



## **Participant Information Leaflet for Staff using PECS with individuals with ASD/IDD Study**

**Study Title:** Staff perspectives on factors affecting the implementation of the Picture Exchange Communication System: A qualitative analysis

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### **Introduction**

You are invited to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully. Talk to others about the study if you wish.

Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

### **Who is organising and funding the study?**

Thank you for considering taking part in this research project conducted by Andreas Paris as part of a doctoral dissertation project for the fulfilment of the requirements of the PhD in Education and Psychology programme at the University of Warwick. This study has now received ethical approval to start the recruitment of participants for the project.

### **What is the study about?**

This research project is looking at how the Picture Exchange and Communication System (PECS) is implemented in different settings in order to support individuals with Intellectual and/or Developmental Disability (IDD) and/or Autism (ASD). Our aim is to learn more about how PECS is implemented at your place of work to support individuals with IDD and/or ASD. More specifically, the focus of this project is to explore what the implementation of PECS looks like at your place of work, how it is implemented, any factors affecting its implementation, and your experiences and views about the intervention. The research data will help extend our understanding of the implementation of the PECS protocol and the necessary interventions required to improve its delivery. This information may be used to suggest possible ways that different settings can achieve successful implementation of PECS to support their service users.

### **What would taking part involve?**

This is a qualitative study including interviews with key members of staff involved in the implementation and delivery of PECS. No assessment of the quality of the PECS intervention or the implementation and delivery process will be conducted.

Participation in this study will involve taking part in an online interview (through SKYPE) conducted by the doctoral researcher Andreas Paris, which will be arranged at a convenient time during work hours. During the interview you will be asked a series of open-ended questions to help you share your experiences regarding PECS being implemented at your place of work.

A unique SKYPE account and password will be emailed to you for the interview, so you don't need to use your own account or signup for a new one. Your interview will be audio recorded. If you are not comfortable with being recorded, I will take notes of the information provided. All the information you will provide will be anonymised. The interview should last between 45 and 60 minutes.

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

No. Participation in this study is completely voluntary and choosing not to take part will not affect you or your service users in any way. You can also choose to withdraw your participation at any time, without giving a reason by contacting one of the research team. Further details about withdrawing from the study are provided later on in this document.

### **What are the possible benefits of taking part in this study?**

You have been invited to participate because of your experience in implementing the PECS protocol with individuals with IDD and/or ASD. This means you can offer valuable insights into the barriers and facilitators, as well as the processes regarding PECS. Therefore, the researchers would really like to hear about your opinion on how you view your experiences regarding the implementation of PECS at your place of work. Your participation in this study can also provide a good opportunity for you to share the PECS implementation journey at your place of work. This will offer an example of how different settings and organisations can further support individuals with IDD and/or ASD by implementing PECS.

### **What are the possible disadvantages, side effects or risks, of taking part in this study?**

The individual participants taking part in the interviews will share personal data such as their name, role and educational and professional background, which might lead to identification of the participants by people familiar with the setting. Although the risk of such a thing happening is low, preventative measures will be taken to ensure the data of the participants are protected. That is why the data related to this study will be treated as highly confidential at all times and the necessary measures will be taken to ensure prevention of loss or damage of data, and prevention of anyone besides the research student and staff members involved in this project gaining access to these data. Any identifiable information related to you will be anonymised, and you will be given a pseudonym/code name, so that your data remains confidential. Any identifiable information about your place of work, service users or other members of staff that might be mentioned during the interview will also be anonymised. There is a requirement of participants to provide a certain amount of time to answer the interview questions. The interview should last between 45 and 60 minutes, which could consist a small time burden

### **Expenses and payments**

No compensation or reimbursement will be provided for your time, but this will be counterbalanced by the opportunity to share your experiences and contribute to the knowledge gained on PECS implementation.

### **Will my taking part be kept confidential?**

Yes. Your personal data (name, email address and telephone number) will be stored securely in a password protected database on a University provided secure drive, separately from your interview data. The hard copy of your consent form will be scanned and stored electronically on the local server managed by staff at the University of Warwick. The hard copies will then be securely destroyed. Online webform versions will be saved onto a local server managed by staff at the University of Warwick.

A unique SKYPE account and password will be emailed to you for the interview, so you won't need to use your own account or signup for a new one. I (Andreas Paris; PhD student) will record your answers or, if you are not comfortable with being recorded, I will take notes of the information provided. All the information you provide will be anonymised; a pseudo-anonymised participant identification number will be given to your interview, including the time and date and this will be kept in a password protected electronic database on a university. Interviews will be audio-recorded using SKYPE's built-in encrypted software recorder. Your interview recording will be immediately saved onto the University's secure server and permanently deleted from SKYPE account and the computer used.

