**Project ASSENT December 2021 Newsletter**

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| **Headed by:** University of East Anglia  **Funded by:** Nuffield Foundation | Santas Hat, Christmas, Claus, Santa, Xmas, Hat, Red |
| **Progress update on Project ASSENT**  Since the last newsletter, a lot has happened on Project ASSENT. The project which was carried out over 3 years, started in 2018 and ended in July 2021.  For our end of project report which is available in standard format, easy text and easy read formats, please visit:  The full report can be found:  **End of Project ASSENT Conference 2021**  Regardless of the limitations brought about by COVID-19 pandemic, the end of project conference went ahead with adaptations. It was held online and was attended by over 60 delegates representing our various stakeholder groups e.g researchers, REC members, adults with capacity and communication difficulties and their supporters.  Team members presented findings and delegates were opportuned to listen to the experience of one of our stakeholders alongside their supporter.  You can catch up on the conference using the link below:  **Project ASSENT web-based guidance**  The project led to the development of a web-based guidance about including adults with capacity and communication difficulties in research. The guidance was launched at our End of Project Conference. The guidance has three sections:  1. ‘The Law and Ethics’ – focuses on the research provisions of the Mental Capacity Act (2005) and makes reference to its accompanying Code of Practice.  2. ‘Capacity and Decision-making’ - focuses on the process and procedures for including people in ethically-sound research.  3. ‘Adaptations and Accommodations’ – focuses on the practical supports for including people with capacity and communication difficulties in research.  Initial feedback from the 31 stakeholders who reviewed the guidance highlighted the need to expand the scale of evaluative feedback, respond to feedback already received and support its embedding in research practice across the health and social sciences. | |
| **Project ASSENT Extension**  We are pleased to let you know that Project ASSENT has received further funds from NUFFIELD Foundation to extend the project for one more year (October 2021 to September 2022).  The project extension will allow the team to respond to the intial feedback from our stakeholders. To do this, we will complete the following activities: | |  |
| **Planned activities for project ASSENT Extension**  **Targeted feedback from our key stakeholder groups**  This wil involve socliciting targetted feedback through focus group discussions and paried interviews. Focus group discussions will be held with researcehrs, REC members and practitioners while paired interviews will be held with adults with capacity affecting conditions and their supporters or carers.  **Development of authentic case-based resources**  In recent to the intial feedback on the web-based guidance, we need to diversity the case scenarios to provide more examples of how to involve people with capacity and communication difficulties in research. To make the we-based guidance more meaningful, we want to add some real-life interactions between adults with capacity and communication difficulties and the person who knows them best. This is so that researchers can learn about the communication process and feel confident about including such individuals in their projects. We are looking to gather approximately 12 scenarios from colleagues in research and practice. Case scenarios will be gathered through a brief, structured, narrative interview. | |
| **Seminar series tartetting researchers at all stages of their career** | |
| We will be offering a series of seminar to researchers in health and social sciences department and institutions in england and Wales throughtout the duration of the project extension. The ‘Lost Voices’ seminar will present key findings from this research and showcase the ASSENT web-based guidance. The seminar will be delivered by members of Project ASSENT team. We plan to run seminars within UEA, inviting other stakeholders to join in or contact universities with health and social sciences departments and offer to deliver the seminar to their academic community. If the seminar will be of interest to your academic community, please contact Dr Karen Bunning ([K.Bunning@uea.ac.uk](mailto:K.Bunning@uea.ac.uk)) to book a session for your department or institution.  These activities will lead to a refined version of the web-based guidance based on stakeholder views and opinion. It will also support the embeding of the guidance in research practice across the health and social sciences. This we believe will enhance its relevance and usability.  **Progress Update**  As at the time of writing this newsletter, we have written up the study documents (e.g., participant information sheets and consent forms) and are in the process of obtaining ethical approval.  **Publications:**  Check out our most recent publication:  Jimoh OF, Ryan H, Killett A, Shiggins C, Langdon PE, Heywood R, et al. (2021) A systematic review and narrative synthesis of the research provisions under the Mental Capacity Act (2005) in England and Wales: Recruitment of adults with capacity and communication difficulties. PLoS ONE 16(9): e0256697. https://doi. org/10.1371/journal.pone.0256697  **The next paper…**  Karen Bunning, Oluseyi Jimoh, Rob Heywood, Anne Killett, Hayley Ryan, Ciara Shiggins, Peter E. Langdon: Survey of ethical review and recruitment processes under the research provisions of the Mental Capacity Act (2005) for England and Wales, with reference to adults with capacity and communication difficulties. The paper focuses on the ethical processes used for including people with capacity-affecting conditions and associated communication difficulties who may be unable to give informed consent to research participation. It also looks at the practical implications for how people with capacity and communication difficulties may be included in ethically-sound research. We aim to submit this before the end of December 2021. | |

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

**As we approach the seasonal break of 2021,The ASSENT team wishes everyone a safe, joyful, and lockdown-free Christmas break.**

