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Evaluation of the Dementia Action Plan 2018-2022: Interim findings

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Title: Evaluation of the Dementia Action Plan for Wales 2018 - 2022: Interim report

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

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Glossary

Acronym/Keyword	Definition
DAP	Dementia Action Plan for Wales, 2018-2022
DSW	Dementia Support Worker
DNR	Do Not Resuscitate
DOIIG	Dementia Oversight of Implementation and Impact Group
EAG	Evaluation Advisory Group
ICF	Integrated Care Fund
ILS	Independent Living Services
LGBTQ+	Lesbian, gay, bisexual, transgender and queer/questioning people (with the + representing other identities including non-binary)
LPA	Lasting Power of Attorney
MAS	Memory Assessment Service
MCI	Mild Cognitive Impairment
MHSOP	Mental Health Services for Older People
OT	Occupational Therapist
RIF	Regional Integrated Fund
RPB	Regional Partnership Board
TAI	Team Around the Individual

1. Background

The Dementia Action Plan

- 1.1 [The Dementia Action Plan for Wales](#) 2018-2022 (henceforth the DAP) was launched in February 2018. It presented Welsh Government's vision for Wales to be a dementia-friendly nation that recognises the rights of people with dementia. The implementation of the plan was supported through the provision of dedicated funding under the Integrated Care Fund (ICF), and then its successor, the Regional Integrated Fund (RIF).
- 1.2 The DAP's objectives are 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 as for as long as possible.
- 1.3 The plan also incorporates objectives pertaining to furthering the learning and development of the health and social care workforce, and to providing training for families and carers of people living with dementia.
- 1.4 Actions to meet the DAPs objectives were taken forward between 2018 and 2022 to deliver commitments set out in Welsh Government's 2016-2021 Programme for Government, [Taking Wales Forward](#), and in the overarching strategy, [Prosperity for All](#).
- 1.5 The DAP was developed through consultation with people living with dementia their families and carers, and service providers. It is based on the principles of the rights-based statements of the [Dementia Action Alliance](#). The statements were developed by people living with dementia and their carers and reflect what they felt was essential to their quality of life.
- 1.6 Seven Regional Partnership Boards (RPBs) were set up in 2016 to promote partnership working across health, social care, and the voluntary sector. The DAP tasks RPBs with reviewing existing dementia services and care pathways in their respective areas to identify gaps and develop new services which are aligned with

existing services for older people. In addition, the Dementia Oversight, Implementation, and Impact Group (DOIIG) was established to inform, oversee, and monitor progress against the DAP. The DOIIG includes people living with dementia and their carers.

1.7 A companion document to the DAP - [Dementia Action Plan: Strengthening Provision in Response to Covid-19](#) - was published in 2021 following the Covid-19 pandemic. Given the impact of the pandemic and the restrictions put in place to support the response, the document recommended there be an increased focus on the following areas:

- The person living with dementia and their carers in their home (their own home, care home settings)
- The person living with dementia and their carers living in a community
- The person living with dementia and the services they need to support health such as hospital care.

1.8 The companion document specified renewed areas of focus for RPBs for 2021-22, and also outlined actions within the DAP that were considered at that time to have been completed, best addressed in other ways, or which were being deprioritised to focus resources differently given the impact of the pandemic on people living with dementia.

1.9 This evaluation will inform the successor arrangements to the current Dementia Action Plan, and the companion document published in September 2021 will act as a bridging plan whilst the priorities for the successor arrangements are identified.

The evaluation

1.10 In 2019, Welsh Government commissioned Opinion Research Services (ORS) to evaluate the DAP. 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 of person-centred care and support.

1.11 The evaluation's overall objectives are to:

- Assess the contribution the DAP has made to improving opportunities for people to live as well as possible for as long as possible, and as independently as possible in their own communities
- Assess how the actions set out in the DAP have been interpreted and understood, and the extent to which they have been implemented across health and social care settings
- Assess the extent to which the principles and actions set out in the DAP have resulted in changes to the commissioning practices of RPBs to meet the needs of people living with dementia, their families and carers
- Assess the extent to which the commissioning and development of services to meet the needs of people living with dementia, their families and carers are being co-produced in partnership with these groups
- Explore whether and how the DAP takes account of meeting the needs (including language) and preferences of people living with dementia, their families and carers, taking into account diversity and protected characteristics.
- Identify gaps in existing dementia care and support services not addressed in the DAP
- Explore whether and how the DAP has contributed to the development of a Team Around the Individual (TAI) approach to dementia care.
- Understand the composition, practices and contribution of the TAI approach¹ to meeting the needs of people living with dementia, their carers and families, and including its contribution to influencing the attitudes, behaviours, professional and cultural practices around dementia care in different settings
- Identify gaps in the existing data, and propose which, if any, may be addressed to strengthen the contribution assessment
- Capture new data about the views and experiences of people living with dementia, their families and carers with respect to assessing the role and

¹ N.B. 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.

impact of the TAI model of care and support, including the role of the Dementia Support Worker (DSW).

- During the course of this evaluation the terminology has evolved and so the term TAI will be replaced throughout with MDT approaches and person-centred provision. Similarly, the term ‘Dementia Support Worker’ has not been universally adopted and used, so for the purposes of the evaluation we will aim to understand the roles of Dementia Navigators, and other similar support roles, which may have other titles.

- 1.12 The evaluation’s methodology was informed by a scoping phase which took place in 2019. The evaluation was paused during the Covid-19 pandemic and recommenced in 2022, with its first phase of primary research. This report summarises the interim findings from the scoping phase and the first phase. The second phase of the evaluation is underway, and its findings will be reported at a later date.
- 1.13 The second phase of this evaluation will build upon the first phase, looking further at the opinions of practitioners as well as people living with dementia and their carers.

Overview of report structure

- 1.14 The remainder of this report is structured as follows: the methodology is set out in the next chapter; followed by the findings from both the scoping phase and phase one of the evaluation.
- 1.15 The report then sets out interim conclusions and makes recommendations based on current findings. To conclude, next steps are considered.

2. Methodology

Overview

2.1 The evaluation's scoping phase comprised:

- A review of the relevant literature on the TAI approach and Dementia support workers
- Scoping interviews with key stakeholders
- A workshop with the DOIIG
- Workshops within RPB areas.

2.2 The evaluation's first phase of primary research included an online survey and interviews with people living with dementia and their carers. The following sub-sections outline the methodology in more detail.

Scoping Phase

Scoping interviews

2.3 In Autumn 2019, ORS conducted nine scoping interviews with academics and specialists in mental health and dementia from the statutory and voluntary sectors, and one service user. All were identified by Welsh Government.

2.4 The scoping interviews explored participants' views on the DAP's aims and foci; implementation (including enablers, barriers, and regional variations); and communication around, and monitoring of, the DAP. The interviews informed the evaluation's methodology and focus, as well as the findings presented in this report.

Workshop with the Dementia Oversight of Implementation and Impact Group (DOIIG)

2.5 ORS conducted a workshop with eight DOIIG members in December 2019. Lasting three-and-a half hours, the workshop involved in-depth discussion of the TAI approach; pathways from the DAP's activities to its outputs and outcomes; and other areas of importance for the evaluation. The workshop provided insight to inform the evaluation's methodology, rather than the findings presented in this report.

RPB area workshops

2.6 ORS ran nine two-hour workshops in RPB areas across Wales, one in March 2020 (in person), five between May and July 2021 (online), and three between November

2022 and January 2023 (online). Participants were RPB members and stakeholders and practitioners identified by RPB members. Table 1 shows the numbers of workshop attendees from each RPB area.

Table 1: Regional Partnership Board area workshop attendees

RPB area	Number of attendees
Betsi Cadwaladr (West)	6
Betsi Cadwaladr (Central)	6
Betsi Cadwaladr (North)	19
Cardiff and Vale	16
Cwm Taff Morgannwg	13
Aneurin Bevan	12
Hywel Dda	16
Powys	6
Western Bay	13

- 2.7 The workshops began with a presentation from each RPB on their regional strategy and how it has developed since the DAP's inception. Presentations at the 2022-23 workshops also included an update on the DAP's implementation post-pandemic. ORS then facilitated in-depth discussions on the implementation of the DAP.
- 2.8 One workshop was held in person and eight workshops were held virtually. The workshops were either audio recorded or video recorded, depending on the format. ORS researchers wrote up the notes and analysed them thematically.

First phase of primary research

Survey for people living with dementia and their carers

- 2.9 The survey for people living with dementia and their carers mostly focused on the experiences of the person living with dementia, with questions on their dementia diagnosis, post-diagnosis support and future plans. There was a small number of questions specifically about the carer's experiences. It was devised by ORS in partnership with Welsh Government and the Evaluation Advisory Group (EAG). The

survey questions are included in an appendix to this report. The EAG is a group of stakeholders, practitioners, and people with lived experience of dementia, some of whom are also DOIIG members who were consulted during the development of the survey and topic guides used in depth interviews.

- 2.10 Lead dementia contacts at the RPBs contacted colleagues and third sector organisations, who publicised the survey to people living with dementia and their carers. These contacts shared information and links to the survey with prospective participants via email and publicised it via their websites and on social media. ORS also shared the link via their social media (Annex C). RPBs and third sector organisations re-posted the survey links and distributed paper copies via practitioners, if requested, to boost response rates.
- 2.11 The survey and all supporting materials were bilingual, although no responses were received in Welsh². The survey took 10-15 minutes to complete. It was live between 16th March and 28th May 2023 and was hosted online, with paper copies provided on request. At the end of the survey, respondents were asked whether they would participate in an in-depth interview if requested, to further explore their views on the topics of interest. Those who agreed were included in the interview sample.
- 2.12 All survey responses submitted by the closing date in which at least one of the questions was answered, were included in the analysis, regardless of whether any profile questions were answered. A total of 158 questionnaires were submitted, which included 141 online responses and 17 paper copies.
- 2.13 The first question in the survey asked was ‘Who is completing the questionnaire?’. This question was mandatory so that carers completing the survey on behalf of the people living with dementia were taken to the carers section at the end of the survey, whereas respondents living with dementia skipped that section.
- 2.14 The results of this question are presented in table 2. They show that the vast majority (88%) of respondents were carers completing the survey on behalf of a person living with dementia, 7% were completed by a person living with dementia, and 5% were completed by a person living with dementia and their main carer together.

² Due to space constraints, we were unable to ask a question around Welsh language proficiency and so we do not know how many respondents are Welsh speakers.

Table 2: Who is completing the questionnaire?

	Number of respondents (unweighted count)	% of respondents (unweighted valid)
The person with a dementia diagnosis	11	7%
The person with a dementia diagnosis and their main carer together	8	5%
The main carer of the person with a dementia diagnosis	139	88%
Total	158	100%

- 2.15 As the survey was targeted to both people living with dementia and their carers, the approach taken was to frame the majority of questions towards the person living with dementia. It was hoped that where the person living with dementia was unable, their carer(s) would help them fill out the survey collaboratively. In the vast majority of cases, however, the carer completed the survey on behalf of the person living with dementia, and the limitations are noted: in particular, the carer's view of the experience of the person living with dementia cannot be assumed to reflect the view of the person living with dementia, particularly where it comes to views of the services offered/received, some of which the carer may not have been present for. Carers may not have considered the need for and importance of offering a Welsh language service for example. There was also a section of the survey specifically for carers, if applicable, to fill out with their own views.
- 2.16 This report shares the experiences of a range of participants. However, they should not be seen as representative of the views of people living with dementia and their carers due to the sampling approach and relatively small sample size.
- 2.17 Survey respondents' characteristics are summarised in Table 3³; where the survey was being completed by a Carer (or in a pair), the survey asked for the characteristics of the person with dementia, rather than those of the carer.

³ Please note that the figures may not add up to 100% due to rounding. *% denotes a proportion of less than 1% but more than zero.

Table 3: Characteristics of survey respondents

Characteristic	Category	Number of respondents (unweighted count)	% of respondents (unweighted valid) ⁴
Gender ⁵ (n = 158)	Male	72	46%
	Female	59	37%
	Not known	27	17%
Age (n = 158)	Under 75	26	16%
	75-84	51	32%
	85 or over	36	23%
	Not known	45	28%
Year of diagnosis (n = 158)	Pre 2018	21	13%
	2018 or 2019	25	16%
	2020 or 2021	34	22%
	2022 or 2023	43	27%
	Not known	35	22%
Living situation (n = 158)	Live alone	29	18%
	Live with partner	79	50%
	Live with other relatives/live with others (i.e., in a care home)	25	16%
	Not known	25	16%

⁴ Percentages may not sum to 100 due to rounding.

⁵ Another gender category ("Other") was included in the survey, with a free text drop-down field for respondents who selected it to self-identify. However, no survey respondents selected this category.

Area type (n = 158)	A city/town	58	37%
	A village	62	39%
	Rural or countryside	12	8%
	Not known	26	16%
Regional Partnership Board area (n = 158)	North Wales	52	33%
	West Wales	36	23%
	Powys	9	6%
	West Glamorgan	5	3%
	Cwm Taf Morgannwg	0	0%
	Cardiff and Vale of Glamorgan	10	6%
	Gwent	15	9%
	Not known	31	20%

Interviews with people living with dementia and their carers

- 2.18 The qualitative research involved interviews and a focus group⁶ 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.
- 2.19 Most interviewees were recruited via the online survey. The rest were recruited via RPB and third sector networks whereby a contact from the RPB or a third sector organisation put the person living with dementia or carer in contact with ORS if they had expressed an interest in taking part or felt that the person could provide useful insight. Most participants had received, or cared for someone who had received, a diagnosis of dementia from 2018 onwards, although a few had received diagnoses pre-2018.

⁶ Participants were part of a regular social group. They were offered individual interviews, but opted to take part as a group. We looked to run a few small groups to increase engagement numbers but were only able to arrange one.

- 2.20 Participants were offered a telephone, online or face-to-face interview. Most were conducted by telephone or online, but six interviews and the focus group were conducted face-to-face.
- 2.21 Five interviews were one-to-one with a person living with dementia, 31 were one-to-one with a main carer, and nine were joint with the person living with dementia and carer(s). The focus group consisted of three pairs of participants (a person living with dementia and either their spouse or a close relative).
- 2.22 All interviews were conducted between 2 May and 3 August 2023. The small group session was held on the 21 June 2023.
- 2.23 The interview topic guide was designed by ORS in conjunction with Welsh Government and the Evaluation Advisory Group (EAG) to explore the journeys of people living with dementia, from when they first consulted a GP or a memory clinic, through receiving a diagnosis and then to the present day, exploring the support they had received and would prefer. The topic guide can be found at Annex D of this report.
- 2.24 At the end of the interview, participants were asked if they would be happy to participate in another interview in a year to 18 months. All were offered a voucher or a charitable donation to be made on their behalf (£15 per person) in recognition of their time and effort.
- 2.25 Interviews were audio- or video-recorded with participants' permission, transcribed, and analysed thematically. The coding framework was inductive, with themes identified by researchers.

Geographical spread and protected characteristics

2.26 The table below shows participants' geographical spread.

Table 4: Geographical spread of interview participants

RPB Region	Number of participants
Cardiff and Vale	6
Cwm Taf Morgannwg	0
Gwent	12
North Wales	12
Powys	1
West Glamorgan	7
West Wales	18

2.27 Of the 59 participants, three did not specify their RPB area. Of those participants who did, there was at least one in every RPB except Cwm Taf Morgannwg.

2.28 Four of the people living with dementia had 'young onset' dementia (when a person develops dementia before the age of 65).

2.29 One carer participant (and the two people living with dementia for whom they care) identified as Black, Asian, and Minority Ethnic, three participants (one couple and one individual) identified as LGBTQ+, and five participants (four people living with dementia and one carer) considered themselves disabled. This data was gathered when we asked participants about their living circumstances, to start gaining an understanding of their situation, rather than for a quantitative count.

3. Findings

- 3.1 In this section, the key findings from the scoping interviews, RPB area workshops, survey for people living with dementia and their carers, and interviews with people living with dementia and their carers, are summarised separately in turn.

Scoping interviews

Understanding the DAP

- 3.2 When asked to describe the aims of the DAP, scoping interviewees emphasised cultural change and greater understanding within society, leading to a dementia-friendly Wales; introducing uniformity of service across various areas of need; keeping people living at home; providing services that adapt to changing needs; and uplifting standards of care for people living with dementia.

*“Pushing a dementia agenda to every single forum... And then how we actually support advancements in the care and intervention that people should have.”
(Participant in scoping interviews)*

- 3.3 Person-centred, needs-led care was mentioned frequently as the key element of the DAP, with the DSW and multi-agency working and care as integral to this. The involvement of people living with dementia was also seen as key.

“It is useful to have the multidisciplinary approach From a clinical aspect, the multidisciplinary team is really important. In the plan, everything is centred around the person whose life is affected by dementia.” (Participant in scoping interviews)

- 3.4 Participants highlighted staff upskilling/training and workforce development as another key element of the DAP, in providing effective care and support for people living with dementia.

“Having a workforce which talks the same language across services and understands the same things ... there’s no point in having a good service without a workforce who are fully understanding of how to deliver the service in the best way.” (Participant in scoping interviews)

- 3.5 In the scoping interviews, other important elements of the DAP were thought to be timely assessment and diagnosis, and the need for ongoing support during that process. Specifically, participants mentioned the need for key contacts (like support

workers) who are proactive in offering support as it becomes available or when the person living with dementia or their carer(s) become eligible to access it. Other important elements of the DAP thought to be in need of consideration to improve its delivery included: dementia prevention; care for the person throughout their dementia journey; better support and understanding for the families, friends and carers of people living with dementia; understanding the needs of people living with dementia in rural areas; and ensuring information is available when needed.

Communicating the DAP

- 3.6 Participants were asked how well they felt that the DAP is being communicated. Whilst some said it had been communicated well, there was some concern over whether its messages had consistently reached those who are delivering care and services to people living with dementia, and that there is still a way to go to ensure that this happens.

“There are pockets that have had good communication with respect to the plan, but...there is always work to do on that – particularly in terms of frontline staff and people with lived experience. I think that, on the ground, we need to do more around engagement so that the overarching vision of the plan is continually articulated.” (Participant in scoping interviews)

Implementing the DAP: What’s working well?

- 3.7 Participants stated that progress is being made with the DAP’s implementation but acknowledged that fully achieving the Plan’s aspirations will require generational culture change. Successor arrangements to the DAP were thought to be potentially useful to specify the actions required within the complex system in order to ensure that all of the DAP’s actions and outcomes are implemented, given the scale of change.

“Progress is going in the right direction...positivity around it has increased. It’s about understanding that as much as we would love for everything to take off and be successful straight away, things do take quite a bit of time.” (Participant in scoping interviews)

- 3.8 Achieving full implementation of the DAP was also said to require a whole system commitment to doing so within a reasonable timeframe, along with sufficient funding and accompanying guidance; and clear direction from Welsh Government on each agencies’ expected contribution to it. One participant suggested that a body headed

by a 'Dementia Tsar' should have been appointed at the outset to spearhead the DAP's implementation.

3.9 Participants highlighted that the following elements of the DAP and corresponding service delivery and coordination were working well.

- Multi-agency and multi-disciplinary working. The RPBs were said to have facilitated this through bringing partners together. However, elements of their approach were also criticised (as outlined in the following sub-section)
- Integrated dementia care throughout Wales (i.e. strong partnership working between health and social care) was felt to be working well, although some participants felt that there was some way to go before full integration is achieved. [The Good Work Framework](#) was said to have facilitated integrated working between health and social care, although some felt that further work was needed to ensure its consistent implementation. It was anticipated that the joint workforce strategy (which was being developed when the interviews took place) would further foster integrated working between health and social care
- Services across Wales were thought to have improved how they share learning to some extent, although more could be done in relation to this. Specifically, it was thought that communication with third sector services had improved, especially in terms of staff learning and development which has improved service standardisation and accessibility
- Reflecting the ethos and values of the [Social Services and Wellbeing \(Wales\) Act 2014](#), the concept of 'person-centred' care and support was becoming more embedded, including the recognition that family and friends are also affected by dementia.
- Memory assessment services were praised, though participants noted the need for continued support for GP-led clinics and memory clinics to improve access to a timely and accurate diagnosis; ensure the care pathway is working as it should around assessments and appropriate referrals; and ensure proper understanding is offered to people with dementia.
- More effective use of medication to manage dementia symptoms
- Training and qualifications for practitioners

- Service user involvement and community-based activities (although the need to broaden community-based services was also highlighted).

Implementing the DAP: What's working less well?

- 3.10 Wales's RPBs were said to be implementing the DAP differently. Scoping participants largely considered this to be appropriate in the context of addressing local need; although they also felt that the differences are not wholly accounted for by population need, but also underpinned by different foci in RPB funding applications (e.g., some RPBs were said to be focusing on small, simple projects, whilst others were more strategic in their aspirations; some RPBs with high numbers of Welsh-speaking people living with dementia, carers, and staff [North and West Wales for instance] prioritised Welsh language service provision more than others). Moreover, some RPBs were thought to be more innovative and quicker to implement change than others. This was explained partly in terms of individual personalities and relationships on the Boards. In addition, it was perceived that some do not work collaboratively to a sufficient degree and do not adequately involve people living with dementia in service development. Capacity issues within RPBs (exacerbated by Covid-19) had reportedly also affected their implementation of the DAP, as had inaccurately viewing dementia as a mental health issue.
- 3.11 There was some feeling that differences in service infrastructure across Wales had led to fragmented and inconsistent service delivery and a "postcode lottery" in terms of different areas' progress with implementing the DAP. Social, geographic, and cultural differences were also said to underpin variations in the DAP's implementation between areas.
- 3.12 As noted above (3.10), mixed views were expressed around the extent of integrated working between health and social care, with some participants identifying shortcomings. These were largely linked to the different systems and models of care operating within each RPB area. However, it was hoped that the DAP, and any successor arrangements, with its focus on person-centred care, will stimulate more collaborative practices and processes over the long-term.
- 3.13 Some scoping interview participants suggested that the deployment of DSWs has not been as successful as planned, due to the role being interpreted and rolled out differently in different regions, or in some instances due to DSWs reportedly being re-purposed as generic mental health workers.

