

Towards an NHS toolkit for obtaining consent for hospital admission from adults with learning disability incorporating a novel virtual world experience and a specialist interview technique.

Investigators

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Background

People with learning disabilities (LD) have poor access to health care which may be worsened by sub optimal methods of assessing capacity to consent to treatment. Capacity to consent requires a person to take in and retain information about a treatment and its possible risks and benefits in order to make a decision. Assessment of capacity depends on effective information giving and an efficient way of eliciting the understanding on which the decision is based. We know that people with LD learn best from multimodal experiences. Immersive Virtual Reality has been shown to support learning and we propose that this technique may enhance recall and understanding in people with LD which will be tested by using a modified Cognitive Interview (CI).

Aims

To investigate the viability of a customised Immersive Virtual Environment (IVE) as part of a toolkit (product) that will better enable NHS staff to gain consent from marginalised groups. We will:

- Develop an IVE using Second Life based on Imperial College London's prior work with Second Health and other virtual hospital environments
- Find out how people with LD participate in this environment, in particular the physical and technical barriers that may affect this experience
- Explore the CI as a means of assessing recall and understanding of this environment
- A custom designed interactive IVE will be built by ICL based on their existing third generation virtual world hospital environments (e.g. 'Second Health') in the 3D virtual world of Second Life. IVE is a rapidly developing field and is likely to move towards interoperability with open source technology and further refinements, greater accessibility, operational flexibility, deployment and security options that will help to make it even more suitable for application within an NHS product.
- The IVE contains a storyboard scenario, pre-programmed to represent the anticipated patient experience and ready to be triggered by the person with LD or their helper. The scenario will include clinical 'people' and interactive medical equipment to provide a suitably realistic and memorable experience. Real people could play the roles of clinicians as if they were players (avatars) in a computer game but it is more economical to use pre-programmed robots. Therefore suitably interactive robots will be developed during the course of this project.

- We do not know how easy it will be for people with LD to engage with the IVE concept and they may need assistance with engagement. Protocols will be produced which will enable a Research Assistant (RA) to be trained for this purpose. During the process of engagement, non technical operational issues may arise which will be captured and used to form the basis of a guide for carers and support workers.
- The new interactive IVE, training material about how to use the IVE experience, and a user friendly guide for users / carers on how best to support people experiencing the IVE will form the basis of the toolkit.

Plan of Investigation

This independent study* will investigate the viability of a customised Immersive Virtual Environment (IVE) as part of a toolkit that will better enable NHS staff to gain consent from marginalised patients, and with regard to a potential market. We will experiment with this method and begin to refine it and define the components needed for the next stage toolkit. The IVE will be tested by a small group of people with LD. We will explore how they use the simulated environment, gain their views on the experience, and assess their recall and understanding using the CI. The feasibility of using the CI will be explored in terms of its potential place in the toolkit. Key deliverables in the toolkit are the customised IVE, training videos and guidance for health care workers.

We expect the use of IVE and the CI to be valuable in enabling adults with LD to participate in the consent process in respect of the Mental Capacity Act 2005. The proposed toolkit will be used to enhance clinical information-giving and improve the assessment of capacity. There may be a cost benefit in developing a product that by enhancing decision making, improves treatment compliance potentially leading to earlier discharge with no increase in readmission rate.

The toolkit should have broad applicability and if the feasibility study, which is focussing on a specific and difficult to reach target group, is successful, we will elaborate and extend its components and begin to develop versions for different patient groups and conditions in preparation for future product development.

Progress to date

We have been particularly grateful to the Grace Eyre Foundation whose IT suite will now form the core facility for the research. Three computers, one associated with a large interactive whiteboard, are now loaded with the Second Life software and four Grace Eyre service users have accessed the IVE in a group that included research team members, Nikki Green (LD secretary) and Grace Eyre staff - most themselves SL novices. Using a range of keyboard and pointer devices, everyone was first shown something of the SL environment and then given access via three pre-existing avatars on separate computers to the programme itself. All the avatars, when in proximity to each other, could be seen together on the large whiteboard as well as the other two screens in the same room and this seemed to support service users' understanding of the nature of the interactivity to various degrees. We were very much encouraged by this outcome as they were pre-study volunteers and there had been no selection process involved.

Imperial College has allocated an island adjacent to other medical projects of theirs and other organisations in the SciLands, a continent of some 60+ islands dedicated to Science, Technology and Medicine, upon which they will develop the research environment. We are in the process of designing this featuring key landmarks from the Brighton area, including the Royal Sussex County Hospital, to enhance identification and simultaneously working on the storyboard, environmental furniture and necessary infrastructure.

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Key references

- Conboy-Hill, S. (2006) Vulnerable Adults: Assessing Capacity to Consent Clinical Psychology Forum 158 pp 19-239.
- Health Care For All: Report of the Independent Inquiry into access to health care for people with learning disabilities' Sir Jonathan Michaels July 2008
- Health Inequalities: Progress and Next Steps DoH 2008 Memon, A. and R. Bull (1991) The cognitive Interview: its origins, empirical support, evaluation and practical implications. Journal of Community and Applied Psychology 1 pp 291-307
- Mental Capacity Act 2005 Chapter 9 OPSI Parsons, S. & Mitchell, P. (2002) The potential of virtual reality in social skills training for people with autistic spectrum disorders. Journal of Intellectual Disability Research 46 5 pp 430-443.
- Second Life: a 3-D virtual world created by its residents; www.secondlife.com
- Second Health: an Imperial College research project for NHS London; www.secondhealth.org



Viewing movies inside the virtual hospital



A virtual polyclinic



Inside the virtual operating theatre