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Evaluation of the Dementia Action Plan 2018-2022: Interim report summary

Executive Summary

1. Research aims and methodology

- 1.1 This paper summarises the findings from the initial phases of the evaluation of the [Dementia Action Plan \(DAP\) 2018-2022](#), undertaken by Opinion Research Services (ORS) between 2019 and July 2023. The objectives of the DAP were: to increase public knowledge of how people can reduce their risk or delay the onset of dementia, increase public awareness of how to identify the signs of dementia and seek early diagnosis, improve rates of timely diagnosis, and help people living with dementia to live as well as possible, as independently as possible, and for as long as possible. The overall evaluation seeks to assess the implementation and impact of the DAP, against its aims and objectives, but with a particular focus on the provision person-centred care and support. The evaluation has so far comprised a scoping stage and a first phase of primary research.
- 1.2 The scoping phase involved a review of relevant literature, a workshop with the Welsh Government Dementia Oversight, Implementation and Impact Group (DOIIIG), nine interviews with key stakeholders, and workshops with stakeholders and practitioners representing Wales's seven Regional Partnership Boards (RPBs). Scoping activities were intended to inform the development of the research, but data from the interviews with stakeholders and RPB workshops with stakeholders are also included in the interim report. Scoping activities commenced in 2019 but were curtailed due to the Covid pandemic. Following re-engagement with RPB stakeholders, the scoping phase was completed in 2022.
- 1.3 The first phase of primary research included both an online survey and qualitative research, during 2022 and 2023, to explore the diagnosis and subsequent support experiences of people living with dementia and their carer(s). The online survey received 158 responses: 139 completed by the main carer, 11 completed by the person living with dementia, and eight completed by the person living with dementia and their main carer together. Most questions referred to the experiences of the person living with dementia, with a small number of questions specifically about the carer's experiences. The qualitative research involved interviews and a focus group with a total of 59 participants, 43 of whom were carers and 16 of whom were people living with dementia, representing experiences relating to 45 people living with dementia. The evaluation methods in both the scoping and primary phases were selected to ensure that the opinions of stakeholders, practitioners, people living with dementia, and carers are all taken into consideration.
- 1.4 Further information on the second phase of the evaluation is provided in the 'Next steps' section (Section 4).

2. Key findings

Understanding and implementing the DAP

- 2.1 Echoing some of the DAP's stated aims, there was a broad consensus amongst stakeholders and RPB workshop participants on the most important elements of the DAP, as follows:
- Increasing understanding and awareness of dementia within society and focusing on dementia prevention
 - Improving uniformity of services
 - Uplifting standards of care for people living with dementia and tailoring person-centred care to the needs of the individual
 - Keeping people living at home for as long as possible
 - Training and workforce development
 - Ensuring information about dementia, and dementia services, is available to those receiving a diagnosis and their carers, when needed
- 2.2 There was general positivity amongst stakeholders about the implementation of the DAP, at the time this data was collected (between 2019 and 2022). It (along with its associated funding) was thought to have offered suitable governance and provided a vehicle for partnership and cross-sector working. It was perceived to have placed people living with dementia and their families/carers at its heart through promoting the use of multi-disciplinary teams (MDT), person-centred care, care planning and co-production. It was said to have made dementia a strategic priority for health boards and local authorities. The development of new structures such as steering/strategy groups, forums, and panels to drive improvements was also highlighted.
- 2.3 Some barriers to implementation were highlighted by stakeholders, most notably around the challenges posed by variable health and social care infrastructure across Wales, inequitable service provision, and inconsistent access to dementia services. Maintaining the pace of delivery to match demand; capacity issues within RPBs, health boards and social care; and a degree of strategy 'fatigue' were also noted (with RPBs needing to deliver various strategies, as well as the All-Wales Dementia Care Pathway of Standards).
- 2.4 Other areas of concern for stakeholders included RPBs remaining "heavily medically oriented" and treating dementia as a mental health issue without considering social factors; a lack of support for research and collaboration (for example, between health and social care); and the need for greater focus on end-of-life care.
- 2.5 At the time of data collection (between 2019 and 2022), stakeholders felt that achieving the DAP's aims required longer-term embedding of values and long-term culture change, which should not be limited to the DAP's timescale. There was recognition that the longer-term [Regional Integration Fund \(RIF\)](#) funding which succeeded the original Integrated Care Fund (ICF)¹ contributed to a longer-term focus on achieving the DAP's aims.