- 3.14 Some felt that more feedback is needed from both service providers and service users around experiences in social care. It was suggested that those ‘with the loudest voices’ get heard and that there is a need for more consultation with social care practitioners and recipients alike.
- 3.15 As noted elsewhere (3.10), there was some disagreement around the extent of peer support and sharing of good practice between services across Wales, but acknowledgement that networks are being established to facilitate this.
- 3.16 The following aspects were also mentioned by scoping interview participants as needing improvement to ensure the DAP’s full implementation.
- Encouragement and support for research and collaboration, including systematic monitoring of the DAP
 - A greater focus on end-of-life care and consistent training and support (especially for care home staff) in having difficult conversations around palliative and end-of-life care.
 - Hospital care for people living with dementia should be more specialist, flexible, person-centred, with all staff seeing dementia as “their business”
 - A delay in the appointment of the national Allied Health Professional Consultant⁷
 - Support services for those with early onset dementia post-diagnosis
 - Service provision in rural areas
 - Meeting demand for services both for people living with dementia and to support carers
 - Different experiences of accessing dementia services via GPs
 - Staff retention issues in social care
 - Top-down leadership approaches within services is constraining best practice in dementia care and the person-centred approach. Staff were said to need greater autonomy to provide flexible, needs-led services
 - Financial cuts to social care services had meant that people living with dementia and their carers and families had to pay for some services, which was said to be difficult for some to manage
 - Accountability and scrutiny within funding streams

⁷ The development of an All Wales Dementia Allied Health Practitioner Consultant post (to give advice and support to health boards and local authorities to drive forward service improvements) was listed as a ‘key action in the DAP, but at the time of the scoping interviews the appointment was yet to be made.

- Access to community-based services for people living with dementia in care homes – there is a need to ensure they continue to feel connected to their communities
- More demonstration from RPBs of their consideration for protected characteristics, including addressing the link between dementia and learning disabilities
- Focus on *embedding* the DAP rather than speedy action or ‘quick fixes’
- Consideration given to where decision-making for dementia services sits between mental health and social services.

Delivering dementia services in Welsh

- 3.17 Participants were asked to reflect on the DAP’s progress in delivering services in Welsh. Participants reported that there is undoubtedly progress being made and a willingness and drive to provide equal access to services in Welsh. However, challenges remain, particularly regarding the availability of Welsh speaking staff in health and social care; gaps in understanding of how many Welsh speakers there are in the workforce and how many have had training in working with people living with dementia.
- 3.18 Initiatives are ongoing to fill these knowledge gaps, upskill people in the Welsh language, and to recruit skilled Welsh speaking staff. The [‘Work Welsh’](#) initiative and the [‘More than just Words’](#) strategy were mentioned in a positive context, but it was recognised that health boards and the social care sector will struggle to find the numbers of Welsh speaking staff to fully meet their aims and expectations.

RPB area workshops

- 3.19 Several key themes emerged during the workshops, where participants discussed what they felt was working well and less well. Each topic area is discussed in turn in the following sub-sections.

Regional and multi-agency working

- 3.20 Reflecting feedback from the scoping interviews, mixed views were expressed regarding the extent to which the DAP had facilitated regional and multi-agency working.
- 3.21 The DAP was said by some to have provided a vehicle for partnership working, co-production, and multi-disciplinary patient care; to have raised the profile and

awareness of dementia; and to have made dementia a strategic priority for health boards and local authorities.

“[The DAP] gives a good lever to pull on the slightly less willing partners who have a whole host of other priorities...It gives a clear view of, ‘What do we deliver, how do we do that in partnership, what sort of roles and responsibilities are there?’ ” (Powys RPB area workshop)

3.22 However, others felt that leadership and joined up working were currently lacking. It was also considered somewhat challenging to ensure social care representation on steering groups, due to resource pressures in the sector.

3.23 Several RPBs said they were already implementing or planning their future approach to dementia services at the time of the DAP’s inception. The DAP gave them a blueprint for how to achieve this and the impetus to take a more collaborative approach to implementation, including with people living with dementia and their families and carers.

“It crystallises thinking. When you benchmark yourself against a document...it helps refocus the mind and concentrates senior leadership...in terms of prioritisation.” (North Wales RPB area workshop)

3.24 Some participants also said that the DAP had offered governance, guidance, and direction by necessitating the development of regional and localised strategies, as well as new structures such as steering/strategy groups, forums, and panels to drive them.

3.25 Third sector involvement was considered inconsistent in some regions in the early stages of DAP implementation, although it was generally felt that this has improved over time. The need to enable the third sector to contribute at a strategic level whilst also not demanding too much of them was also noted.

3.26 The DAP and the [Good Work Framework](#) were thought to have encouraged needs assessments and dementia service mapping within RPB regions, and the subsequent identification of gaps in service provision.

3.27 Some RPBs have employed independent consultants to assist with this and with developing their frameworks and strategies. This has enabled them to identify areas of good practice to be built upon. In West Wales for example, this was said to have helped build a programme management and service delivery structure.

Funding

- 3.28 Some felt that when the DAP was initially introduced, regions were put in a position where they had to identify priorities and apply for funding before having had the time to develop a cohesive regional strategy, which left them, “in a bit of a strategic vacuum” (West Wales RPB area workshop). Since then, the regional steering group in question had facilitated the development of the regional action plan through effective collaboration, according to participants.

“There really was a genuinely cross-sector approach on that dementia steering group. It was fairly active, and we put together an ambitious, costed programme in response to the resources that were available.” (West Wales RPB area workshop)

- 3.29 Several participants across the RPBs felt that ICF funding had driven improvements in service delivery and collaboration. They felt that it had provided opportunities to implement or trial new solutions or broaden the scope of work being done (for example, developing new provision for young onset dementia) and raised the profile of dementia strategies at a corporate level. For others, it stimulated conversations around clinical and non-clinical approaches and ensured the involvement of the third sector.

“A consequence of the ICF funding has been we are talking a lot more, we are sharing the problems a lot more, and we are more invested in having a more joined up approach ... For example, mental health services for older people [MHSOP] nurses have been attending our specialist MDT [multi-disciplinary team] meetings. They are able to signpost us to [what] needs to be resourced.” (Cardiff & Vale RPB area workshop)

- 3.30 In north east Wales, DAP-associated funding has enabled the provision of a specialist Allied Health Professional team, comprising a speech and language therapist, a physiotherapist, an occupational therapist, and a dietician. Their remit is to look at what support is needed post-diagnosis, offering a longer-term, person-centred approach. This was felt to have been a success in terms of collaborative working and supporting people to embed and adapt behaviours and develop coping strategies.

- 3.31 However, several issues around funding were highlighted. Participants frequently highlighted the difficulties caused by insufficient funding (including ICF / [Regional](#)

[Integration Fund \[RIF\]](#) and other funding streams) leading to inadequate service provision, recruitment constraints, and competition between teams.

“The level of funding isn’t commensurate with the level of support and the level of service that we want to provide. Because the need is so great you just cannot make the money stretch far enough.” (Cardiff & Vale RPB area workshop)

3.32 Representatives from one RPB highlighted the challenges created by population-based funding allocations. They felt that this constrains creative thinking and service provision.

“I find it really frustrating in the way the funds are allocated to [our RPB] ... There seems to be no consideration to the fact that we have the highest ageing population in Wales ... the distance staff have to travel, the time ... How is this fair?” (Powys RPB area workshop)

3.33 However, participants at the Powys RPB area workshop also noted that the available funding has enabled investment in quality management systems and a dedicated programme manager to develop partnerships and drive improvements.

3.34 The complex and short-term nature of funding combined with an over-reliance on grants was said to constrain the provision of sustainable, holistic services and support for people living with dementia and their families and carers. It was hoped that the new five-year approach to RIF funding will help address this.

3.35 Other funding-related problems included a “disconnect” between Welsh Government and RPBs regarding the short deadlines for funding applications. A West Glamorgan RPB representative suggested, however, that the blame for this does not lie solely with Welsh Government; if RPBs had proper service mapping and strategies in place, they would know what their ‘gaps’ and commissioning priorities are and be able to quickly tailor funding applications accordingly.

Staff deployment and development

3.36 RPB area workshop attendees identified a range of positive and negative aspects in relation to dementia service staff deployment and development. As already noted, several welcomed that DAP funding had enabled new staff to be appointed. For example:

- Non-clinical prescribers with the ability to undertake assessment and diagnosis

- Embedding advanced practice roles within memory assessment services to improve diagnosis processes
- Dementia link workers [the equivalent of a DSW]
- Dementia supportive community connectors
- Dementia home treatment teams
- An Allied Health Professional Team to provide specialist post-diagnosis support.

3.37 The DAP and the Good Work Framework were seen to have facilitated staff learning and development in terms of standardisation and accessibility. For example, Cardiff & Vale RPB has invested significant time and resources into developing an accessible and standardised dementia training pathway that cuts across health, social care, the third sector and informal carers. In Cwm Taf Morgannwg, a successful application for RIF funding to expand the dementia care training team will ensure that all relevant staff will be trained in level 2 and 3 dementia care, mapped to the [Good Work Framework](#).

3.38 However, ongoing workforce recruitment and retention challenges within both health and social care were also identified. One specific concern was the lack of consultant psychiatrists with an interest in dementia and older adult mental health who can contribute their expertise within the steering and working groups designed to drive forward regional visions for dementia care.

3.39 In addition, the high turnover of staff within the care sector was said to lead to a lack of continuity in care for people living with dementia. More widely, time-poor workforces have less opportunity to engage on a strategic level.

Person centred care and the MDT model

3.40 A key element of the DAP was the use of Multi-Disciplinary Team (MDT) models to provide more person-centred approaches, which involves tailoring services to the needs of the individual living with dementia and their carers and families, as part of an MDT, whereby clinicians and practitioners of varying disciplines proactively communicate about the needs of an individual, and whereby the person living with dementia and their main carers are actively involved in care planning.

3.41 Most RPBs are implementing some form of MDT model. Some reported having done so prior to the DAP. While there have been some challenges around the implementation of such models, they are largely seen to be important in facilitating

person-centred care for people living with dementia, building on the [Social Services and Well-being \(Wales\) Act 2014](#).

- 3.42 Some regions felt that placing MDT models at the centre of their regional strategy has promoted collaborative working, positive relationships, and sharing effective practice between teams. It was also seen to have facilitated an understanding of the importance of informal carers and communities in dementia care and support, and an ability to develop a more nuanced understanding of people's experiences of living with dementia.

"I see it as all encompassing: comfort blankets around people with dementia and their loved ones. Having the ability to contact just the one person when they have a problem is the biggest difference and also the fact that that person knows...the...nuances of [their family] relationships ... It is all those little details that we were missing before." (Cardiff & Vale RPB area workshop)

- 3.43 However, there was some feeling that the concept is interpreted differently across and even within the regions. In some RPB areas, the model has facilitated strategy and service development and a person-centred service culture; in others, it has been viewed more negatively.

- 3.44 For instance, some participants noted that the MDT approach would be too expensive to implement and would pull funding from essential services. Another suggested that it was a "minefield" which would benefit from a designated coordinator from health or social care.

Placing people living with dementia at the heart of service design and delivery

- 3.45 There was a strong sense that the DAP had placed people living with dementia and their carers and families at its heart, and that the emphasis on ensuring that people are able to live well with dementia for as long as possible was long overdue.

"It's the one thing...that's making a huge difference to people. The well-being side of it. Someone with dementia is still a person, so making them able to navigate easier within their day-to-day life." (Cwm Taf Morgannwg RPB area workshop)

- 3.46 Although most participants recognised the need to further increase the meaningful engagement of people living with dementia in steering and working groups, the clearer focus on co-production within the DAP was thought to have increased

engagement with people living with dementia and their carers and families, and also with professionals, which was felt to have been empowering for all.

“It has helped us really think about how we embrace families and informal carers as colleagues, as equal value in importance... They say, “You know I should be included under the Dementia Action Plan”, which brings a wonderful empowerment.” (Cardiff & Vale RPB area workshop)

- 3.47 Participants shared some examples of actions they had taken to increase the involvement of people living with dementia and their carers and families in shaping services. For instance, West Wales RPB workshop attendees had fostered co-production with people living with dementia and their carers and families by establishing forums and small grants for new community-based services, such as memory cafes, that work collaboratively with the RPB.

“Through the dementia supportive connector role, we’ve established the Living with Dementia forum and a dementia provider forum ... The small grant scheme is...about pump priming small projects - things like memory cafés - to become established.” (West Wales RPB area workshop)

- 3.48 In addition, Cwm Taf Morgannwg RPB is working with [Co-production Cymru](#) to develop its approach to involving people living with dementia and their carers and families in developing memory assessment service pathways. The ‘Hackathons’ (interactive and consultative events) run in Cwm Taf Morgannwg were also praised for their inclusive and collaborative ethos.

Meeting the needs of all people living with dementia

- 3.49 RPB representatives discussed how they were addressing the needs of all people living with dementia, including disabled people who live with dementia, people who prefer and/or have a clinical need to access services in Welsh, ethnic minority people and LGBTQ+ people. Overall, inclusivity was said to be improving, but it was said that more efforts need to be made to ensure true equality of access.
- 3.50 Actions were being taken to improve dementia services for disabled people. For instance, West Glamorgan RPB had expanded end of life care for adults with learning disabilities living with dementia to avoid them having to go into care homes for this support. Cwm Taf Morgannwg RPB was standardising its communications for people living with dementia who are d/Deaf and hearing impaired. In addition, North Wales RPB workshop attendees referred to a booklet they had developed

with the transgender community regarding options for dementia services and support.

- 3.51 Rurality was raised as an issue, in Powys especially, where good governance, accountability, and equity in service delivery was said to be particularly important to ensure access and quality of services for everyone, regardless of location. Some RPB workshop attendees highlighted the need to improve coordination between services, and to ensure consistent and equitable service delivery throughout Wales.

“Consistency across the region.... doesn’t necessarily mean it looks the same everywhere ... but where we can be absolutely sure that the outcomes that we are supporting for people with dementia are equitable across the region.” (West Wales RPB area workshop)

- 3.52 Examples of work underway to expand services for people with young onset dementia were given. For instance, West Wales RPB workshop attendees highlighted a new day service being established in Pembrokeshire specifically for people with younger onset dementia.
- 3.53 RPB representatives highlighted that current dementia services did not fully meet the needs of those living with young onset dementia. One challenge identified with developing these services was that relatively low patient numbers make it difficult to commission and resource regional bespoke services. This has resulted in individuals living with young onset dementia receiving a ‘second-class service’ whereby services are not as tailored to their age-related needs. It was said that this needs to be addressed given the rising number of those diagnosed at a younger age and their differing needs.
- 3.54 RPB representatives perceived that implementation of the [Active Offer](#)⁸ varied according to the proportions of Welsh speakers in particular areas⁹. It was said to be particularly strong in north west Wales, where more Welsh is spoken.

Covid-19: Challenges and moving forward

- 3.55 Participants discussed how Covid-19 had affected DAP implementation and their plans to move forward during the pandemic recovery phase.

⁸ The Active Offer places a responsibility on health and social care providers to offer services in Welsh, rather than on the patient or service user to have to request them.

⁹ This perception however could not be verified via other data in this report.

3.56 RPB representatives inevitably reported that the pandemic had impeded their implementation of the DAP. With many employees' roles repurposed, dementia services slowed or temporarily stopped. For example, memory assessment and diagnosis services were paused during the pandemic. Although these were reinstated in 2021, the impact was anticipated to persist for some time, due to later and more challenging presentations. It was felt that continued and increased collaboration between health and social care was needed to mitigate this.

3.57 However, pausing and restarting some initiatives, such as [John's Campaign](#), had enabled providers to harness learning from the pandemic, and to subsequently reinstate John's Campaign.

"We were doing so well with the John's Campaign ... We even had specific rooms for people who were staying with their loved ones to get refreshments from And then Covid hit ... We are getting better at it again now because of the precautions that we know that are effective." (North Wales, West RPB)

3.58 During the Covid-19 lockdowns, some of the greatest impacts were linked to isolation and decrease in activity and stimulation for people living with dementia. This was said to have contributed to a deterioration in wellbeing and to have accelerated their dementia. RPB representatives also noted that more people living with dementia had refused external support through fear of Covid-19 being brought into the home. However, they also highlighted the crucial role of the third sector in sustaining service provision during the pandemic.

3.59 Covid-19 lockdowns were also said to have impeded data gathering, in-person training, and communication with people living with dementia and their carers and families, especially due to the continued effects of the shift to using more digital over face-to-face communications.

3.60 RPB representatives also identified that the pandemic had fostered several improvements, adaptations, or programmes in order to deal with issues caused by Covid-19 in service co-ordination and delivery, such as:

- The national [Get There Together](#) programme, aimed at rebuilding people's confidence in accessing their communities following the pandemic
- The national, regional, and local increase in creative thinking and collaborative work that was stimulated by the pandemic

- The positive reframing of relationships between people living with dementia and staff in some clinical settings, so that the care provided becomes less clinical and professional, and more personable
- Using digital technology to deliver and/or enhance dementia services, such as virtual appointments, or the use of digital technology to stream exercise classes from a leisure centre into local community centres, and to help people living with dementia and their carers to maintain contact with their families and to take part in activities to increase stimulation and decrease isolation. However, this was not universally seen as an improvement, with some groups, including older people, preferring face-to-face communications.
- Increasing support for carers (many of whom had reached crisis point during the pandemic) through increasing respite provision and deploying dementia advisors
- Implementing a virtual multi-disciplinary team in West Wales RPB, whereby videoconferencing tools are used to facilitate multi-agency collaboration and improve diagnostic options.

Dementia services across Wales

- 3.61 RPB area workshop participants highlighted a range of ways in which they felt dementia services in Wales should be improved.
- 3.62 In relation to GP referrals, the need to increase GP referrals from primary care into specialist dementia services (like [Dementia Connect](#)) was highlighted, as was the need to improve and standardise data collection underpinning referrals to increase accountability. More broadly, it was suggested that GPs should consider social prescribing as an alternative to medication for some people living with dementia and their carers and families.
- 3.63 Some participants highlighted that there were inconsistencies in dementia assessment and diagnosis. Most of them attributed this to a lack of guidance and joined up thinking on what practice in these areas should look like. One also noted that some people living with dementia did not currently qualify for support because they were assessed using [Mental Health Measure](#) criteria. They linked this to the dominance of the medical model of dementia.

“We have a medicalised approach to diagnosing and co-ordination of care that isn’t needed. You need a medical model to inform it, but people with clinical skills working to put those skills into something much more practical in a social context.” (West Glamorgan RPB area workshop)

3.64 The need to improve access to a timely dementia diagnosis was highlighted. North Wales RPB had started to address this through lowering diagnosis thresholds and ensure that those with Mild Cognitive Impairments (MCI) are placed on a support pathway as soon as possible.

3.65 A lack of or variable post-diagnosis support was also highlighted as an area for potential improvement to dementia services.

“As a community-based service, we pick up what happens at the other end of that diagnosis at hospital. On a couple of occasions, we have had extremely angry families who have been given a diagnosis but don’t understand the context in which it was given because there was no follow-up information or signposting.” (West Glamorgan RPB area workshop)

3.66 More effective advanced care planning, and more wellbeing and therapeutic support on acute medical wards was also said to be needed. In fact, therapeutic support in general was said to need better resourcing to improve staff capacity, supervision, support, training, and guidance.

3.67 Other desired improvements to dementia services which were highlighted by RPB members included:

- Developing ‘one-stop-shop’ dementia hubs
- Improving hospital environments
- Improving transitions between care settings
- Increasing support for unpaid carers
- Building delivery and growth plans in partnership with communities
- Re-examining pathways and service provision to avoid duplication.

3.68 The following challenges were said to have faced or be facing those implementing the DAP. Developing cohesive services from the patchwork of service provision that came before the DAP had been a significant challenge for RPBs, as had aligning the DAP with existing regional and local infrastructure. Some felt that the delivery of the DAP was compromised at the outset by the absence of a pre-existing overarching regional strategy in their area, and that more engagement with frontline

staff in the early stages would, in hindsight, have been beneficial in enabling the DAP to be successfully implemented. (Echoing to some extent what was said about RPB readiness to respond to the ICF funding in the early stages of implementation – see 3.35).

3.69 The volume of dementia-related policies and strategies was thought to have caused confusion and duplication of effort. In addition, participants noted some strategy ‘fatigue’, given RPBs have national, regional and local strategies to respond to and deliver, as well as the [All-Wales Dementia Care Pathway of Standards](#).

3.70 Conversely, participants also noted that the DAP had fostered the improvement of dementia services in Wales, especially the [Good Work framework](#), dementia care mapping, and the person-centred focus.

“It was wonderful to see that dementia care mapping was added to the DAP ... It was recognised...that to enable dementia care mapping you needed a lead or team...We have developed an individual referral pathway...so now we can map an individual for discharge or care planning, so staff are starting now to realise that actually dementia care mapping can be a really useful tool.” (Cardiff & Vale RPB area workshop)

3.71 The DAP was said to have raised awareness that people living with dementia should be supported to live well in their communities without rejection or prejudice.

“What it did say to Wales was, ‘Wake up; don’t use an excuse to not support Mr Jones who’s isolated because he’s living with dementia. You’re a community group, you need to start including people regardless’. An equality shout-out to people that, ‘You’re leaving that person isolated because you are worried about dealing with challenging behaviour’.” (Cwm Taf Morgannwg RPB area workshop)

Survey of people living with dementia and their carers

3.72 The pie charts and bar charts in this section show the proportions (percentages) of respondents who gave the labelled responses. Green shades represent positive responses; yellow shades represent neutral responses; and red shades represent negative responses. The bolder/darker shades are used to highlight responses at the ‘extremes’, for example, ‘strongly agree’ or ‘strongly disagree’.

3.73 In several places within the commentary, the proportion of respondents who ‘agree’ has been calculated by grouping response options together (e.g., strongly and tend

to agree/disagree). Due to rounding, these grouped percentages may differ slightly from the sum of the smaller percentages shown in the charts.

