

## **Information Sheet**

### **The Feasibility of Training Caregivers of Children with ASD to Implement Social-Communication Therapy Remotely via Telemedicine: A Feasibility Study**

Supervisors:	Email:	Phone:
Dr Tom Loucas	<a href="mailto:t.loucas@reading.ac.uk">t.loucas@reading.ac.uk</a>	+44 118 378 4697
Dr Fiona Knott	<a href="mailto:f.knott@reading.ac.uk">f.knott@reading.ac.uk</a>	+44 118 378 7539
Researcher:		
Wafa Alatar	<a href="mailto:wafa.alatar@pgr.reading.ac.uk">wafa.alatar@pgr.reading.ac.uk</a>	+966 506159972

We are asking you to help us with some research which is looking at ways to make early intervention more easily available to children with autism spectrum disorder and their families. As a first step, we want to evaluate the feasibility of using telemedicine to offer parents training in how to most effectively support their children's social-communication. Telemedicine is the remote delivery of healthcare services using electronic communication means, such as over the internet, to improve patient's health status. The approach we are testing involves using video-conferencing to allow speech and language pathologist to work with parents in their homes.

The study will compare the remotely delivered intervention to the intervention delivered face-to-face in the clinic. Therefore, the study will involve two groups of participants, a group will receive their intervention sessions in the clinic and the second group will receive the intervention over the internet. This piece of research is looking at whether it is possible to provide intervention using telemedicine. The intervention is running for only a short period and is using a new way of delivering the intervention. Therefore, it is not possible to say if whether you will see any change in your child's social-communication.

#### **Why I have been invited to take part?**

You have been invited to take part in this study because you are a parent of a young child with autism spectrum disorder who has been seen at the Autism Centre at Prince Sultan Military Medical City (PSMMC-AC). The research is taking place at the PSMMC-AC.

#### **Do I have to take part?**

Your participation in the research is entirely voluntary. If you do take part, you can choose to stop at any time. Whether you take part or not will not affect any services you receive from PSMMC. If you choose not to participate, the researcher may ask you about the reason behind not participating for research purposes. However, you have the right to give reasons or not.

#### **What will taking part involve?**

If you choose to take part, we will ask you to complete the social-communication questionnaire, which is used to assess your child's risk for autism, and the Vineland-II, which is used to assess your child's behaviours. The tests will be administered to ensure your child is suitable to take part in the study. The tests results will be kept anonymously with the other information collected during the study. If your child is not suitable to take part in this study, this will not affect him/her from getting the services at PSMMC-AC.

If your child is suitable to take part, you will be contacted by the researcher to arrange an introductory session (in-clinic or from your home) to which is expected to take 30-min to talk about the intervention nature and goals. Moreover, the introductory session will involve describing the goals of the eight intervention sessions, how the video-feedback method will be implemented. It will also address how you will transfer/send the training videos to the therapist the day before the session. During the introductory session, you will be encouraged to ask questions to ensure that all procedures are clear.

After confirming your participation and before starting the intervention sessions, you will be given an appointment to evaluate your child's social-communication skills. You will be given a box with a small selection of toys, and you will be asked to play with your child as you do at home. The researcher will collect 10-minutes video of you playing with your child, so we can assess your child's social-communication skills before we start the training. If you can't attend in the clinic, the researcher will assist you to record the video at your home.

You will be offered a series of eight training sessions; once a week over eight weeks. Each session will last for one hour. The session will take place in your home (over the internet using video-conferencing) with the therapist. A trained speech and language pathologist will provide all the intervention sessions.

In each session, you will be taught strategies to enhance your child's social-communication skills. For example, you will learn how to follow your child's lead during play, how to achieve balanced turns in interactions, how to adjust the environment to support your child's attention and engagement, and how to create lots of practice opportunities. Following each session, you will be asked to spend around 30 minutes daily in practising the strategies at home during everyday activities with your child. Each week you will be asked to video 5-minutes of your interaction with your child the day before your session with the therapist. In the session, you will talk through the video with the therapist as part of the training.

At the end of the last session, you will be given an appointment to re-evaluate your child's social-communication skills. The researcher will collect 10-minutes video of you playing with your child in the clinic to allow us to compare the progress after the intervention. If you cannot attend in the clinic, the researcher will assist you to record the video at your home. You will also be asked to complete a short questionnaire about your experience of using video-conferencing for therapy.

In the unlikely event that the therapist becomes concerned about you or your child, the therapist will seek assistance from a senior psychologist to help in the matter.

### **Where the study will take place?**

The researcher will contact you by phone to arrange the day and time that is convenient for you to attend the weekly session from home. The sessions will be held using WebEx, a programme you can install on any computer, smartphone or tablet with an internet connection that allows you to take part in an online meeting. Before each session, the researcher will send you a meeting number that allows you to join the virtual meeting room.

### **How will the information be stored?**

Your data will be kept confidential and securely stored. All data collected will be anonymised, and the information linking your personal details to data collected will be stored separately. Participation involves the use of video to provide feedback on the use of strategies being taught in the training sessions. You will be asked to send the videos the day before the meeting to allow the therapist to review it and be prepared for the sessions. The therapist will download the video into an external password protected memory device.

After the session, the therapist will store the video securely on a password protected computer and only be watched by the therapists involved in the research. The videos will be deleted immediately from the platform and from the memory device.

As soon as the videos have been watched and the information about the progress of the intervention recorded anonymously, they will be destroyed .

Consent forms will be kept for five years after the end of the study and then destroyed. Anonymised data will be used for this study and retained for possible future research .

This study has been reviewed by the University of Reading and PSMMC Research Ethics Committees and has been given a favourable approve for conduct.

**Will taking part affect other services my child receives?**

Participating in this study will restrict your child from receiving regular speech therapy sessions at PSMMC-AC while the study being conducted. However, you can resume the speech therapy sessions right after finishing the eight intervention sessions. Moreover, your child can benefit from any other intervention service, e.g., occupational or behavioural sessions and their regular follow-up sessions will not be affected.

Thank you for taking the time to consider taking part in this research project. Please feel free to ask any **questions** that you may have about this study at any point.

Wafa Alatar  
Postgraduate Research Student

Tom Loucas  
Associate Professor of  
Communication Disorders

Fiona Knott  
Associate Professor of  
Clinical Psychology