

Project ASSENT Newsletter

March 2022



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



Progress Update

Recruitment Drive

Having received ethical approval for the extension phase to project ASSENT, we have embarked on a recruitment drive over the last few weeks. We aim to run a series of focus groups to review the content and presentation in the ASSENT e-guidance. This will give our key stakeholders the opportunity to provide feedback and suggestions so that we can enhance the guidance. We are looking for researchers, members of MCA-approved Research Ethics Committees and practitioners who have interests in adults with capacity-affecting conditions. In addition, we are looking for representatives of our main groups of people with lived experience (e.g. adults with learning disabilities, autism, dementia, aphasia after a stroke, acquired brain injury and mental health conditions), to take part in interviews, either singly or with the support of a familiar person of their choosing. They will have the opportunity to evaluate the section of the e-guidance on 'Adaptations and Accommodations'.

Video Creation

As part of the project extension, we aim to carry out some development work to enhance the relevance and usability of the ASSENT e-guidance. It concerns the video capture of real-life interactions within a familiar communication partnership featuring someone with understanding and communication difficulties associated with a capacity-affecting condition, and a familiar communication partner. Ideally, we would like to video interactions of 4-6 different communication partnerships. The idea is to capture, on video, some real-life interactions of the communication partnership in action. This will provide meaningful examples of the different ways people with capacity and communication difficulties may express their feelings and opinions. The video clips will be around 30-60 seconds long and included within the web-based guidance as exemplars of adapted and accommodated communication.



Researchers at the Open University have helped us in developing a protocol for recruitment to this development work, to ensure ethical practice in accordance with the MCA provisions.

If you know of someone who might be interested in making a brief video for us, demonstrating how they interact with each other, please get in contact with us:

Karen Bunning: K.Bunning@uea.ac.uk

Florence Jimoh: O.Jimoh@uea.ac.uk

Publications

The most recent:

Bunning, K. (2021). Lost voices. People with capacity and communication difficulties are under-represented in research. Research Fortnight, 1st December, p.14.

The paper is available online and spans across different parts of the world, including the UK, Europe, USA, Australia and New Zealand. <https://online.fliphtml5.com/getge/vkfw/#p=14>

Coming out soon:

Karen Bunning, Oluseyi Jimoh, Rob Heywood, Anne Killett, Hayley Ryan, Ciara Shiggins, Peter E. Langdon: 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. This paper was submitted to BMJ Open journal. We have since made minor revisions following editorial review and now awaiting the final decision.

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. Target journal: BMJ



Development days:

Staff training days

- **Research Ethics Committee members**

We are excited to say that Project ASSENT team will be part of the development days organised for Health Research Authority (HRA) Research Ethics Committee (REC) members. REC members review research proposals, ensuring that the rights, dignity, safety and well-being of the people who take part in research are protected. The development days will see us sharing our findings on Project ASSENT with approximately 70 REC members in seven face-to-face development days across England. The training sessions will take place in London, York, Manchester, Birmingham and Reading.

- **Research Design Service Staff**


We are in the process of agreeing dates to share Project ASSENT findings with staff at the Research Design Service (RDS) East of England. 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. The staff development day 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 and 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 2nd March 2022.

Project ASSENT Seminars series 2022

We are offering a series of seminar to researchers and REC members in England and Wales over the next few months. The 'Lost Voices' seminar will present key findings from Project ASSENT research and showcase the web-based guidance.



Project ASSENT Seminar
LOST VOICES IN RESEARCH



GUIDANCE
Including adults with capacity and 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

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

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: 10th March, 14th 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)

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

If the seminar is of interest to your academic community, please contact Sharon Vout, Project Administrator s.vout@uea.ac.uk 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 or O.Jimoh@uea.ac.uk