

## **APPENDIX 8**

### **Research Study Information Sheet**

We would like to invite you to take part the following research study:

#### **“Perceptions of AAC users about the potential of VOCAs to express identity”.**

This information sheet is to tell you more about the study. This is to help you decide whether you would like to take part. Read the information carefully and take enough time to consider if you would like to participate in this study or not. If you have any further questions or would like further information, please feel free to contact me.

If you are under 16, you will need permission from a parent/carer to take part in this research project.

#### **“What is the research?”**

This study is exploring how you, as an AAC user feels about your own Voice Output Communication Aid (VOCA). It aims to identify specific characteristics which you feel are most important to have on your device to express yourself. This study will find out how you feel about the range of voices available and if there are any characteristics you would like to be included.

#### **“Why is this research being carried out?”**

Previously, research has looked at how different aspects of a VOCA impact an AAC user. This has enabled communication aids to include social networking functions, increase portability and fix issues, such as device breakdown.

Although VOCAs are always being adapted to include more features, only recently has research started to look at the voice output characteristics. This research will explore how you feel about your device to allow everyone involved in the use, manufacturing and research of VOCAs to have a better understanding. This research will not contribute to any direct changes to your device. The research is being carried out as part of my Masters with Leeds Beckett University.

#### **Why am I being asked to participate in this study?**

As someone who uses a VOCA, your thoughts, opinions and feelings about the voice output on your device are important and we would like to give you an opportunity to express these views.

To avoid a conflict of interest, if you have received Speech and Language Therapy from the HDFT within the past 5 years, you are not able to participate in this study.

#### **“Do I have to take part in the study?”**

No, taking part is voluntary.

#### **“What happens if I take part?”**

You need to contact me (Sarah Marshall) and together we will organise a convenient time for an interview at a location of your choice. I will send a list of questions/topics before we meet to give you time to think about and prepare your answers. The interviews will not be longer than two hours but this is only a guide and you can stop whenever you want to.

The interviews will be video recorded to ensure I gather all of your thoughts, feelings and views. It also ensures I don't miss visual cues such as gestures or facial expressions.

**“Am I able to have someone with me during the interview?”**

Yes. You can bring a communication partner to the interview. This individual will also need to give consent for anything they say to be recorded.

**What if I change my mind?**

You are able to leave the study at any point up to 8 weeks after the date of your interview. After this, your data will have been transcribed and anonymised and I will not be able to identify which data is yours.

**“Will my data be kept confidential?”**

Everything you discuss will be kept confidential. However, in the rare occasion where concern is raised about your safety or the safety of others, we may have to break confidentiality. This will be fully discussed if confidentiality becomes an issue.

**“Will people know it's me?”**

Any information that identifies you will only be seen by people from the university who are involved with the research project. Data will be stored and protected under the rules of the Data Protection act 1998. Any data used in the public domain will be anonymous.

**“How can I find out the results of the study?”**

You can ask to receive a summary of the findings from the researcher during the interviews. The researcher will then send you a copy of the findings when they are written up.

**“How do I know it is safe for me to be involved in the study?”**

The research has been approved by the Faculty Research Ethics Committee, Faculty of Health and Social Science at Leeds Beckett University. Their role is to protect your safety, rights, wellbeing and dignity.

In the case of an emergency during the interviews, the researcher cannot take responsibility for your safety.

**“What if I have a complaint or concern about the research study?”**

If you have any concerns you can talk to me (Sarah Marshall) or my supervisors, Nicole Whitworth and Amanda Hynan. If you are unhappy with me or Leeds Beckett University you can also contact Communication Matters (email address). Communication Matters is a charitable organisation for people who use AAC and they have agreed to act as an independent advocate for my study.

**“I have a question or concern, how do I contact the researcher?”**

Researcher Name: Sarah Marshall

Email: (email)