can take place over the phone or via a videoconference. The interview will take approximately 30-45 minutes of your time. The interview will be audio recorded using an encrypted device and later transcribed. If the interview takes place via a videoconference, there will be an option for the interview to be video recorded (audio and visual recording). This is optional and you will be asked for your recording preference.

Do I have to take part?

No. Participation is entirely voluntary and it is up to you whether or not you would like to participate. You are free to withdraw at any time, without explanation. If you do agree to participate you can stop at any time, without explanation.

What are the possible benefits of taking part?

If you do take part you will be contributing to our knowledge and understanding of how Social Stories™ are used within schools. This may include, whether the training was useful, how practical Social Stories™ are when used in schools, if any extra support is needed when using Social Stories™ and any other information that may help us to inform and improve the training and delivery of Social Stories™.

What are the possible disadvantages and risks of taking part?

The interview will take approximately 30-45 minutes of your time.

Some parents may find talking about autism distressing. If at any time you feel distressed or do not want to continue, you can withdraw from the study. Please do not hesitate to discuss any issues with the research team who will be able to direct you to appropriate support.

What if there is a problem?

If you have a concern about any aspect of this study, you can speak to the research team who will do their best to answer your questions. Contact details are listed at the bottom of this sheet.

If you wish to make a complaint (or talk about making a complaint) you can contact the PALS (Patient Advice and Liaison Service) team. They offer confidential and free service to guide you through the different services available at Leeds York Partnership Foundation Trust.

Patient Advice and Liaison Service (PALS)

[DETAILS]

If you remain unhappy and wish to complain formally, you can contact:

[SPONSOR DETAILS]

Will taking part in this study be kept confidential?

What you say in the interview will be kept strictly confidential, in that the recordings on the encrypted devices will not be shared with anyone other than the people within the research team. By signing our consent form you agree that we may quote some of the things you have said when we write up the research or when we produced our FAQ document. Any information we use in this way would be completely confidential; your name and your place of work will not appear in any of the reports, publications or presentations.

How will data be kept secure?

Our procedures for handling, processing, storage and destruction of data are compliant with the Data Protection Act 2018. Data will be kept securely on encrypted and password protected files on servers accessible only to the research team. Data will be used anonymously and we do not ask you to give your

name and your e-mail address is stored separately from your responses. All data will be managed in ways compliant with the General Data Protection Regulation (GDPR) and the Data Protection Act (2018). For more details on data protection legislation, please visit the following webpages:

<https://www.york.ac.uk/healthsciences/research/trials/trials-gdpr/>
<https://www.york.ac.uk/healthsciences/research/trials/trials-gdpr/research-participants/>

Leeds and York Partnership NHS Foundation Trust is the sponsor for this study based in the United Kingdom. We will collect information from you for this research study in accordance with General Data Protection Regulation (GDPR) and will act as the Data Controller. This means that we are responsible for looking after your information, using it properly and ensuring this research project is compliant with GDPR. On behalf of Leeds and York Partnership NHS Foundation Trust, the University of York will keep identifiable information about you for 10 years after the study has finished and anonymised data will be kept indefinitely.

Who is organising and funding the research?

The research is being organised by Leeds and York Foundation Partnership NHS Trust. It is being paid for by NIHR Health Technology Assessment (HTA). The research is supported by York Trials Unit and the Department of Health Sciences at University of York.

Who has reviewed the study?

This study has been reviewed and given a favourable ethical opinion for conduct by North East-York Research Ethics Committee (19/NE/0237). It has also been approved by the Health Research Authority (HRA) and The University of York Department of Health Sciences Ethics Committee.

Contact for further information

If you would like any further information about this study contact:

[TRIAL COORDINATOR DETAILS]

If you decide to take part in this study you will be given this information sheet and a signed consent form to keep.

Thank you for taking the time to read this information sheet.



ASSIST2 QUALITATIVE INTERVIEWS PARTICIPANT INFORMATION SHEET: EDUCATIONAL PROFESSIONALS

Study title: Autism Spectrum Social Stories™ in Schools Trial 2 (ASSIST2)

This leaflet lets you know about our qualitative research study linked to the ASSIST2 trial. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it will involve.

Please take some time to read through the following information carefully and discuss it with others if you would like to. If there is anything that is not clear or you would like more information please contact us using the details at the end of this leaflet. Take time to decide whether or not you want to take part.

What is the purpose of the study?

As you are aware, the ASSIST2 trial aims to establish whether Social Stories™ can be used to help primary school children with Autism Spectrum Disorder (ASD) by reducing challenging behaviour and improving social interaction, communication and emotional health. The study aims to see if Social Stories™ are clinically effective in helping children with ASD and also if they are cost effective.