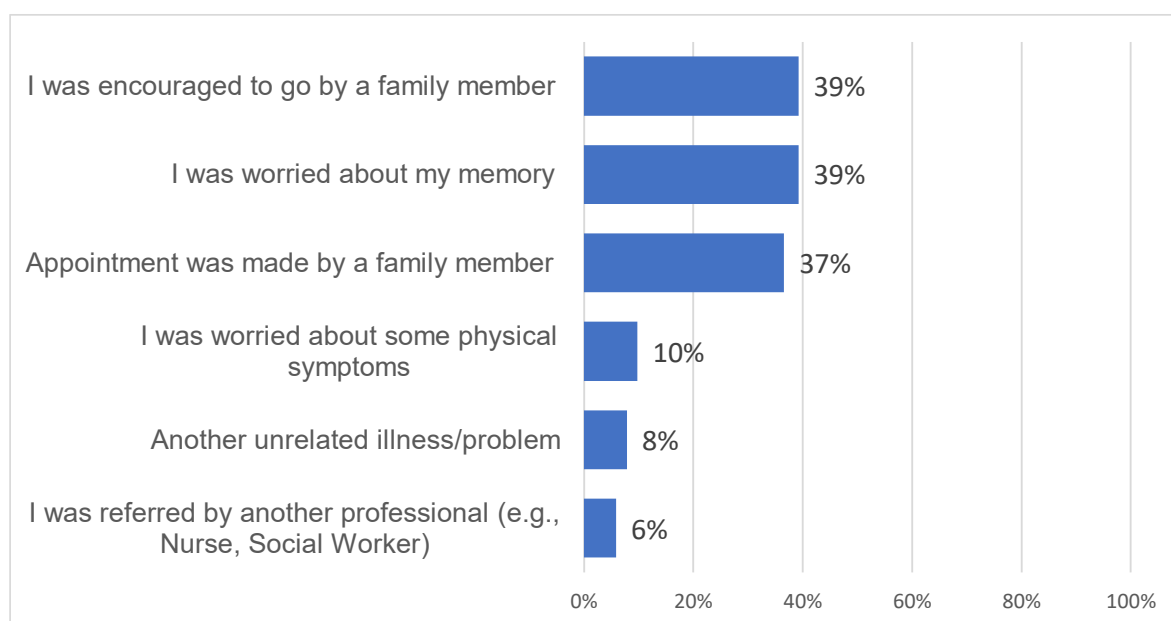
3.74 The base numbers indicate the number of respondents who gave a valid response to each question, as do the percentages.

3.75 The questions asked in the survey all relate to the person living with dementia, even though in the majority of cases the survey was completed on their behalf by the main carer, or by the person living with dementia and their carer together.

Section A: About your dementia diagnosis

3.76 The first question in the main survey allowed multiple responses. It asked, 'Thinking about your dementia diagnosis, why did you first visit the GP?'. Respondents were asked to 'select all that apply'.

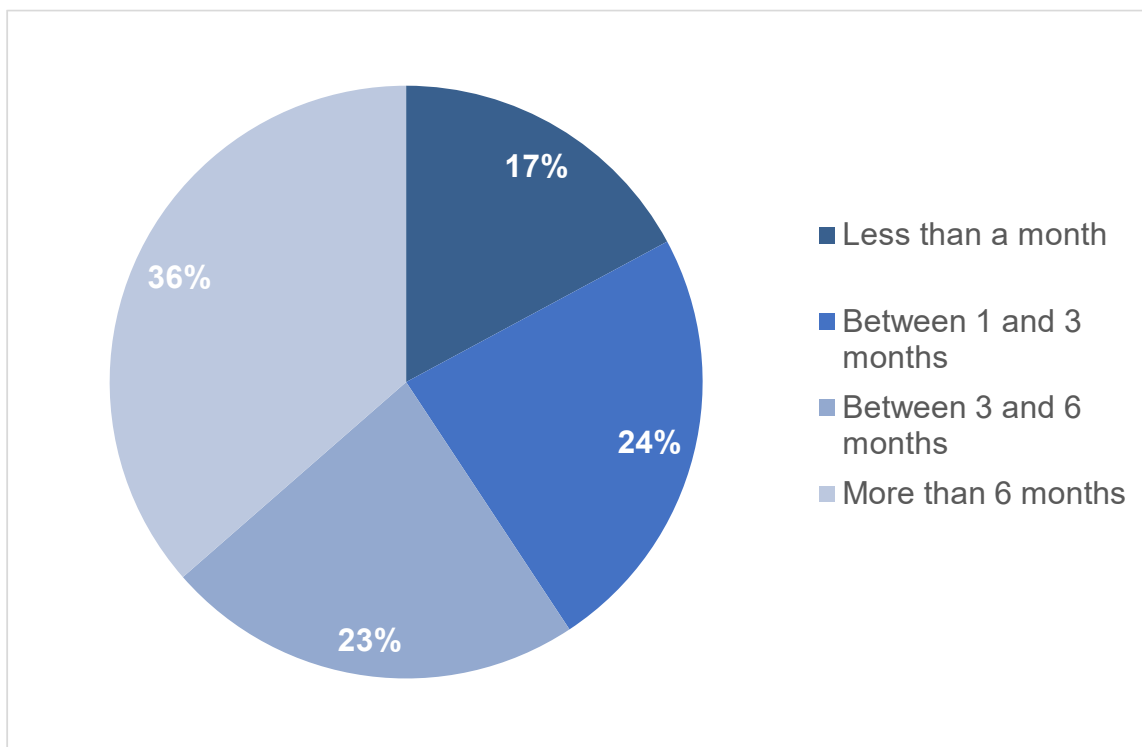
Figure 1: Thinking about your diagnosis, why did you first visit the GP?



Base: Respondents who provided an answer (n=153), Total number of responses (212)

3.77 Nearly two fifths of respondents (39%) reported that the person living with dementia first visited the GP because they were worried about their memory or were encouraged to go by a family member. A slightly lower percentage (37%) said an appointment was made for the person living with dementia by a family member.

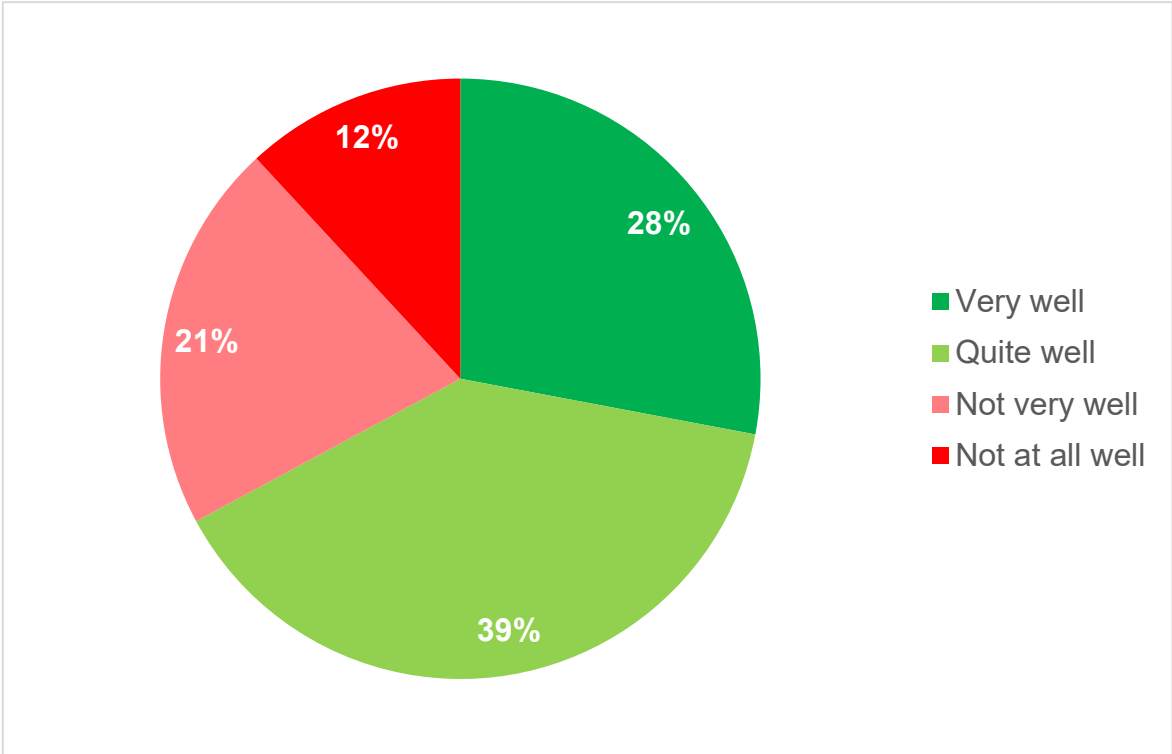
Figure 2: Wait time between first visit to the GP and dementia diagnosis



Base: Respondents who provided an answer (n=140)

3.78 When asked how long it took to receive a diagnosis after first visiting the GP, the most frequent response (36%) was 'more than six months'. Similar proportions of respondents reported that the person living with dementia waited between one and three months (24%) and between three and six months (23%) to receive a diagnosis after visiting their GP. 17% reported a wait of less than a month.

Figure 3: How well was your diagnosis/condition explained to you?



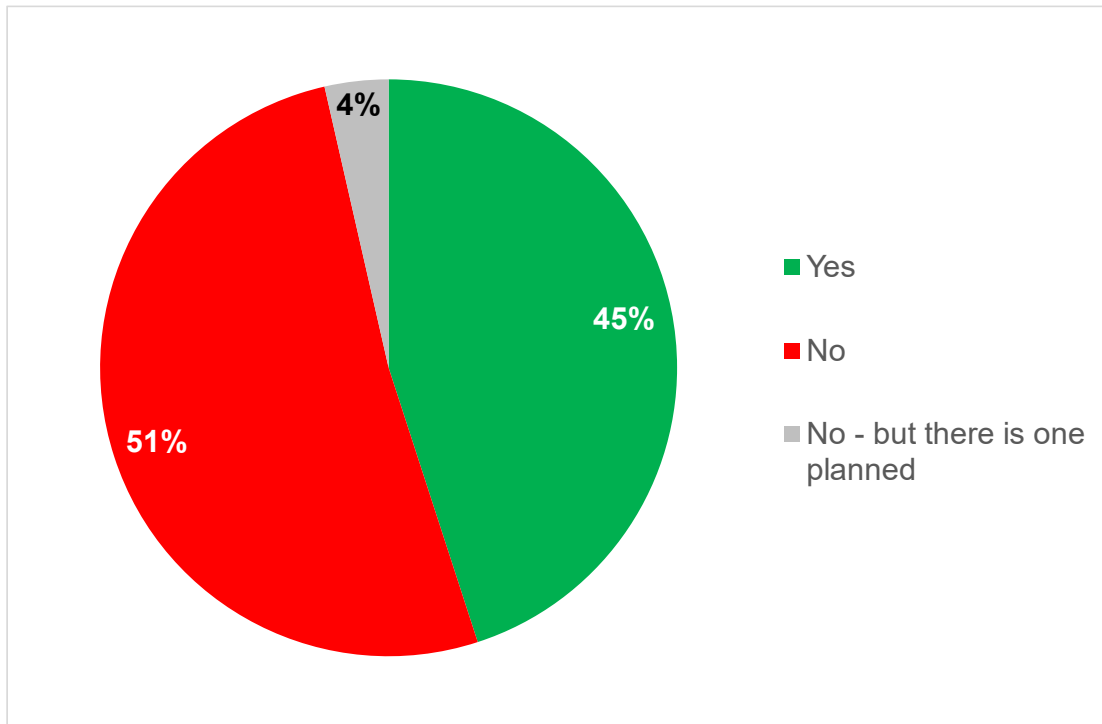
Base: Respondents who provided an answer (n=143)

3.79 Lastly in this section, the survey asked how well the dementia diagnosis was explained to the person living with dementia. Two thirds (67%) said that the diagnosis/condition was explained to the person living with dementia either 'quite well' or 'very well'. Conversely, one third (33%) reported that the diagnosis/condition was explained 'not very well' or 'not at all well'.

Section B: Support after your dementia diagnosis

3.80 This section discusses the support received after the dementia diagnosis was made. Figure 4 shows that half (51%) of respondents reported that the person living with dementia did not have an assessment of their needs after their diagnosis.

Figure 4: After you were diagnosed, did you have an assessment of your needs?

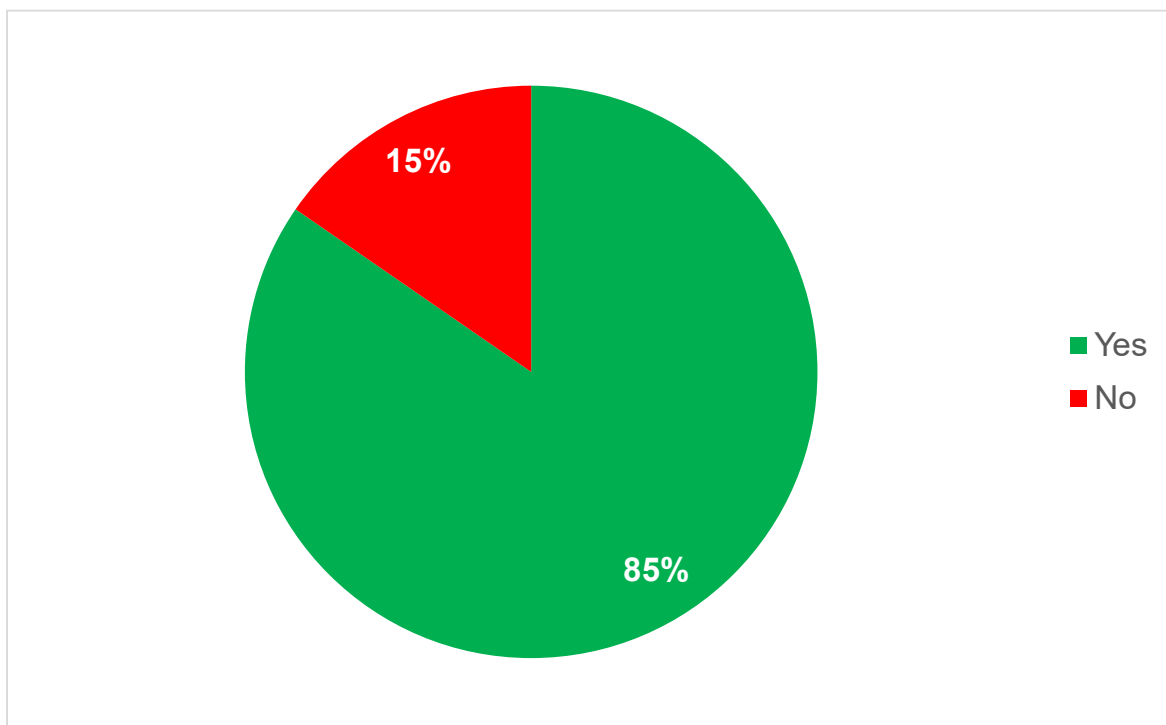


Base: Respondents who provided an answer (n=140)

3.81 Over two fifths (45%) of respondents reported that the person living with dementia had a needs assessment. These respondents were asked a further question about whether the person living with dementia was offered the right help to meet their needs.

3.82 Figure 5 demonstrates that over four fifths (85%) of respondents where the person living with dementia did have an assessment, felt that they were subsequently offered the right help to meet their needs. Just 15% of these respondents reported that the person living with dementia had not been offered the right help to meet their needs.

Figure 5: Were you offered the right help to meet your needs?

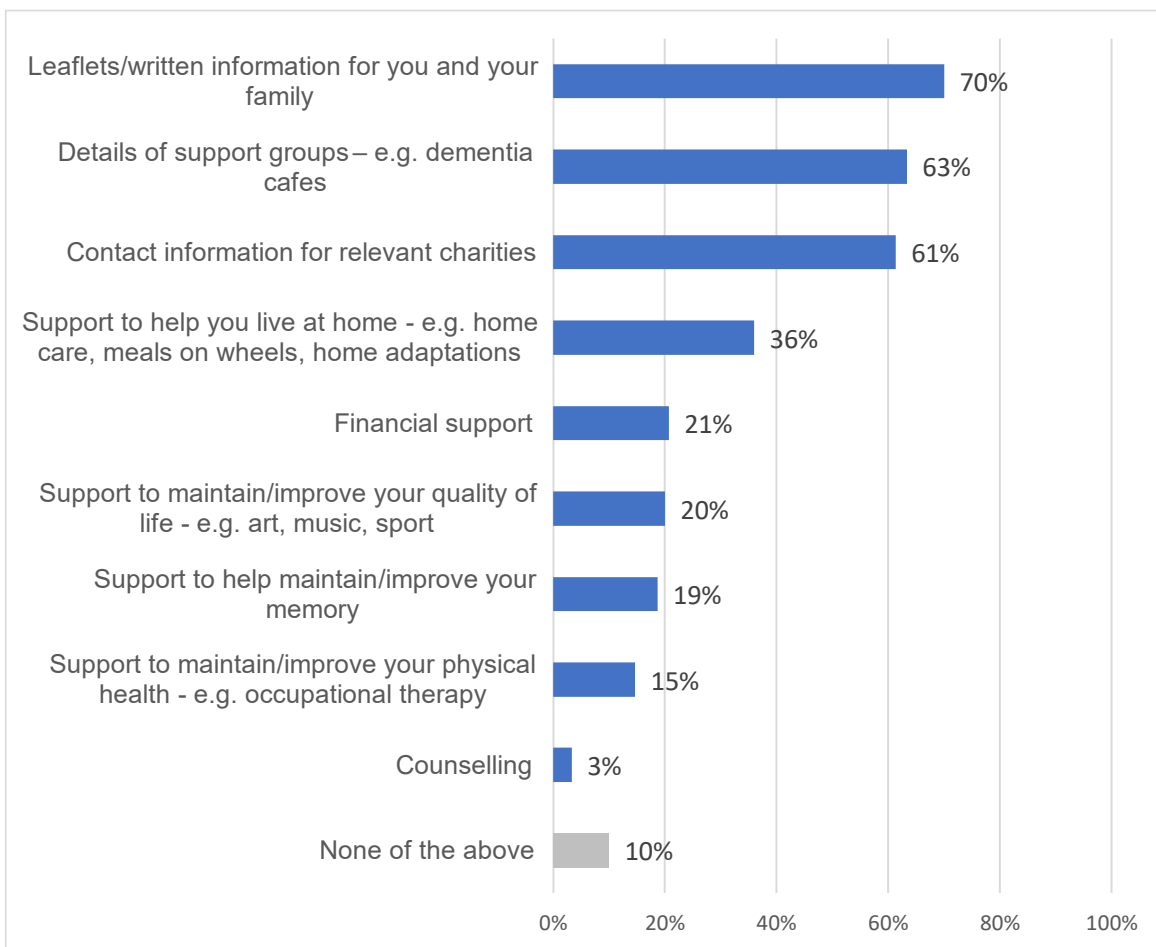


Base: Respondents who had received an assessment and provided an answer (n=52)

- 3.83 All respondents were then asked if the person living with dementia had received any support options from a list provided¹⁰. Respondents could select more than one answer. On average respondents selected at least three response options.
- 3.84 Figure 6 shows that seven in ten respondents (70%) reported that the person living with dementia had received leaflets or written information since their diagnosis, while over three fifths reported that they had received details of support groups (63%) and contact information for relevant charities (61%). Just over a third reported that the person living with dementia had received support to help them live at home. Other types of support reported included financial support (21%), support to maintain or improve quality of life (20%), support with memory (19%), support with physical health (15%), and counselling (3%). One in ten (10%) reported that the person living with dementia did not receive any of the support options listed.

¹⁰ Respondents were not asked whether they had received any of the support options in Welsh.

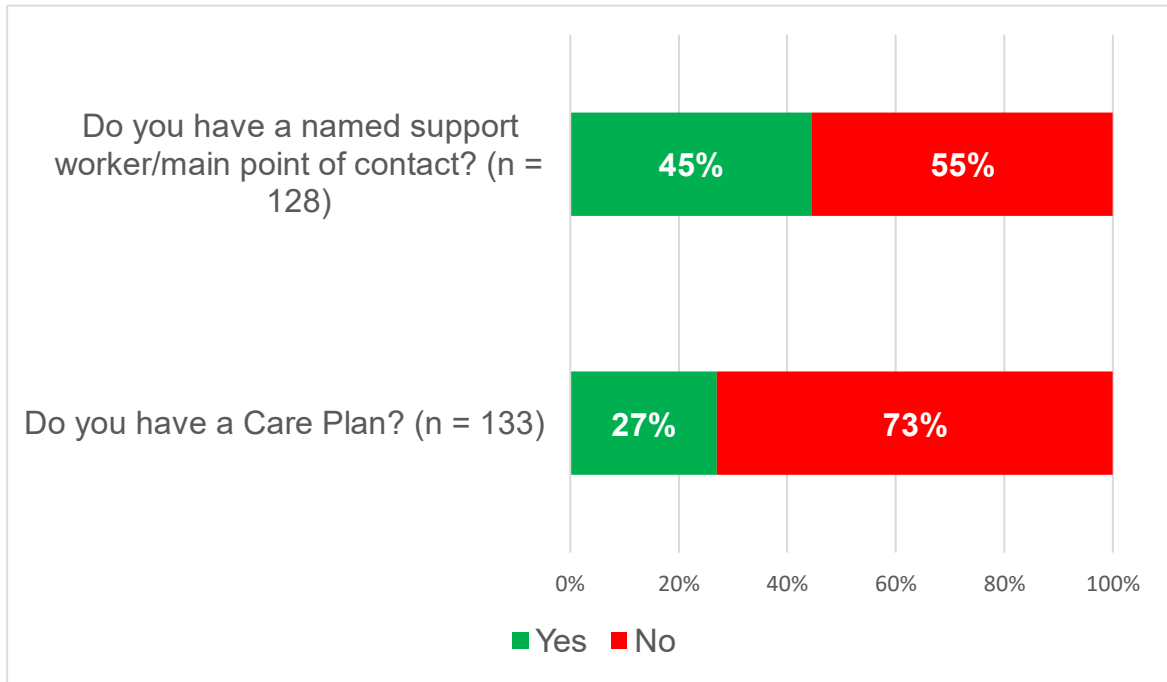
Figure 6: Support received since your diagnosis



Base: Respondents who provided an answer (n=150), Total number of responses (477)

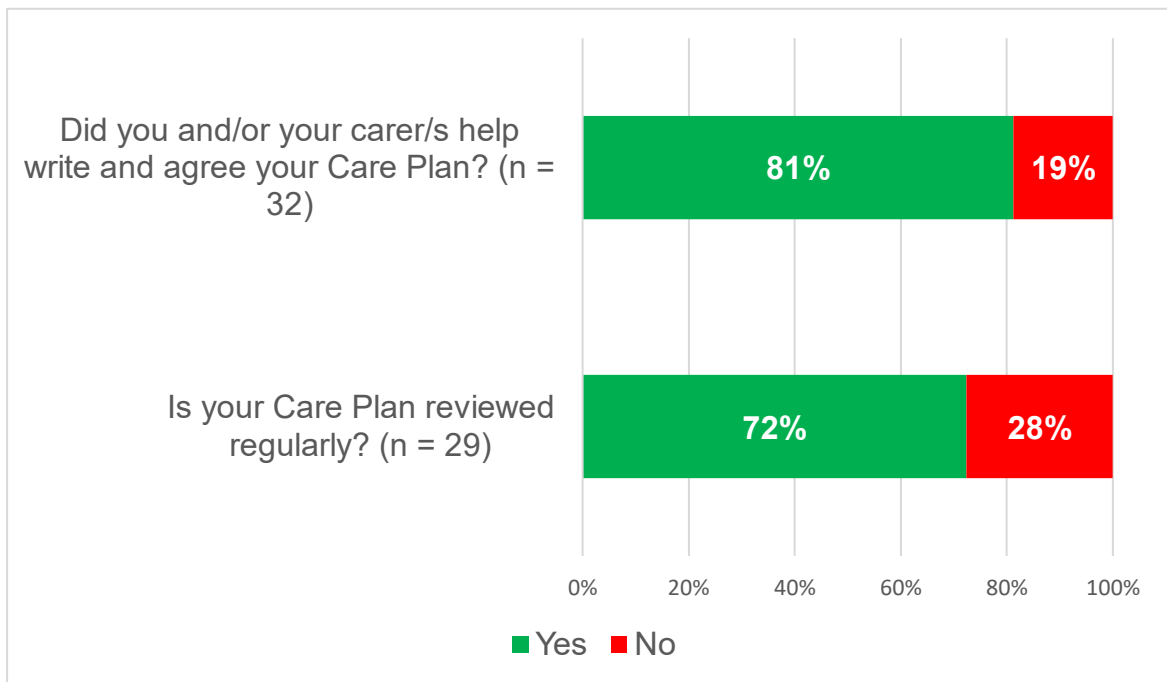
3.85 When asked about the support currently in place, over two fifths (45%) of respondents reported that the person living with dementia had a named support worker or point of contact. However, less than three in ten (27%) said that the person living with dementia had a care plan.

