

Post diagnostic support in the UK: fragmentation and fragility

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Topic Post diagnostic support

Abstract

The overall aim of the PriDem project is to develop and test new ways of providing post diagnostic support for people with dementia. One component of the project involves exploring current models of post diagnostic support to find out which aspects work well and identify where changes are needed.

Current UK models were identified through desk-based research and an internet mapping survey. We conducted qualitative, semi-structured telephone interviews with managers and commissioners of selected services. These focused on their experiences of providing or commissioning post diagnosis support, views on aspects of the recent NICE guidelines for dementia care, and the role of primary care in providing post diagnostic support. Initial analysis has highlighted the fragmentation and fragility of existing services, with a lack of coherent pathways, involvement of multiple agencies, and a shifting service landscape due to short-term funding. Varying levels of primary care involvement were described. Barriers to primary care led post diagnostic support included conflicting priorities; lack of skills and knowledge; and a perceived lack of interest in dementia among some GPs. Broader challenges to providing post diagnostic support were a service-led approach with an emphasis on 'plugging' people into existing services rather than providing person-centred care; managing caseloads; and difficulties in capturing outcomes. Some examples of joined-up services were identified; this included a 'frailty hub' involving weekly meetings of primary care, secondary care and neighbourhood services where individual patients were discussed.

The next phase of the project will focus on a small sample (up to six) of services selected from this initial work. It will involve observation of service delivery and interviews with frontline staff, people with dementia, and informal carers.