

# Project ASSENT Newsletter

## March 2022

### Easy Text



**Headed by:** University of East Anglia

**Funded by:** Nuffield Foundation

## Progress Update on Project ASSENT

### Recruitment Drive

We have started to **invite people** to **take part** in **Project ASSENT Extension**.

We will have **group discussion** with:

- **Researchers**
- **members of Research Ethics Committees**
- **Practitioners**

They will tell us **what they think** about the **online guidance**. We will use the **suggestions** they give us to **make** the online **guidance better**.

We will speak with **adults living with capacity and communication difficulties**.

This includes **adults living with:**

- **learning disabilities**
- **autism**
- **dementia**
- **aphasia after a stroke**
- **acquired brain injury**
- **and mental health conditions.**

We will speak with **adults living with capacity and communication difficulties on their own** or **with** the **support** of someone who knows them well.

They will look at the section of the online guidance that is about **Practical supports** for **including people in research**.

## Video Creation

We want to make **video clips** showing **real-life examples of communication** occurring **between people with capacity and communication difficulties** and **those who know them best**. We want to show how **adults with understanding and communication difficulties** **communicate** with others. Showing how **adults with understanding and communication difficulties** communicate with others will make the online **guidance better** and more useful.

We want to make **video clips** of **4 to 6 people with capacity and communication difficulties** and **those who know them best**. The **videos** will **show examples** of how **adults with capacity and communication difficulties** **express themselves**.

For example:

- how they show **agreement** or **positive feelings** towards something.
- how they show **disagreement** or **rejecting something**.



The **video clips** will be about **half a minute to one minute long**.  
The **video clip** will be **included** as examples in our **online guidance**.

The work of researchers at the **Open University helped us** to **put together** the **process** we need **to follow** to **create** the **videos**. The process we put together for creating videos will **make sure everyone is protected**.

If you know someone **interested in making a brief video** for us,  
**Get in touch with:**

**Karen Bunning:** [K.Bunning@uea.ac.uk](mailto:K.Bunning@uea.ac.uk)

**Florence Jimoh:** [O.Jimoh@uea.ac.uk](mailto:O.Jimoh@uea.ac.uk)

## **Publications**

### **Our most recent paper:**

A **paper** entitled "**Lost voices**. People with capacity and communication difficulties are **under-represented in research**" has been published



The paper points to the fact that **adults with capacity and communication difficulties** are still being **left out in research**.

The paper is **available online** in **many countries** across the world. for example:

- UK
- Europe
- USA
- Australia
- New Zealand.

**Link to the paper:**

<https://online.fliphtml5.com/qetge/vkfw/#p=14>

**Coming out soon:**

The **next paper** is entitled: “How are adults with capacity-affecting conditions and associated communication difficulties **included in ethically-sound research?** A documentary-based **survey of ethical review** and **recruitment processes** under the research provisions of the Mental Capacity Act (2005) for England and Wales”.

The paper **focuses on** the **process of including in research, people:**

- with **capacity-affecting conditions**
- with **communication difficulties**
- who may be **unable to give informed consent**

The **paper** has been **submitted** to a reputable journal, known as '**BMJ Open**'.

BMJ Open has sent it back to us for corrections. **We** have **made** the **corrections** and **sent it back** to BMJ Open. We are **waiting** for their **final decision**.

### **In preparation:**

We are now **preparing** the **next paper** entitled: "**Current practice** and **values** across **multiple stakeholders** about the inclusion of adults with impairments of capacity and/or communication within research: triangulation from a mixed methods study".

We plan to **submit** this paper to **BMJ**. **Further updates** to be provided **later**.



## Development days:

### Staff training days

- **Research Ethics Committee members**

We are happy to let you know that we will be **sharing Project ASSENT findings** with **Research Ethics Committee (REC) members** during their **training days**. **REC members** are teams who **read research proposals** and **say whether it is safe and sound or not**.