Figure 7: Support currently in place



Base: Respondents who provided an answer (Base numbers shown on chart)

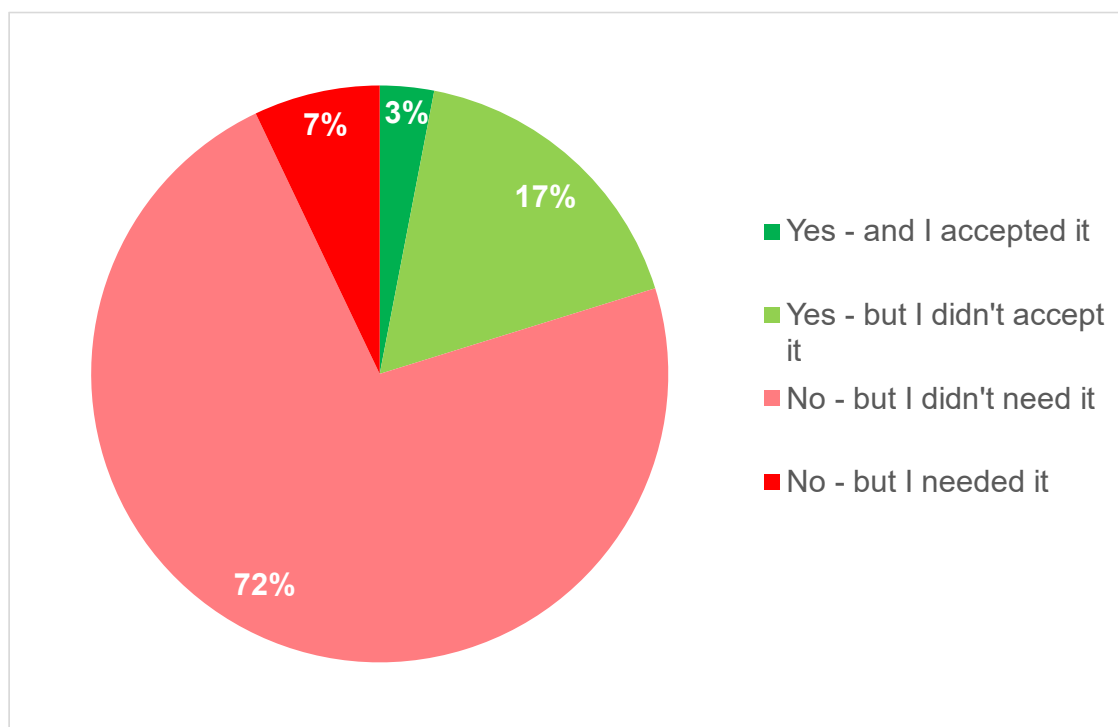
Figure 8: About the care plan



Base: Respondents who have a care plan and provided an answer (Base numbers shown on chart).

3.86 81% of respondents reported that the person living with dementia and/or their carers were involved in helping to write and agree their care plan, whilst over seven in ten (72%) respondents reported that the care plan gets reviewed regularly.

Figure 9: Were you offered support/information in Welsh?

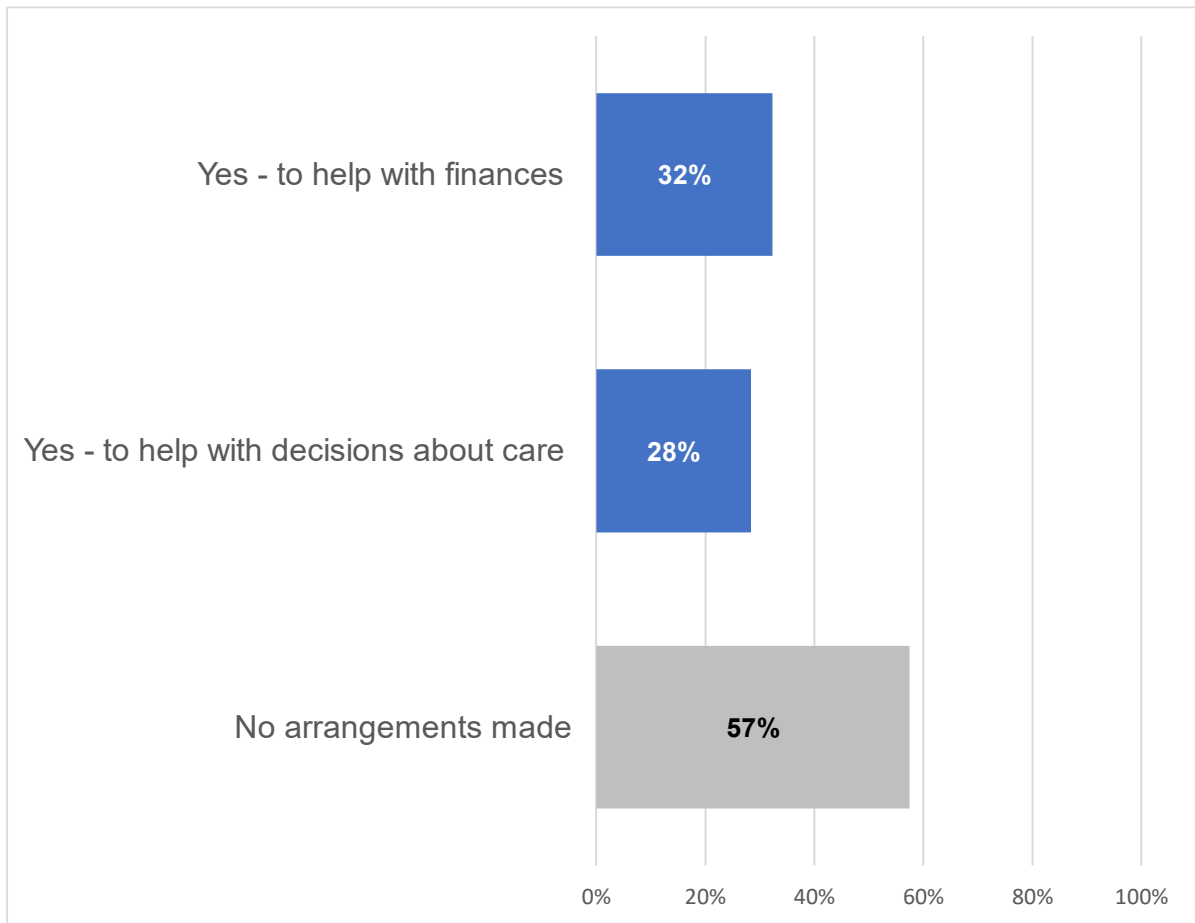


Base: Respondents who have a care plan and provided an answer (n=29)

- 3.87 Six of the 29 respondents who noted a care plan reported the person living with dementia was offered support or information in Welsh. The majority of respondents (21 of 23) who noted an existing care plan and were not offered support/information in Welsh reported the person living with dementia did not need it. However, two respondents indicated that it was needed but not offered. According to Welsh Government's [More than just Words](#) policy, all service users should receive an Active Offer, which means being offered provision in Welsh without having to request it. The survey data therefore indicates that this element of the policy is not being consistently implemented.
- 3.88 It is worth noting that although a Welsh Language version of the survey was available, we didn't receive any responses in Welsh, meaning that Welsh speakers are under-represented by the sample, and it is worth bearing that in mind when reading the findings relating to this question.

Section C: Planning for the future

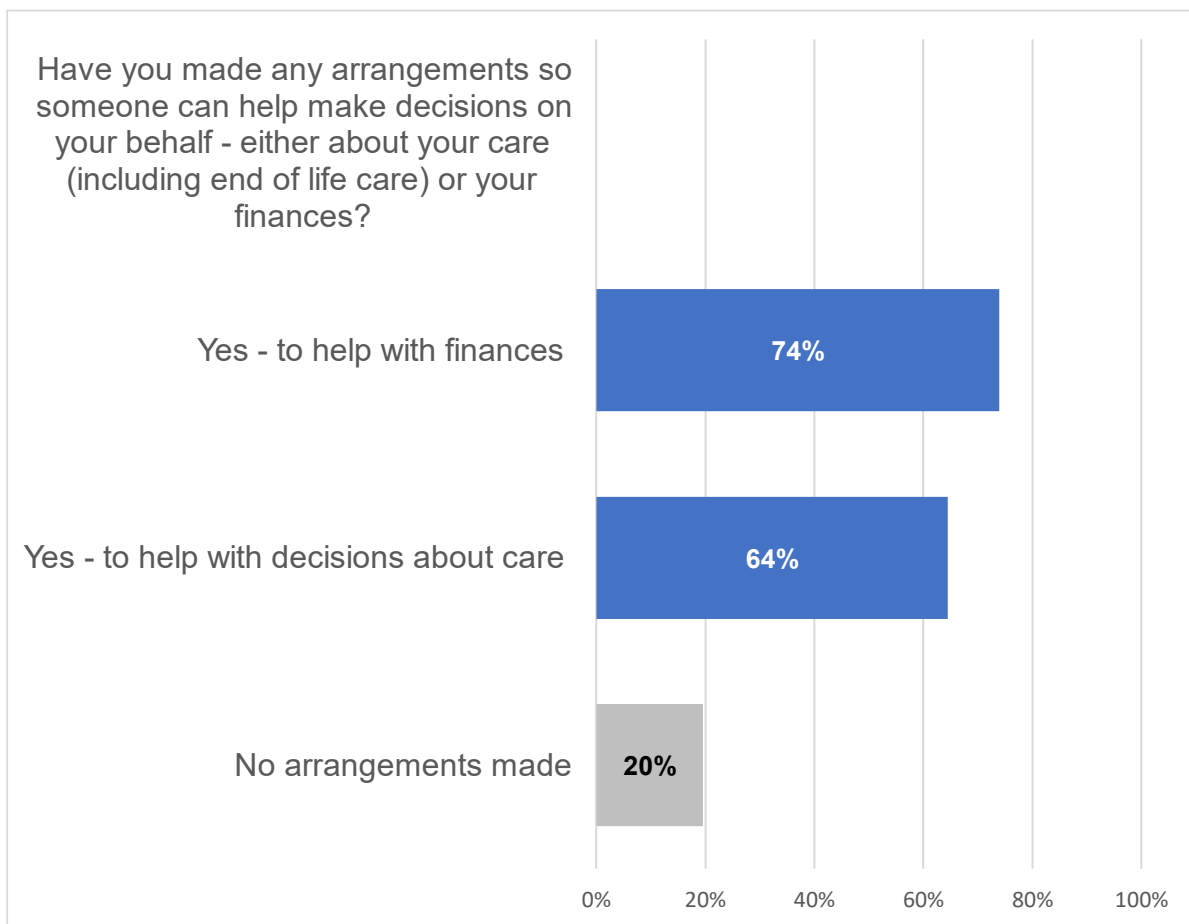
Figure 10: Since your diagnosis, have you had any information, advice, or support around making future decisions about your care (including end of life care) or your finances?



Respondents who provided an answer (n=127), Total number of responses (150)

- 3.89 Figure 10 indicates that only around three in ten respondents reported the person living with dementia has had information, advice, or support around making decisions on future care (28%) and finances (32%) since their diagnosis.
- 3.90 However, as shown in Figure 11, around two thirds or more of respondents reported that the person living with dementia had made arrangements so someone could make decisions on their behalf around future care (64%) and finances (74%). This indicates that people living with dementia and their carers are mindful of making plans even if they have not had advice, support, and information to do so.

Figure 11: Planning for the future (decisions on your behalf)

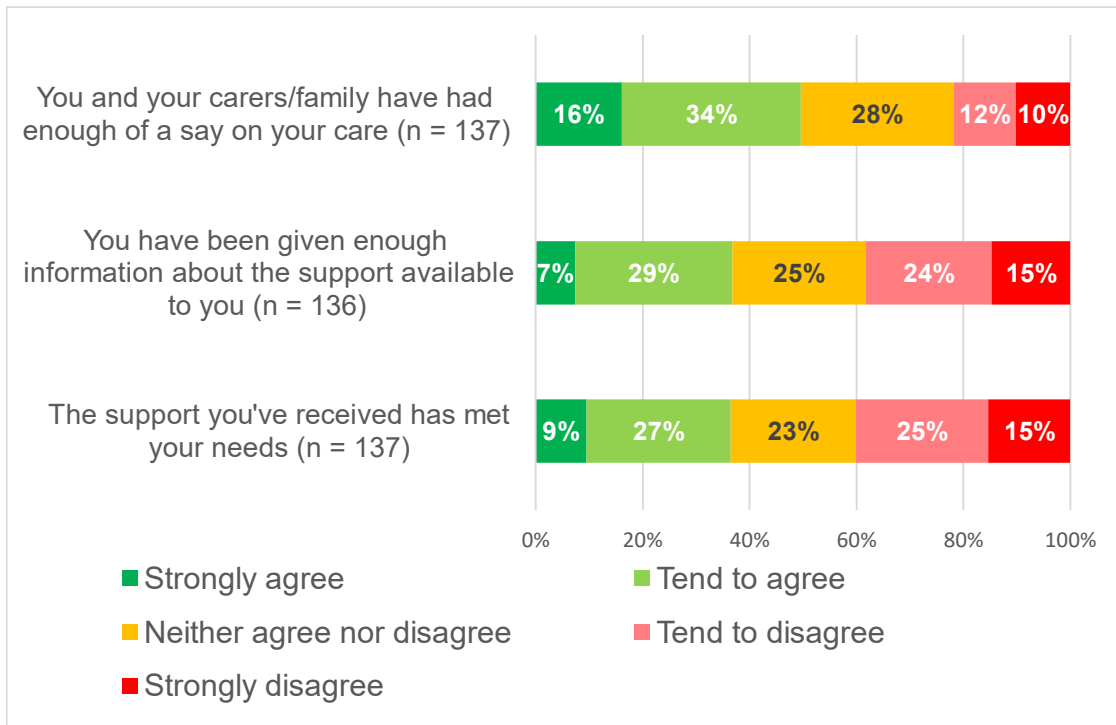


Respondents who provided an answer (n=138), Total number of responses (218)

Section D: Overall thoughts

3.91 Respondents were asked about levels of agreement with a series of statements about the care and support the person living with dementia had received.

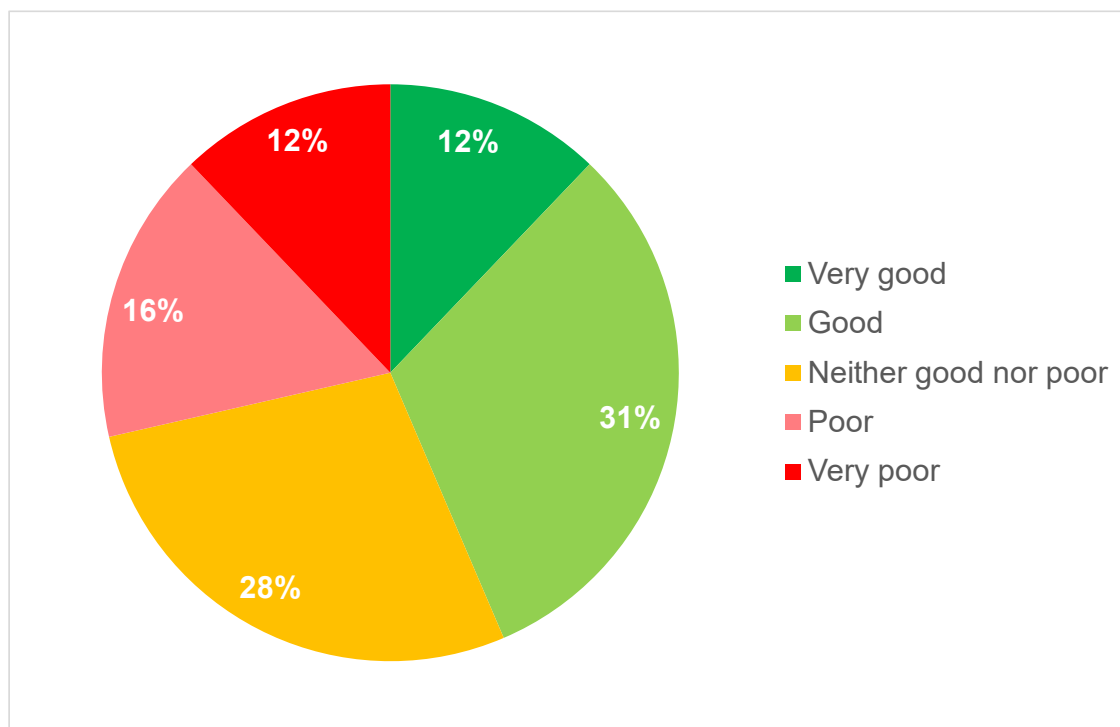
Figure 12: Since your diagnosis, do you agree or disagree that...?



Base: Respondents who provided an answer (Base numbers shown on chart)

3.92 Half (50%) of respondents agreed that the person living with dementia and their carers/families had enough of a say on their care. Agreement falls to just over a third on whether there had been enough information about the support available (37%) and whether the support received had met their needs (36%).

Figure 13: Overall, how would you rate the support you've received since your diagnosis?



Base: Respondents who provided an answer (n=140)

3.93 44% of respondents said they rate the support the person living with dementia had received since the dementia diagnosis as good or very good, whilst 29% rated it as poor or very poor. A further 28% stated that this support was neither good nor poor.

What, if any, support would you have liked but did not get?

3.94 Respondents were invited to comment freely on what support they would have liked but did not get (in free-text answers to an open question). A few would have liked to receive an earlier, speedier diagnosis and a more effective referral process. Some of these respondents complained of problems accessing GPs for initial appointments and then having to wait long periods amounting to several months for assessments and diagnoses, which delayed treatment and appropriate support. This is illustrated in the quotes below from the survey responses to this question.

“Had I been diagnosed earlier I might have had more understanding of what early support was available and how I could be more involved in making decisions while I was able.” (Survey respondent, person living with dementia)

3.95 Respondents suggested that practitioners should recognise the knowledge and lived experience of carers when making a diagnosis, rather than relying solely on the person living with dementia’s reflections on their own health. The impact on carers and family should also, it was felt, be part of the diagnostic process.

“Obtaining a diagnosis was a struggle as responses were taken at face value, e.g. ‘I’m coping fine.’ Impact on family / carers seemed not to be taken into account and it was only through constant pressure and knowledge of the system that any progress was made.” (Survey respondent, carer)

3.96 A few respondents had been signposted to third sector organisations (Alzheimer’s Society, Age Cymru, Pembrokeshire Association of Voluntary Services and NEWCIS¹¹ were mentioned). However, many complained of having little, no, or only short-term help from the statutory sector following initial diagnosis. Respondents would, therefore, have liked to be offered more consistent help and support.

“We were discharged by the memory clinic, and there was no other support available ... We felt totally on our own, and no-one [was] tracking the decline in my mother’s condition.” (Survey respondent, person living with dementia and carer)

3.97 Some respondents would have liked to see improvements in access to day care, support groups, befriending services, dementia clubs, and other activities for people living with dementia. At the very least, information about the support services available would have been welcome. Transport to dementia groups was also suggested.

3.98 Easier and quicker access to social workers and assessments would be very welcome for people living with dementia too.

“We have been told that we may be entitled to support but until we have had an assessment by social services, we cannot access it. We have now been waiting a year for a social services assessment.” (Survey respondent, person living with dementia and carer)

3.99 Respondents would also have liked easier access to local expertise in the form of dedicated dementia specialists in primary care, regular home visits from dementia nurses, and access to named professionals with a thorough knowledge of local services. More frequent appointments and direct personal access to other clinicians including GPs, consultants, and psychiatrists to provide regular monitoring; reviews of care needs; and psychological support to help people living with dementia and their carers deal with the devastating impacts of dementia were also desired.

