bristol
dementia
wellbeing
service

Devon Partnership NHS
NHS Trust

Alzheimer's Society
Leading the fight against dementia

Evaluation of year

2015 - 2016

Contents

Glossary

AS	Alzheimer's Society
BDWS	Bristol Dementia Wellbeing Service
CCG	Clinical Commissioning Group
CQUIN	Commissioning for Quality and Innovation
DN	Dementia Navigator
DNA	Did Not Attend
DP	Dementia Practitioner
DPT	Devon Partnership NHS Trust
GP	General Practitioner
KPI	Key Performance Indicator
PWD	Person with dementia

Executive Summary

In 2014, Devon Partnership NHS Trust (DPT) and the Alzheimer's Society (AS) were commissioned to provide a **"Primary-care led Integrated model for people with dementia and their families and carers in Bristol."** The ideas behind this service were that it would bring together a range of different services that people with dementia use, bridging the gap between health and social care and setting up a system which would help GPs to better address the needs of people with dementia. By having the service working through GP surgeries, the idea was that GPs would learn more about caring for people with dementia, and people with dementia and their carers would find it easier to get the care they want.

The Bristol Dementia Wellbeing Service works by providing each GP surgery with a named Dementia Practitioners and Dementia Navigator who are responsible for supporting people with dementia. They also provide training and support to GPs within that surgery as well as help with diagnoses if necessary. When someone is diagnosed with dementia, they are offered an appointment with a Dementia Practitioner or Navigator within four weeks of the diagnosis, during which conversations will initially be held about a range of topics, but include starting to develop a Wellbeing Plan. Ongoing support is then provided through a named Dementia Navigator, who will maintain regular (at least 6-monthly) contact with the person with dementia and their carer.

The service also provides education and support to a range of services working with people with dementia across Bristol, as well as with hospital and Mental Health services to ensure that people with dementia and their carers get the support they need across the city. Community Development Workers are also helping to make sure that everyone who needs support, gets support, and to help fight stigma and discrimination against people with dementia.

In order to see whether or not this service is doing what it set out to do, an evaluation has been taking place, looking at the first 12 months of the service May 2015 to May 2016.

Data collection for the evaluation included questionnaires with people using the services and carers, interviews with carers and people with dementia, questionnaires with GPs, interviews with people helping to develop the service and key performance indicators.

Questions were asked about the levels of social isolation and the quality of life of people with dementia and their carers, and this data showed low levels of capability to experience wellbeing, limited social connectivity and relatively high levels of social isolation.

Interviews were also carried out which provided the opportunity to probe these issues further. Overall, people are very reliant on their own personal and family networks and for some, the diagnosis has made it harder to connect to friends who don’t understand, and their social networks have become smaller. Even within families, there tends to be a close “inner circle” who understand and provide direct input. For many of the interviewees, the dementia navigator is providing input that helps increase social networks and gives ideas to improve quality of life, as well as being an important social contact themselves.

Overall, the interviews reveal the complexities of living with dementia and of caring for someone in dementia, and the huge benefit that Dementia Navigators bring by being someone available at the end of the phone. They are people who understand in a world where people don’t understand what it is really like to live with dementia or care for someone with dementia. Dementia Navigators are providing a support, even if it is not used often, and are offering guidance and information where needed. For those who received their diagnosis more than 18 months ago, there has been a clear improvement in service provision since the Bristol Dementia Wellbeing Service started. There are ongoing concerns about social care provision and access, particularly around respite and nursing care, and it is clear that the role of the Dementia Navigator with regards to social care provision is potentially important.

In terms of how the organization itself is working, questions were asked about the processes involved in setting up the service and new groups learning to work together. This part of the evaluation shows how this is a complex and innovative service that has, not unexpectedly, met challenges in the start-up phases, but which has been successful in overcoming challenges because of a culture of flexibility and ongoing communication. Good interaction and team-work have been central to ensuring the success of the service, between all levels of stakeholders.

Key performance data shows that the services is meeting its targets and receiving positive feedback from service users. There is also evidence from a GP’s survey that the service is having a positive impact on helping GPs to effectively manage people with dementia and their family and carers. The vast majority of GPs asked said that they would recommend the service.

Looking forward, there may be some ongoing issues around the boundaries between the work being done by Dementia Practitioners and Navigators, and work that is related to social care provision. This is partly due to cuts in social care, but also because of the need to improve understanding of the role of the Bristol Dementia Wellbeing Service.

Conclusion

Overall, there is clear evidence of satisfaction with the service from people using the service as well as people delivering the service. For people delivering the service, the set-up has been challenging, but many of the challenges have been overcome, working with a flexible atmosphere with a culture of “doing things differently”. For people using the service, the BDWS provides back-up, the important function of “being there” if needed to provide information and support and also facilitates access to networks of support and services. Key Performance Indicators show that the service is heading towards meeting, or is meeting, targets and the Friends and Family test reports high levels of satisfaction.

1 Background

1.1 Bristol Dementia Wellbeing Service purpose and context

In 2011, the Local Action Plan for Dementia for Bristol set out a vision for dementia care in Bristol:

"That all people in Bristol with dementia receive a timely diagnosis, in a place appropriate to their needs, with a range of ongoing support available to them. We expect people with dementia to receive excellent care from diagnosis to end of life, by staff expertly trained in dementia, whether the person is at home, in a care home or in a hospital. We expect all family/carers to be properly supported and to have access to a break from the stresses that caring can bring. We expect our services to be joined up and enable people to live well with dementia. Our overarching aim is for Bristol to be a dementia friendly city."

In order to achieve this vision, the proposal was made to put in place a Primary Care-led integrated model for people with dementia and their families and carers in Bristol. In 2014, the Bristol Dementia Wellbeing Service, a partnership between the Alzheimer's Society and Devon Partnership NHS Trust (DPT) was commissioned to provide such a service.

Building on the vision, the principles of the service were based around the integration of services, the personalisation of care withfor people with dementia and their carers at the centre of the model and the support to GPs to enable the provision of dementia care that meets the needs of people with dementia and their carers. The basic premise was one of a service that is part of the community, and which "normalises" dementia care at community level, making dementia care "everybody's business." The service would combine the clinical expertise of DPT in relation to older people's mental health with the strong community-level expertise of the Alzheimer's Society which was already providing services throughout Bristol to support the health and social care needs of people with dementia and their carers.

The service provides:

- Early diagnosis of dementia
- Post-diagnosis follow-up
- Community Development (through Community Development Workers)
- Medication advice and clinical expertise
- Group support and interventions in the community
- Ongoing wellbeing support
- Complex interventions
- Crisis support
- Care home support
- End of Life support

The original strategic documents outlined a series of aims and objectives, around which the service has been built and against which it will be evaluated. This evaluation is of the first 12 months of the service, from May 2015 to May 2016.

(2011) Local Action Plan for Dementia, Bristol.

1.2 Operational approach and design

The community-based service is designed around teams which are integrated with Bristol's GP surgeries, with each practice having a named Dementia Practitioner (DP) and Dementia Navigator (DN) responsible for supporting people with dementia. Community Development Workers are also in action, ensuring engagement with groups who traditionally may not be accessing support, as well as working to fight stigma and discrimination at the community level.

There is also a single point of access ("Access Point") through whom direct referrals can also be made. The service is grouped into three community teams, based in three settings across Bristol:

- Central and East Bristol – Brookland Hall
- North - Trinity
- South - Symes

The Access Point operates from 8am to 8pm Monday to Friday from Brookland Hall. For out-of-hours support, the service collaborates with Bristol Mental Health Crisis service.

Referrals can be made for any person who requires assessment of a possible dementia or any person diagnosed with a dementia and there is no age restriction (lower or higher). The aim is that GPs are supported to carry out diagnoses as far as possible, but Dementia Practitioners will provide diagnoses for particularly complex cases, and the Memory Service will diagnose the most complex cases. The service works with local hospital trusts and neuro-psychiatric services to provide a fully-integrated memory assessment service.

Following diagnosis, every person with the diagnosis and their carer is offered an appointment with a Dementia Practitioner or Navigator within four weeks of the diagnosis, during which conversations will initially be held about a range of topics, but include starting to develop a Wellbeing Plan. Ongoing support is then provided through a named Dementia Navigator, who will maintain regular (at least 6-monthly) contact with the person with dementia and their carer, providing some or all of the following:

- Signpost to a range of services to support the person with:
    - Mental and physical wellbeing
    - Social networks
    - Carer wellbeing
    - Relevant information
    - Self-management
    - Social Services, including referral for a carer's assessment
    - Befriending Services

- Education, Information and support re: future planning, maintaining independence, including living arrangements, maintaining relationships, driving, finances and benefits
- Contingency (crisis) and advanced care planning
- Legal considerations such as Lasting Power of Attorney Advanced Directives
- One-to-one and group activities in partnership with other organisations and Dementia Wellbeing Service staff.

Wellbeing Plans are a core part of the post-diagnostic support provided by the service, setting out areas of importance to the person with the diagnosis, what activities and groups they might like to take part in, what support they feel they need, and what is being done to meet these needs. It also outlines medication regimes, social care support and risks and crisis support. The Wellbeing Plan is to be completed and uploaded within 20 days of the introductory assessment visit, and reviewed on a 6-monthly basis.

