

HIPS/25/17 - Developing inclusive dementia post-diagnostic support for people living in care homes and their carers

Tailored support after being diagnosed with dementia, known as Post Diagnostic Support (PDS), is recognised to be helpful for people living with dementia and those who support them. Scottish Government targets guarantee access to a year of PDS for people diagnosed with dementia. However, not everyone diagnosed with dementia is able to access PDS. This is a particular problem for people living in care homes. Widening access to PDS including supporting people living with advanced dementia has been identified as an area requiring research to change practice in recent national guidelines and policy documents.

We propose a programme of research involving people living with dementia, their carers (personal and professional), health and social care staff and the organisations who commission and deliver PDS. We aim to understand current practice and address unmet needs by co-designing a PDS intervention tailored to those living in care homes. We will also identify measures which can be used to judge how useful PDS has been. We will be supported to do this research by a panel of people with lived experience and professionals representing local and national organisations with influence over PDS content and delivery. These groups will ensure our work is focused and connected to practice, increasing the chance of delivering meaningful change.

The intervention developed in the study will be suitable to test in UK-wide research to establish how helpful and acceptable it is, whether it provides value for money and, if so, how this can be rolled out nationally.