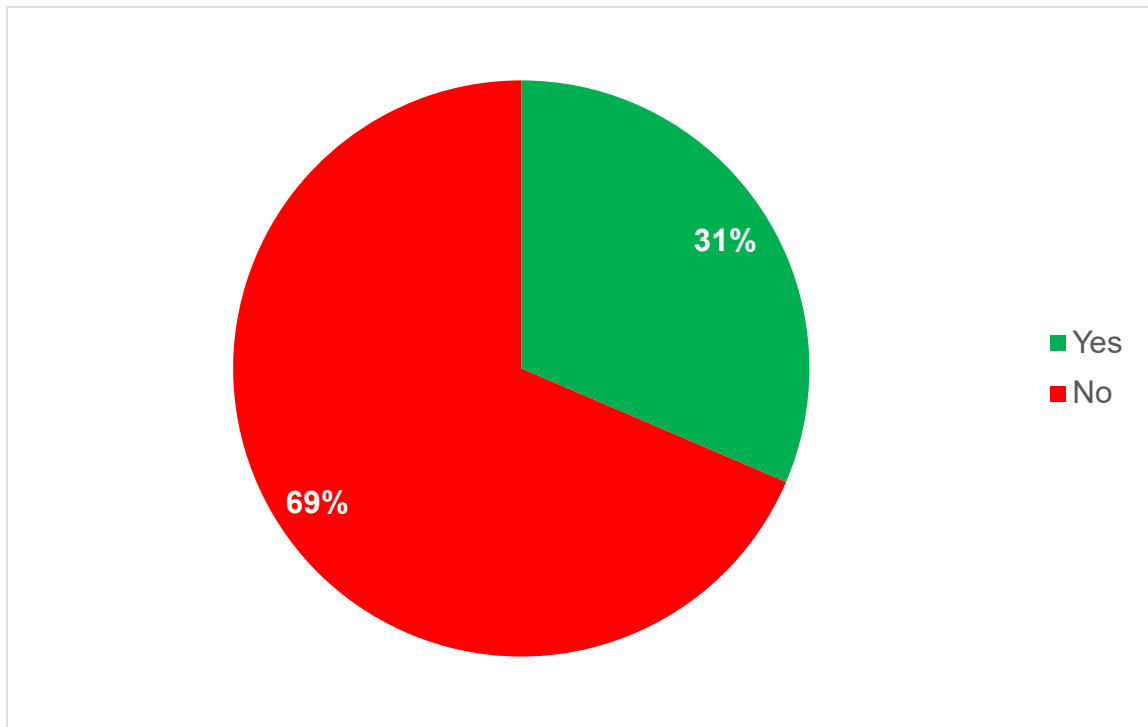
¹¹ NEWCIS (North East Wales Carers Information Service) provides information, support, training, and counselling to carers in North East Wales.

- 3.100 It was reported that more ongoing advice and information to help people understand about dementia, the progress of the condition and what they should expect to happen would also be helpful.
- 3.101 Respondents would also have appreciated more support with practical matters such as financial planning, benefits, obtaining power of attorney, and information on end-of-life care. Some wanted help with filling out forms. Others reported they needed help with the personal care of the person they cared for, including continence support.
- 3.102 A joined-up approach to care and support was identified by some respondents as a need to facilitate care planning and ensure a holistic approach to care. One respondent suggested a one-stop-shop approach.
- “The whole system is disjointed, and each part of the service operates in isolation, no joined up thinking or service across specialties. You end up on long waiting lists for each service separately. Occupational Therapy, physio, Independent Living Services, home adaptations and so on.” (Survey respondent, carer)*
- 3.103 Respondents would also have liked to see more support for family and carers, and more regular carer assessments. Support with their mental health needs, advice on coping with challenging situations, and help with home adaptations were specifically mentioned, along with affordable respite care.
- 3.104 Some respondents also called for more person-centred and needs-led services and support for people living with dementia and their carers; more compassion from practitioners; and more attention to care planning and having care plans in writing.

Section E: Support for carers

3.105 The last section of the survey was specifically for carers to complete.

Figure 14: Has there been an assessment of your needs as a carer?

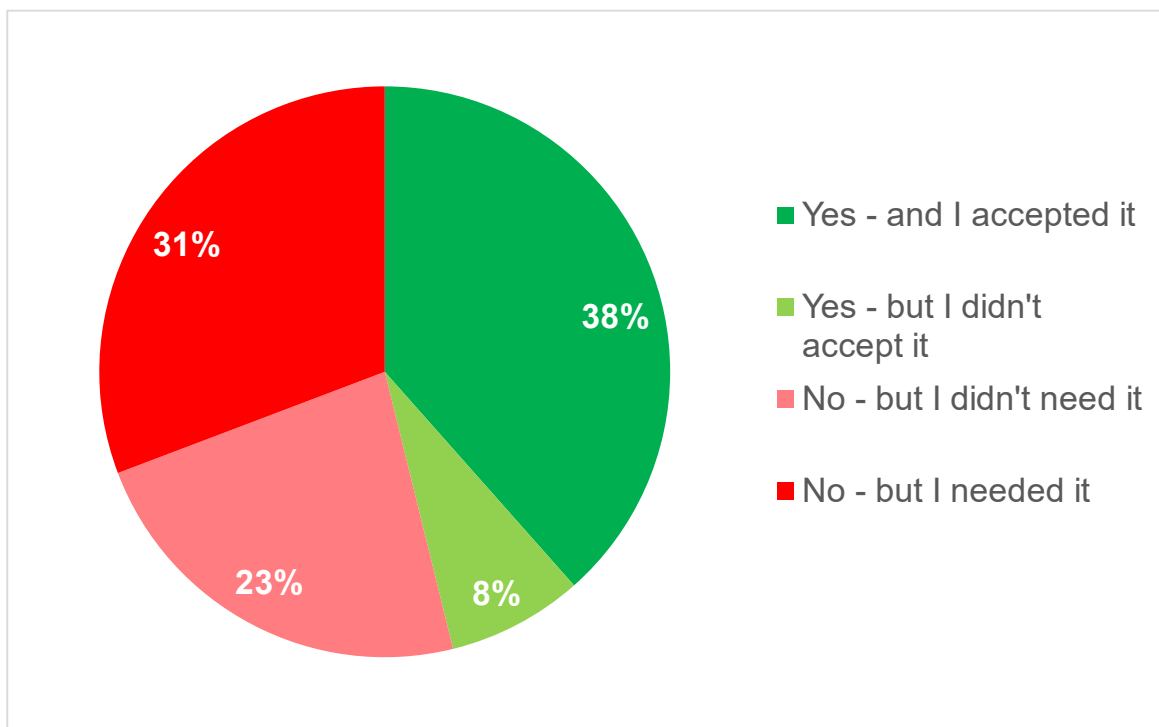


Base: Respondents who are carers and provided an answer (n=124)

3.106 Of 124 responses from carers, 31% reported that they had received a needs assessment whilst 69% had not.

3.107 More than half (54%) of carers who reported that they had had their needs assessed were not offered respite care, including around three in ten (31%) who indicated they needed it. This could be an area of focus for the future.

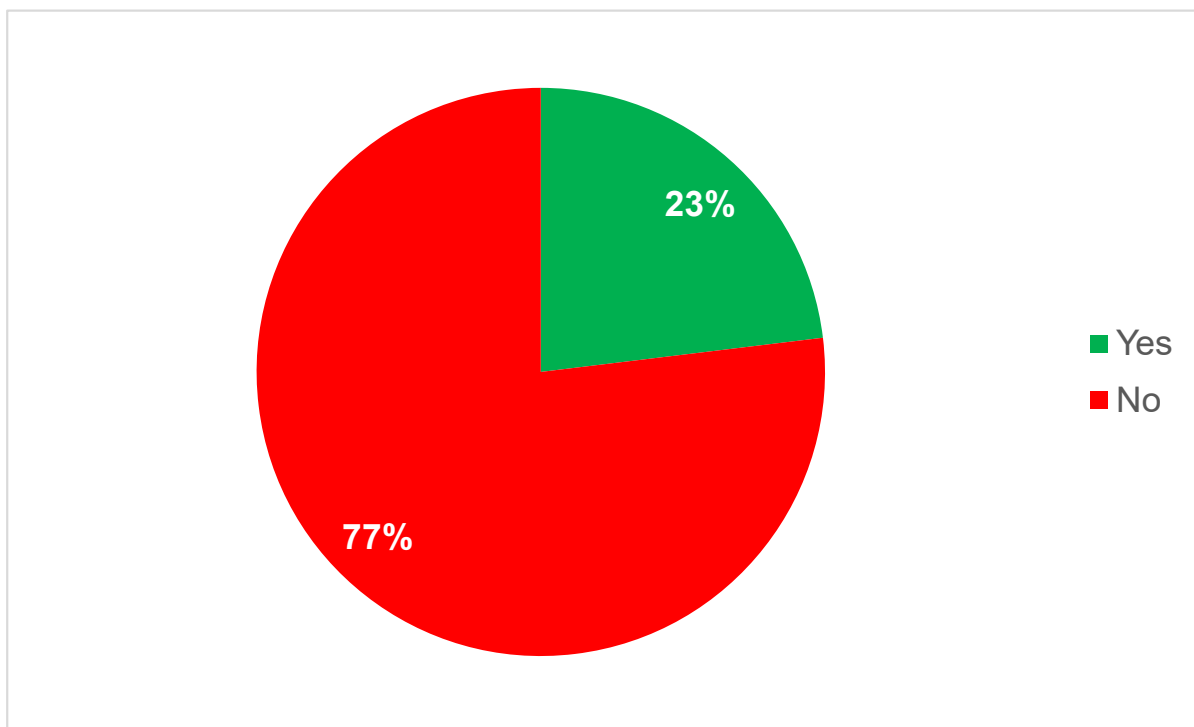
Figure 15: Have you been offered respite care?



Base: Respondents who are carers, have had their needs assessed and provided an answer (n=39). Note low base numbers.

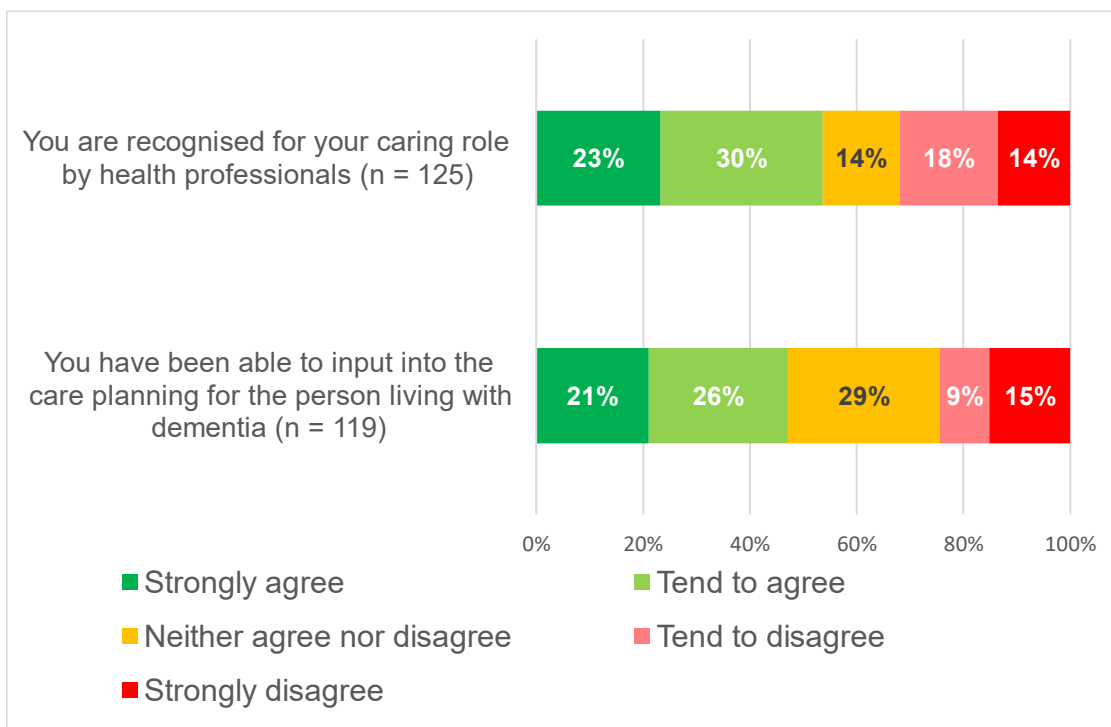
3.108 Less than a quarter (23%) of carers who reported that they had received respite care felt it met their needs.

Figure 16: Has this respite care met your needs?



Base: Respondents who are carers, have had their needs assessed, been offered and accepted respite care and provided an answer (n=13). Note low base numbers.

Figure 17: Do you agree or disagree that you are recognised for your role as a carer and involved in care planning?



Base: Respondents who are carers and provided an answer (Base numbers shown on chart)

- 3.109 Just over half (54%) of respondents who are carers agreed that they are recognised for their caring role by health professionals. However, almost a third (32%) disagreed.
- 3.110 Around half (47%) of respondents who are carers agreed that they can input into care planning for the person living with dementia. However, almost a quarter (24%) disagreed.

How could your experience as a carer be/have been improved?

- 3.111 Survey respondents were invited to comment freely on how their experience as a carer could be or could have been improved. Many carer respondents highlighted the fatigue, continuous stress, and mental health difficulties they have faced, as well as the loneliness and sense of abandonment by practitioners. As such, they would have liked to see more help for carers (from statutory or voluntary services) in the form of physical and emotional support, and practical assistance. Some also mentioned that carers need help applying for benefits and dealing with other financial issues, as well as access to carer/peer support groups.

“Nobody has enquired about how I’m coping - I am elderly myself and now have health problems which I feel are due to caring for my husband.” (Survey respondent, carer)

- 3.112 Many respondents highlighted challenges in accessing respite care, which was considered essential in improving their wellbeing and ability to cope. The excellent service offered by NEWCIS was mentioned by one respondent, but many others felt highly frustrated by the lack of provision available to them and the challenges of having to organise it for themselves.

“Respite care has been granted but availability very poor and is something the carer has to organise themselves whilst worn out, stressed and potentially ill themselves.” (Survey respondent, carer)

- 3.113 A few respondents reported that they had received no support at all for their loved ones and in that context, anything would be welcome. Many would have liked more post-diagnosis information about the likely progression of dementia and the possible challenges ahead, and would prefer to receive this directly from practitioners, including GPs. They complained about the efforts needed by carers to source information for themselves, though a few did acknowledge the help received from [Age UK](#).

- 3.114 More advice and training for carers was suggested to help them enhance support mechanisms for the person living with dementia, access support for themselves, and deal with challenging behaviours and the practical issues that arise.

“I meet my mum’s needs by dealing with each crisis as it occurs with no formal training. A series of discussions with a professional into how to prepare for the future would have made a huge difference.” (Survey respondent, carer)

- 3.115 Many respondents would have like more direct and personal interaction with practitioners, whether from social services or health. Having a named professional as a key contact was frequently mentioned, as was having continuity of support throughout the life of the people living with dementia.

- 3.116 Respondents frequently mentioned the need for practitioners to treat carers with respect, actively listen to them, and acknowledge their expertise in relation to the patient. They stressed the importance of not taking the person living with dementia’s behaviour during short interviews at face value, but to consider the carer’s observations and knowledge as a true record of their condition. Carers would also

have liked to be able to have private conversations with practitioners without the person living with dementia being present.

3.117 Carers suggested other changes to improve their experiences of caring for people living with dementia.

- Organisations adopting a joined-up approach and liaising with each other
- All people living with dementia having a care plan and social services assessments
- Practitioners and organisations adopting a person-centred approach to the needs of the person living with dementia and their carers
- More local support groups and day centres
- Increased carer's allowance and access to direct payments for care. Financial help for those not eligible for carer's allowance
- More support from employers for employees who are carers: for example, paid time off for appointments during working hours.

Interviews with people living with dementia and their carers

3.118 This sub-section outlines the findings from the depth interviews which ORS conducted with people living with dementia who received diagnoses of dementia in or after 2018 and/or their carers.

Obtaining a diagnosis

3.119 The DAP aspires that experiences of getting a dementia diagnosis include early and accurate diagnoses through ensuring that everyone who is referred for an assessment of dementia receives a first assessment within 28 days and a working / preliminary diagnosis within 12 weeks (when it is clinically possible to do so).

3.120 To enable people to seek help earlier, the DAP calls for:

- More non-specialist professionals across the statutory and third / independent sectors to be trained to identify those who might have the early signs and symptoms of dementia, and have clear information about where and how to refer on appropriately
- The development of a consistent pathway to enable people to get a timely diagnosis, care and support. This includes closer relationships to GPs and other health professionals working in the community to promote appropriate assessment before referral to memory services.

3.121 Participants were asked to discuss their experiences of receiving a dementia diagnosis, either for themselves or for a loved one. Most sought a diagnosis due to a change in memory or cognitive function (observed by themselves, or more often by close family and friends). In some cases, dementia symptoms had come to light because the spouse or partner of the person living with dementia had died, meaning that the situation became more apparent to family members.

“You forget your car keys; you forget one or two little silly things. It really hit home when I got up one morning, went on Facebook and noticed it was my daughter’s birthday ...I was horrified...That led me to visiting the GP.” (Person living with dementia, North Wales, young onset diagnosis)

3.122 Some had sought a diagnosis because they recognised symptoms from previously caring for a family member with dementia. In some cases, concerns about memory or cognitive function were raised by health professionals or by a GP during an unrelated appointment.

3.123 Some carers acknowledged that they or the person they care for had been reluctant to seek a diagnosis. This was most commonly because they and/or the person living with dementia did not accept there was a problem, because they attributed cognitive decline to isolation during Covid-19, or because they feared the potential consequences (for example, loss of driving licence, institutionalisation, and loss of liberty).

“She’d actually made an appointment with the doctor about her memory, then cancelled it...She knew there was something wrong and wanted help ... but was so frightened of being locked up.” (Main carer for a person living with dementia, Gwent)

3.124 Similarly, several carers reported that the person living with dementia refused to accept or was unable to understand their diagnosis, when they did receive one. In such instances it was said to be difficult or impossible to access appropriate support. One carer expressed frustration that her father had been able to simply discharge himself from the memory clinic.

“Dad rejected the diagnosis and took himself off the books with the memory clinic, and they obliged, without contacting his GP or family. We were quite angry about that.” (Main carer for a person living with dementia, West Wales)

Diagnosis routes

3.125 Many participants reported that the person living with dementia initially visited their GP when concerns emerged about their memory or cognitive function. Typically, GPs ordered blood tests or scans, or referred participants to their local Memory Advice Service¹² (MAS). Where individuals were already in the care of mental health teams, cognitive testing was undertaken by mental health practitioners.

3.126 Participants reported mixed experiences of GP-led diagnosis. Where people living with dementia and their carers praised their interactions with GPs it was because they felt listened to and taken seriously, or because they felt that the GP had a good manner. Long-standing relationships with GPs were often considered beneficial in seeking a diagnosis.

“I have known my doctor for years. I think when I went and said, ‘Something is not right here’, he took me seriously straight away instead of fobbing it off...He sent me to the memory clinic, and I got tested.” (Person living with dementia, North Wales, young onset diagnosis)

3.127 Others found talking to their GP difficult and uncomfortable. This was exacerbated for carers / family members when discussions took place with their loved one present. The person living with dementia did not necessarily understand what they were being tested for, and the carer / family member sometimes wished to keep the diagnosis from them in order to avoid distress, meaning they felt that the GP was not always respectful of their wishes. This illustrates an element of tension between the ethics of keeping the patient informed, and their wellbeing, where the news of the diagnosis is considered by carers to be too distressing or confusing for the person living with dementia.

“I have to say I don’t feel inclined to go back to the doctor and ask questions ... I find him combative and patronising.” (Person living with dementia, West Glamorgan)

3.128 Some GPs would reportedly not discuss dementia assessment or diagnosis with carers because a lasting power of attorney (LPA) was not in place at that point. In addition, several carers felt that GPs did not take their concerns seriously enough.

¹² The Memory Advice Service (MAS) provides tailored information and support to those who are worried about their memory and their families and carer. They also undertake detailed assessments of memory and cognitive processes.

- 3.129 Several carers had felt that GPs were hesitant to make diagnoses. In some cases, this was thought to be because GPs did not understand enough about dementia or were inexperienced in administering diagnostic tests.
- 3.130 In some cases, referral to the MAS resulted in a visit to a clinic for testing; in others, home or (during Covid-19 lockdowns) online visits were undertaken.
- 3.131 Some carers found having the cognitive tests difficult for the person living with dementia and as a result, also upset the carer themselves. Some even described the process as “horrendous” and “gruelling”. For example, one carer described their loved one’s distress upon being asked when their spouse had died, which they had forgotten about as a result of the dementia.

“It was not good. The nurse came in and asked her various questions ... Her confusion was rife: she wasn’t taking in anything that was going on. Then unfortunately the nurse asked when my father had passed away. She had forgotten that already. She broke down totally.” (Main carer for person living with dementia, Gwent)

Timeliness of diagnosis

- 3.132 The time taken from first approaching a GP or memory clinic to receiving a diagnosis was reported to range from between a few days to over four years. The online survey also showed that the length of time varied between first discussions of memory issues and diagnoses of dementia. Among the interviewees who discussed young onset dementia, a shorter time to diagnosis seemed to be more typical. Further research is needed to explore whether this is typical of individuals with young onset dementia more generally, and the possible reasons for this.
- 3.133 Participants’ feelings about the diagnostic process were often coloured by its length and the extent to which they had to ‘push’ to get a diagnosis. Some participants (both people living with dementia and carers / family members) were pleasantly surprised by how swiftly a diagnosis was made and expressed relief and appreciation about the way the process had been undertaken.
- 3.134 Many diagnoses, however, were thought to have been delayed, often due to Covid-19, but also other factors including co-morbid diagnoses such as Parkinson’s Disease or post-stroke cognitive decline, and the limited availability of psychologists.

3.135 A few carers described instances on behalf of the person living with dementia of delayed assessment and diagnosis because of pre-existing mental health conditions where these or other circumstances masked dementia symptoms - such as being kept in hospital under the [Mental Health Act 1983](#).

