Exploring models of post diagnostic support in England

Alison Wheatley, Greta Brunskill, Claire Bamford, Louise Robinson, on behalf of the PriDem team

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, with a focus on support led by primary care. We used qualitative methods to explore current models of post diagnostic support to find out which aspects work well and identify where changes are needed. We then selected six services from our initial work to explore in depth. This involved observation of service delivery as well as interviews and focus groups with health and social care professionals, people with dementia, and informal carers.

In this presentation, we compare three contrasting models of post-diagnostic support: a comprehensive secondary care-led model; a comprehensive Admiral Nurse-led model based in a GP practice; and a GP-led model covering multiple practices. The models varied along a number of axes, including where, when, how often, and by whom services were provided. The exact nature of the post-diagnostic support provided also varied; while each of the services offered regular review and follow up for people with dementia, other features such as access to rapid advice from specialist mental health services or shared access to primary care notes were not available in every service. Services also varied according to how well they were embedded within the local dementia care pathway. We draw on our data from people with dementia and their families to evaluate some of the benefits and challenges of each approach for service users, as well as data from staff in linked local services to explore the benefits and challenges from a professional perspective.

Data collected as part of this project are currently being used as part of a co-design process to inform the development of a new intervention to provide post-diagnostic support for people with dementia.