

# Embedding a Human Rights Based Approach to Dementia Care

<https://www.neurodegenerationresearch.eu/survey/embedding-a-human-rights-based-approach-to-dementia-care/>

## Principal Investigators

Kinderman, Peter

## Institution

Mersey Care NHS Trust

## Contact information of lead PI

### Country

United Kingdom

## Title of project or programme

Embedding a Human Rights Based Approach to Dementia Care

## Source of funding information

NIHR

## Total sum awarded (Euro)

€ 554,622

## Start date of award

01/05/2014

## Total duration of award in years

2.4

## The project/programme is most relevant to:

Alzheimer's disease & other dementias

## Keywords

### Research Abstract

The main research question is: Does the application of a Human Rights Based Approach to Health Care lead to improvements in the care and well-being of people with dementia in an inpatient/care home setting? In line with this, the study aims to evaluate whether the delivery of Human Rights Training to staff and the subsequent introduction of a Human Rights Based Assessment Tool impacts on both the care and well-being of individuals with dementia. Both the

Assessment Tool and Human Rights Based Training Package have been developed and piloted by Mersey Care NHS Trust. The current proposal is to extend the pilot study by implementing and further evaluating the impact of the Training Package and Assessment Tool in NHS Mental Health Trusts and care homes. The Human Rights Based training is a one day training package designed to raise staff awareness of the Human Rights Act and provide guidance in implementing a Human Rights Based Approach to Dementia Care. It also trains staff in using the Human Rights Based Assessment Tool and includes a specially commissioned DVD, which encourage interactive learning of Human Rights based approaches when making clinical decisions. Following the training, the Human Rights Based Assessment Tool – “Getting it Right” – will be implemented at the intervention site. Three booster sessions will be delivered, monthly, to aid embedding a Human Rights Based Approach to care. The intervention package is described more fully in the detailed project plan. The research will use a cluster randomised design to compare the impact of implementing the intervention, i.e. the training package, Assessment Tool, and booster sessions on 10 intervention sites as compared to 10 control sites. The control sites will continue with treatment as usual. No active placebo is indicated. Control sites will receive the training following the conclusion of the research. Baseline measures will be completed 1 week prior to an intervention site receiving training. Demographic data and an assessment of cognitive impairment, as measured by the Alzheimer’s Disease Assessment Scale (ADAS-Cog), will be completed to ensure that the participants from hospital inpatient and care home settings are comparable on these factors. Demographic data will also be collected from staff at the sites to compare level of training and experience. The primary outcome measure used in the research will be the Quality of Life in Alzheimer’s disease (QOL-AD; Logsdon, Gibbons, McCurry & Teri, 1999) to assess the subjective well being of the person with dementia as it is brief, has demonstrated sensitivity to psychosocial intervention, correlates with health-utility measures, and can be used by people with MMSE scores as low as 3. The QOL-AD proxy version will also be used to elicit the views of both the staff and family carer supporting the individual with dementia. Health economic measures, EQ-5D and ASCOT, will also be completed. A care plan audit will be conducted at each site to provide a measure of the documented plan of care for each service user. An audit tool has been specifically designed for the study. This will aid in establishing whether Human Rights Based training is an explanatory variable in any changes in care and well-being observed over and above a standard training package as it allows for presence of Human Rights based language and concepts in care plans to be directly assessed. The standard of care provided at the site and its link to well-being will be assessed via Dementia Care Mapping (DCM; Bradford Dementia Group, 1997) – an observational assessment yielding quantitative measures of well-being and ill-being for the individual with dementia. Vignette based semi structured interviews will be conducted with multi-disciplinary staff at various grades at each site. The interviews focus on the staff’s decision making processes in relation to complex clinical decisions and aim to assess whether the introduction of a Human Rights Based Approach provides staff with a more robust decision making framework. Family carer well being will be assessed via the Warwick Edinburgh Mental Well-Being Scale (WEMWBS) and the Zarit Burden Interview (ZBI) will explore their perception of caring responsibilities. There are currently no existing measures to directly evaluate the extent to which an individual perceives that their basic Human Rights of Fairness, Respect, Equality, Dignity and Autonomy (The FRED A principles) are being upheld. A preliminary piece of work will develop such a questionnaire. The resulting questionnaire will undergo initial validation in this study. In order to assess knowledge acquisition and attitude change during the training pre and post-training measures of Human Rights knowledge and attitudes will be

collected via the Human Rights Knowledge and Attitude Quizzes, as recommended by “A Guide to Evaluating Human Rights Based Interventions in Health and Social Care” (Donald, 2012). This data will be collected on the day of the training. Subsequent to the 3rd, and final, booster session post-intervention measures will be taken: QOL-AD, QOL-AD proxy, Dementia Care Mapping, Care plan audit, vignette based semi-structured interviews, FREDa questionnaire, WEMWBS and ZBI. The intervention and control groups will be compared using analyses of variance, adjusted for cluster randomisation, on scores on the QOL-AD, FREDa questionnaire scores, WEMWBS, ZBI and scores of well-being and ill-being from the Dementia Care Mapping process. Vignette based interviews will be analysed using thematic analysis as outlined by Braun & Clarke (2006). The main benefits expected as a result of the research are: Increased subjective and objective well being of people with dementia in inpatient wards or care settings. This will be seen in an increased standard of care for people with dementia in inpatient or care settings and improvements in the reported subjective wellbeing of people with dementia. Additionally, we predict that a successful intervention will result in staff working on dementia inpatient wards or care settings having a more robust framework in which to make complex clinical decisions on a day to day basis. The additional validation of the FREDa questionnaire would also allow to assessment of service user’s opinion on the level to which their basic Human Rights are respected. This will have significant utility in future research and care management.

### **Lay Summary**

**Further information available at:**

#### **Types:**

Investments > €500k

#### **Member States:**

United Kingdom

#### **Diseases:**

Alzheimer's disease & other dementias

#### **Years:**

2016

#### **Database Categories:**

N/A

#### **Database Tags:**

N/A