“They did therapy on him [for what they thought was a mental health condition] ... After five months, they said they couldn’t do any more for him and ...he was discharged. Then...they had a psychologist come on board ... She...did all the cognitive tests and asked for a review of his scans and they diagnosed him with vascular dementia.” (Main carer for person living with dementia, North Wales)

Receiving a diagnosis

3.136 It was often reported that the person living with dementia had received their diagnosis in person at the time of testing or during a home visit afterwards. Others reported that the person living with dementia received their diagnosis by post, by telephone or, particularly during the pandemic, in an online conversation. Not all people living with dementia received a formal letter of diagnosis, although some said they would have liked one.

3.137 A few people living with dementia and carers felt that the diagnosis was well explained, either by the GP or the memory clinic. However, some felt that the information received about the diagnosis and the accompanying process was over-medicalised, inaccessible, and lacked detail.

“The psychologist sent mum a copy of the report. I couldn’t understand why they’d done that, because there was no follow up; there was no phone call at that point, or anything from anybody to explain to mum what this report meant. It was quite medical and quite technical.” (Main carer for a person living with dementia, Powys)

3.138 How well the diagnosis process was explained strongly influenced how carers and people living with dementia felt about the whole experience. Some carers praised their GPs and other practitioners such as psychologists and psychiatrists for clearly explaining what would happen next. Where this was not explained so well, people living with dementia were more likely to be left feeling fearful or confused. Both people living with dementia and their carers often particularly appreciated efforts made to meet face-to-face (especially during the pandemic) and valued a person-

centred approach. Others did not receive any explanation or follow up or felt that the explanation was 'vague' and 'rushed'.

"I was told, 'Unfortunately we have to tell you your husband's brain is showing distinct signs of Alzheimer's disease'...and gave me a letter saying he had been diagnosed with Alzheimer's ... She just said, 'You'll be assigned a nurse and called back a few times a year.' And that was all that was said to me. Quite frankly, I thought she couldn't get rid of me quickly enough." (Main carer for a person living with dementia, West Glamorgan)

3.139 A few participants, both people living with dementia and their carers, also highlighted the need for clear and direct information about the diagnosis to facilitate their understanding of the diagnosis and next steps.

3.140 People living with dementia invariably felt distressed and upset after their diagnoses. They described feeling 'shocked', 'devastated', 'angry', or being in denial.

"It's almost like you can see the bus coming but you don't know if you're going to get hit or not and you don't know how much damage..." (Person living with dementia, North Wales, young onset diagnosis)

3.141 However, some carers felt vindicated, particularly in situations where they felt they had needed to push to get a diagnosis. For some, it was a relief to have a clearer understanding of the situation in order to plan for the future, put an LPA in place, and access relevant support.

3.142 The loss of the person living with dementia's driving license was a particular cause of distress. Some felt that the licence withdrawal was unjustified or untimely. More than one person living with dementia reported having passed DVLA cognitive tests weeks before being told by their GP or MAS that they would have to relinquish their license.

"Surrender[ing] my driving licence...horrified me. I think it's wrong that one minute you can drive and half an hour later you can't. It came as a shock ... I actually paid for a driving assessment myself ... The guy said ... 'I can't even understand why you're here. Your driving is exceptional'." (Person living with dementia, North Wales, young onset diagnosis)

3.143 Many people living with dementia had been prescribed medication to try and slow their condition, and although some had experienced adverse side effects, most had

been able to find, or were in the process of finding, suitable medication with their GP.

Accessing support

3.144 The DAP sets out to enable access to a number of different support mechanisms by providing equality of opportunity for people with lived experience of dementia so that they are able to utilise support wherever it is available. People living with dementia and their carers outlined their experiences of finding routes into services.

3.145 Overall, carers expressed mixed views about the support they or the person living with dementia had been offered and had received. Some described an 'uphill battle' in accessing support, whilst others felt they were proactively offered plenty of support.

3.146 Some carers also described the support the person living with dementia received as inconsistent, or that it was only offered when they reached problems or a crisis.

"You still seem to have to wait until there is a crisis before things get done. Once you're actually there in A&E and things are looking pretty dire, then things snap into place But as a carer then, you're totally powerless." (Main carer for person living with dementia, Gwent)

3.147 It was found that people living with dementia and carers who had prior experience of dementia, either through another family member or work, were more likely to be able to find the support they needed as they were more aware of what was available and what they or the person living with dementia should be entitled to.

3.148 Most participants, carers in particular but also some people with lived experience (and especially those with lived experience of early-onset dementia), felt they had to find their way as they went along, with some describing a 'snowball' effect whereby discovering one avenue of support led them to finding out about something else.

"I didn't realise there were Admiral Nurses out there. Then when the Admiral Nurse started telling me about all these things, I thought, 'I didn't know about that'." (Main carer for a person living with dementia, West Wales)

3.149 Not many people living with dementia and their carers felt that they had been given opportunities to feed back on the services or support they receive. Those who had did so through questionnaires filled during support sessions for either the person living with dementia or their carer, or council members visiting groups or settings.

Some said that the questions had been ‘tricky’ to answer but felt that it had helped them feel listened to.

3.150 Experiences of follow-up support immediately post-diagnosis for people living with dementia were mixed. Some were happy with the immediate follow-up support received. This typically involved check-ins from their GP, printed information from their GP or the memory clinic about different types of dementia and details of relevant local charities and support groups, and introductions to a relevant specialist or support practitioner. A few were offered six- or 12-week training courses to provide useful information for either the person living with dementia or carer about dementia (views on courses are discussed in more detail in paragraphs 3.202, 3.222, 3.223. 3.232).

3.151 However, many people living with dementia and carers said that they received no or little follow-up support immediately post-diagnosis from their GP or the MAS.

“The GP has not been involved since. We asked, ‘What happens now?’...and they said, ‘That’s it’ ... I felt we were left a bit high and dry.” (Main carer for person living with dementia, North Wales)

3.152 In more than one instance, promises were made of a referral to a psychologist or psychiatrist, but either the referral was never made or the appointments failed to materialise.

3.153 A specific issue was reported by some carers whereby when follow-ups were made, GPs insisted on talking to the person living with dementia, even when they lacked capacity to converse coherently. It was felt in these cases that the GP was simply following procedure and not considering the needs of the person living with dementia. As with the point above at 3.127, this suggests a tension between the ethics of keeping the patient informed, and their wellbeing, from the perspective of carers who feel the news to be too distressing or confusing for the person living with dementia.

3.154 Some carers who felt they had received enough information felt well supported by practitioners, key workers or organisations. They commended organisations including the Alzheimer’s Society, NEWCIS, the Carer’s Trust, Admiral Nurses, their GP and other healthcare practitioners, and their social worker. For example, some mentioned receiving a monthly newsletter from NEWCIS detailing available support,

which they found very useful. Many, though, described feeling “overwhelmed” by the task of information-seeking at the outset.

“You ... feel overwhelmed by it in the beginning. Now if I need anything, I will find it ... I’ve got to the stage now where if I need information, I’ll find someone or ring the Alzheimer’s Society or ring the social worker and find it from there ...” (Main carer for a person living with dementia, Gwent, young onset diagnosis)

- 3.155 Some carers suggested that a comprehensive directory of support should be made available to them, to make this task easier. One carer suggested that post-diagnosis support directories should be structured chronologically.

“Ideally a great thing would be to have a list of everything you can do given to you, and in the order you should do it in if possible. Each individual thing is a process. So, for me as a carer [it is important] to know what to do next.” (Main carer for a person living with dementia, West Glamorgan)

- 3.156 Few carers described receiving support to maintain or improve the physical health of the person living with dementia, though one mentioned a physiotherapy group they attended, and a few had received home visits from a physiotherapist.

- 3.157 Most carers felt that the support with physical health for the person living with dementia met needs, although most of the time this was not felt to be directly linked to their dementia care. Physical health conditions were not necessarily discussed with reference to a dementia diagnosis, but just as part of ‘old age’.

- 3.158 Many carers had issues in trying to find suitable practical support or care for the person living with dementia. Carers often stated that they had no prior experience of dementia so felt that they were left unsupported whilst trying to work out themselves what to do for the best.

“There didn’t feel to be any practical support and day-to-day. How do you care, I suppose. You’re making it up as you go along, and you have no idea if you’re doing it right.” (Main carer for a person living with dementia, West Wales)

- 3.159 People living with dementia and their carers identified the following gaps in or issues with post-diagnosis support:

- Being offered lots of printed information but not the practical support they needed

- More opportunities would be welcomed to meet others in similar circumstances to reduce isolation
- More direct and regular access to practitioners was needed, to assist and guide them in the same way as someone with a physical illness. For example, some reported issues with getting hold of the right person to speak to, or lacked confidence to make contact when they were struggling
- More information about relevant statutory health and social services as opposed to information about third and voluntary sector services would be welcomed.

Key workers/contacts for information or support

3.160 The DAP aspires to provide dementia support workers in the form of multi-disciplinary teams who are able to adapt what is required as a person's needs change. The role is designed to be an access point for people living with dementia, to have access to:

- Cognitive stimulation programmes
- Allied health professionals, rehabilitation and re-ablement services
- Assistive technology and/or equipment and making adaptations to the environment to maintain or improve a person's independence, safety and wellbeing
- Flexible, enabling and personalised support
- Advocacy support.

3.161 It should be noted that key workers or main support contacts were generally known to participants by their first names; most carers and people living with dementia did not have any awareness of their job titles and were often confused around which organisation(s) they represented, or whether or not the contact had come about as the result of any kind of referral. As such, it is not possible within this report to equate 'key workers' or 'key contacts' with the DSW role.

3.162 Many carers and people living with dementia reported they had a support worker, dementia navigator or some kind of 'key worker' as a single point of contact. Several said they were not offered a key worker but had found for themselves contacts within different organisations who they approach with questions or issues. These organisations included Alzheimer's Society, Admiral Nurses, the Carer's Trust, NEWCIS, and many others. A mix of people living with dementia and their

carers described being contacted directly by such workers following diagnosis, suggesting that a referral had taken place via GPs or the MAS. Referral to support workers is an area which would benefit from further exploration.

- 3.163 Some participants reported that the person living with dementia's key workers were a mental health/district nurse or a social worker. While the former were widely praised, views on social workers were mixed. Some people living with dementia said theirs was helpful and organised, whilst others reported they had only heard from theirs once, with no follow-up contact.
- 3.164 Key workers/contacts were said to go out of their way to find the right information for the people living with dementia and/or their carer about available services and support, often putting them in direct contact with organisations. They had also, it was said, submitted social services assessments or referrals to physiotherapists and occupational therapists; made requests for safety checks on behalf of people living with dementia and their carers; and identified what people living with dementia and their carers were eligible for, and helped them fill in the requisite forms.

"For five years she was our rock ... She used to come every time, and she'd ring me up, 'Oh, I've just seen this, this is what you could do'. I felt that she was making a real effort to help us." (Main carer for person living with dementia, Cardiff and Vale)

- 3.165 Furthermore, those who had recently lost a person they cared for said that the support they received did not stop with their death; it continued to be offered should they want it.
- 3.166 Only a few people living with dementia said the service and support they received from their support/key workers could have been improved, and even then, only in terms of more frequent contact.
- 3.167 Carers who said they did not have a main point of contact or key worker were often left feeling that much of the work to find out about available support was left to them and felt they lacked knowledge of some types of support as a result.

Social support

- 3.168 Social activities were said to be essential for people living with dementia and their carers. The importance of social prescribing was therefore highlighted by carers and people living with dementia who had attended regular coffee mornings, peer support groups, arts and crafts sessions, music groups (such as Music for Dementia, the

Old Ladies Choir, and the Forget Me Not Chorus), and Men's Shed or Veterans Groups linked with the Alzheimer's Society. Others were involved with animal charities or animal sanctuaries as a form of therapy, such as Gwent Wildlife Trust. Others found the best support in groups they already attended pre-diagnosis, such as bowls clubs or knitting groups.

- 3.169 Many people living with dementia and carers spoke of the benefits of music in stimulating memories, suggesting that music-based therapy had been the most important form of therapy in their case.

"Somebody mentioned this choir to me. We went along and as my granddaughter says, 'It was banging' ... [My wife] was so happy, face lit up ... it was fantastic. I remember her daughter saying, "How the hell does mum learn the words?" I said, "That's the thing, the way they do it, dementia people [sic] do remember the words." I can see that with Forget Me Not, [she] came alive and absolutely loved it." (Main carer for a person living with dementia, Cardiff and Vale)

- 3.170 Many groups are for people living with dementia-only, others just for carers, and some for both. Certain groups invite both, but then split them so that carers and people living with dementia can talk to people in similar situations. The emotional support and advice provided by the friends made within these groups was often heralded as their biggest benefit: hearing others' stories lets individuals know that they are not alone in what they are experiencing.

Independent living support and home care

- 3.171 The DAP has aspirations to help people living with dementia live independently and in a way that provides a good quality of life through provision of a range of housing choices, such as supported housing or extra care facilities, and access to physical adaptations in existing homes. It aims to enable access to assistive technology and / or equipment and make adaptations to the environment to maintain or improve a person's independence, safety and wellbeing.
- 3.172 Some people living with dementia had accessed support to help them live independently at home, such as stair rails and downstairs bathrooms, safety tests, occupational therapy, panic buttons, meals, cleaners, and gardeners. Most of these provisions were arranged by support services, although some arranged them themselves. Other participants felt that they did not want or need help at home yet, but felt confident and reassured that they knew where to go when the time came.

- 3.173 Suitable home care was often cited as the hardest form of support to access. Carers who had tried to source this often found themselves on lengthy waiting lists, leading many to turn to private care, which could be expensive.
- 3.174 Although some carers did manage to get care packages in place through social services, this was often only once the person living with dementia had reached crisis point. Indeed, carers frequently described having to 'fight' for assessments and subsequent care.
- 3.175 Many had struggled to find appropriate personal assistants. Some said they had been assigned personal assistants who were not suitable or properly trained, or did not turn up when they were supposed to. However, once appropriate personal assistants had been found and a routine was established, participants spoke highly of them.

Counselling and emotional support

- 3.176 Not many carers or people living with dementia had received counselling, although many of the main carers we spoke to felt that this would be highly beneficial, as they recognised the need to talk about how their caring role was affecting them as well as their loved one. Of those who had accessed counselling services, these were often sourced through groups like NEWCIS. Some had been offered counselling and felt reassured to know that the option was there if they needed it.
- 3.177 Most carers felt they had sufficient emotional support from friends, family or peer support groups. On the other hand, some people felt that caring roles had strained their relationships with family members – especially if it was felt that the responsibilities were falling unfairly on one person.

Financial and legal support

- 3.178 Many participants received Carer's Support, which is payable to those who care for someone for at least 35 hours a week, or Attendance Allowance, which is payable to cover extra costs associated with caring for someone with a severe disability. Several reported that they had received specific funding such as ['Bridging the Gap'](#) funding via NEWCIS for respite care/sessions; lump sums for a short break; money for taxis; partial funding for Continuing Health Care (nursing home) and home care; and funding for aids and adaptations to properties.
- 3.179 People living with dementia and carers who received financial support often only knew it was available to them if they had been told, either by their key

worker/contact or through word of mouth. Not many people had thought to actively look for this support, and even when they knew it was available, many found the process of applying to be complicated. Some participants said that application support had been provided by Age Cymru, Citizens Advice or the Alzheimer's Society.

- 3.180 Some carers identified sources of information, advice and support they had received concerning future decisions about care. They mentioned attending a useful course about LPA, learning from friends and others with dementia, discussions with healthcare professionals, lawyers, and Admiral Nurses, information in carers' magazines, and assistance from organisations like Alzheimer's Society, Macmillan Cancer Support, and a local 'hospice at home' charity.

Barriers to accessing support

- 3.181 Covid-19 was said to have impeded access to support for people living with dementia and their carers. Several people living with dementia had received diagnoses during lockdowns, which delayed medical appointments and tests and often delayed diagnosis, and reduced the subsequent support available to them, especially at-home care, peer support, and face-to-face groups and activities. Issues around accessing post diagnostic support also impacted on those who had received their diagnosis prior to the pandemic.
- 3.182 Means testing, and the cost of care was cited as a barrier for some people living with dementia, who said that they pay for all or most of the support they access (day centre placements and home-support particularly) and expressed concern around what would be available for those unable to pay privately. It was seen to be unfair that this is the case for dementia when it was perceived not to be for other conditions.

"Alzheimer's and dementia are not treated the same as if you've got an ulcer on your leg. It's not your fault you've got dementia ... Other people perhaps don't have networks or can't afford to pay privately." (Main carer for a person living with dementia, West Wales)

- 3.183 Others were distressed that they were expected to be 'self-funding' due to having savings or other assets as it was felt that they could be left with nothing to pass on to their children, or to provide for their own future needs.

- 3.184 As mentioned elsewhere (in 3.178), complicated application forms and processes were a barrier to accessing financial support. Forms can be difficult to complete independently if dementia causes issues with spelling, poor eyesight and shaking hands. One participant also mentioned that their neurodiversity made filling out complex forms even harder, which caused her to put off doing so.
- 3.185 Another barrier to accessing support is that a person living with dementia may struggle to accept or understand their diagnosis and therefore to engage with services. Indeed, a few carers found that they would organise care or support, only for their loved one to reject it through denial, embarrassment, or not wanting a stranger in their home.
- “They’ve offered to have people come in and take him out for a drive. They’ve opened up all these groups ... He doesn’t really talk to anybody... I think there’s probably a lot out there ... but he just doesn’t want to access any of it.”* (Main carer for a person living with dementia, North Wales)
- 3.186 Sometimes, a person living with dementia’s impairments can make it difficult for them to access activities. For example, people who are d/Deaf may struggle to engage with a Talking Café. A small number of participants had comorbidities such as Type 1 Diabetes or Parkinson’s Dementia. This had been problematic in terms of accessing support, as there was a need to ensure it could accommodate all of their impairment/s, which had not been possible in some cases. On a related note, one person found that not many support services cater for vegans.
- 3.187 All participants were asked whether they felt their geographical location affected their access to support. A few felt that living in a rural area made accessing services more difficult. People perceived that accessing residential spaces for people living with dementia would be easier in larger towns or cities but recognised that the demand in these areas would also be greater.
- 3.188 Where geographical access was an issue, this was largely when people were already socially isolated and where their carer was unable to drive. Public transport links became crucial in these cases, and if services were not local then it would create barriers to accessing them.
- 3.189 A small number of carers (mainly those who had moved to the area to care for a loved one with dementia) had issues accessing services in certain areas if they were not registered as a carer with the local authority. This was challenging for

people who were actively denied support as a result of not being a registered carer, as they had to access care and respite support privately and pay for it without any financial subsidy from the local authority. There were challenges for the carer getting registered due to their uncertain future plans and the time they would have to dedicate to doing so.

- 3.190 Many people living with dementia and their carers felt fortunate to live where they did, largely in relation to accessing local services such as NEWCIS and voluntary service umbrella organisations, or in terms of their proximity to GP surgeries or bus stops.

Involvement in making decisions about the future

- 3.191 Embedded in the DAP is the involvement of people living with dementia and their carers and family in the development and delivery of their care. This includes creating more opportunities for people with and affected by dementia across Wales to participate and engage in education, training and research activity, and be at the centre of decision-making in their own care. The DAP calls for a system that supports people in the early stages of dementia to ensure that they have the information and opportunity to make decisions about their own future care.
- 3.192 When discussing decision-making about the future, many people living with dementia and carers seemed worried and confused about what was to come and how they might cope with it. Others reported they try not to think too much about the future. Some planned to look into their options only when they had to, as they felt that planning for the future had the potential to upset them and therefore they put off doing it.

“It’s so stressful thinking of the future when you have no idea what the future is going to be.” (Main carer for a person living with dementia, West Wales)

- 3.193 A few examples of future care planning were given. One carer had completed an advance care plan in consultation with their loved one, and another had received help and advice from their social worker and from a residential home. A few others said that they had been involved in decisions but did not specify how.
- 3.194 Everyone who had the capacity, felt that they had enough input into their care or that of the person living with dementia they cared for and took an active role in care planning. They noted that support had been tailored to accommodate the person living with dementia and the carer’s changing needs.

“I take an active role, because obviously we want the best for my mum. Social workers listen, they’re brilliant, they really do take on board everything I can see is needed and put it in place.” (Main carer for a person living with dementia, North Wales)

3.195 A few participants highlighted the autonomy of the person living with dementia in decisions. However, the extent to which a person living with dementia can be involved in decisions around their future is dependent on their level of cognition, and some participants highlighted related challenges. Where the person living with dementia was not accepting of their diagnosis, no longer remembered their diagnosis, or had been ‘protected’ from their full diagnosis, carers described struggling to put support such as a care package, befriending or respite in place for them. Others described similar problems around LPA and “Do Not Resuscitate” orders where involvement in the process would be too distressing for a person living with dementia who no longer has the capacity to understand why such things might be necessary.

3.196 Participants also received information and support around other aspects of planning for future care, such as: access to care homes, making a will, the ambulance green pod system for medication¹³, Do Not Resuscitate (DNR) and general information about the health of the person living with dementia.

“We’ve discussed the health side of it with the GP ... Alzheimer’s Society were really good ... We [made arrangements] while [the person living with dementia] was still very aware of what was going on.” (Main carer for a person living with dementia, Cardiff and Vale, young onset diagnosis)

3.197 One carer highlighted the support they had received from an Admiral Nurse ¹⁴ and how reassuring it was to have the paperwork in place detailing their, and the person living with dementia’s, wishes for living arrangements and end of life care. They suggested that other services like memory clinics and charities should work with people with lived experience of dementia in a similar way to prepare records for carers and their loved ones to retain for reference.

¹³ [PODs scheme](#) (Patient’s Own Drugs)

¹⁴ Admiral Nurses are specialist dementia nurses provided by Dementia UK. Further information can be found here: <https://www.dementiauk.org/information-and-support/specialist-diagnosis-and-support/what-is-an-admiral-nurse/>.

3.198 When discussing making decisions around care, many carers highlighted the perceived inflexibility in care provision. As mentioned previously, some felt that they did not receive support until problems occurred and they had to seek it out, at which point they were put on waiting lists. Others felt it was difficult to tell whether the system would be able to meet their future needs but hoped it would. Many were concerned about the future availability of care homes and respite care, and the continued funding of their support. Furthermore, many carers expressed anxiety over what support would be available to help them manage their own health issues which could eventually compromise their ability to care for the person living with dementia.