Dementia Practitioners offer more complex support especially when there are significant behavioural and psychological symptoms evident that impact on the life of the person with dementia and their carers. These services can include:

- Specialist assessment and advice
- Occupational therapy, physiotherapy, specialist social work advice and expertise.
- Specialist assessment and initial wellbeing planning
- Risk assessment and helping with learning and planning how to manage risk
- Provision of education and group work to the wider community and users of the service
- Support and advice to all nursing care homes to reduce hospital admission
- Assistive technology options (assessing need and referring to social services)
- Therapeutic interventions
- Medicines management including pharmacological support and guidance
- Helping carers to safely manage behavioural changes in the person's home
- Offering an urgent response either via the Access Point service or via the locality team (if appropriate and possible) and linking with out-of-hours and crisis services
- Educating and training care home staff to work with people whose needs change significantly
- Supporting end of life care services with advice
- Provide input to prevent any unnecessary hospital admission.

The work of Dementia Practitioners therefore spread beyond direct intervention to education and support to a range of services working with people with dementia across Bristol. They have an important role to play in education and training, in particular by helping people with complex needs be supported in the most suitable way possible.

In order to help avoid unnecessary hospital admissions, the Bristol Dementia Wellbeing Service also works jointly with Bristol Community Health which provides a rapid response service for people requiring admission or discharge from an acute hospital. In terms of other interfaces with other service providers, the BDWS also links with the Bristol Mental Health Crisis Service (in relation to crisis services, dementia in-patient wards and Mental Health assessment and recovery services), acute hospitals and Bristol City Council Care Direct.

1.3 Evaluation purpose

The commissioning particulars for the Bristol Dementia Wellbeing Service, clearly set out the need for rigorous evaluation as part of the services, with agreement made of an evaluation of the first 12 months of the programme and then at least every 18 months after. The purpose of such evaluation is to provide ongoing data to assess whether the service is delivering the objectives set out in the service specification as well as to look at the processes through which the service is being run.

The evaluation is designed so as to provide data to inform service planning and organisational processes, provide accountability and give important feedback. In terms of service planning, the evaluation will provide information on what is working, what is working less well and why. Information from the 12-month evaluation is to be fed back into all elements of the service to help decision-making about resource allocation and how systems might be improved. The data will also help demonstrate positive outcomes and how they are happening, which provides accountability. The information can also be fed back to all stakeholders to show what is happening in practice, how the service is being experienced, how effective and efficient it is, and what changes could be made in the future.

An evaluation framework was agreed with the commissioners, based on the aims and objectives of the service as outlined in the service specification. The data collected against the framework is a mix of qualitative and quantitative, including performance measures, qualitative interview, survey and quality of life measures.

2 Approach and methodology

2.1 Evaluation approach

This evaluation is specifically looking at the service, rather than patient outcomes. We are not, at this stage, evaluating the service against clinical outcomes, but in terms of whether it did what it planned, how it happened and what we can learn looking forward. It is therefore a non-experimental evaluation, not seeking to compare findings against a control of any sort, but to look in-depth at this one service and what has been achieved. The fact that this is a mid-term evaluation, rather than a full-term evaluation is particularly important when viewing the design and outcomes of the evaluation. It is a formative evaluation: looking at what has been happening so far, how far the evaluation has gone towards achieving particular objectives and what can be learnt from it. Looking forward, a future evaluation may be viewed as more summative, during which we would look more particularly at assessing progress according to outcome.

In order to develop an evaluation framework, a logic model for the service was developed. This outlines the aims, objectives and outcomes for the service, along with indicators which can be used to assess progress according to those outcomes. The aims were taken from the project specification and service proposal, the objectives emerged from the service proposal and the outcomes were found in the project specification with additional outcomes subsequently identified by the evaluation team and agreed by the service leadership team. Indicators had been defined as part of the service key performance indicator set, but again, additional indicators were identified by the evaluation team and agreed by the service leadership team.

In defining how to collect data against these indicators, a mixed-methods approach was used, using data from different sources and of different types to provide data which builds up a picture of how the service is performing against originally stated aims and objectives.

2.2 Evaluation framework

Aims and Objectives	Outcomes	Indicator
1. To help people with dementia access the services they need **Objectives:** We will offer a personal tailored plan throughout each individual's lifetime. We will provide a single point of contact We will provide an urgent response We will provide a Dementia Navigator for everyone diagnosed with dementia We will enable people to build and access local support networks We will work with families and people using the service to plan ahead.	1.1 High level of satisfaction with service from all stakeholders. 1.2 Service users and carers involved in service planning. 1.3 Service users and carers receive the services they need. 1.4 Service users and carers feel supported in their local area.	1.1a Friends and family test (KPI 5) 1.1b Proportion of service users reporting high levels of satisfaction with the services. 1.2a Number of service users and carers involved in service planning. 1.3a Friends and family test. 1.4a Totally number of services users with a well-being plan completed within 20 working days of assessment against total number of service users with an assessment in the period (KPI4) 1.5a Growth in local support networks available to service users and carers.
2. To provide the right treatment and support options at the right time, so a person with dementia can stay at home for as long as possible **Objectives** We will offer a personal tailored plan throughout each individual's lifetime We will provide an urgent response We will provide a Dementia Navigator for everyone diagnosed with dementia. We will support people with significant behavioural and psychological symptoms through more intensive care and support. We will work with families and people using the service to plan ahead. We will regularly update the plans in review meetings with our Dementia Navigators and Dementia Liaison Co-ordinators. We will encourage carers to look after their own health and wellbeing and take breaks.	2.1 High level of satisfaction with service from stakeholders. 2.2 Increased number of carers who have had their health and support needs reviewed and planned for. 2.3 Reduction in the number of crises in the community leading to inappropriate unscheduled care (e.g. A&E, walk in centres, un-planned admission to residential and nursing care, hospital and use of out of area beds). 2.4 People with dementia receive the most appropriate care to manage challenging behaviour. 2.5 People with dementia stay at home for as long as possible.	2.1a Friends and family test (KPI5) 2.1b Proportion of wellbeing plans completed within 20 working days of assessment. (KPI4). 2.2a Proportion of identified carers with their needs assessed and planned for. (KPI 17) 2.3a Proportion of people with dementia on caseload with one or more emergency admission to inpatient services as part of their current referral episode. (KPI 21) 2.4a Proportion of stakeholders who feel confident to manage challenging behaviour. 2.5a Proportion of carers of people with dementia who feel satisfied with how long the person with dementia remained at home.

3. To enable people with dementia to remain active citizens We will engage and educate the community We will enable people to build and access local support networks We will raise awareness and tackle myths about dementia.	3.1 Quality of life for people with dementia is maintained. 3.2 Individuals' have suitable local support networks. 3.3 Dementia awareness within Bristol is increased.	3.1a Quality of life 3.2a Size of local support networks around individuals and their carers. 3.3a Levels of dementia awareness.
4. To provide high quality integrated person-centred care We will provide a single point of contact We will offer a personal tailored plan throughout each individual's lifetime We will provide a Dementia Navigator for everyone diagnosed with dementia. We will enable people to build and access local support networks We will help GPs become dementia-care experts. We will work with local hospital trusts and neuro-psychiatric services to develop a fully integrated service.	4.1 High level of satisfaction 4.2 All individual using the Bristol Dementia Service has a personal plan and a Dementia Navigator. 4.3 Increased experience of involvement in the planning process by service users and carers. 4.4 Increase in individuals' local support networks. 4.5 GPs have increased confidence in caring for people with dementia. 4.6 Increase the number of people with a diagnosis on practice registers. 4.7 People with dementia and their carers experience improved support from their GP. 4.8 Local services work together to provide dementia care for individuals.	4.1a Friends and family plus 4.2a Proportion of people using BDS who have a dementia navigator. 4.3a Proportion of people who report feeling involved in the planning process. 4.4a Size of local support networks around individuals and their carer. 4.5a Increase in GP self-assessed knowledge and confidence about caring for people with dementia. 4.6a Number of people with a diagnosis on practice registers. 4.7a Friends and family plus 4.8a Number of services working in partnership to deliver dementia care.
5. To provide high quality advice and support for other providers, especially primary care on assessment and management interventions We will provide a single point of contact We will help GPs become dementia-care experts. We will work with partner agencies to maximize support and reduce the potential for crisis. We will work with partners to deliver optimal palliative care as recommended by the European Association for Palliative Care.	5.1 Achieve dementia diagnosis rate of 80% by 2018/19 5.2 Increase the number of people with a diagnosis on practice registers. 5.3 Reduced use of anti-psychotic medication. 5.4 Reduction in the number of crises in the community leading to inappropriate unscheduled care (e.g. A&E, walk in centres, unplanned admission to residential and nursing care, hospital and use of out of area beds). 5.5 GPs feel supported by dementia services to effectively manage people with dementia and their family and carers in primary care.	5.1a Diagnosis rates (KPI 1) 5.2a Number of people with a diagnosis on practice registers. 5.3a Proportion of service users on antipsychotic medication. (KPI 6) 5.4a Proportion of people with dementia on caseload with one or more emergency admission to inpatient services as part of their current referral episode. (KPI 21) 5.5a Proportion of urgent requests for advice responded to in 4 hours. (KPI 9) 5.5b Proportion of non-urgent requests for advice responded to in 48 hours. (KPI10)

	5.6 Service providers have increased confidence and knowledge about caring for people with dementia	5.5c Proportion of referrals acknowledged within 10 working days. (KPI 11) 5.5d Proportion of wellbeing plans sent to GP within 10 working days. (KPI12) 5.5e Increase in GP self-assessed knowledge and confidence about caring for people with dementia. 5.6a Increase in service provider self-assessed knowledge and confidence about caring for people with dementia.
6. To promote support and inclusion for people with dementia and family/carers using the service We will work with the community to build a dementia-friendly city We will raise awareness and tackle myths about dementia.	6 . Creation of a Dementia Friendly Bristol. 6.1 Increase in individuals' local support networks. 6.2 Improved quality of life of people with dementia.	6a Dementia awareness understanding within Bristol. 6.1a Size of local support networks around individuals and their carers. 6.1b Reduction in social isolation 6.2a Quality of life of people with dementia and the people who care for them.
7. To support the development of the workforce and volunteers providing the service with the right attitudes and skill mix.	7. Decreased stigma within the workforce 7.1 A peer support network is in place and supporting individuals and their carers. 7.2 Improved staff job satisfaction	7a. Perception of stigma amongst workforce from service users and carers. 7.1a Proportion of people using services and their carers supported by a peer support network. 7.2a Staff retention, sick days, absence days, reported job satisfaction.