We will attend **seven face-to-face training days**. Each time, we will be sharing what we found out on project ASSENT with **about 70 REC members**. The training days for REC members **will take place** in:

- London
- York
- Manchester
- Birmingham and
- Reading.



## Research Design Service Staff

We have also been invited to share what we found out in Project ASSENT with **staff at the Research Design Service (RDS) East of England**. The **RDS** are **experts who support researchers to write good project plans** and to submit it to those who can sponsor it.

The **RDS covers six counties:**

- Bedfordshire
- Cambridgeshire
- Essex
- Hertfordshire
- Norfolk and
- Suffolk.

We are **still discussing possible dates** but it is **likely to be in May 2022**. We are really looking forward to it.

## Advisory Group





The **Advisory Group** for Project ASSENT extension **continues from the original project.**

It is made up of **people from different backgrounds.** This includes:

- **representatives** of the **community of people living with disabilities.** Some of whom **may experience problems with understanding, communicating or expressing their ideas.**
- people who **support** them
- **representatives** from the **Health Research Authority**
- and people who have served on **research ethics committees.**

The group will continue to **help keep Project ASSENT relevant and accessible** to all stakeholder groups. The group **will meet twice** during the project period of **12 months** (October 2021-September 2022). The **first meeting** took place on **Wednesday 2<sup>nd</sup> March 2022.**

**Project ASSENT Seminars series 2022**

We are **sharing** the **findings** from **Project ASSENT** with other **researchers online**. We are sharing with researchers in **Universities across England and Wales**. The seminar **titled 'Lost Voices'** will also showcase the **web-based guidance**.



**Project ASSENT Seminar**  
**LOST VOICES IN RESEARCH**

**GUIDANCE**  
Including adults with capacity and/or communication difficulties in ethically sound research

**Including adults living with capacity and/or communication difficulties in ethically sound research**

The seminar will present the findings from Project ASSENT (2018-2021) covering:

- The Law and Ethics
- Capacity and Decision making
- Adaptations and Accommodations

This seminar will be of interest to researchers at all stages of their career in the health and social sciences and members of Research Ethics Committees.

For more information about project ASSENT visit our website: <https://www.uea.ac.uk/groups-and-centres/assent/>

**Seminar dates in 2022:** 10<sup>th</sup> March, 14<sup>th</sup> July  
**Time:** 12 noon – 1pm  
**Venue:** MS Teams

For further information or to book your place, please contact Sharon Vout our project administrator (S.Vout@uea.ac.uk)

**Facilitators**

**Dr Karen Bunning**  
Associate Professor in Developmental Disability & Speech and Language Therapy, UEA

**Professor Rob Heywood**  
Medical Law Expert, UEA

**Professor Peter Langdon**  
Clinical and Forensic Psychologist, Univ. of Warwick

**Dr Anne Killett**  
Associate Professor, Occupational Therapy, UEA

**Dr Clara Shiggins**  
Postdoctoral research fellow (Centre for Research Excellence in Aphasia Recovery and Rehabilitation, Australia)

**Dr Florence O Jimoh**  
Senior Research Associate, Project ASSENT, UEA

**Past and upcoming seminars: Wednesday 23rd February, Thursday 10th March and Thursday 14<sup>th</sup> July**  
**Time: 12 noon – 1pm**  
**Venue: MS Teams**

If the seminar is of interest to you or the people you know, **please contact Sharon Vout**. Sharon is our Project



Administrator [s.vout@uea.ac.uk](mailto:s.vout@uea.ac.uk). **Sharon** will **help** you to **book** a session.

## Future Updates



We will send our **newsletter** to you **once every three months**.

You can also **ask** us to send it to you **by contacting**:

[S.Vout@uea.ac.uk](mailto:S.Vout@uea.ac.uk) or [O.Jimoh@uea.ac.uk](mailto:O.Jimoh@uea.ac.uk)