“I do worry about the future as he is going to get worse...I do worry...what care will be available in the future. If he needed total care and I needed a break, would there be respite? Would there be a care package?” (Main carer for a person living with dementia, Gwent, young onset diagnosis)

3.199 In terms of improving flexibility within the system, people living with dementia and their carers offered suggestions such as speeding up assessment processes, providing clear information on appropriate services, and support to remove the need for them to search for this. It was felt that swifter assessment and diagnosis, as well as the provision of information about available local services would give people living with dementia and their carers more options to engage with appropriate support at an earlier stage.

3.200 Some carers had already taken the decision to move the person living with dementia into a care or nursing home. They felt that the person living with dementia’s personal care and support needs were largely being met by the home. There were some issues, though, with Covid-19 preventing visitors, especially for those who had only just moved into their home before the first lockdown, and the ongoing effects of this on people living with dementia, carers, and families.

3.201 Some carers spoke about particular issues with making end-of-life and DNR decisions. Two explained that they had not wanted to upset their loved ones by discussing DNR in their presence. However, GPs reportedly ignored these requests.

“I spoke to the GP about [DNR], and he said, ‘I can’t do that unless your wife is present.’ I said, ‘I don’t want to upset my wife by talking about it because she’ll think, ‘He wants to get rid of me’. ... Anyway, he wouldn’t do it and wouldn’t put it

in place...[stating], 'The only way I can do that is to get her capacity assessed and use the lasting power of attorney and the capacity assessment'. But it's another hurdle.' (Main carer for a person living with dementia, Cardiff and Vale)

3.202 People living with dementia and their carers frequently raised the subject of an LPA when discussing decisions around future health, care, or finances. Most participants had arranged LPAs themselves, often prior to the dementia diagnosis and sometimes with support from their GPs, the Alzheimer's Society, Admiral Nurses, NEWCIS, Carers Centres, or friends and family.

"The Alzheimer's Society provide a service where they guide you through each section ... We had a witness come and we followed it step-by-step, sent it back, they checked it all for us. It was wonderful." (Main carer for a person living with dementia, North Wales)

3.203 There was high awareness of the advantages of an LPA and many carers had put one in place or were planning to, although one did not feel ready to do so and would have welcomed more information on this. Several participants mentioned that the process of applying for LPA was straightforward, whether they had arranged them through solicitors or online themselves (at relatively little cost compared to a solicitor).

3.204 Several carers felt they had been well supported to make financial arrangements for the future, whether in terms of LPA, care home arrangements and housing, wills, continuing care funding, and funeral plans. They mentioned receiving this support from family members, a [Solace](#) training course, the [React Team](#), solicitors, and websites like Age UK.

"Solace...ran an eight-week session with all sorts of issues, legal, social. We met with social people, legal people...Every week had someone different talking about the issues." (Main carer for a person living with dementia, Cardiff and Vale)

3.205 A few people living with dementia were unsure how to make arrangements concerning access to bank accounts, paying for care homes, or paying for home adaptations, whilst others said they had received no financial advice, support, or information whatsoever.

Support for carers: Carers' needs assessments

3.206 Carers' needs assessments were explored as part of a wider evaluation of the [Social Services and Wellbeing Act](#) which made it a requirement for carers to have

needs assessments carried out. Local authorities have a duty to meet all eligible carers' needs through a carers support plan. The findings below agree to a greater extent with the findings from that evaluation.

- 3.207 Participants who cared for a person living with dementia were asked whether they had received an assessment of their needs as a carer. Experiences were mixed: some reported they had not, some that they had, and a few said they were unsure, as they had had discussions with social services about potential sources of support, but were not certain as to whether this constituted a formal needs assessment.
- 3.208 Some of those who had not received a needs assessment were currently awaiting one and had been told by social services that this would take several months. Reasons given by other participants for not receiving a needs assessment were:
- The person living with dementia's refusal to accept their dementia diagnosis;
 - A lack of awareness of needs assessments;
 - A lack of time to arrange and participate in a needs assessment; and
 - A feeling that they could cope without external support.
- 3.209 Some of those who had received a needs assessment also referred to the length of the wait, ranging from a few months to several years, and the need for carers to be proactive in asking for support rather than it being offered to them.
- "I could've done with some more support. I should've been more determined and said, 'What the hell has happened with my carer's assessment?'" (Main carer for a person living with dementia, Cardiff and the Vale)*
- 3.210 A few of the carers who had received needs assessments said they were not offered any support because they were not deemed to need it. Some had been offered respite and/or day care, and a carer's allowance.
- 3.211 The valuable support received from Admiral Nurses while waiting for, and after receiving, a needs assessment was noted. For example, the nurses had offered emotional support to some participants, and had contacted hospitals and social services on their behalf. One carer stressed that needs assessments should be repeated annually because carer support needs change in line with the progression of the person living with dementia's symptoms and needs, as well as with changes in their own circumstances.

- 3.212 The DAP outlines specific support for families and carers including personalised respite. It recognises that the ability of individuals with dementia to live at home for as long as possible is often dependent on the support of families and carers, and that support for the carer can help to prevent crisis and help maintain their own physical and mental wellbeing as well. Therefore, the DAP aspires that all carers must have reasonable breaks from their caring role and have a life beyond caring. This means ensuring that respite provision needs to be flexible to meet the needs, expectations and preferences of the person with dementia, their family and carers.
- 3.213 Carers were asked whether they had accessed respite care and the reasons for this. They were also asked about the timeliness and effectiveness of respite care, and whether they had received support from community organisations.
- 3.214 Some participants had accessed respite care, which was provided by personal assistants and care homes, community organisations, friends, and family, and via other informal arrangements. Others had not accessed respite care. Mixed views were expressed about the timeliness and effectiveness of the respite care accessed.
- 3.215 Several carers had accessed day and residential respite care at local care homes and were generally satisfied with the quality of the care received. However, several said that the cost of accessing this kind of respite care is prohibitive, especially when carers are older and have health issues that mean that they must also stay in care homes alongside the person living with dementia.
- 3.216 A couple of carers had accessed respite care using funding from NEWCIS, for which they were grateful. They explained that the funding could be used flexibly to cover day or residential respite care. Funded respite care had also been accessed through the Carer's Trust or Macmillan, although the latter was accessed when the person living with dementia had an illness unrelated to their dementia that required significant care.
- 3.217 Several carers occasionally arranged for informal respite care through friends and family. However, most carers said that they would prefer to use care homes for respite because they did not wish to rely on friends and family for this purpose. One carer reported that social services had not offered them respite care because they were aware that a relative shares their caring responsibilities with them, even though they would have welcomed more formal support.

- 3.218 Most carers who had not accessed respite care felt it would be unsuitable for the person living with dementia through disrupting their routine or that the person living with dementia would feel “abandoned” or bewildered through not fully understanding the situation. Indeed, one carer described how they had to terminate a respite care session early because the person living with dementia had become very distressed at the care home. Another carer stopped accessing respite care because the person living with dementia was unwilling to accept assistance with personal care.
- 3.219 Some carers had not taken up respite care because the duration of the available care was too short or too long. Others said that respite care was not yet needed because the person living with dementia they cared for was still able to be safely left alone for short periods of time.
- 3.220 A few carers who had not accessed respite care expressed the desire to do so or said that they had requested it and were waiting for further information from the relevant agencies. They tended to emphasise the emotional strain of caring for a person living with dementia without respite support.

“It would just be nice to have a break where we know he’s cared for. Just for my own peace of mind ...” (Main carer for a person living with dementia, West Wales)

- 3.221 Several carers who had accessed respite care said they would have liked to have done so earlier. One of these carers said that they were only offered respite care for the person living with dementia after they disclosed to their GP that they were thinking about taking their own life and that of the person living with dementia.

Other support for carers

- 3.222 Although most carers had not accessed additional support from community organisations (some because these organisations did not have appropriate respite care in place), those who did said that they had received assistance from:
- Solace Carer’s Support Service: carer’s support group sessions;
 - Age Cymru: a support worker provided support temporarily, but this had since ceased due to discontinuation of funding;
 - Helplines (unspecified): someone to talk to in confidence when participants were feeling low or overwhelmed by their caring responsibilities;
 - Local Mind services: which one participant had paid for due to a reported lack of other available support.

3.223 Furthermore, some carers had been able to access community activities, sometimes specifically for carers, other times groups which were available for anyone. These ranged from things such as free-of-charge art classes (run by a local artist with Welsh Government funding), a local knitting group and a creative writing group. Some participants highlighted, though, that the community activities they had been offered were unsuitable because they did not align with their interests or were inaccessible (an evening meal with music at a venue located on top of a hill, for example).

3.224 Many of the main carers we spoke to felt that they had no time to access support, especially those who worked in addition to their caring responsibilities. In the same vein, carers often felt that it is not just time they lack to attend, but also the energy to do so.

“You can’t really get the time off to go to a group. It would be nice to do something like that if there was something on a weekend.” (Main carer for a person living with dementia, North Wales)

3.225 It was noted that some support groups are not available to a person living with dementia without a carer present. This is a barrier for people living with dementia who would prefer to go alone and allow carers any ‘time off.’ As such, some participants felt that that more groups should be for people living with dementia only. Conversely, a number of people felt that there are too many carer-only groups, which were not accessible to them if they could not leave their loved one for any length of time.

3.226 Although most carers did not discuss receiving any training and support to assist them in their caring role, the following was received by some:

- Training and guidance from Alzheimer’s Society, Age UK, and Age Connect on the nature and impact of dementia, LPA, how the person living with dementia may see the world, and the financial and other support which may be available for carers;
- A five-week training course by Carer’s Trust, which was not dementia-specific, and was attended by carers for people with other diagnoses;
- Online dementia awareness training;
- Informal support and guidance from friends with experience of caring for people living with dementia;

- Support from social workers to ensure they could access all the benefits they were entitled to (attendance allowance for example); and
- Legal advice to arrange LPA.

3.227 Carers who accessed training found it helpful and informative, getting the most from dementia-specific rather than generic carer training. Carers who attended sessions in-person said that they had benefitted from sharing experiences with others in similar positions. Informal support from friends with caring experience had also helped carers to understand and contextualise the person living with dementia's behaviour.

"I've got a friend who will come and see [the person living with dementia I care for] ... She's worked with elderly people and people with dementia and she's very good with me. I'll say, 'He did this', and she'll go, 'Yes, but think of it like this.' It's so much easier when somebody stops you and turns it around." (Main carer for a person living with dementia, North Wales)

Recognition of a carer's role

3.228 Carers who expressed more positive views about the extent to which they felt recognised in their caring role said that medical professionals treat them with kindness and respect; enquiring about their health and wellbeing, complimenting them on how well they care for the person living with dementia, and explicitly acknowledging the challenges they face in their caring role.

3.229 Conversely, carers who were more negative tended to refer to instances where they had felt under-valued, overlooked, or patronised by medical professionals. For example, in one case A&E staff refused to let a carer sit with the person living with dementia they cared for to reassure them as they were being assessed, resulting in the person living with dementia "sobbing like a small child".

3.230 Another carer felt that carers' concerns are trivialised by medical professionals.

"I think the carers are trivialised. I think the whole thing works on the assumption the carer is not sufficiently educated enough to care.... You're a non-person. All you are, is a pair of hands keeping a person alive." (Main carer for a person living with dementia, West Glamorgan)

3.231 A few carers noted that they had initially felt recognised in their caring role but had had no or little contact with medical professionals since the diagnosis of the person

living with dementia they care for. Difficulty in accessing financial support (such as Carer's Allowance) was seen as another example of how carers are undervalued.

Improving the situation for carers

- 3.232 Participants discussed a variety of ways in which their situation as a carer could be improved. These focused on the type, timing, and accessibility of the support offered to them and the person living with dementia.
- 3.233 Regarding the type of support offered to carers and people living with dementia, carers said that they would like affordable respite care that meets their needs as well as those of the person living with dementia. For example, carers who are older and have health issues themselves could stay with the person living with dementia in the respite centre and receive their own care – not only to alleviate the pressure of being a carer, but also to access direct support for themselves. One carer, who had a serious medical condition, stated that she would have welcomed support to cope with the physical demands of caring for a person living with dementia, as they both had various health and mobility issues.
- 3.234 Some carers reported that guidance on what to expect as the person living with dementia's symptoms worsen, and access to regular counselling or simply having "someone to talk to", would also help. Having some specific information on the likely trajectory of the person living with dementia's condition, in written format especially, as carers said it can be hard to retain information that is provided verbally.

"What's missing is there's an element of the overall oversight for practical reasons, and also you don't necessarily know what is coming next and what stages you might go through and how fast you might go through those." (Main carer for a person living with dementia, West Wales)

- 3.235 One carer felt that it would be helpful for more carers to understand what the person living with dementia is experiencing in terms of their symptoms. They described a useful exercise in a training session they attended that simulated dementia symptoms.

"We were sent on a course and put in a room with music blaring out. We were given ear defenders so we couldn't hear much, but we could hear something, and we were given glasses with fog lenses to understand how people with dementia are seeing the world and hearing things ... Those sorts of things would help

carers because sometimes you just need that understanding.” (Main carer for a person living with dementia, West Wales)

- 3.236 Regarding the timing of support offered to carers and the person living with dementia, there was some feeling that support should be offered earlier rather than later, by which time situations have often become untenable. Related to this, the need for more support for carers to be available outside of working hours was highlighted.
- 3.237 There was some feeling that appropriate support should be easier for carers to access. It was suggested that this could be achieved through having a single point of access for carers. Similarly, one participant noted that there does not seem to be a consistent support offer for people living with dementia and their carers.
- 3.238 Having a dedicated liaison person in GP practices to signpost people living with dementia and their carers to relevant services and support could also help to streamline and expedite access to appropriate support, it was said.
- 3.239 Related to the timing of and access to support, participants emphasised the need to receive a timely needs assessment from social services to ensure that they (and the person living with dementia) can access support as and when required. The need for the person living with dementia to receive a swift assessment for and diagnosis of dementia was also mentioned in the context of accessing timely support.
- 3.240 Reflecting points made elsewhere, other participants mentioned that their situation would be improved if they received financial support, as their monetary situation had worsened since becoming a carer. More compassion and understanding from medical professionals would also be welcomed.
- 3.241 Finally, it was said that more pro-active support for carers is needed.

“There needs to be more reaching out to carers rather than the other way around ... At the moment it’s very much that the carers have to look for help themselves.” (Main carer for a person living with dementia, North Wales)

4. Interim Conclusions and Recommendations

Understanding and implementing the DAP

- 4.1 Echoing some of the DAP's stated aims, there was a broad consensus amongst stakeholders and RPB area 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.
- 4.2 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 MDTs, 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.
- 4.3 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).
- 4.4 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.

- 4.5 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 RIF funding which succeeded the original ICF contributed to a longer-term focus on achieving the DAP's aims.

Monitoring the DAP

- 4.6 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 area 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, 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

- 4.7 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.
- 4.8 In the survey and in-depth interviews, many 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.
- 4.9 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 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.

- 4.10 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

- 4.11 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.
- 4.12 Around half of survey respondents reported that the person living with dementia had received a needs assessment 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.
- 4.13 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.
- 4.14 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.
- 4.15 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 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

- 4.16 The provision of person-centred care via the TAI model and the provision of Dementia Support Workers was considered by stakeholders and RPB area 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.
- 4.17 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.
- 4.18 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 area workshop participants to be improving, but it was generally felt that there is a 'long way to go' in ensuring equity.
- 4.19 While stakeholders and RPB area workshop participants felt that progress is being made on Welsh language provision, challenges remain in delivering an active offer especially in areas with low numbers of Welsh speaking health and social care staff.

4.20 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

4.21 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.

4.22 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 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.

4.23 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.

Conclusion and areas for consideration

4.24 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.

4.25 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, including in the Welsh language.

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 framework 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 the 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.

5. Next Steps

- 5.1 The second phase of the evaluation will further explore stakeholders' and practitioners' experiences of implementing and delivering the DAP, identifying challenges and enablers so that these can be built upon or addressed going forward. Phase two will also involve a longitudinal revisit of some of the people living with dementia and their carers interviewed in phase one to explore any changes in the support services they accessed over a six-to-twelve-month period.
- 5.2 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.
- 5.3 A second round of in-depth interviews with people living with dementia and carers will be conducted in early 2024. The topic guide for the second set of interviews will largely remain the same, but additional topic areas will be considered in discussion with the EAG. Some of the second-round in-depth interviews will be conducted with participants from Phase 1, to enable a longitudinal study and some use of case studies.
- 5.4 The final report and recommendations will follow these next steps, in 2024.

Annex A: Survey Questionnaire



Dementia Survey 2023

Have you, or has somebody close to you, been diagnosed with dementia in the last five years? If so, we'd really like your help.

We want to understand more about people's experiences of living or caring for someone with dementia in Wales and would like to hear from you. It should only take 10 - 15 minutes and the information we collect will help us understand what current support looks like and help improve services for the future.

Welsh Government has asked an independent organisation called Opinion Research Services (ORS) to collect the data on its behalf.

You don't have to answer any questions you don't want to (apart from the first one), and the information you give us will be treated carefully under the latest Data Protection laws. ORS won't keep any information that could identify you after the end of 2024 at the latest unless you agree to take part in more research. For more information, see ors.org.uk/privacy and the enclosed Welsh Government privacy notice.

If you have any questions about this project or if you need help filling in the questionnaire, please contact me at ORS on 01792 535300 or harriet.hendra@ors.org.uk. If you would like to speak to someone from Welsh Government, you can contact Hannah Smith (Knowledge and Analytical Services) at Welsh Government - Hannah.smith002@gov.wales or 03000 622 308.

When you have completed the questionnaire, please return it to ORS in the Freepost envelope provided as soon as possible. If you prefer, you can fill in the survey online at: www.opinionresearch.co.uk/LivingWithDementia2023

Thank you for your help. Yours sincerely,

Harriet Hendra

Researcher (ORS)

How to complete the questionnaire

For most questions, please tick clearly inside a box

For some questions you may be asked to tick more than one box

QA. Who is completing the questionnaire...?

The person with a dementia diagnosis

.....
The person with a dementia diagnosis and their main carer together

.....
The main carer of the person with a dementia diagnosis

IF YOU ARE COMPLETING THE QUESTIONNAIRE AS 'THE MAIN CARER OF THE PERSON WITH A DEMENTIA DIAGNOSIS', PLEASE COMPLETE IT FROM THE PERSPECTIVE OF THE PERSON WITH THE DEMENTIA DIAGNOSIS.

Section A: About your dementia diagnosis

These questions can be answered by the person living with dementia or by their carer on their behalf. PLEASE TICK ONE BOX ONLY UNLESS IT SAYS OTHERWISE

Q1. Thinking about your dementia diagnosis, why did you first visit the GP?

TICK ALL THAT APPLY

I was worried about my memory

.....
I was worried about some physical symptoms

.....
I was referred by another professional (e.g., Nurse, Social Worker)

.....
I was encouraged to go by a family member

.....
Appointment was made by a family member

.....
Another unrelated illness / problem

Not sure

Q2. About how long did you have to wait between your first visit to your GP and getting your dementia diagnosis?

Less than a month

Between 1 and 3 months

Between 3 and 6 months

More than 6 months

Not sure

Q3. How well was your diagnosis/condition explained to you?

Very well

Quite well

Not very well

Not at all well

Not sure

Section B: Support after your dementia diagnosis

These questions can be answered by the person living with dementia or their carer on their behalf.

PLEASE TICK ONE BOX ONLY UNLESS IT SAYS OTHERWISE

Q4. After you were diagnosed, did you have an assessment of your needs (i.e., did anyone ask you what you needed/wanted)?

Yes ANSWER Q5

No GO TO Q6

No – but there is one planned GO TO Q6

Not sure GO TO Q6

Q5. After this assessment, were you offered the right help to meet your needs?

Yes

No

Not sure

Q6. Which of the following have you received since your diagnosis? **TICK ALL THAT APPLY**

Leaflets / written information for you and your family

Contact information for relevant charities

Details of support groups – e.g., dementia cafes

Support to maintain/improve your quality of life – e.g., art, music, sport

Support to help you live at home – e.g., home care, meals on wheels, adaptations to your home

Support to help maintain/improve your memory

Support to maintain/improve your physical health – e.g., occupational therapy

Counselling

Financial support

None of the above

Not sure

Q7. Do you have a named support worker/main point of contact?

Yes

No

Not sure

Q8. Do you have a Care Plan?

Yes GO TO Q9

No GO TO Q12

Not sure GO TO Q12

Q9. Did you and/or your carer/s help write and agree your Care Plan?

Yes

No

Not sure

Q10. Is your Care Plan reviewed regularly?

Yes

No

Not sure

Q11. Were you offered support/information in Welsh?

Yes – and I accepted it

Yes – but I didn't accept it

No – but I didn't need it

No – but I needed it

Not sure

Section C: Planning for the future

These questions can be answered by the person living with dementia or their carer on their behalf.

PLEASE TICK ONE BOX ONLY UNLESS IT SAYS OTHERWISE

Q12. Since your diagnosis, have you had any information, advice or support around making future decisions about your care (including end of life care) or your finances?

PLEASE TICK ALL THAT APPLY

Yes – to help with finances

Yes – to help with decisions about care

No arrangements made

Not sure

Prefer not to say

Q13. Have you made any arrangements so someone can help make decisions on your behalf - either about your care (including end of life care) or your finances?

PLEASE TICK ALL THAT APPLY

Yes – to help with finances

Yes – to help with decisions about care

No arrangements made

Not sure

Prefer not to say

Section D: Overall thoughts

These questions can be answered by the person living with dementia or their carer on their behalf.

PLEASE TICK ONE BOX ONLY UNLESS IT SAYS OTHERWISE

Q14. Since your diagnosis, do you agree or disagree that...?

a) You have been given enough information about the support available to you

Strongly agree

Tend to agree

Neither agree nor disagree

Tend to disagree

Strongly disagree

Not sure

b) The support you've received has met your needs

Strongly agree

Tend to agree

Neither agree nor disagree

Tend to disagree

Strongly disagree

Not sure

c) You and your carers/family have had enough of a say on your care

Strongly agree

Tend to agree

Neither agree nor disagree

Tend to disagree

Strongly disagree

Not sure

Q15. Overall, how would you rate the support you've received since your diagnosis?

