



# Project ASSENT Newsletter

## June 2022



**Headed by:** University of East Anglia  
**Funded by:** Nuffield Foundation



## Progress Update

Project ASSENT was extended to enable us to respond to feedback and revise our online guidance. We set out to do this by asking for feedback from our key stakeholder groups - researchers, members of MCA-approved Research Ethics Committees and practitioners who have interests in adults with capacity-affecting conditions through focus group discussions. We also engaged with adults living with capacity-affecting conditions and their carers or supporter through paired or one-to-one interviews.

### Update on focus group discussions and interviews

We are pleased to let you know that we have completed recruitment of participants for our project. As planned, we carried out two focus group discussions with each of the following stakeholder groups: researchers, practitioners and members of MCA-approved Research Ethics Committees. Focus group discussions were held online via Microsoft Teams. The participants looked at the online guidance slide by slide and gave feedback on different aspects including content, presentation, navigation and language.

We also interviewed adults with lived experience of learning disabilities, autism, aphasia after a stroke and acquired brain injury, eight of them in total. We were not able to recruit adults with dementia and mental health conditions. Interviews were carried out with the adult on their own or with the support of a familiar person of their choosing. Interviews took place online using Microsoft Teams or in person.

The research team are conducting analysis of the discussions and interviews. From first glance, we have been able to identify lots of suggestions to make the online guidance better. We will make the suggestions into action points for the company that is helping us with developing the online guidance. We will be sharing more about this with you in the future.



## A new researcher for impact case

We have just welcomed Alex Tiseo to the ASSENT team on a temporary contract using impact funds from UEA. Alex is a postgraduate researcher in law and is examining the proposed changes to the Mental Capacity Act (2005) Code of Practice that is currently open to consultation (ending 7<sup>th</sup> July).

## Publications

### The most recent:

Bunning, K., Jimoh, O. F., Heywood, R., Killett, A., Ryan, H., Shiggins, C., & Langdon, P. E. (2022). 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. *BMJ Open*, 12(3), [e059036]. <https://doi.org/10.1136/bmjopen-2021-059036>

### In preparation:

Authors: Langdon, PE, Killett, A et.al.

Title: 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. Ready to be submitted.

## Staff training days:

### Research Ethics Committee members

We have been sharing our findings on Project ASSENT with Health Research Authority (HRA) Research Ethics Committee (REC) members. To date we have completed training sessions in London Euston, York and Manchester. The sessions were well received by REC members, with attendance at each session well above 70. We have four more face-to-face sessions coming up, details below:

- 13<sup>th</sup> July – London, Oxform Circus



- 8<sup>th</sup> September – Birmingham
- 20<sup>th</sup> October – Reading
- 24<sup>th</sup> November - London South.

## Research Design Service Staff

We contributed to a one-off training session for the Research Design Service (RDS) East of England on Wednesday 15<sup>th</sup> June. The RDS is made up of experts who support researchers in developing and submitting high quality grant applications to funding programmes. The RDS covers six counties - Bedfordshire, Cambridgeshire, Essex, Hertfordshire, Norfolk and Suffolk.

## Advisory Group

The Advisory Group for Project ASSENT extension have been kept up to date with the progress of the project through minutes of meeting and newsletters. The group will continue to help keep Project ASSENT relevant and accessible to all stakeholder groups. The first meeting took place on Wednesday 2nd March 2022. The next meeting will be held on Wednesday 27<sup>th</sup> July.

## Project ASSENT Seminars series 2022

We have presented two in the series of our seminar to researchers, practitioners and REC members in England and Wales. Each seminar focused on different findings from Project ASSENT. The first seminar was an invitation by Essex University, it was held on the 23<sup>rd</sup> of February 2022 and attended by over 60 people. Karen and Florence presented findings on:

- The law and ethics in research – Mental Capacity Act (2005) and Code of Practice (2007)
- Application of the law in research;
- An introduction to Project ASSENT online guidance.

The most recent 'Lost Voices' seminar was led by Prof Peter Langdon on 10<sup>th</sup> March 2022. He presented findings on:

- Researchers' decision making about inclusion or exclusion of our population;
- Strategies, resources & accommodations used to support research involvement.

It was attended by 35 people.



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

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

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

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

The seminar will present findings from Project ASSENT (2018-2021) covering:  
Stakeholder views and opinions from

- Researchers, REC members, practitioners, gatekeepers and six user groups of adults living with capacity and/or communication difficulties and their supporters.

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 date: 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](mailto:S.Vout@uea.ac.uk))

**Next seminar: Thursday 14<sup>th</sup> July**  
**Presenter: Dr Anne Killett, Associate Professor,**  
**Time: 12 noon – 1pm**  
**Venue: MS Teams**

If the seminar is of interest to you or your academic community, please contact Sharon Vout, Project Administrator [s.vout@uea.ac.uk](mailto:s.vout@uea.ac.uk) who will send you further details about attending or help you to book a session for your department or institution.

## Future Updates



If you have previously signed up to our newsletter mailing list, we will send our quarterly newsletter to you and keep you informed. You can also sign up to receive the newsletter by emailing: [S.Vout@uea.ac.uk](mailto:S.Vout@uea.ac.uk) or [O.Jimoh@uea.ac.uk](mailto:O.Jimoh@uea.ac.uk)