2.3 Data sources and collection

The final column of the evaluation framework outlines the data sources against the indicators.

Indicator	Data collection tool/method
1.1a Friends and family test (KPI 5)	KPI
1.1b Proportion of service users reporting high levels of satisfaction with the services.	KPI
1.2a Number of service users and carers involved in service planning.	PWD and carer interview
1.4a Total number of service users with a well-being plan completed within 20 working days of assessment against total number of service users with an assessment in the period. (KPI4)	KPI
1.5a Growth in local support networks available to service users and carers.	PWD and carer interview
2.1a Friends and family test (KPI5)	KPI
2.1b Proportion of wellbeing plans completed within 20 working days of assessment. (KPI4)	KPI
2.2a Proportion of identified carers with their needs assessed and planned for. (KPI 17)	KPI
2.3a Proportion of people with dementia on caseload with one or more emergency admission to inpatient services as part of their current referral episode. (KPI 21)	KPI
2.4a Proportion of stakeholders who feel confident to manage challenging behaviour.	Stakeholder questionnaire to focus on confidence in practice and knowledge.
2.5a Proportion of carers of people with dementia who feel satisfied with how long the person with dementia remained at home.	PWD and carer interview
3.1a Quality of life	PWD and carer interview, Questionnaire
3.2a Size of local support networks around individuals and their carers.	PWD and carer interview, Questionnaire
3.3a Levels of dementia awareness	PWD and carer interview
4.1a Friends and family	KPI
4.2a Proportion of people who report feeling involved in the planning process.	PWD and carer interview
4.4a Size of local support networks around individuals and their carer.	PWD and carer interview Questionnaire
4.5a Increase in GP self-assessed knowledge and confidence about caring for people with dementia.	Stakeholder questionnaire to focus on confidence in practice and knowledge.
4.6a Number of people with a diagnosis on practice registers.	KPI
4.7a Friends and family plus	KPI
4.8a Number of services working in partnership to deliver dementia care.	Record-keeping

5.1a Diagnosis rates (KPI 1)	KPI
5.2a Number of people with a diagnosis on practice registers.	KPI
5.3a Proportion of service users on antipsychotic medication. (KPI 6)	KPI
5.4a Proportion of people with dementia on caseload with one or more emergency admission to inpatient services as part of their current referral episode. (KPI 21)	KPI
5.5a Proportion of urgent requests for advice responded to in 4 hours. (KPI 9)	KPI
5.5b Proportion of non-urgent requests for advice responded to in 48 hours. (KPI10)	Stakeholder questionnaire re confidence.
5.5c Proportion of referrals acknowledged within 10 working days. (KPI 11)	KPI
5.5d Proportion of wellbeing plans sent to GP within 10 working days. (KPI12)	KPI
5.5e Increase in GP self-assessed knowledge and confidence about caring for people with dementia.	Stakeholder questionnaire
5.6a Increase in service provider self-assessed knowledge and confidence about caring for people with dementia.	Stakeholder questionnaire re confidence, knowledge etc.
6a Dementia awareness understanding within Bristol.	PWD and carer interview
6.1a Size of local support networks around individuals and their carer.	PWD and carer interview
6.1b Reduction in social isolation	Questionnaire. PWD and carer interview
6.2a Quality of life of people with dementia and the people who care for them.	PWD and carer interview. Questionnaire
7a. Perception of stigma amongst workforce from service users and carers.	PWD and carer interview
7.1a Proportion of people using services and their carers supported by a peer support network.	PWD and carer interview

The data collection is mixed-methods, producing a full picture of the service through both qualitative and quantitative data. The evaluation uses five main data sources:

- Key Performance Indicators (KPIs)
- Quality of life and social isolation questionnaire
- Interview
- Stakeholder practice questionnaire
- Process evaluation – stakeholder interviews.

KPIs are collected through Performance Management systems. From the beginning of the evaluation, the Performance Management team discussed the KPIs with the evaluation team, facilitating the development of the evaluation framework. As is discussed in section 3.5 the KPIs evolved through the development of the service, and as such, some of the KPIs were discarded or changed in agreement with the commissioner.

As part of the KPI data collection, a questionnaire was developed to assess satisfaction of the service amongst GPs which was collected as part of the service's CQUIN targets in its first year. In order to add depth to this data, and to make use of this format to collect data of relevance to the evaluation, additional questions were added to this questionnaire to gather data with regards to the clinical confidence of GPs to work with people with dementia. These were rating scale questions and this questionnaire was carried out in July 2015 and repeated in March 2016.

The quality of life and social isolation questionnaire used three measures: **The De Jong loneliness scale, the Lubben Social Network Scale and the ICECAP Quality of Life assessment tool**. These three validated measures were selected due to on the evidence base which points towards the value of their use with elderly people and people with dementia. The questionnaires were sent to a cohort of people who had been seen by the BDWS in August 2015. The questionnaire was first posted in November 2015, and then again in April 2016. There was a response rate of 26% in round 1, and a lower response rate of 15% in round 2.

Interviews were carried out with people with dementia and their carers. The sampling approach to these interviews was pragmatic, as it is important to ensure that people are not approached who may be upset by the request for interview (for example if the person with dementia has recently died, has become more ill or confused, or does not recognise the diagnosis). Dementia navigators and practitioners were asked to identify people on their caseload who might be happy to be interviewed, and then asked their permission. This of course raises possible selection bias, with the DN only identifying people who would give a positive response, or those who have been less complex as cases. However, the responses do not show that necessarily to be the case, as responses provide a good range of positive and neutral views.

The interviewer contacted potential interviewees to see if they would like to be interviewed face-to-face or by telephone. Again, both approaches have benefits. Face-to-face interviews are likely to be more in-depth. However, they are more intrusive and difficult for interviewers to arrange within a short time-frame. Telephone interviews have the advantage that carers can speak on their own if required, and they can happen more spontaneously. An interview schedule was used and transcripts were analysed thematically.

Finally, the process evaluation sought to examine how the service had developed and been implemented from the perspective of staff involved. Such an evaluation seeks to identify key challenges and facilitators to the process, and can be used to learn lessons for other such service developments, as well as for the service itself. The design involved a rapid assessment of the Bristol Dementia Wellbeing Service using qualitative semi-structured telephone interviews.

Participants were purposively selected from a range of professionals to ensure diversity in terms of professional group and seniority. Eleven interviews were conducted using a topic guide, at the interviewees' convenience and lasted 20 minutes on average. The topic guide included 14 open-ended questions covering topics such challenges encountered in setting up and delivering the service, how resources were deployed, training, support, service organisation, current issues and how could the service be improved.

3 Findings according to data type

3.1 Social isolation and connectivity questionnaire and interviews

The issues of social isolation, connectivity and quality of life are amongst the more complex of factors to evaluate, as they are qualitative and subjective concepts, difficult to explain and for people to describe. However, evidence shows increasing numbers of elderly people experiencing social isolation and that people with dementia and their carers are likely to see a decrease in social connectivity. Understanding what makes for a good quality of life for people with dementia and their carers is central to ensuring that a dementia wellbeing service meets the needs of the population.

There are a number of outcomes within the evaluation framework that relate to quality of life, social isolation and social connectivity:

- **Outcome 1.5 - Service users and carers feel supported in their local area**
- **Outcome 3.1 - Quality of life for people with dementia is maintained**
- **Outcome 3.2 - Individuals have suitable local support networks**
- **Outcome 4.4 - Increase in individual's local support networks**
- **Outcome 6.2 - Improved quality of life of people with dementia**
- **Outcome 7.1 - A peer support network is in place and supporting individuals and their carers.**

The evaluation data against these outcomes is collected through the social isolation, connectivity and quality of life questionnaires, as well as by the one-to-one interviews. As outlined above, the questionnaire used three validated measures, sent out to 144 people who had been seen by the service in August 2015. The questionnaire was repeated in March 2016.