Monitoring the DAP

- 2.6 There was some feeling among stakeholders that the DAP was helping to identify service gaps and shape regional outcome measures; that the current level of monitoring was sufficient for the short-term and at a high-level; and that the data being collected was beginning to be used to change practice on the ground. However, other stakeholders and RPB workshop participants highlighted the need for a more systematic monitoring approach and for more in-depth qualitative information-gathering to inform service development, alongside the numerical data. 'Fatigue' around reporting,

¹ [The Integrated Care Fund \(ICF\)](#) was a Welsh Government funded preventative programme (2014-2022) which aimed to integrate and encourage collaborative working between social services, health, housing, and the third and independent sector to improve the lives of the most vulnerable people in Wales. From 1 April 2022, these funds have been replaced by a new five-year [Regional Integration Fund \(RIF\)](#) with an annual investment of £144 million. As before, the fund will be distributed by Wales' seven Regional Partnership Boards (RPBs).

and a lack of clear data collection guidance and proper reporting tools from Welsh Government were also raised as challenges in this context.

Assessment and Diagnosis

- 2.7 Access to a timely diagnosis was a strong theme in the DAP. Accordingly, the primary research phase of the evaluation explored people's experiences of dementia assessment and diagnosis.
- 2.8 In the survey and in-depth interviews, most respondents reported that the person living with dementia sought a diagnosis after either themselves, family members, or medical professionals observed changes in memory and cognitive function. Some interview respondents said they or the person they cared for had put off seeking a diagnosis out of fear of the consequences or because the person exhibiting symptoms would not accept that there was a problem.
- 2.9 In-depth interview participants reported that the person living with dementia generally visited their GP in the first instance. Views were mixed on whether the person living with dementia and/or carer felt listened to, taken seriously, and was treated in a caring manner. Initial visits usually resulted in a Memory Assessment Service (MAS) referral, but not always immediately. Diagnosis times varied, but many reported a wait of more than six months following the first visit to the GP (36% of survey respondents and many of those taking part the in-depth interviews), and sometimes much longer. A perceived reticence to diagnose on the part of GPs and MAS was noted.
- 2.10 Stakeholders reported inconsistencies across the assessment process, resulting from a lack of guidance and joined up, robust views on what assessment should look like.

Post-diagnostic support and information

- 2.11 The evaluation, in looking to understand experiences of person-centred care and support, had a key focus on the provision of support and information for people living with dementia, and carers, following diagnosis.
- 2.12 Around half of survey respondents reported that the person living with dementia had received a needs assessment² following a dementia diagnosis. The type of support identified following a needs assessment was generally considered appropriate: 85% of those who reported a care plan was in place felt that the right help had been offered to meet the person living with dementia's needs. Survey and in-depth interview participants reported that leaflets, written information, details of support groups, and contact information for relevant charities were typically provided post-diagnosis, prior to and independently from receiving needs assessments.
- 2.13 There were mixed views around the amount, quality, and timeliness of the support available to both those who had received a needs assessment and those who had not. In in-depth interviews, several carer participants reported that they had to seek support themselves or that it had been offered too late to be beneficial. The survey results showed that less than half (44%) of respondents rated the support the person living with dementia had received since diagnosis as good or very good, whilst around three in ten (29%) rated it as poor or very poor.
- 2.14 Those who were dissatisfied with information provision would have liked to see more direct support and personal contact with practitioners for the person living with dementia. There were also some complaints about over-medicalised and inaccessible information impeding understanding.
- 2.15 A minority of survey respondents said the person living with dementia had a care plan in place, and access to a named 'key worker' varied. Given the low numbers in receipt of a needs assessment following their diagnosis, it is possible that deficiencies in these areas are linked. In in-depth interviews, where the person living with dementia had a key worker, they typically praised their