Very good

Good

Neither good nor poor

-
- Poor
-
- Very poor
-
- Not sure

Q16. What, if any, support would you have liked but didn't get? **WRITE IN BELOW**

Section E: Support for carers

These questions are for the carer/s of the person living for with dementia.

PLEASE TICK ONE BOX ONLY UNLESS IT SAYS OTHERWISE

Q17. Has there been an assessment of your needs as a carer?

- Yes ANSWER Q18
-
- No GO TO Q20
-
- Not sure GO TO Q20

Q18. Have you been offered respite care?

- Yes – and I accepted it ANSWER Q19
-
- Yes – but I didn't accept it GO TO Q20
-
- No – but I didn't need it GO TO Q20
-
- No – but I needed it GO TO Q20
-
- Not sure GO TO Q20

Q19. Has this respite care met your needs?

Yes

No

Not sure

Q20. Do you agree or disagree that...

a) You have been able to input into the care planning for the person living with dementia?

Strongly agree

Tend to agree

Neither agree nor disagree

Tend to disagree

Strongly disagree

Not sure

b) You are recognised for your caring role by health professionals?

Strongly agree

Tend to agree

Neither agree nor disagree

Tend to disagree

Strongly disagree

Not sure

Q21. How could your experience as a carer be/have been improved? **WRITE IN BELOW**

Section F: Background Information

These questions help us to know we are talking to a wide range of people. The questions in this section are optional. Please tick 'prefer not to say' if you don't wish to answer.

Q22. Are you (the person with a dementia diagnosis)?

Male

Female

Other – please write in below

Prefer not to say

Q23. Date of birth (of person with a dementia diagnosis). **PLEASE WRITE IN BOXES BELOW**
Please provide year only if prefer not to give full date of birth

		/			/				
--	--	---	--	--	---	--	--	--	--

Prefer not to say

Q24. When was the diagnosis of dementia made? **PLEASE WRITE IN THE BOXES BELOW**
If you cannot remember, please provide an approximate month and year

Month	Year			
/				

Prefer not to say

Q25. Who else lives with you (the person with a dementia diagnosis)?

Live alone	<input type="checkbox"/>
Live with husband / wife / partner	<input type="checkbox"/>
Live with other relatives	<input type="checkbox"/>
Live with others (i.e., in a residential/care home)	<input type="checkbox"/>
Other – please write in below	<input type="checkbox"/>
Prefer not to say	<input type="checkbox"/>

Q26. In which part of Wales do you (the person with a dementia diagnosis) live?

Blaenau Gwent; Caerphilly; Monmouthshire; Newport; Torfaen	<input type="checkbox"/>
Bridgend; Merthyr Tydfil; Rhondda Cynon Taf	<input type="checkbox"/>
Cardiff; Vale of Glamorgan	<input type="checkbox"/>
Carmarthenshire; Ceredigion; Pembrokeshire	<input type="checkbox"/>
Denbighshire; Flintshire; Wrexham	<input type="checkbox"/>
Neath Port Talbot; Swansea	<input type="checkbox"/>
Isle of Anglesey; Gwynedd; Conwy	<input type="checkbox"/>
Powys	<input type="checkbox"/>
Prefer not to say	<input type="checkbox"/>

Q27. Which of the following describes the type of area you (the person with a dementia diagnosis) lives in?

A city/town	<input type="checkbox"/>
A village	<input type="checkbox"/>

Rural or countryside

Prefer not to say

Q28. Which of the following describes your (the person with a dementia diagnosis) sexual orientation?

Heterosexual / straight

Homosexual / Lesbian or gay

Bisexual

Other

Prefer not to say

Q29. What is your (the person with a dementia diagnosis) ethnic group?

White

Black / African / Caribbean / Black British

Mixed / Multiple ethnic group

Asian / Asian British

Other ethnic group

Prefer not to say

Thank you for completing this survey. We may want to get in touch again in future, maybe with another questionnaire or to talk about your experiences in more detail. To do this, we need your personal details and to have the consent of both the person living with dementia and their carer (if applicable). You don't have to take part in anything; you can say no at any time. We will never try to sell you anything. If you would like to talk about your experiences in more detail, please fill in the enclosed form to give us your contact details. We have included two freepost envelopes so you can send the questionnaire and your contact details to us separately, meaning that the answers you've already given will be completely anonymous.

THANK YOU for taking the time to complete this questionnaire. Please return it to Opinion Research Services in the FREEPOST envelope as soon as possible. If you've lost our envelope, please return to the below address (no stamp required).

Opinion Research Services, FREEPOST (SS1018), PO BOX 530, Swansea, SA1 1ZL

Annex B: Regional Partnership Boards

Table 1 (Annex B): Defined Regional Partnership Boards Areas

Regional Partnership Board	Local authorities within Regional Partnership Board area
North Wales	Local authority - Isle of Anglesey Local authority – Gwynedd Local authority – Conwy Local authority – Denbighshire Local authority – Flintshire Local authority – Wrexham
West Wales	Local authority – Ceredigion Local authority – Pembrokeshire Local authority - Carmarthenshire
Powys	Local authority – Powys
West Glamorgan	Local authority – Swansea Local authority - Neath Port Talbot
Cwm Taf Morgannwg	Local authority – Bridgend Local authority - Rhondda Cynon Taf Local authority - Merthyr Tydfil
Cardiff and Vale of Glamorgan	Local authority – Cardiff Local authority - Vale of Glamorgan
Gwent	Local authority – Monmouthshire Local authority – Torfaen Local authority – Newport Local authority – Caerphilly Local authority – Blaenau Gwent

Annex C: Promotional Materials

Information e-mail for the online survey shared with a range of third sector organisations and RPB contacts to disseminate



Llywodraeth Cymru
Welsh Government



Good morning / good afternoon,

I'm contacting you on behalf of the Welsh Government and Opinion Research Services (ORS), requesting your support to access people who are living with a dementia diagnosis and their carers to inform an evaluation we are currently undertaking of the Dementia Action Plan for Wales 2018-2022.

We would be grateful if you would circulate information about this evaluation (see below) as widely as possible across your network, and especially to those who work directly with individuals living with dementia and their carers.

Your support is essential in ensuring that people living with dementia and their carers have the opportunity to participate.

Many thanks in anticipation of your help,

Hattie Hendra

Harriet Hendra

**Researcher | Qualitative Research Team |
Opinion Research Services (ORS)**

**Welsh Government Dementia Survey
2023**



Llywodraeth Cymru
Welsh Government



Bore da / prynhawn da,

Rwy'n cysylltu â chi ar ran Llywodraeth Cymru ac Opinion Research Services (ORS) i ofyn am eich cefnogaeth wrth gysylltu â phobl sy'n byw â diagnosis o ddementia a'u gofalwyr, i gyfrannu at werthusiad rydym yn ei gynnal ar hyn o bryd o Gynllun Gweithredu Cymru ar gyfer Dementia 2018-2022.

Byddem yn ddiolchgar pe allech gylchredeg gwybodaeth am y gwerthusiad hwn (gweler isod) mor eang â phosibl ar draws eich rhwydwaith, ac yn arbennig i'r rhai sy'n gweithio'n uniongyrchol ag unigolion sy'n byw â dementia a'u gofalwyr.

Mae eich cefnogaeth yn hanfodol er mwyn sicrhau bod pobl sy'n byw â dementia a'u gofalwyr yn cael y cyfle i gymryd rhan.

Diolch yn fawr ymlaen llaw am eich help,

Hattie Hendra

Harriet Hendra

**Researcher | Qualitative Research
Team | Opinion Research Services
(ORS)**

The Welsh Government has commissioned Opinion Research Services (ORS) to undertake an evaluation of its Dementia Action Plan 2018-2022. As part of this we are launching a survey to understand people's experiences of dementia diagnosis, and the subsequent support offered or needed. It is designed to be completed by someone living with a dementia diagnosis (with support if needed), OR by a carer of a person living with dementia, OR both together. The survey will only take about 10 minutes to complete, and is available in Welsh and English.

We hope to get the survey circulated to as many people living with dementia, or caring for someone with dementia, in Wales as possible. We are particularly looking to speak to people who have received a diagnosis in the last 5 years, and/or their carers. I have attached a simple A4 flyer/poster about the survey for use where applicable.

You can find the survey here:

www.opinionresearch.co.uk/LivingWithDementia2023

We also have a paper version available for people who are not confident to complete the survey online, which we can send to you, or directly to participants, by post. This can be requested by contacting me at XXX

Please do not hesitate to contact me if you have any queries about the survey or the evaluation as a whole.

Arolwg Dementia Llywodraeth Cymru 2023

Mae Llywodraeth Cymru wedi comisiynu Opinion Research Services (ORS) i gynnal gwerthusiad o'i Chynllun Gweithredu ar gyfer Dementia 2018-2022. Fel rhan o hyn, rydym yn lansio arolwg i ddeall profiadau pobl o gael diagnosis o ddementia, a'r cymorth dilynol sy'n cael ei gynnig neu sydd ei angen. Cafodd ei gynllunio i gael ei lenwi gan rywun sy'n byw â diagnosis o ddementia (gyda chefnogaeth os oes angen), NEU gan ofalwr person sy'n byw â dementia, NEU'r ddau gyda'i gilydd. Dim ond rhyw 10 munud fydd yn ei gymryd i lenwi'r arolwg, ac mae ar gael yn y Gymraeg a'r Saesneg.

Gobeithiwn ddsbarthu'r arolwg i gymaint o bobl sy'n byw â dementia, neu'n gofalu am rywun â dementia, yng Nghymru â phosibl. Hoffem siarad yn benodol â phobl sydd wedi cael diagnosis yn ystod y 5 mlynedd diwethaf, a/neu eu gofaluwr. Rwyf wedi atodi taflen/poster A4 syml ynglŷn â'r arolwg, i'w ddefnyddio lle bo hynny'n berthnasol.

Gallwch ddod o hyd i'r arolwg yma:

www.opinionresearch.co.uk/BywGydaDementia2023

Mae fersiwn papur ar gael hefyd i bobl nad ydynt yn hyderus i lenwi'r arolwg ar-lein, y gallwn ei anfon atoch chi, neu'n uniongyrchol at y cyfranogwyr, drwy'r post. Gallwch ofyn am hyn drwy gysylltu â mi: XXX

Cysylltwch â mi ar bob cyfrif os oes bydd ymholiadau gennych am yr arolwg neu'r gwerthusiad yn ei gyfanrwydd.



Llywodraeth Cymru
Welsh Government



What's it all about?



How to take part



WELSH GOVERNMENT DEMENTIA SURVEY 2023

Have you received a dementia diagnosis, or are you a carer for someone who has?

If so, **the Welsh Government is interested in hearing about any support you receive or need**, and has commissioned Opinion Research Services (ORS), an independent research company based in Swansea, to run a survey on its behalf.

This survey should only take around 10 minutes to complete and will be open until **31st May 2023**.

To take part online, go to www.opinionresearch.co.uk/LivingWithDementia2023 where you will be able to complete the survey.

If you are unable to take part online and would like to request a paper copy by post, or if you would like more information, please contact: Hattie Hendra on 01792 535315 or Harriet.hendra@ors.org.uk

OPINION RESEARCH SERVICES LTD

The Strand, SWANSEA SA1 1AF
01792 535300 | info@ors.org.uk | www.ors.org.uk



Llywodraeth Cymru
Welsh Government



Beth sydd dan sylw?



Sut i gymryd rhan



AROLWG DEMENTIA LLYWODRAETH CYMRU 2023

Ydych chi wedi cael diagnosis o ddementia, neu ydych chi'n gofalu am rywun sydd wedi?

Os felly, **hoffa Llywodraeth Cymru glywed am y gefnogaeth rydych yn ei chael neu sydd ei hangen arnoch**, ac mae wedi comisiynu Opinion Research Services (ORS), sef cwmni ymchwil annibynnol sydd wedi ei leoli yn Abertawe, i gynnal arolwg ar ei rhan.

Dim ond tua 10 munud fydd yn ei gymryd i lenwi'r arolwg hwn a bydd ar agor tan **31 Mai 2023**.

I gymryd rhan ar-lein, ewch i www.opinionresearch.co.uk/BywGydaDementia2023 lle byddwch yn gallu llenwi'r arolwg.

Os na allwch gymryd rhan ar-lein a hoffech ofyn am gopi papur trwy'r post, neu i gael rhagor o wybodaeth, cysylltwch â: Hattie Hendra ar 01792 535315 neu Harriet.hendra@ors.org.uk.

OPINION RESEARCH SERVICES LTD

The Strand, SWANSEA SA1 1AF
01792 535300 | info@ors.org.uk | www.ors.org.uk

Social media examples



Everyone ▾

Have you, or someone you care for, been diagnosed with dementia in the past 5 years? Do you live in Wales? We are working with Welsh Govt to evaluate Wales's Dementia Action Plan - help us by answering our survey here <http://bit.ly/3nbE1u6>
[#beatdementia](#) [#dementia](#)

The screenshot shows a tweet with a green survey image on the left and a photo of an elderly couple on the right. The survey image contains the Welsh Government logo, the RS logo, and the text: "Tell us about your experience of living with Dementia in Wales". The tweet text is: "Have you, or someone you care for, been diagnosed with dementia in the past 5 years? Do you live in Wales? We are working with Welsh Govt to evaluate Wales's Dementia Action Plan - help us by answering our survey here <http://bit.ly/3nbE1u6> #beatdementia #dementia". Below the image are interaction options: "Tag people", "Add description", "Everyone can reply", and a "Tweet" button with a count of 14.

The image shows the survey graphic with the Welsh text: "Dywedwch wrthym am eich profiad o fyw gyda dementia yng Nghymru". It includes the Welsh Government logo, the RS logo, and a photo of an elderly couple.

Annex D: Topic Guide

Service Users and Carers Topic Guide

Introduction

Welsh Government has commissioned Opinion Research Services (ORS), an independent research company, to undertake an evaluation of the Dementia Action Plan (DAP) for Wales 2018-2022.

The Dementia Action Plan was published in 2018 and lays out a range of priorities and actions to help guide Local Authorities and Health boards to plan and develop services for people with a dementia diagnosis and their carers.

The aim of this interview is to capture the views and experiences of people with dementia, their families and carers, and to understand their experiences of receiving a dementia diagnosis and any subsequent support. This interview / workshop should take around 45 minutes to an hour depending on your answers and will cover:

- Your experiences of diagnosis
- Your experiences of accessing support
- Your experiences of receiving support
- Planning for the future
- Support for Carers

If it's alright with you I'd like to record today's session for the purpose of writing up only. The information you provide will be processed securely by ORS and only shared with Welsh Government. Your contact details will not be shared with anyone and you will not be identified as an individual in any way. We may use something you say as a quote, but the reporting will not show your name, or include any information which might identify you. Any information that you provide will be processed by ORS to comply with the United Kingdom General Data Protection Regulation (UKGDPR). ORS will not keep any information that identifies you beyond August 2024 at the latest. For more information, please see our privacy notice at www.opinionresearch.co.uk/privacynoticeDAP (or www.opinionresearch.co.uk/welshprivacynoticeDAP)

In this interview we want to hear all about your experiences. There are no right or wrong answers. You don't have to answer any questions that you're not comfortable with, and we can take a break or stop at any time.

Any questions before we begin?

Section 1: About your diagnosis

1. Are you somebody with a dementia diagnosis or do you care for somebody with a dementia diagnosis? (or it may be both together)
2. Can you tell me a bit about your living circumstances? (e.g. Living alone / with family / supported or residential living)
3. Would you mind telling me a little bit about the diagnosis?
 - a. When and why did you first visit the GP?
 - b. Did you put off visiting the GP for any reason?
 - c. Did you get an MCI (mild cognitive impairment) diagnosis prior to your dementia diagnosis?
 - i. If YES – did that trigger any support prior to dementia diagnosis? And if not, what would have been useful at that stage?
 - d. Approximately how long was the wait between the first GP visit and the dementia diagnosis?
 - e. How well was the diagnosis process explained e.g any scans / tests?
 - f. How well was the resulting diagnosis explained?
 - g. How did you feel about the experience of being diagnosed?

Section 2: Experiences of Accessing Support

4. After the diagnosis, what support were you offered and what did this support look like?
Check for the following:-
 - A dementia support/key worker or equivalent
 - Timely access to intensive support teams
 - Letters / written information
 - Contact info for relevant charities
 - Details of support groups
 - Support to maintain or improve quality of life
 - Support to help you live at home
 - Support to help maintain / improve memory
 - Support to maintain / improve physical health
 - Counselling
 - Financial support.
 - Emotional support from friends and family
 - Peer support / groups
5. Who offered / provided this support? (Ask for each of the services above which participants say they have received)
 - a. Where do you receive this support?
 - i. Where do you go to access support? (e.g. clinic / memory café / community centre / other venues)
 - ii. How far do you have to travel to receive this support? (approx. no of miles / out of county?)
 - iii. How do you travel to services?
 - iv. Do you receive any support that is provided in your own home?
6. Was the support easy to access? Why do you say this?
 - a. Were you able to access all support that you wanted to?
 - b. Was there any support which was offered to you but you weren't able to access? Why was this?

- c. Was there anything that made accessing the support difficult for you? If so, what were those barriers and how could they be avoided in future?
 - Being turned away from mainstream support due to dementia diagnosis
 - Lack of specialist services
 - Lack of information about dementia and local services (from key workers?)
 - Not enough staff
 - Not enough services
 - Lack of services in certain areas meaning you had to travel to access them
 - Lack of Transport services
 - No services appropriate for someone my age / gender / ethnicity / culture / other disability / etc
 - Lack of Welsh language offer
 - Lack of offer in another language
7. Do you feel you have been given enough information about what support and services are available?
- a. Do you have one main point of contact / place you go to for information and advice?
 - b. Do support / key workers have good knowledge of dementia and local services?
 - i. (IF YES) Has any information been especially useful?
 - ii. (IF NO) Was there anything missing from the information and support you were offered?

Section 3: Experiences of Receiving Support

8. Does the support you receive consistently meet your needs?
9. Do you feel as though you have enough input into your care?
 [Is it tailored to your specific lifestyle and needs?]
- a. Are you actively involved in care planning?
10. Is the system flexible enough to be able to arrange support as needed?
 [Are things too process-driven or formal?]
- a. How could it be improved?
11. How well were the roles of different professionals explained to you?
12. Do the professionals and support staff you see communicate with each other and work together well?
 GPs / memory clinics / support workers / navigators / care staff / other nursing/medical staff
13. Do support / key workers have good knowledge of dementia and local services? Can you give examples of support you have been signposted to?
14. Is there anything else you need that you haven't been offered or don't receive?
- a. Why do you think you have not been offered / do not receive this?
 - Being turned away from mainstream support due to dementia diagnosis
 - Lack of specialist services
 - Lack of information about dementia and local services (from key workers?)
 - Not enough staff
 - Not enough services
 - Lack of services in certain areas meaning you had to travel to access them
 - No services appropriate for someone my age / gender / ethnicity / culture / other disability / etc
 - Lack of Welsh language offer

Lack of offer(s) in another language

SECTION ONLY FOR WELSH SPEAKERS Go to 16 if not Welsh speakers

15. Are you a Welsh speaker? And was your preference for provision in Welsh? **Prompt: e.g. assessment and diagnosis/ care and support services / community and social opportunities/ support and information around finances and planning for the future**
- a. Were you offered support in Welsh?
 - i. **(If NO)** – Why do you think that was? And what was the impact of not having access to support in Welsh?
 - ii. **(If YES)** – Did you take up that offer? What was your experience of receiving Welsh-language support and what was the impact for you of receiving support in Welsh?
 - b. What support were you offered in Welsh? Were you able to access it and if not, why not?
 - c. What were your experiences of receiving support in Welsh and what impact did it have for your quality of life?
16. Do you feel as though you are able to ask for and discuss the services you need? Why do you say this?
- a. Have you ever been given the opportunity to have your say about any of the services / support you use / receive? **If yes - Can you tell me a little about that experience? Prompt: was this a questionnaire / service feedback / focus group / consultation event / co-production in service design?**
17. Do you think that the services available to you would be different if you lived in a different part of Wales, or even a different part of your county? Why do you say this? **Prompt if needed: Do you feel you've missed out on services you've heard about elsewhere?**
18. What are your experiences out-and-about in your day-to-day life? (e.g. GPs / other health services /Public transport/ shops / supermarkets/cafes / community centres / libraries / gym / hairdressers/ social activities etc...)
- a. Do you find that people are generally helpful and understanding?
 - b. Do you feel able to ask for help, or to explain to people that you have a dementia diagnosis?
19. Do you feel able to live your life the way you want to? Do you feel able to make choices about your life? **prompt: e.g. of lifestyle choices, how you dress, what you eat and drink, where you socialise, what activities you take part in, choices about friendships or relationships**

Section 4: Planning for the future

20. Do you/they feel that you have a say about your future? Are you consulted about the decisions made about your life and your future?
21. Since the diagnosis, what information, advice or support have you had around making future decisions about care (including end of life care)?
- a. Has this been useful, and if not then why?
 - b. How could this be improved?
22. Since the diagnosis, what information, advice or support have you had around making future decisions about finances?
- a. Has this been useful, and if not then why?

- b. How could this be improved?
23. Have you made any arrangements so that someone can help make decisions on your behalf in the future?
- a. If so, has this been useful, and if not then why?
 - b. How could this be improved?
24. Are you aware of the options available and kept well informed of these?

Section 5: Support for Carers (Ask carers only)

25. Have you had an assessment of your needs as a carer?
26. Have you been offered respite care? **If Yes – probe for service provider and basic details of respite offer**
- a. Has this met your needs?
[Are you able to access respite care when and how you like?]
 - b. Have you been consulted on what you need in terms of respite care?
Nature of respite support; geographical accessibility; capacity; flexibility.
27. Have you been offered/introduced to any community services? If so, how useful are these?
28. Do you feel that services and respite have been offered at an appropriate stage for you? **If 'NO' probe further**
29. Do you feel recognised for your caring role by health professionals?
- a. Have you had or are you aware of any training/support available and how to access this?
30. Is there anything that could improve your experience as a carer?
- a. a. What would help you in your role as a carer?

Section 6: Conclusion

31. What has made the most positive difference in your life since diagnosis?
32. If you could ask for one thing/ type of support that you don't currently receive, what would it be?
33. Is there anything else you would like to mention that you haven't had the chance to say, or anything you would like to expand on or emphasise?

Thank and close.