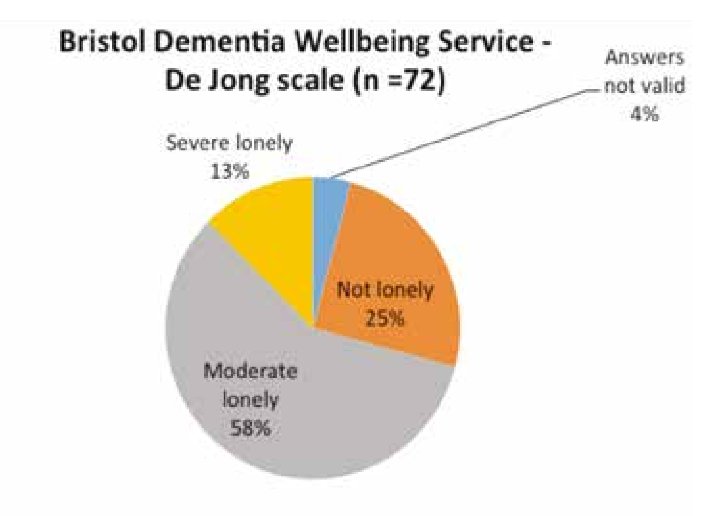


Figure 1: De Jong scale responses

There are limitations to be considered with relation to the comparability of the questionnaire respondents. Due to issues relating to anonymity of respondents, we could not identify whether or not the second round respondents had already completed a first round questionnaire, and as such cannot directly compare the data in terms of change for individuals. We can, however, get an overall view of any obvious trends in changes in responses.

The De Jong Social Isolation scale produces data to report on whether respondents are "not lonely", "moderately lonely" or "severely lonely" and our two rounds of questionnaires show similar responses: In the first round, 66% are in the categories "moderately or severely lonely", whilst 27% are "not lonely". In the second round, 79% reported being "moderately to severely lonely", whilst 21% reported being "not lonely." Putting the data from rounds 1 and 2 together, the scale shows that this is a population that is very likely to experience high levels of loneliness.

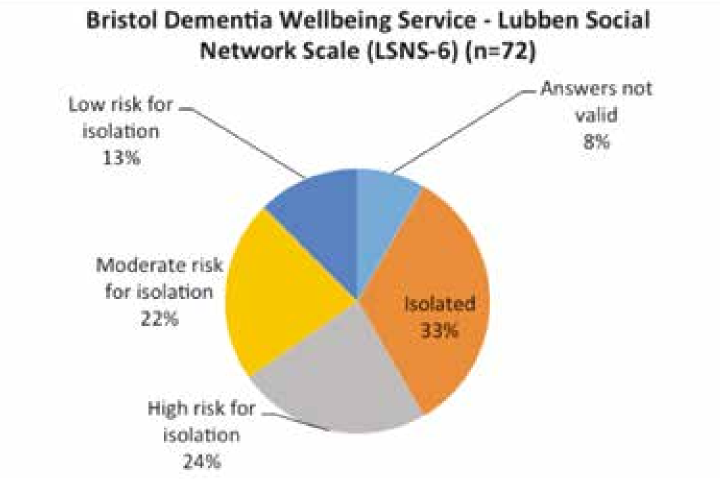


Figure 2: Lubben Social Network Scale compiled responses

The Lubben scales asks people about the extent of and involvement in social networks. The scoring categorises people as being at high, moderate or low risk of social isolation. In both rounds, the largest proportion of respondents are categorised as "at high risk of isolation", with the second round actually producing a higher percentage of respondents at high risk (68%) in comparison to the first round (50%). Again, the first round has a lower percentage categorised as being at moderate risk of social isolation (27%) compared to the second round (14%). Overall, therefore, the picture is of a group of people who tend to be at moderate or high risk of isolation due to limitations of access to social networks and interactions.

Lastly, the ICECAP Capability score assess five different attributes of wellbeing that were found to be of relevance to the quality of life of older people:

- Attachment (love and friendship)
- Security (thinking about the future without concern)
- Role (doing things that make you feel valued)
- Enjoyment (enjoyment and pleasure)
- Control (independence).

Scores are then categorised to give a "capability" score, which relates to the capability of the individual in relation to wellbeing, or quality of life. It would appear that this was found to be a relatively difficult measure for people to complete, as there are high levels of non-valid answers, especially in the second round (25% not valid). As such, it is difficult to look at any comparison between rounds with any great validity. Taking that limitation into consideration however, both rounds had the highest proportion of respondents in the "low capability" category (41% and 57% respectively), but the first round still had 27% in the high capability category, in comparison to only 7% in the second round. Taking the non-valid answers into consideration, overall, this group expresses low capability to experience wellbeing or a good quality of life.

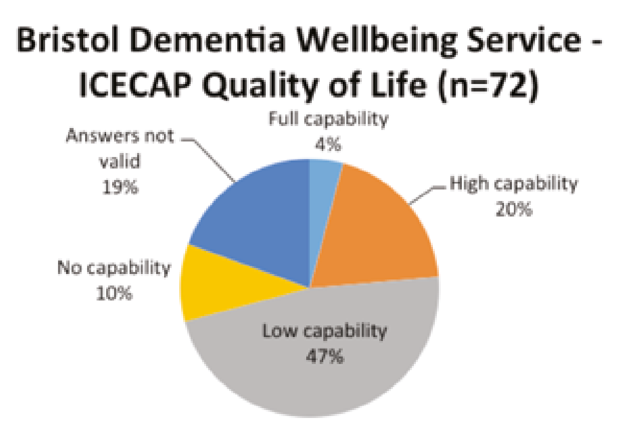


Figure 3 ICECAP Capability scores compiled

Overall, this questionnaire data cannot be used with any validity to claim changes with regards to social isolation, connectivity and quality of life between the two date-points of data collection. However, it does show that the objectives of the service to ensure that quality of life is considered in assessment and service provision are well placed with this population who demonstrate low levels of capability to experience wellbeing, limited social connectivity and relatively high levels of social isolation.

The interviews provided the opportunity to probe these issues further and the detail on these interviews is in section 3.4. Overall, people are very reliant on their own personal and family networks and for some, the diagnosis has made it harder to connect to friends who don't understand, and the social network became smaller. Even within families, there tends to be a close "inner circle" of people who understand and provide direct input. For many of the interviewees, the Dementia Navigator is providing input that helps increase social networks and gives ideas to improve quality of life, as well as being an important social contact themselves.

3.2 Process evaluation

Whilst it is not one of the themes of the evaluation, understanding how the process of the service has been experienced by those working within it is an important piece of learning. The process evaluation asked questions around the setting-up of the service, challenges and facilitators to the success of the service and lessons learnt.

3.2.1 Overall impression of the service

All 11 participants were very positive and confident about the service overall, the way it was implemented and how it how it currently runs. All respondents suggested that the BDWS addressed a significant need and provides improvements compared to the previous model (memory service) and described benefits in three main areas:

1. Patient benefit in terms of a) Providing a different kind of service for people with dementia by having a more confident and skilled GP workforce and Dementia Navigators, and be able to deliver dementia care closer to home b) not discharging patients and keeping all patients under the service: **"It doesn't matter what kind of dementia you have. As long as you have a dementia you will receive the same kind of support over time."**
2. A better model of care and of service delivery, by moving away from largely psychiatric services, and also in terms of affordability as specialist-led clinic is perhaps more expensive for the CCGs.

3. Benefiting the city of Bristol in terms of adding to its goal of being a dementia-friendly city. Also the level of collaboration between primary and secondary care in dementia in Bristol is probably the greatest in the country.

Responses indicated that planning and setting up the service was relatively challenging, however successful. Participants emphasised the fact that this was a unique opportunity and **"selling the idea was not difficult"**, and as this was something new and not based on a pre-existing model it was a huge learning curve for everybody involved. Participants felt that it was important it was mostly their service specification, **"it was our thinking"** and that the **"commissioners were very brave in how they set up the service specification that allowed the Partnership to bid for it"**.

Overall, participants felt that getting the service off the ground was a great achievement and a great collaborative experience. Equally, this presented challenges in terms of not knowing what kind of problems to expect and in terms of being a very "ambitious" service. The service was seen as ambitious because of it being based on a new way of doing things, a new approach to service delivery, linking up services and providing a primary-care based approach to dementia care.

3.2.2 Challenges

Although the implementation of the service was successful, participants identified a number of challenges in setting up the service. New challenges were also identified during the first year of the service.

Challenges during the development and set-up of service

1. Organisational shifts

Challenges were identified in terms of moving services from secondary care, in particular in relation to working culture:

> "I don't think we've quite managed to help staff understand that they'll need to manage that in a different way than if you're in secondary mental health services."

> "I think that whole ethos of working in a much different way was a challenge to a lot of people… to then rub up alongside a service for the Alzheimer's Society, which is a very different ethos".

There was also the uncertainty in terms of changing employer, as staff had to transfer from one organisation to another, terms and conditions moved to DPT, and some staff that had their contracts moved to the Alzheimer's Society.

> **"when you… go for a new job, you apply and you go for an interview, hopefully you are successful, then you start a new job… all that process was taken away from us. We were in effect transferred from one NHS employer to another. I think that was a challenge that we had to get our heads round."**

Finally there were physical challenges involving staff moving from one organisation to two other organisations and also in terms of physically moving out of one building into three other buildings. This, interviewees suggested, was time-consuming and the distance between DPT and Bristol posed challenges as Bristol is significantly different to Devon and Exeter:

> **"Different locations, how people operate differently and that required a number of visits to Bristol, as time's gone on really we understand that Bristol's not that far away actually".**

2. Change in people's roles and work

Participants suggested that there has been a lack of clarity for some about how the navigator and practitioner role differs from what was in place before, and that some memory nurses and practitioners have found it difficult to adapt to the radical change in their role and their remit: "Bringing them out of their Callington Road base and asking them to work in the community".

> **"They become more dementia generalists…The OTs don't get to do much occupational therapy and the physios likewise… some of them are missing the opportunity to use their specialist skills."**

Some participants also suggested that it is challenging to be involved in a variety of tasks rather than being a "specialist".

