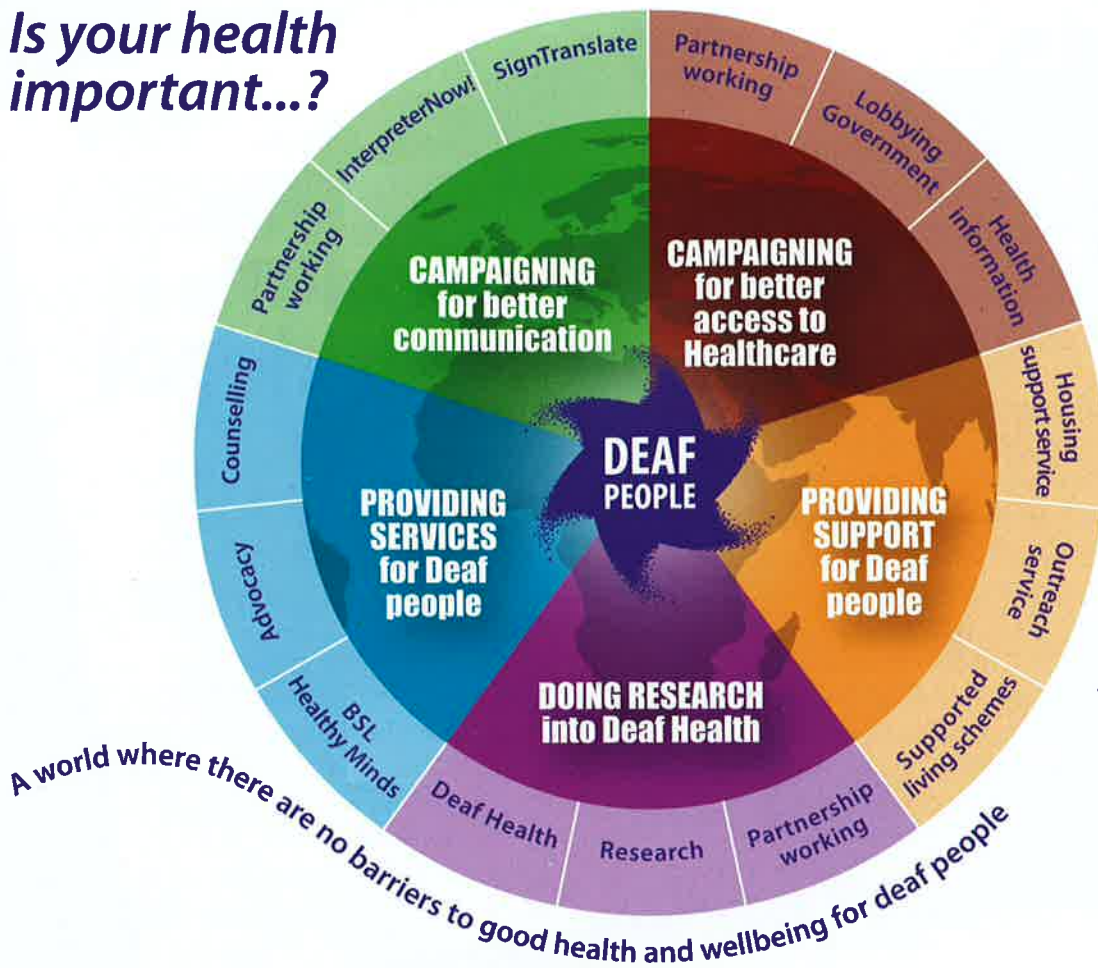


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Research Deaf with Dementia project update

A unique project working to improve life for Deaf people with dementia



The Deaf with Dementia (DwD) research project started in April 2010 (and will finish in December 2012) and aims to improve early diagnosis and management among Deaf people who use British Sign Language (BSL).

It is funded by the Alzheimer's Society, and is a partnership between the University of Manchester, University College London (UCL), City University London and RAD (Royal Association for Deaf People). DCAL researchers are involved from UCL, as well as DCAL associates based at City University London. The project is led by the University of Manchester.

This research study is the first of its kind anywhere in the world. The team that is carrying it out encompass both Deaf and hearing researchers, and a wide range of professional backgrounds (including social work, speech and language therapy and clinical psychology) as well as multi-disciplinary academic excellence in dementia, Deaf studies, linguistics and neuroscience. The team also includes a key specialist service provider.



Good progress for DCAL's study area

Within the DwD project there are three studies being carried out. DCAL/UCL is primarily responsible for Study1 which focuses on the Older Healthy Deaf Brain. This study includes

developing a profile of normal ageing within the Deaf Community from a cognitive perspective. This will be used to develop a screening instrument for dementia in BSL that is culturally appropriate and that is normed for the Deaf population.

DCAL is glad to let readers know that the data collection for the cognitive screening instrument has now finished so that we have norms for healthy Deaf people. A test is now being used clinically to check the scores of people referred for cognitive difficulties against the normal range for their age. This means that in conjunction with DCAL, the National Hospital for Neurology and Neurosurgery (a UCL Partner) in Queens Square, London can offer appointments in their Cognitive Disorders Clinic for Deaf referrals. Appointments are for patient care rather than data collection.

DCAL revisits the England Deaf Derby and Joan club

Previously we reported on the DCAL research team's trip to the October 2010-England Deaf Derby and Joan (EDDJ) club annual get-together at Pontins, Lowestoft, Suffolk. It was with EDDJ members in Lowestoft that the team was able to collect a considerable amount of the data needed to establish the normal profile for healthy older Deaf signers.

Thanks to an award from the University College London (UCL) Beacon Public Engagement programme, four members of DCAL staff attended the October 2011 EDDJ annual holiday get-together, this time held in Prestatyn, Wales, to feed back our results from the previous year and to engage older deaf people with research at UCL using information stalls, posters and fun activities. A bonus of the visit was that the team was also able to complete data collection. Thanks to their willingness to take part in the research the team recruited 13 participants from the EDDJ member aged between 80-89 years. In all, the DwD project has been able to collect data from 226 Deaf people, with ages ranging between 50 and 89. This is an impressive achievement.

The DCAL team received a very positive response from people at the EDDJ and would like to thank both the EDDJ committee and attendees for their support. The team will look forward to providing full results in the near future.

Find out more, get involved!

To find out more about the Deaf with Dementia research project and to keep up to date with progress, please go to the project web site for information in both BSL and English: www.manchester.ac.uk/deafwithdementia

In addition the project is presently seeking people from the general Deaf community who have been diagnosed with dementia (and their carers) to take part in an interview about their experiences of living with dementia day to day. This is part of Study 2. *See the website for details.*

The Deaf with Dementia project Objectives

The research project is:

- Developing a screening instrument for dementia in BSL that is culturally appropriate and normed for the Deaf population
- Investigating the experience of dementia directly with Deaf people and their carers in order to provide an evidence base for culturally sensitive service provision
- Working with the wider Deaf community and service providers (such as the Alzheimer's Society) to better understand key features of acceptable and targeted information and support for Deaf people

The Government has released a policy document: Living well with dementia: A National Dementia strategy (published February 2009). The three broad objectives which underpin the Deaf with Dementia specific research studies were designed to dovetail with the National Dementia's Strategy's emphasis on: early identification; broad based community awareness; improved information provision; outcome driven service provision, where outcome also encompasses cultural sensitivity/acceptability.

In the Deaf with Dementia research project, the culture of Deaf people is being investigated as the starting point in the identification of markers of acceptable and preferred outcomes in dementia care.

