A Guide to Inclusive Research with Older People

This guide was produced collaboratively by a team of older people and academic staff and led by a student researcher, Julie Forster. It is intended for academics, students or members of the public who are interested in pursuing inclusive research.

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What is NUAGE?

- The Newcastle University Ageing Generations Education (NUAGE) module was introduced in 2014 to students from any discipline studying at Newcastle University.
- We designed and developed NUAGE through consultation and collaboration with students, academics and a team of older people.
- We recruited older people from VOICE, an organisation hosted by Newcastle University that aims to involve older people in local academic activity. Through their involvement with NUAGE, the team of individuals working on NUAGE named themselves ‘Experts by Experience’ (ExBex).
- NUAGE is a cross-faculty module, devised in response to the University’s overarching goals, which aims to approach the subject of ageing from a variety of angles, covering areas from health to technology and the arts.

From teachers to researchers:

- NUAGE is innovative in its inclusion of older people in both the design and delivery of teaching sessions for undergraduate students.
- Over the years ExBex members have become an integral part of the teaching team.
- In the past our evaluation of the module used traditional academic research methods.
- We believed that an inclusive approach to evaluation, involving the Exbex team members would be beneficial.

What is inclusive research?

- It is a type of research that is carried out ‘with’ or ‘by’ members of the public, rather than ‘to’, ‘about’ or for them.
- Inclusive research embraces a democratic approach, in which participants work collaboratively to address a particular issue that is important to them.
- There are a range of approaches to this type of research and variation exists in the terminology used to describe them. Inclusive research covers overlapping subtypes, such as ‘user-led research’, ‘community research’ and ‘participatory action research’.
Examples of inclusive research

- The concept of inclusive research is relatively new, and originated from research with people with learning difficulties.
- Health and social care research is predominantly where the inclusive approach has been used – e.g. areas of pain management, strokes, falls and assistive technology.
- There are no existing examples of projects applying an inclusive approach to educational research in the university setting.

How did we adopt the inclusive approach?

- We held a series of consultations with older people to develop a strategy to evaluate the NUAGE module.
- ExBex team members with experience of the NUAGE module, and other volunteers without previous experience worked with academics to design the strategy.
- These older people decided that evaluation of NUAGE should focus on the long-term impact on participating students, rather than the short-term impact - such as student satisfaction - or the impact on members of the public.
- We anticipated long-term impacts to include influence on students’ careers and academic choices, and changes to their perception, and interaction with older people.
- After we selected long-term impact on students as the focus for the evaluation, we began to formulate a research plan.
- Older members of the public expressed a wish to be involved in the research design, data collection and analysis.
- We held a series of training meetings to discuss methods of contact with students, to draft questionnaires, and to consider ethical approval and data protection legislation.
- The team decided that collecting data through questionnaires and semi-structured interviews would be most appropriate.
- Newcastle University granted us ethical approval to move forward with our inclusive research project.

Data collection and analysis

- We contacted NUAGE alumni from 2014-2018 via Facebook or E-mail.
- We asked alumni for their permission to be sent a research questionnaire. One of the questions asked for students’ permission to undertake an informal research interview.
- ExBex team members took part in the interview process.

Questionnaire findings

- Of the 74 alumni whose contact details we had on record, the response rate for the questionnaire was 35.14%.
- Questionnaire responses increased from 2014-2018 (Figure 1). In the early stages of NUAGE, we did not ask for contact details from alumni, as we did not anticipate a future research project.

Figure 1 shows the year alumni respondents completed NUAGE.

- Figure 2 shows the degree programmes studied by alumni who completed the questionnaire. This was proportional to the programmes taken by the students undertaking the module.

Figure 2 shows the degree programme studied by the respondent.
• In 50% of the responses, students cited the involvement of ExBex, with individuals acknowledging this contact as being one of the highlights of the module.
• According to the responses, 65.3% of alumni suggested that NUAGe had impacted their personal lives, for example improving their confidence in communicating with older people.

Interview findings
• We completed six interviews via Skype (2), telephone (1) or face-to-face (3). ExBex members participated in five interviews.
• Prior to the interview, Exbex members reviewed the questionnaire data for the individual they were interviewing. Team members met 15-30 minutes before the interview to agree on the interview format and identify important questions to include.
• The degree of involvement in the interview was flexible, depending on the preference of the ExBex member.
• There was no evidence that alumni felt uncomfortable by the presence of an ExBex member.
• Exbex members, who took part in the process, made a significant contribution to the interviews by responding to students’ thoughts and asking following up questions.

What are the advantages of this type of research?
• This approach to this type of research is more democratic than traditional academic research – those involved collaborate to agree on a research focus and design the project.
• Inclusive research has a degree of flexibility - team members can decide on their level of involvement depending on their own skills and preferences. For example, in our project some ExBex members preferred to be involved in face-to-face interviews rather than Skype interviews.
• Members of the public provide an alternative perspective on the research process to academic team members. In our study, they asked additional questions during the interviews that academic staff may not have thought of.
• Inclusive research can provide a sense of purpose and satisfaction as well as increasing knowledge, skills and self-confidence for the older people involved.

What are the challenges of this type of research?
• Trust is an important requirement for inclusive research projects to be successful. ExBex members have worked collaboratively with academic staff and students from the beginning to design and develop NUAGe. The fact that there is already a certain level of rapport between team members allowed the project to be completed more easily.
• The main issue with this research and other types of inclusive project is the representativeness of those involved. One aim of inclusive research might be to involve marginalised groups of society, but this is not always possible.
• This type of research is time-consuming, as appropriate training methods need to be implemented before individuals can be part of the research team. For example, ExBex members had to be briefed on General Data Protection Regulation (GDPR) before being involved in the research project. These concepts frustrated ExBex members with regards to how tightly bound guidelines are around research.

**Conclusion**

• We adopted an inclusive research approach to evaluate a university module about ageing
• Despite the challenges of an inclusive approach, we worked collaboratively to successfully collect and analyse data from NUAGE alumni about the long-term impact of participation
• An inclusive approach to educational evaluation is feasible and effective

A reflection on inclusive research by student coordinator, Julie Forster:

*Having been a team member in this inclusive research project, I have seen how beneficial this type of research is compared to classical research. Involving older people as part of the research team in an area they are interested can enhance the research process. Their thoughts and opinions are key and they can provide an alternative perspective that can be intuitive. ExBex members have been agreeable to be part of different aspects of the research process. As the research has progressed ExBex have been willing to take more ownership of the research process. This was particularly noticeable in the interviews ExBex were involved with. In my opinion, the inclusive research approach has a number of advantages for both the individual involved and research carried out.*

**Further Information**

• INVOLVE supports active public involvement in NHS, public health and social care research: [https://www.invo.org.uk/](https://www.invo.org.uk/)
• National Coordinating Centre for Public Engagement (NCCPE) supports universities to engage with the public: [https://www.publicengagement.ac.uk/](https://www.publicengagement.ac.uk/)