

# QUESTIONS TO ASK BEFORE PARTICIPATING IN AUTISM RESEARCH

## SECTION 1: PARTICIPATION

### Why should we do this?

- What will I learn about my child from joining this study?
- Will there be any benefit to us if we participate?

### The participants

- How were the children chosen for the study?
- Why was my child selected?

### Giving permission

- In addition to my consent, does my child need to give assent?

### What if we don't want to?

- Are there any consequences for not participating?  
e.g. to my child's care, your opinion of us, our place on the waiting list
- Can we withdraw from the study at any time, even after it's started?
- Are there any consequences for withdrawing early?  
e.g. health impacts of withdrawing treatment, having to return equipment

### Confidentiality

- Are my participation and results anonymous and confidential?
- What steps will be taken to ensure that we can't be identified from the results?

### What will you need from us?

- Is there any cost to us of participating? e.g. buying equipment, travel expenses
- What other information about my child will you need? e.g. diagnostic reports
- Will you need anything from me or other family members?  
e.g. completed questionnaires or medical history
- Can we continue with our current therapies during the study?

## SECTION 2: STUDY ORGANISERS

### **Who are the people behind the research?**

- Who's funding the study?
- What organisations or institutions do the researchers belong to?
- Are government departments or agencies involved?
- Will anyone make money from this study or the results?
- Are there any potential conflicts of interest? e.g. owning stock in the company

### **Regulations**

- What regulations govern this particular type of research?

### **Research staff**

- Who will be conducting the testing?
- What qualifications or experience do the research staff have?
- Who will be supervising the study?

## SECTION 3: STUDY DESIGN

### What are you trying to find?

- What are the goals or hypotheses of the study?
- Has this research question been studied before and if so, what was the outcome?
- What is the benefit to the understanding of autism?

### Safety

- Has the study design been approved by research and ethics committees?
- Are there any risks for my child?
- How will safety be ensured and monitored?

### What will you do?

- Explain what will happen - what tests or therapies will you be using?
- Have these been used before? When and how?
- How will you know if the research is a success?

#### *For randomised control designs:*

- How will children be assigned to the different study groups?
- What is the chance my child will receive the treatment?
- Will I know if he was in the control or treatment group at the end of the study?
- If he was in the control group, will he be able to have the treatment later on?
- If he was in the treatment group, will he be able to continue it after the study?

## SECTION 4: STUDY DATA

### **What information will you get?**

- What data will you collect, and how?
- What will you do with that data?

### **Security?**

- Who will have access to the raw data?
- Where will the data be kept?

### **Photographs and video**

- Will you be taking any images of my child during the study?
- If so, will they be retained? How and where?
- Who owns the rights to use photographs or videos taken during the study?

## SECTION 5: DURING THE STUDY

- How long will it take?
- How many sessions will you need?
- Where will the testing take place?
- If the testing is in my home, is there anything special I'll need to do or provide?
- Can I be there during the testing?
- Who will be alone with my child?
- How will you communicate with me during the study?
- Will the study stop for any reason, like if you run out of money?
- Who can I contact if I have concerns or questions?
- Will you let me know if new information becomes available during the study?

## SECTION 6: AFTER THE STUDY

- How will I know when the study is finished?
- Will you give me my child's results?
- Will I receive the overall study results?
- What will you do with the information you collect?
- Will the results be published?
- Where will the results be published?
- What will happen if the study is a success?
- What if it's not a success?