

Title of research: Developing a dementia information portal for Deaf British Sign Language users: a pilot study.

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Context: There are 100,000 Deaf British Sign Language (BSL) users living in the UK (IPSOS Mori GP Survey, 2010). This is a cultural minority group, which uses BSL as a distinct separate language from English (Ladd, 2003). There are 750,000 people in the UK living with dementia (DOH, 2009). One in four people in the general population are 65 years of age. An Adult Social Services survey (2010) determined there were 24,070 Deaf older people in the UK; however, it is not clear how many of those are BSL users. In England, the National Dementia Strategy (DoH, 2009) identified clear objectives to achieving early identification of dementia, including an information campaign made accessible for all using good quality information. However, this information has yet to be distributed in BSL and knowledge about dementia in the Deaf community is acknowledged as being poor (Parker et al, 2010). Led by the University of Manchester (Young; PI: www.manchester.ac.uk/deafwithdementia), the Deaf with Dementia [DwD] project has developed ground-breaking research into this hitherto neglected area. Early findings have highlighted the barriers Deaf people experience when seeking information or identifying services in their own language. The DwD study has conducted focus groups in BSL with 26 Deaf people who do not have dementia and nine BSL interviews with Deaf people with dementia and their carers. Analysis of this data has indicated that access to information in BSL is a key issue encountered by all Deaf people involved in this study and accessible provision would substantially increase quality of life and satisfaction with services. Additionally, there are 45 mobile BSL apps and 71 dementia apps available to purchase but none directly relate to information about dementia in BSL. This pilot study will build directly upon the findings of the DwD study and will develop, pilot and evaluate a dementia information portal that will share information about dementia in BSL and will explore making this available as a mobile app.

The research is proposed as part of the Social Research with Deaf People (SORD) and Dementia and Ageing Research Theme (DART) focus on dementia, evidenced through their joint working on the DwD study.

Research aims and objectives: There are 3 primary research aims: 1) To develop and pilot a dementia information portal (ideally with a mobile app) that will share information about dementia in British Sign Language; 2) To evaluate the usefulness of having such information in BSL; 3) To provide the foundation for a larger scale study, including greater appreciation of the role of information in supporting Deaf people living with dementia and their families.

References

- Clarke, C.L., Wilkinson, H., Keady, J. and Gibb, C. (2011) Risk Assessment and Management for Living Well with Dementia. London: Jessica Kingsley.
- Clarke C.L. & Wilson V. (2007) Learning – The Heart of Practice Development. in: K. Manley, B. McCormack & V. Wilson (Eds) International Practice Development in Nursing and Healthcare. Blackwell Publishing, Oxford. Pp. 105-125.
- Department of Health (2009). Living well with dementia: A National Dementia Strategy. London: DH.
- IPSOS Mori GP Patient Survey 2009/10
- Ladd, P. (2003) Deafhood: Understanding deaf culture. *Multilingual Matters* Clevedon.
- Parker, J., Young, A. & Rogers, K. (2010). 'My Mum's Story': A Deaf daughter discusses her Deaf mother's experience of Dementia. *Dementia*, 9(1), 5-20
- People Registered Deaf or Hard of Hearing Year ending 31 March 2010, in England NHS Information Centre for Health and Social Care (part of the Government Statistical Service) ISBN 978-1-84636-467-9 www.ic.nhs.uk
- Rogers, K.D., Young, A., Lovell, K., Campbell, M., Scott, P. R., & Kendal, S. (2012) The British Sign Language Versions of the Patient Health Questionnaire, the Generalized Anxiety Disorder 7-Item Scale, and the Work and Social Adjustment Scale *J. Deaf Stud. Deaf Educ.* (2013) 18(1): 110-122 first published online November 28, 2012 doi:10.1093/deafed/ens040

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