The interviews will be transcribed verbatim and saved on University's secure server. Audio files will be retained on the local server in a different location (to the aforementioned data) until transcribed and transcripts have been backed up securely. Andreas Paris (PhD student) will be responsible for this process. Your interview will be de-identified during this process and information about your place of work, any names of service users or staff will either be removed or replaced with pseudonyms. Transcripts of interviews will be saved and stored in this location, but for up to 10 years in accordance with the policy of the University of Warwick. No personal data will be transferred or shared to other organisations outside of the University, or outside the EEA for the purposes of this project.

We might use some direct quotes from our interviews in our research report/publication, but these cannot be directly or indirectly used to identify you in any way

### **What will happen to the data collected about me?**

As a publicly-funded organisation, the University of Warwick have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, such as this, we will use your data in the ways needed to conduct and analyse the research study.

We will be using information from you in order to undertake this study and will act as the data controller for this study. We are committed to protecting the rights of individuals in line with data protection legislation. The University of Warwick will keep identifiable (*name and email address*) information about you for 10 years, in line with the University's data storage policies and will then be deleted.

Research data will be **pseudonymised** as quickly as possible after data collection. This means all direct and indirect identifiers will be removed from the research data and will be replaced with a participant number. The key to identification will be stored separately and securely to the research data to safeguard your identity.

### **Data Sharing**

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. The University of Warwick has in place policies and procedures to keep your data safe.

This data may also be used for future research, including impact activities following review and approval by an independent Research Ethics Committee and subject to your consent at the outset of this research project.

For further information, please refer to the University of Warwick Research Privacy Notice which is available here: <https://warwick.ac.uk/services/idc/dataprotection/privacynotices/researchprivacynotice> or by contacting the Information and Data Compliance Team at [GDPR@warwick.ac.uk](mailto:GDPR@warwick.ac.uk).

### **What will happen if I don't want to carry on being part of the study?**

Your participation is completely voluntary. It is your choice whether you would like to participate in this study. If you decide to participate in the study, you will have to sign a consent form confirming your informed consent for participation.

You have the right to withdraw from this study at any point if you wish so. During the interview, just let me know that you would like to withdraw your participation and we will stop the interview. You can ask for a break at any point and if you would like to continue participating in the study after the break, we can continue the interview. However, if after the break you feel you don't want to continue participating in the study you can withdraw your participation. You can also choose to not answer any questions that you are not comfortable answering.

You also have the option to withdraw your data from this research project after the interview has been completed, as long as you request it by contacting me until the point when the transcript of your interview has been anonymised and the data analysis commences (December 2020).

If you withdraw from the study before the transcript process starts (December 2020), all your data and information will be deleted. To safeguard your rights, we will use the minimum personally-identifiable information possible and keep the data secure in line with the University's Information and Data Compliance policies.

### **What will happen to the results of the study?**

The data collection is expected to commence in May 2020 and is expected to be completed by December 2020. The data analysis is scheduled to be conducted as soon as the data collection is completed, and the interviews are transcribed. Once the data analysis is completed, the case study research project write-up will take place. Results of the study are planned to be submitted for publication in scientific journals. Results may also be presented at conferences, scientific meetings and workshops, and for teaching purposes. No identifiable information about the staff members participating nor the children and young people mentioned during the interviews will be reported, and any such data will be anonymised and pseudonyms will be used in any reports of the results of this study. The name of the setting (where you work) will be anonymised.

### **Who has reviewed the study?**

This study has been reviewed and given favourable opinion by the University of Warwick's Humanities and Social Science Research Ethics Committee (HSSREC Reference Number: 124.19-20).

### **Who should I contact if I want further information?**

If you would like to ask any questions about this research project or if you would like to discuss any aspects of the study further, please feel free to contact: Andreas Paris (PhD Researcher; [A.Paris.1@warwick.ac.uk](mailto:A.Paris.1@warwick.ac.uk)) or Professor Richard Hastings (Supervisor; [R.Hastings@warwick.ac.uk](mailto:R.Hastings@warwick.ac.uk))

## **Who should I contact if I wish to make a complaint?**

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed. Please address your complaint to the person below, who is a senior University of Warwick official entirely independent of this study:

### **Head of Research Governance**

Jane Prewett

Research & Impact Services

University House

University of Warwick

Coventry

CV4 8UW

Email: [researchgovernance@warwick.ac.uk](mailto:researchgovernance@warwick.ac.uk)

Tel: 024 76 522746

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer, Anjeli Bajaj, Information and Data Director who will investigate the matter: [DPO@warwick.ac.uk](mailto:DPO@warwick.ac.uk).

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).

**Thank you for taking the time to read this Participant Information Leaflet**