The majority of participants identified that caseload management has been challenging, specifically in relation to in-depth assessments. Staff coming from secondary care had to learn to work in a different way regarding their caseloads, which involved not doing as many in-depth assessments: "Their caseloads now are really huge and they're almost doing too good a job with everybody...when you're being overwhelmed by the number of referrals you simply cannot spend and devote the amount of time and support that you might need to that person".

3. Staffing levels

There were challenges in terms of finding medical staff and recruiting enough memory nurses and memory practitioners.

4. GPs understanding the service

It took more time and GP engagement than anticipated and for General Practices to understand the service that was commissioned and the roles of BDWS staff.

5. Working with other services

Participants suggested that sometimes the BDWS have been filling social services gaps and taking on more work and responsibility than what was agreed. This then had an impact on their workload: "then we will be bogged down with not doing what the service is commissioned to do".

> **"It's not always easy to get a foot in the door of a busy practice but memory nurses and practitioners persisted".**

6. Training

It was suggested that, in the initial stages of the service, getting the managers to engage in management development was difficult. Also attendance to GPs' educational days has not been good. In addition, it was suggested that there should be more early communication with navigators and it would have helped to have rolled out the navigator input a bit more slowly, and work with the Alzheimer's Society in terms of boundary setting.

7. Systems and IT

There were some challenges in terms of systems and IT as the infrastructure was in Devon and the BDWS in Bristol.

> **"We couldn't simply roll out the way in which we work everywhere else because of the different geography and the different partners that are in place in Bristol... remote working, then having to have multiple logins for different IT systems and processes... at the time the service was being set up it was a big change for people".**

> **"We have pushed tablets out quite extensively amongst our nursing staff in Devon. That's not appropriate in Bristol because they're not using the same clinical packages; however, the staff do all have lightweight laptops, which they've adjusted to very quickly".**

There were challenges around the transfer from the old system in the initial six-month period as Bristol staff were using a clinical system which is shared by the Bristol health community and is different from that of DPT.

On-going challenges

Following the set-up period, some challenges remain, whilst some new challenges have been identified.

1. Staffing gaps

This is an ongoing challenge. All participants identified current gaps in staffing mainly in terms of professional categories rather than numbers. The main concern was not having a permanent consultant at the moment in one of the sites. Other staffing gaps include speech and language therapists as when this service is needed the BDWS currently have to **"go…through the main hospital and there are delays"**. Other issues included staff sick leave, for example the physiotherapist for Bristol being on long-term leave and also pressures for the administrative staff when staff are off sick long-term and the rest of the administrators are under pressure. In addition, it was suggested that practitioners feel that they're too busy and that there aren't enough of them. However it was suggested (see above) that the reason for this could be because of **"the way they perceive and manage risk"**.

> **"Not having that one lead consultant in post to take more of a leadership and management position"… "Locums are temporary and expensive. It's not a long-term solution".**

2. GPs' responsibilities and understanding of the service

To many, this is an unresolved challenge. Most interviewees described how GPs appear to be leaning heavily on the practitioners, who end up having to make a lot of the clinical decisions and diagnoses for the GPs. This impacts on the BDWS by creating confusion about how involved BDWS staff should be. As a result it was suggested that BDWS staff are overworked and taking on more responsibility and work than they are commissioned to do. In addition participants suggested that BDWS staff still have to explain to some GPs how the service works.

> **"If somebody needs safeguarding or there's risks associated with them we automatically take that as our responsibility but I'm not really sure that it is any more and I've been told we should be handing back things like that to the GPs".**

> **"GPs still treat us like a secondary mental health service and expect us to be coordinators when we're not."**

What adds to this issue, is the fact that there are differences between GP practices and GPs. Participants described that some GPs are fully supportive but others less so and there is **"discrepancy in terms of understanding, ethos and all of those sorts of things. Could literally have two GPs in the same practice who may have different ideas"**.

Increasing GPs' skills and confidence was identified as a significant challenge. This was evident in the confusion regarding the formulation of diagnosis, a complex issue where participants offered various perspectives. Most participants suggested that GPs have not been diagnosing as much as expected and this should/was expected to be increased: **"what was planned was the GPs would be doing the vast amount of diagnosing of dementia and that clearly isn't the case"**. However others suggested that this was expected and felt this will not change, as GPs don't have specialist knowledge: **"I think in many cases it's fine for GPs to do it, but as is always the case one doesn't know what one doesn't know"**. Pressing GPs to diagnose, they suggested could lead to diagnostic errors.

All participants recognised that GPs are currently under a lot of pressure and that impacts and sometimes causes the communication issues as well as their over-reliance on the BDWS. Also it was suggested that GPs do not have the time to do in-depth assessments and diagnosing, and since GPs don't have an hour to spend with patients the majority of diagnosing will have to be done by the BDWS.

Finally, participants identified differences in perceptions diagnosing. GPs are more comfortable with a diagnosis that is not so clear-cut.

> **"GPs are so busy, under so much pressure at the moment that they can't do a lot of the things they'd like to do."**

> **"For the Dementia Wellbeing Service a case enters their workload if it is definitely defined as dementia. For a GP that patient is our patient no matter what they are. Having a clear-cut switch on/switch off is less important"**

Moreover, for BDWS staff it is important not only to have a specific diagnosis but one that is as accurate one as possible.

> "there seems to be some kind of tension in the service between getting an accurate or good enough diagnosis of dementia and making sure that we investigate thoroughly … is a bit of a bugbear of mine: not just giving people a diagnosis or a good enough diagnosis but giving them a really accurate diagnosis if we can."

3. Working with other services

Some participants said that the BDWS is taking on too much as other services expect the BDWS to take on responsibilities beyond the service specifications.

> "We're the service for people with dementia, it becomes an opportunity for other parts of the pathway to say, 'That's not our responsibility. This service will do it.' We never envisaged that this service would be a catch-all for everything.

One area of particular pressure comes from social services, with BDWS being treated as a way to fill the gaps in social care provision.

> "Social services have had a lot of budgets removed and are facing a lot of pressure so there are lots of people with dementia in Bristol who have care needs but are on a waiting list for a care package or the funds aren't available to give them a care package. They're struggling. They've got needs. The navigators know about more of these people 'cause they go and see people with dementia who are in a neglected state or not having their care needs met, then they feel duty bound to do something…"

4. Training

Some minor issues were identified in relation to training, for example, on a practical level, being separate from Devon. Participants also suggested that staff are sometimes reluctant to engage with what's offered and that there is not having enough time to prioritise training.

> **"for navigators or practitioners … you've got patients, you've got a certain amount of time to review, you have to have your letters out within a certain period of time. There's that constant pressure so giving time up to attend a course or a conference can be quite difficult."**

In addition, clinical supervision for practice leads is problematic as they are far away from DPT, and this is something that is currently being resolved. However, teams report being very close, and always having people to talk to. **"There are plenty of opportunities for discussion."**

5. Shortage of prescribers

Some participants suggested that there is a shortage of people who can prescribe within the service, specifically in terms of having enough clinicians and doctors who can write prescriptions. In addition, it was suggested that although GPs prescribe Donepezil, they need to initiate on request other cholinesterase inhibitors and Memantine.

> **"We're asking the GPs to consider themselves as 'specialists' from the point of view of guidance around prescribing these drugs because we think that the Bristol GPs have got sufficient education and support to be able to safely prescribe those drugs".**

3.2.3 Facilitators to practice change and to implementation of the BDWS

Participants described many actions and experiences that have helped the implementation process.

1. Early communication and support

The CCG engaged in communication with the stakeholder group very early in the set up process. Similarly, people found that managers and consultants in DPT are very approachable and accessible which meant that staff were prepared and aware of what was involved and they were proactive in coming to CCG and discussing issues before they became problems.

There is also support in place in terms of Staff wellbeing group, weekly team meetings, supervision and appraisals.

> **"There's been a lot of working going on in the background to get everybody understanding each other and talking to each other"**

The senior dementia practitioners were also very supportive especially in resolving misunderstanding between the GPs and practitioners. There was also a lot of support available for GPs via the GP lead in the service who GPs could/can contact directly, and who also coordinates an education program for GPs. There was also support for the GPs in terms of providing templates to help with diagnosis and the annual review and IT support.

2. Proposing a new way of thinking about dementia

Interviewees suggested that a particular facilitator is how the service presented dementia as different to mental health and rather a long term condition. Similarly, it was important that this service helped to build up skills in dealing with dementia amongst non-specialist staff. The reference to the **"medical model"** here, relates to the difference in perspectives that might exist between medically and social trained professionals.

> "They've set up a specification that very clearly moves dementia into a different ethos of thinking much more akin to how diabetes was looked at"

> "They'd trained up the social workers in how to do the assessments and it was really interesting getting a different perspective rather than just the medical model"

3. Funding

Many participants suggested that having budget and resources available was key to the successful implementation of the BDWS. Funding has been flexible enough to deal with unexpected issues and it was suggested that funding has helped GPs to feel comfortable with the extra time they put in. There was also money available that allowed staff to do some commissioning themselves which allows for flexibility in practice. Participants also identified that having adequate funding in place is potentially the biggest challenge for rolling out this service to other areas in the country.

4. Staffing

Staffing levels was reviewed regularly and predicated on modelling. Despite some issues with staffing, the service was/is fully staffed apart from some medical posts. With the Alzheimer's part of the contract a couple of new posts were added early on to fill identified need.
The staffing is therefore being established according to an evidence based and ongoing assessment of the service.

