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Participation in research as a means to explore the challenge of still being an active citizen following a diagnosis of dementia

In this paper I will use participation in research as an exemplar of a situation where a diagnosis of dementia triggers a social positioning as 'vulnerable' leading to competence to consent being questioned and family views sometimes taking precedence. I will draw on examples from the PRIDE study, an ESRC-NIHR programme grant which seeks to develop an intervention to promote independence in people living with mild dementia.

A diagnosis of dementia often shifts a person's social status. Opportunities for the person with dementia to be autonomous in decisions and agentic in constructing access to social activities can diminish. The research aim is to qualitatively explore the social structures which enable or restrict opportunities for the person with dementia, living in the community, to demonstrate autonomy and citizenship in everyday life. This talk will draw on three data sources: researcher reflections, semi structured interviews and focussed observations with people living with dementia. Using data from the study I will highlight the ways in which 'vulnerable' people are working to remain active citizens following diagnosis, encouraging a challenge to the narrative of deficit which is often embedded in biomedical models of dementia.