



## Case Study Database Information for Participants



We would like to invite you to take contribute a case study to the Communication Matters Case Study Database. Before deciding if you would like to be involved you need to understand why these case studies are being collected. This document tells you the purpose of the Case Study Database and what you will be asked to do if you take part. Please ask if there is anything that is not clear or if you would like more information.

Please take time to read the following information carefully and discuss it with others if you wish.

### **What is the purpose of the Case Study Database?**

There is a need for more research in the field of Augmentative & Alternative Communication (AAC). There is a lot of useful information that is currently not published or shared. Also most of the published research into AAC is about single case studies (i.e. one person) or small groups of participants. Few studies present information about groups of people who use AAC. Group information is the kind of data that service commissioners look for to inform service provision and development. Lack of group information means that AAC services remain poorly developed.

The Case Study Database will collect information about how AAC is used and who benefits from AAC. The purpose of the Database is to give researchers access to information that they might otherwise not be able to gather and to provide group information. By providing this information to researchers Communication Matters hopes to help them to improve our understanding of AAC and to develop new ideas. Findings from research into AAC could help the Government, the NHS and local authorities to put in place better services for people who need to use AAC to communicate and their families and carers. Research findings may also help educators and therapists to work more effectively with people who use AAC.

### **Why am I being invited to take part?**

As someone who uses, or has used AAC, you are perfectly placed to share your experiences. These experiences will help inform practice, research and service provision. You will be contributing to a unique information resource.

## Case Study Database – Information for Participants

### **What happens if I do decide to take part?**

You will be asked to complete a questionnaire about yourself, how you use or have used AAC, and your aspirations. The questionnaire will be available as an electronic form. Whilst we would encourage you to complete the whole questionnaire, it is acceptable to leave questions that you do not want to answer.

You will also be sent a consent form which you will be asked to sign. The consent form details where your information will be stored and how that information could be accessed. Communication Matters will store your contact information (name, address etc.) separately from your case study information. Communication Matters will not pass your contact information to any other individual or organisation.

Your case study information will be kept in the Case Study Database. Communication Matters will contact you from time to time to see if you would like to update the information.

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

No. It is up to you to decide whether or not to take part.

### **Are there any benefits to taking part?**

There are no direct benefits to you. There is the potential for indirect benefit to you and other people who use AAC. In the future it is hoped that the information in the Case Study Database will increase our understanding of AAC and also support the identification of gaps in our research evidence, practice knowledge and service provision.

### **How do I know the study is safe to take part in?**

The case study collection process has been looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This process has been reviewed and approved by The Faculty Research Ethics Committee, Faculty of Health Psychology and Social Care, Manchester Metropolitan University.

Researchers who want to access the case study information will be required to complete a data access request form. Their request will be reviewed by members of the Communication Matters Independent Research Panel against agreed criteria. The Panel is a group of people with a range of perspectives on AAC who provide advice to Communication Matters on its research activities. A recommendation will be made to the trustees of Communication Matters who have the final decision on whether to support the research. All research projects requesting access to case study information must provide evidence of ethics approval.

## Case Study Database – Information for Participants

### **What are the procedures for protecting my identity?**

Communication Matters is registered with the Information Commissioner as a Data Controller. Communication Matters will comply with the data protection principles of the Data Protection Act 1998 in the way it handles your information.

Communication Matters will store your contact information (name, address etc.) separately from your case study information. Communication Matters will not pass your contact information to any other individual or organisation. When information is supplied to researchers it will be anonymous.

### **What if I want to withdraw my case study from the Case Study Database?**

You can advise us at any time by contacting the Communication Matters Case Study Database Manager. Once you have notified us that you wish to withdraw we will remove your case study information and your contact information.

### **Who is in charge of the case study data collection?**

The Case Study Database has been developed by Manchester Metropolitan University as part of the AAC Evidence Base research project. The research project is led by Communication Matters and funded by the National Lottery through Big Lottery Fund.

Dr Janice Murray is in charge of this phase of the case study data collection.

She can be contacted at MMU by:

- Telephone: 0161 247 2570

- email: [j.murray@mmu.ac.uk](mailto:j.murray@mmu.ac.uk)

- post: Dr Janice Murray, Faculty of Health, Psychology and Social Care, Manchester Metropolitan University, Hathersage Road, Manchester, M13 0JA.

### **Who can I contact if I have questions?**

You can contact Dr Janice Murray (details above) or Communication Matters:

- telephone: 0845 456 8211

- email: [research@communicationmatters.org.uk](mailto:research@communicationmatters.org.uk)

- post: Communication Matters, Catchpell House, Carpet Lane, Edinburgh, EH6 6SP