5. Staff motivation and experience

Motivation was identified as an important personal factor across professional groups as was having very experienced staff:

"Very high quality of navigator staff coming from all different sorts of backgrounds and different ages."

"Practitioners have been in post in secondary mental health services or the memory service for many years so they're very, very experienced".

Some staff knew each other well as they had worked together in the past in secondary care, but there is also evidence that although some of the staff came from different sectors such as the Alzheimer's Society, the DPT, and the NHS, they have worked really well together and were very committed. The success of the service also derived from having the right disciplines who can deliver an all-inclusive approach to dementia such as GPs, navigators and practitioners.

6. Flexibility

Another extremely important to the success of the service is the flexibility that is built into the model, with managers reporting how they are free to try out approaches, within certain parameters, and adapt depending on how it works out.

Such an approach is particularly important in the face of changes in partner organisations and services, as well as in relation to creating a service that is adaptable to the needs of its client base.

"I suppose there is a service improvement PDSA (Plan, Do, Study, Act) type model: we're planning things, we're doing them, we're studying the effects of them and then we are adapting, abandoning or changing them in some ways."

7. Building relationships

Whilst relationships with the GPs in particular is identified as an ongoing challenge, the work done to establish these relationships were identified as an important facilitator to the service. Building relationships & visiting practices regularly was identified as vital in setting up the service. This involved stakeholders meetings on a monthly basis, and also memory nurses and practitioners visiting the practices regularly. The fact that Devon Partnership NHS Trust has had experience of linking into primary care was vital to setting up the service and early communication.

Another important element of relationships building has been between BDWS and DPT directors, with board meetings being held in Bristol, bringing the service into the view of the Executive team, and keeping the communication open.

"It's not always easy to get a foot in the door of a busy practice but they have persisted, visited and built relationships".

8. GPs Prescribing

Although there are still some issues with prescribing, some participants suggested that much of prescribing has moved into primary care and there is little prescribing happening within the service. There is also support for GPs and advice on what they might prescribe and dosage.

9. Training

There was a good induction programme for new staff and staff could/can apply to attend paid courses. Internally, there was also a range of training options and some ad hoc training. Early investment in education was also important.

10. Infrastructure and IT

The services identified a local technology partner early on which helped as staff had access to the full range of corporate services but their local IT support was provided by an NHS provider locally

3.2.4 Plans in place and proposals to improve service

Participants pointed to several actions already taken to deal with on-going problems and potential challenges. There are plans in place to resolve the confusion over responsibility between the GPs and the BDWS as well as confusion over the role of practitioners within the BDWS, especially regarding their caseloads and spending less time with less complex cases. Also the GP lead and the commissioners are looking into the GP responsibilities and how to further develop GPs confidence in diagnosing and quality of GP-led diagnosis.

In addition, participants suggested that further work is needed in clarifying work responsibilities with other organisations. The BDWS is also building up relationships with the older adults' mental health wards at Callington Road, and they attend the ward round every week and with a drug and alcohol service, ROADS, to look at how there can be better communication.

Similarly, it was suggested that the management team are considering how to move forward in a more cohesive manner and that there are plans to be made to improve the Clinical leadership structure in the next 12 months. There are also plans to recruit two senior medical posts and there was a suggestion for employing more administrators or having a locum solution when people are off sick. Also there is a need to develop the non-medical prescribers and there are plans to increase the number of non-medical prescribers in the service this year.

Participants also suggested that more work could be done to promote training and also in terms of offering staff the opportunity to specialise. Similarly, participants suggested that the service would improve if people could share specialist knowledge, for example, learning disability, hoarding and human rights, and there are plans to identify and develop specialism champions across the service this year as part of the 2016/17 CQUIN targets.

There are also plans in place to develop links with epilepsy neurologists and the Parkinson's neurologists which will make the patients' pathway much smoother. In terms of technology, there are plans to get the team fully embedded with the Connecting Care project, which they have not yet fully engaged with.

Finally, it was suggested that now that the service has been operational for 15 months, time could be given to include staff in discussions around what has been learnt to date, and where people see the service going.

3.2.5 Process evaluation summary

The process evaluation shows how this is a complex and innovative service that has, not unexpectedly, met challenges in the start-up phases, but which has been successful in overcoming challenges because of a culture of flexibility and ongoing communication. Good interaction and team-work have been central to ensuring the success of the service, between all levels of stakeholders.

A particular area of challenge has been around engagement with GPs, which, due to the high workload of the GPs has proved difficult, but this is recognised and work is continuing to make these relationships work. There were a number of organisational issues to overcome from the start, including IT issues and location of offices, but these have been addressed. For many workers, understanding roles and responsibilities and the culture of a different way of providing a dementia service took time, but again, this is an issue that has been addressed.

Looking forward, there may be some ongoing issues around the boundaries of the role of BDWS with regards to social care provision and diagnostic practice, and continuing work to be done with establishing successful working relationships with GPs that work for all parties.

3.3 Experiences of people who use services and carers - semi-structured interviews

The majority of the interviews were carried out with carers who were experiencing a range of different caring situations, with some completely on their own, some with some other limited additional support and some with a wider network of family and friends sharing the caring.

There is evidence from the interviews that the Dementia Navigators are helping to increase access to groups, activities and peer support through provision of information about activities. They are providing information about **"lots of useful activities"** which are helping to keep people occupied. People talk about being involved in memory cafes, singing for the brain and peer support groups most commonly, or of having tried them. However, what is clear, and obvious, is that different people need different types of support, with some appreciating memory cafes whilst others find them **“patronising”**, and some wanting more than **“another cup of tea and cake.”** Those who have access to peer support groups, or just peer support through other types of support network, value that highly.

For some therefore, there are options of attending groups and meeting others, which is very important: “She (Mother) has a better social life than she used to have!” For many of the carers, however, getting to a group is not possible, because they cannot leave the person they care for, or cannot get them out of the house. In such cases, access to support is very limited and the Dementia Navigator becomes a very important contact – the social network itself “Just having someone to talk to really. It really helps.”

This points towards what is expressed as the most important role of the DN – being there to call if needed. This provides a huge relief for most of the interviewees, who, even if they have not had a great deal of interaction with their DN, know that they have someone to call if they need to. The interviewees have differing types of interaction with their DNs, with some having close contact and ongoing discussions in-between 6-monthly visits, whilst some have little contact. When people have had little contact, it can be because they feel they are currently managing, or also because **“I don’t like to bother people”**. In both these groups of people, there are still reports that it is important to know that they have someone to call if needed, and that this helps a great deal.

There is evidence from some of the interviewees of the difference between service since the BDWS was established. For some, they have seen the shift with the one person they care for, whilst for others, they are comparing to care received for a parent or other relative in the past. The overwhelming feeling is that when they were reliant on the Memory Service, support was extremely limited, if not non-existent, and that this has really changed since BDWS was set up. They now feel they have support and someone to contact, whilst previously they only had basic information then had to **“try and follow-up with nurses.”** One man was particularly pleased because he feels that the BDWS model really fits to feedback he made about the type of support he needed – having one person for him to contact who could manage support.

There is also evidence that people see this shift in relation to how they interact with their GP, with people often saying that their GP is **“very nice”** but is **“not a specialist and doesn’t work in this all the time”**. Interviewees appreciate that they now have a DN (and some also mention the Dementia Practitioner role if they have had contact), who is the “specialist” and can provide them with that type of support and help them coordinate and manage the complexity of care.

This issue of how people don’t understand as they don’t **“work in this all the time”**, is also reflected in discussions around stigma and lack of understanding in the community. It is recognised that there has been a shift as dementia is becoming **“less taboo”** than it was, due largely to increased coverage in the media, on television and so on. However, the over-riding sentiment is that **“people just don’t understand”**, and that this is because they **“don’t have to deal with it all the time.”** This non-understanding relates really to “all the other bits” – by which is meant not just memory problems, but more challenging behaviours, sleep patterns and so on. There is a lack of understanding as to what dementia really looks like, and in particular, how it is experienced for those who care for someone with dementia, both in terms of the strain and difficulties of caring, but also in terms of emotional strain: "People don't understand that he is not the man I married."

During these discussions about understanding in the community, the clarity in expressing this lack of understanding was resounding. There is very much a shared experience of the loneliness of caring, an overwhelming sense of people being on their own and that the wider world just does not understand. For some, this lack of understanding has led to breakdown in friendships, with social networks slipping away. And for some, there is a lack of understanding amongst family members, which causes friction.

The complexity of negotiating the different elements of services is clear from the interviews, and whilst the role of the DN is recognised in relation to helping manage this complexity, it is still something that weighs heavily on some carers. All carers interviewed spoke of some area that they were having problems, or thought they would have problems, negotiating (often related to social care), and many spoke of how **"busy"** their lives were with trying to work it all out. The often daily activity of having to follow up phone calls, trying to track down a service or find out about appointments was seen as very stressful to many.

One area of continuing concern that is raised by many, is social care, in terms of respite and nursing care. Even for those who have not yet needed such support, people express concerns over availability and access to respite and nursing care. For those who have tried to get support, there are reports of very long waiting times for responses and assessments, and once people have been assessed, many find that **"if you have any money at all then they don't want to talk to you."** Respite is mentioned by nearly all interviewees. Some have had successful experiences of using residential respite when needed, usually in the case of an emergency such as the carer being admitted to hospital, but for many, there is a general need for respite. The vast majority of the carers interviewed, do so on their own, some with only three hours cover during a week. The understanding of what is available is limited, although there is a general recognition that respite is difficult to access and that it has to be **"right"** for the loved one.