² The purpose of an assessment for care and support is to work with an individual, carer and family, and other relevant individuals to understand their needs, capacity, resources and the outcomes they need to achieve, and then to identify how they can best be supported to achieve them. The Social Services and Wellbeing (Wales) Act 2014 lays out a [code of practice](#) for needs assessments, which states that local authorities **must** offer an assessment to any adult where it appears to that authority the adult may have needs for care and support.

knowledge of services and the support they offered, such as printed information; information about dementia courses, support groups and peer support; and information about support to live at home, activities to stimulate the memory, financial assistance, and making future decisions.

Access to person-centred provision

- 2.16 The provision of person-centred care via the Team around the Individual (TAI) model and the provision of Dementia Support Workers (DSWs) was considered by stakeholders and RPB workshop participants to be a key element of the DAP. At the time of data collection between 2019 and 2022, most RPBs were implementing some form of MDT model. This evaluation has shifted its focus, from looking at the TAI model and the DSW role, to understanding MDT approaches and the provision of person-centred care and support, because of a lack of consistency of interpretation of the TAI and DSW elements across the RPBs. Improvements were felt by stakeholders to have been made in terms of empowerment and engagement between people living with dementia, families/carers, and professionals, through the clearer focus on co-production within the DAP.
- 2.17 Evidence across people living with dementia and their carers suggested that provision of person-centred care was varied; in the survey only half (50%) of respondents agreed that the person living with dementia and their families had enough of a say in their care. Similarly, just under half (47%) agreed that the person living with dementia and their carers/families had enough of a say in their care, with almost a quarter (24%) disagreeing. These figures are similar to for people living with dementia in receipt (or not) of a needs assessment and care plan.
- 2.18 Inclusivity for people living with dementia with protected characteristics and those living in rural areas (where accessing services may be more challenging) was said by stakeholders and RPB workshop participants to be improving, but it was generally felt that there is a 'long way to go' in ensuring equity.
- 2.19 While stakeholders and RPB workshop participants felt that progress is being made on Welsh language provision, challenges remain in delivering an active offer³ especially in areas with low numbers of Welsh speaking health and social care staff.
- 2.20 Survey respondents had mixed views on whether the person living with dementia has had enough influence over their own future care, including end-of-life care. Some participants reported the person living with dementia had received little or no information, advice, or support around making decisions on their future care (28%) and finances (32%) since their diagnosis. In contrast, others (in both the survey and in-depth interviews) highlighted support on future care needs and decisions received from a range of sources, such as Admiral Nurses, courses or written information provided by charities such as Alzheimer's Cymru and MacMillan, and conversations with peers or healthcare professionals.

Support for carers

- 2.21 Most carers in both the survey (69%) and in-depth interviews reported that they had not received an assessment of their needs. Those who did had experienced lengthy waits for assessment and/or had proactively sought out support. Few had received training to assist them in their caring role.
- 2.22 Around half of carers in the survey had accessed respite care and reported mixed views about its timeliness and effectiveness. It was felt that the availability of respite care and support outside of working hours is limited. Where respite was provided by friends and family, this was often out of necessity due to a perceived lack of other affordable options. However, some unpaid carers

³ The 'active offer' is one of the core aims of the [More Than Just Words strategic framework](#) (Care Inspectorate Wales). An active offer is when a service is provided in Welsh without someone having to ask for it. It means providers naturally anticipate the needs of Welsh speakers.

described being denied funding respite on the grounds that they are not a sole carer and share (if only to a small extent) their caring role with another family member.

- 2.23 In the survey, unpaid carers had mixed views around whether they felt recognised for their caring role by professionals. Some interview participants felt that medical professionals treat them with kindness and respect, but others felt under-valued, overlooked, or patronised.

