WS2: Good practice in post-diagnostic dementia care

WS2 explored the views and experiences of key stakeholders on current post-diagnostic dementia care and good practice. We collected data in two phases: WS2.1 focused on service managers and commissioners; WS2.2 focused on service users (people with dementia and their family carers) and frontline staff.

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Methods: Qualitative (interviews focus groups and observation)

Outputs:

1) Summary of stakeholder views on delivering post-diagnostic support in primary care (Wheatley et al 2020)

2) Summary of barriers and solutions to providing good post-diagnostic support (Wheatley et al 2021)

3) Components of good post-diagnostic support and how to deliver them in practice (Bamford et al 2021).

WS2.1: Current and proposed models of primary care-led, post-diagnostic dementia care: views of service commissioners and managers.

We carried out 49 interviews and one focus group with participants in England and Wales. Participants were based in NHS Trusts, social care and third sector organisations. Participants included commissioners, service development leads, service managers and team leads/senior staff. We completed data collection in August 2019. We asked questions about the types of post-diagnostic support provided by the services, the challenges and solutions around providing sustainable support, and their views on good practice in post-diagnostic support.

The findings highlighted the diverse approaches to post-diagnostic support in England and Wales in terms of funding, content, delivery and relationship to primary care. Participants expressed concerns over the feasibility of the capacity, capability and willingness of primary care staff to extend their role in post-diagnostic support. A further finding of concern was the lack of shared understanding of post-diagnostic support with some participants viewing this as a one-off meeting following diagnosis, and others seeing it as the provision of ongoing holistic support throughout the illness. These findings are described in more detail in a paper Wheatley et al 2020.

WS2.2: Case studies exploring views of service users and frontline staff

We explored six sites in more detail which were either based in, or had strong links to, primary care and reflected the diversity of post-diagnostic dementia care identified in WS2.1. The sites comprised:

- Specialist dementia (Admiral) nurse based in general practice
- General Practitioners with extended roles working across general practices
- Specialist-led step up/down model based in secondary care
- A wrap-around specialist-led service
- Enhanced secondary care memory assessment service
- Third sector community-based memory support workers

We explored the views of frontline staff, service users and professionals working in related services through interviews and focus groups. We observed services on several occasions to gain insight into day-to-day delivery of post-diagnostic support. We completed data collection in November 2019. The final dataset comprised 5 focus groups; interviews with 10 frontline staff, 31 carers, 21 people with dementia and 26 linked professionals. The dataset also included detailed fieldnotes from observation of 6 clinics, 4 groups, 20 home visits and 6 meetings. Data analysis focused on identification of key components of post-diagnostic support and factors influencing their delivery. We also collated examples of the different ways in which sites provided the key components and how different services linked together. The findings indicated that while some services offered a wide range of support, no single service delivered all aspects of post-diagnostic care.

Data from WS2.1 and WS2.2 were then combined to identify:

- Barriers to the provision of post-diagnostic dementia care and strategies that had been used successfully to overcome these (Wheatley et al 2021)
- The range of components of post-diagnostic dementia care provided across all services (Bamford et al 2021).