Dementia Navigators have helped people to negotiate these difficult waters, and it is recognised that it is not **"their job"** to organise respite or nursing homes. **"Housing is not their problem, but she is doing her best. She keeps in touch with it all."** What they have done is point towards possible options, been there to help with difficult decisions and uncovered pieces of information that can't be found. Some of the social care needs, however, can be urgent, with one lady having lived **"out of a suitcase"** for two years as she is on a housing list but "not a priority" despite a diagnosis of dementia. Some people have waited more than 6 months for a social care assessment.

Quality of life means different things to different people, but can be grouped into three main themes: Keeping active, getting out and just **"keeping going"**. Keeping active usually involves keeping up similar types of social interaction and activities as before illness, as far as possible. Seeing family and friends and then also participating in groups if relevant. For some, **"getting**

out" is as far as activity can get, and sometimes for a carer just means getting to the shops for two hours a week, or getting someone out of the house for a short walk. Many of the carers spoke of just **"keeping going"**. There is a sense that both their quality of life and the quality of life of the person they care for is reliant on their obligation to **"keep going"** – but also that there can be a sense of satisfaction, or of obligation in caring which means that it is part of a quality of life.

Any negative reports about the Dementia Navigators tended to relate to a lack of follow-up on something that was promised, for example information not being provided, or help not being forthcoming once it was discussed. For some, just being signposted is not enough, and there is a wish for more direct input in finding out and then making sure a service happens (particularly in relation to social care). However, overall, the general sense was that the DN role is hugely valued because just knowing that someone is available on the other end of the telephone is extremely helpful, even if it is not used. Attributes of a good Dementia Navigator focused on their friendliness and accessibility.

"Even if they don't know they will find out for me. We were lost before."

"Our DN is brilliant - really down to earth and friendly".

"She's a big rock."

"The world would have been a much darker place without her."

"It is good to know someone is interested in us."

"So friendly."

3.3.1 Befriending service

An additional focused piece of work has been carried out by the Alzheimer's Society to look in particular the befriending service provided as part of Bristol Dementia Wellbeing Service. This service was mentioned during the interviews for the evaluation, being cited as an important source of support for people who are often otherwise very isolated.

This piece of work highlights the different ways in which the service inputs on quality of life, often by helping the person with dementia to go out and do something they enjoy. This includes particular activities such as cycling and walking but also **"see places I've known all my life: docks, the zoo, the museum, arnolfini. I look forward to going out."**

> **"I'm amazed really how I got on with X because in a way I'm a shy person - I can't make conversation." "I've never been hung up about other people - I find you both very friendly. You're enjoyable to walk with, easy to talk to."**

What emerges strongly from this data is people reporting how much they **"look forward"** to this interaction, as it gives people something positive to think about in the days leading up to the activity, and then to reflect on afterwards. The other element that is very important is how easy people find it to get on with their befriender.

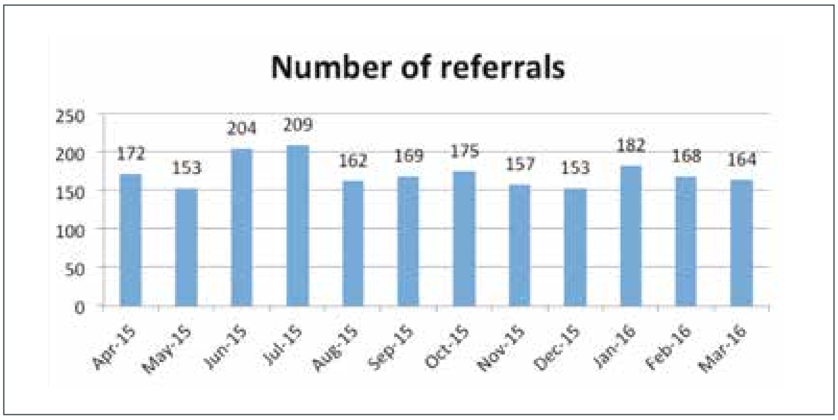
Overall, just having this contact is helping people to leave the house, to engage in things they wouldn't otherwise engage in, and feel more confident. The sense from these few statements is that the befriending service is impacting on quality of life, giving people something to look forward to, new interests and an improved sense in own abilities.

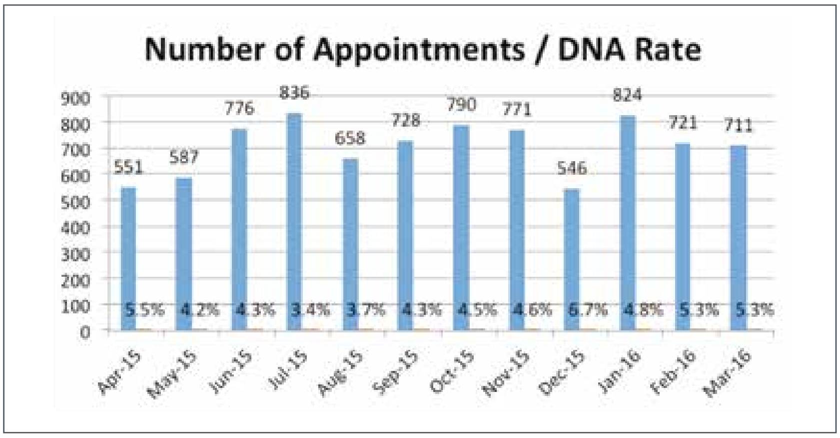
3.3.2 Interview data summary

Overall, the interviews reveal the complexities of living with dementia and of caring for someone in dementia, and the huge benefit that Dementia Navigators bring by being someone available at the end of the phone. They are people who understand in a world where people don't understand what it is really like to live with dementia or care for someone with dementia. Dementia Navigators are providing a support, even if it is not used often, and are offering guidance and information where needed. For those who received their diagnosis more than 18 months ago, there is a clear improvement in service provision, which is valued. There are ongoing concerns about social care provision and access, particularly around respite and nursing care, and it is clear that the role of the Dementia Navigator with regards to social care provision is potentially important.

3.4 Performance data

Key Performance data is collected by the Performance Monitoring team, and used to assess the progress of the service. Some of the basic service data collected gives an overview of the volume of referrals and appointments the BDWS is working with, showing that the number or referrals has remained generally consistent throughout the year with a higher level of appointments now than in April 2015 and a low number of DNAs.





Some of the performance indicators were adopted for use within the evaluation framework, so as not to duplicate effort or replicate data sets. Originally, the following indicators were identified to be used in the evaluation:

KPI 5	**Friends and family**
KPI 4	**Proportion of wellbeing plans completed within 20 working days of assessment**
KPI 17	**Proportion of identified carers with their needs assessed and planned for**
KPI 21	**Proportion of people with dementia on caseload with one or more emergency admission to inpatient services as part of their current referral episode**
KPI 1	**Diagnosis rates**
KPI 6	**Proportion of service users on antipsychotic medication**
KPI 9	**Proportion of urgent request for advice responded to in 4 hours**
KPI 10	**Proportion of non-urgent requests for advice responded to in 48 hours**
KPI 11	**Proportion of referrals acknowledged within 10 working days**
KPI 12	**Proportion of wellbeing plans sent to GP within 10 working days.**

However, through the development of the service, some of these KPIs were not used, either because of recognition that they could not be recorded or that they were unnecessary. KPIs 11 and 12 were both dropped because acknowledge of referrals was deemed unnecessary by GPs, and all wellbeing plans are sent to GPs once completed.

Area	Recommended	Not Recommended	Total Responses	Extremely Likely	Likely	Neither Likely or Unlikely	Unlikely	Extremely Unlikely	Dont Know
Bristol Dementia Partnership	100%	0.00%	59	55	4	0	0	0	0

Figure 4 Friends and family (KPI 5) Results 1st April 2015 - 31 March 2016

Friends and Family data reports on responses to the question: "would you recommend this service to your friends and family." Looking at the responses overall, the results are very positive. The number of responses, however are very low. If broken down according to month, responses were first collected in July, which saw the highest number of responses (14), and there is no real evidence that response rates are increasing.