3. Conclusion and areas for consideration

- 3.1 This interim evaluation report concludes that while the DAP (and the associated ICF and RIF funding) has provided impetus and a dedicated focus for the strategic development of services and support for people living with dementia and their carers, issues and challenges remain. These are mainly around monitoring and data collection; the time taken to get diagnoses and needs assessments for people living with dementia and their carers; and the consistency of access to support, key workers and information following a dementia diagnosis. It must be noted, however, that the implementation of the DAP was dramatically hindered by the Covid pandemic, and several of the RPBs were only in a position to consolidate and implement their renewed strategies in 2022. The second phase of the evaluation and final report may show further developments and improvements.
- 3.2 Based on the interim findings in the summary above, the following themed areas for Welsh Government consideration regarding future dementia service provision, and any successor strategies to follow from the DAP are proposed (and will be explored further in the final report):

Implementation and monitoring

- Continue work to streamline and standardise service provision across Wales, while being mindful of local and regional need.

Assessment and diagnosis

- Continue work to reduce waiting times for assessment and diagnosis and increase referrals from primary care into specialist dementia services.
- Develop a consistent approach to memory assessment via the production of standardised tools and guidance around the process.

Post-diagnostic needs assessment and support

- Ensure all people living with dementia and carers have a single point of contact post-diagnosis to provide support and accessible information and help them develop a care plan. A dedicated liaison in GP practices could also signpost people to relevant services and support.
- Work with social services to ensure that timely needs assessments are undertaken for all, so that people living with dementia and carers can access support as quickly as possible. These should be reviewed regularly to accommodate changing support needs.
- Address the ongoing issues of long waits for carer needs assessments and the scarcity of respite care that meets the needs of carers and people living with dementia. Models of short- and long-term respite, including befriending services and community-based activities, could be considered.
- Provide advice and support around planning for the future, including having early conversations about end-of-life care.
- Promote and support respectful, compassionate and understanding treatment of carers by medical professionals, and recognition and value of their caring role.

Workforce and training

- Seek to address workforce recruitment and retention challenges within dementia care and continue to roll out the delivery of dementia training to health and social care staff across the board.

- Examine the DAP and the Good Work framework⁴ and training standards to establish cross-over and identify priority areas to be taken forward over the next few years.
- Continue to address the recruitment and training of Welsh-speaking staff.

Inclusivity and co-production

- Continue to develop and support mechanisms for co-production in service design and delivery, and the increased use of person-centred care planning, to increase inclusivity for people living with dementia and their carers, and to provide them with more tailored support options.
- Continue to identify the specific needs of people living with dementia and carers with protected characteristics.
- Continue to develop increased support options for Welsh speakers, as well as for others for whom English is a second language.

4. Next steps for the evaluation

- 4.1 The next phase of primary research will be conducted over the coming months with a range of practitioners and stakeholders across all seven RPB regions. This will aim to examine how MDT working toward the provision of person-centred care and the DSW role have been rolled out in different regions, and to identify best practice examples.
- 4.2 A second iteration of the online survey will be conducted during the winter of 2023/24, to be followed by a second round of in-depth interviews with people living with dementia and carers. The online survey and topic guide for the second set of in-depth interviews will largely remain the same for the purposes of comparison, but additional topic areas will be considered in discussion with the Evaluation Advisory Group (EAG). Some of the second round of in-depth interviews will be conducted with participants from Phase 1 to allow for longitudinal study and some use of case studies.
- 4.3 The final report and recommendations will follow these next steps, in 2024.

⁴ The [Good Work Framework](#) (Care Council for Wales) is a learning and development framework for health and social care workers, which aims to help them provide the best possible care and support for those living with dementia. The framework also aims to support people living with dementia, carers and anyone who may come into contact with people living with dementia.

Authors: Harriet Hendra, Hannah Champion, Dave Hammond, Kelly Lock, Bryony Wilson, Alice Dawkins, and Liz Phillips

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Available at: <https://www.gov.wales/dementia-action-plan-2018-2022-evaluation>

Views expressed in this report are those of the researchers and not necessarily those of the Welsh Government.

For further information please contact:

Health and Social Services Research

Email: research.healthandsocialservices@gov.wales

Mae'r ddogfen yma hefyd ar gael yn Gymraeg.

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