As part of this research we would like to explore individual's experiences of using Social Stories™, i.e., how suitable they were for this target group, the support that was required to deliver the Social Stories™ (both individually and at an organisational level), and how practical it has been to implement Social Stories™.

We would also like to use the information we gather from interviews to put together a Frequently Asked Questions (FAQ) document about Social Stories™. Any information that we use from your interview will be completely anonymised before it is included in this FAQ document.

Why am I being asked to take part?

You have been invited to be interviewed because you received training on Social Stories™ as part of the trial and/or were involved in the delivery of Social Stories™ to a child in the study.

What will happen if I decide to take part?

If you do decide to take part you will be asked to sign a consent form that states you are willing to be interviewed.

A researcher will arrange a time with you to conduct the interview. Interviews can take place over the phone or via a videoconference. The interview will take approximately 30-45 minutes of your time. The interview will be audio recorded using an encrypted device and later transcribed. If the interview takes place via a videoconference, there will be an option for the interview to be video recorded (audio and visual recording). This is optional and you will be asked for your recording preference.

Do I have to take part?

No. Participation is entirely voluntary and it is up to you whether or not you would like to participate. You are free to withdraw at any time, without explanation. If you do agree to participate you can stop at any time, without explanation.

What are the possible benefits of taking part?

If you do take part you will be contributing to our knowledge and understanding of how Social Stories™ are used within schools. This may include, whether the training was useful, how practical Social Stories™ are when used in schools, if any extra support is needed when using Social Stories™ and any other information that may help us to inform and improve the training and delivery of Social Stories™.

What are the possible disadvantages and risks of taking part?

The interview will take approximately 30-45 minutes of your time.

What if there is a problem?

If you have a concern about any aspect of this study, you can speak to the research team who will do their best to answer your questions. Contact details are listed at the bottom of this sheet.

If you wish to make a complaint (or talk about making a complaint) you can contact the PALS (Patient Advice and Liaison Service) team. They offer confidential and free service to guide you through the different services available at Leeds York Partnership Foundation Trust.

Patient Advice and Liaison Service (PALS)

[PALS DETAILS]

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Will taking part in this study be kept confidential?

What you say in the interview will be kept strictly confidential, in that the recordings on the encrypted devices will not be shared with anyone other than the people within the research team. By signing our consent form you agree that we may quote some of the things you have said when we write up the research or when we produced our FAQ document. Any information we use in this way would be completely confidential; your name and your place of work will not appear in any of the reports, publications or presentations.

How will data be kept secure?

Our procedures for handling, processing, storage and destruction of data are compliant with the Data Protection Act 2018. Data will be kept securely on encrypted and password protected files on servers accessible only to the research team. Data will be used anonymously and we do not ask you to give your name and your e-mail address is stored separately from your responses. All data will be managed in ways compliant with the General Data Protection Regulation (GDPR) and the Data Protection Act (2018). For more details on data protection legislation, please visit the following webpages:

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Who is organising and funding the research?

The research is being organised by Leeds and York Foundation Partnership NHS Trust. It is being paid for by NIHR Health Technology Assessment (HTA). The research is supported by York Trials Unit and the Department of Health Sciences at University of York.

Who has reviewed the study?

This study has been reviewed and given a favourable ethical opinion for conduct by North East-York Research Ethics Committee (19/NE/0237). It has also been approved by the Health Research Authority (HRA) and The University of York Department of Health Sciences Ethics Committee.

Contact for further information

If you would like any further information about this study contact:

[TRIAL COORDINATOR DETAILS]

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Thank you for taking the time to read this information sheet.



ASSIST2 RESEARCH STAFF FOCUS GROUP PARTICIPANT INFORMATION SHEET

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As part of this research we would like to explore individual's experiences of the goal setting procedures and delivering training to school staff.

We would also like to use the information we gather from focus groups to put together a Frequently Asked Questions (FAQ) document about Social Stories™. Any information that we use from the focus group you participate in will be completely anonymised before it is included in this FAQ document.

Why am I being asked to take part?

You have been invited to participate in a focus group because you were involved in goal setting sessions or delivering the training as part of the Social Stories™ writing process.

What will happen if I decide to take part?

If you do decide to take part you will be asked to sign a consent form that states you are willing to take part in a focus group.

A researcher will arrange a time with you to conduct the focus groups. The focus group will take approximately one hour of your time. The focus group will be audio recorded using an encrypted device and later transcribed.

Do I have to take part?

No. Participation is entirely voluntary and it is up to you whether or not you would like to participate. You are free to withdraw at any time, without explanation. If you do agree to participate you can stop at any time, without explanation.

What are the possible benefits of taking part?

If you do take part you will be contributing to our knowledge and understanding of how Social Stories™ are used within schools and the processes involved in setting goals for pupils.

What are the possible disadvantages and risks of taking part?

The focus group will take approximately one hour of your time.

What if there is a problem?

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