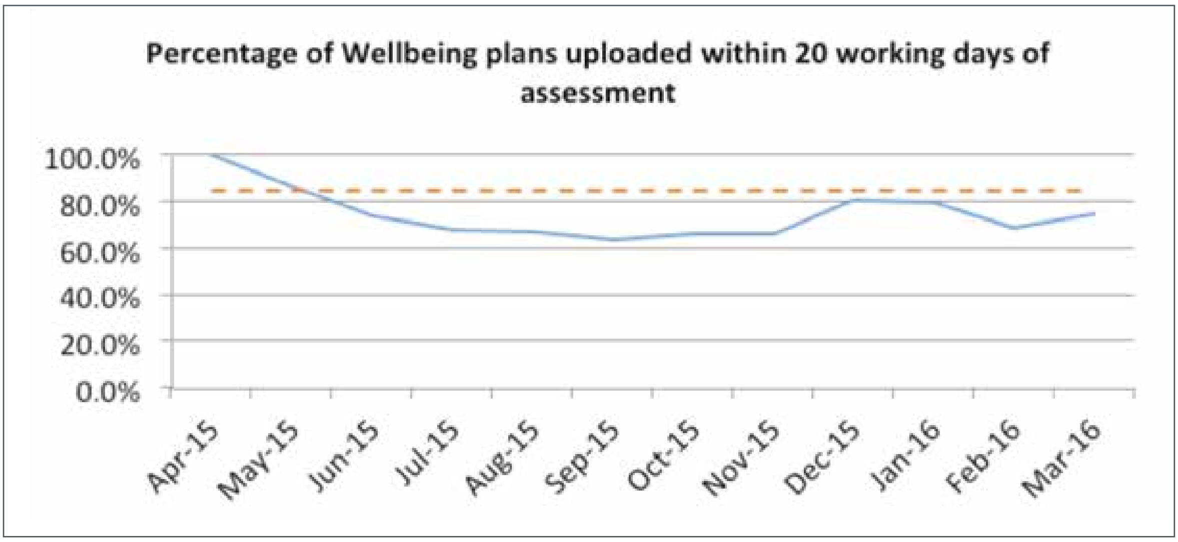


Figure 5: Percentage of wellbeing plans uploaded within 20 working days of assessment

Wellbeing plans are designed with the person with dementia and their carer. They set out what is needed to maintain wellbeing, and what support is needed. The completion of these within 20 days of assessment is an important indicator of performance. Performance is steadily improving, although the data shows lower levels than when data was first collected in April 2015. The data is still clouded with historic errors where old plans have not been correctly identified and a new plan has been uploaded, this shows as out of time when measured against first assessment. Despite the errors in the data, it is important to note that the median number of days for a wellbeing plan to be uploaded was 7 working days for March 2016, therefore well within the 20-day target.

KPI Carers with their needs assessed (KPI17)

Carers details are not noted on RiO and as such, performance data is not available on this indicator. The carer data sits on the CRS system held by the Alzheimer's Society. At this stage it is not possible to easily work out how many carers have had their needs assessed, as it requires reading through each carer record. The indicator has not been set up as dashboard figure. The CRS system only includes those carers who have been spoken to by the Alzheimer's Society, and so might miss carers who have had no contact with the service. A brief review of the CRS system however has shown that these records are in the most case, incomplete. Assessments, where undertaken, have been reported on, however in the vast majority of cases, the full assessment record has not been completed.

Proportion of caseload with one or more emergency admissions to inpatient services (KPI21)

This KPI was changed for two reasons: firstly because the data for it is owned by Avon and Wiltshire Mental Health Partnership NHS Trust (AWP) who are in charge of inpatient services and it was not possible to directly reference inpatient data across the service. Secondly, because through discussion, it was seen as an unrealistic target, with it being very difficult to attribute changes in emergency admissions to the provision of services by BDWS. Instead it was decided that the quality portion of this KPI would be achieved by supporting ward rounds within the Bristol Wards and KPI 10 (below) was developed to track hospital visits.

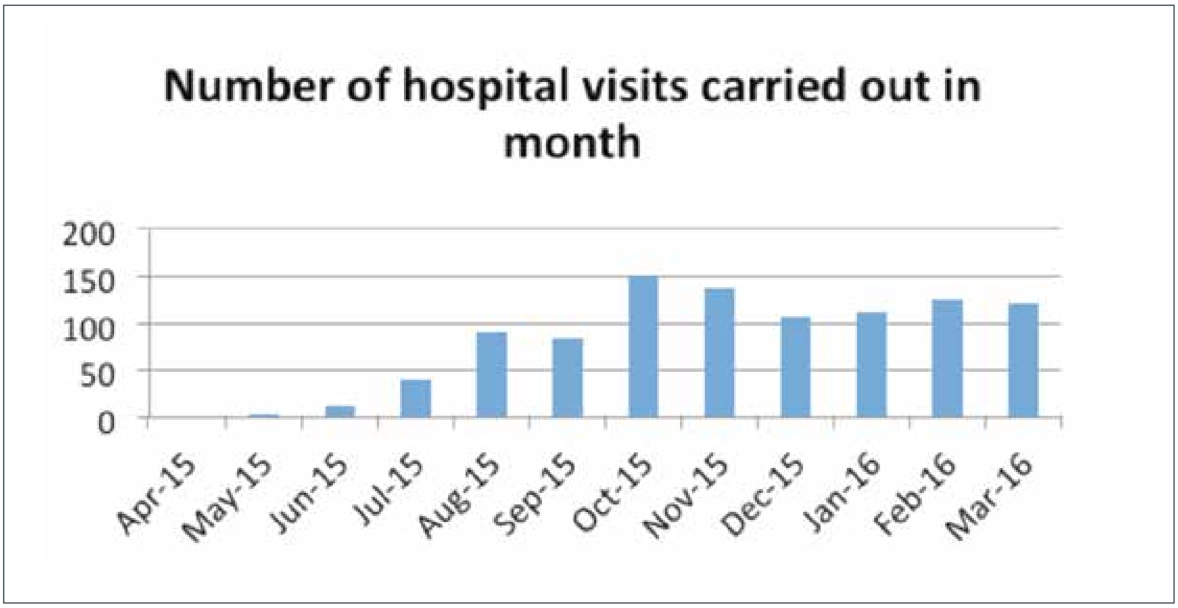


Figure 6: Number of visits by BDWS to inpatients in Callington Road Hospital

The recording mechanism for this KPI was introduced in late June and has taken a while to embed. In March 2016 hospital visits were recorded against 65 individual patients. A patient may not necessarily be open to the service with a wellbeing plan at this stage, but will still receive input from the ward round.

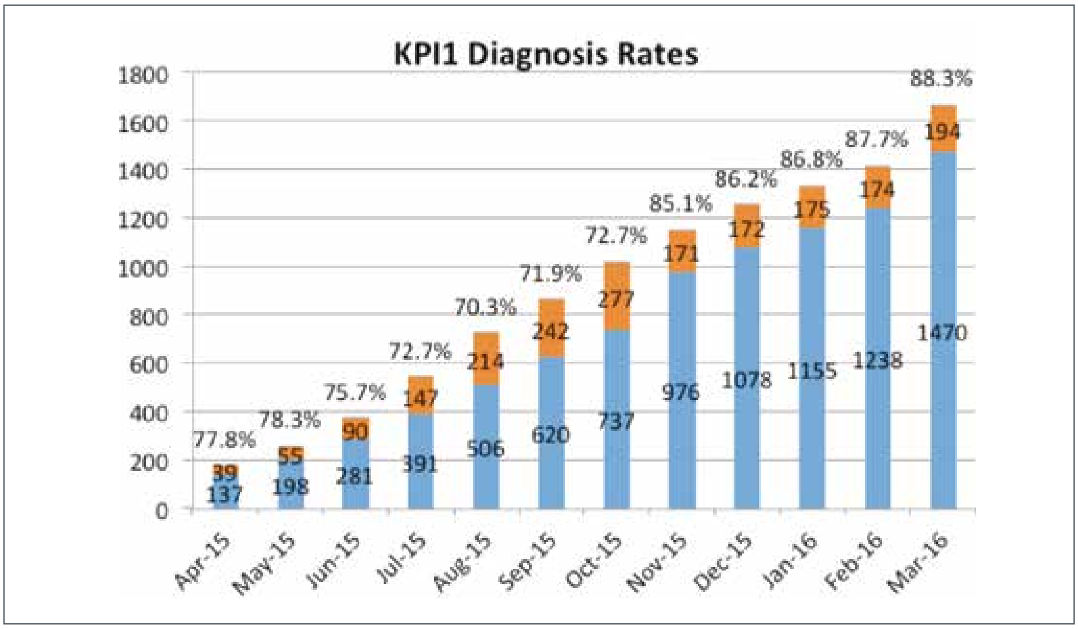


Figure 7: KPI 1 Diagnosis rates

Diagnosis rates provide an important KPI, as the service aims to help improve diagnosis rates. This indicator assesses the number of clients with a wellbeing plan who have a diagnosis recorded on RiO. A target of 90% was set to take into account that at any time there may still be a subsection of clients undergoing memory assessment that would have a plan but not have received a diagnosis. Recorded diagnosis rates have therefore obviously increased steadily over the 12 months recording, resulting in a close to 90% rate.

KPI5 Antipsychotic medication review (KPI6)

Data is not available for this KPI as an adjustment has recently been agreed and the mechanism to record and monitor has only recently been set up. Going forward, if the BDWS instigates the use of antipsychotic medication, the service will carry out or trigger a review at 6 weekly intervals until it is stopped (unless it is not to do with a dementia). If a longer term prescription necessitates a 3-month review rather than a review at 6-weeks, then this will be agreed with the GP and recorded in a documented review plan.

KPI 6 Urgent request for advice responded to in 4 hours (KPI9)

Data against this KPI has been collected via manual spreadsheets which log calls received at the access point. In the last 12 months, the numbers of urgent calls have been very minimal and all calls have been responded to within 4 hours.

Key points about KPIs: The collection of KPI data has not been straight forward, due to the complexities involved in developing collection mechanisms whilst a service is being established, and the need to work with different data systems, both within and across Trusts. It has also been the case that the KPIs have been tested for utility, necessity and relevance as time has gone on, and the set of KPIs has therefore changed through the last 15 months. However, the service and commissioners have worked together to identify the key indicator set, and the system has been flexible enough to work with the evolving reporting process. Going forward, the Performance Management structure is in place to gather data more easily.

One area that needs to be further considered is the use of CRS and RiO. As is noted above, Alzheimer's Society use CRS to record their data on carers, whilst RiO does not report on carers. As such, Dementia Navigators are finding themselves having to enter data into two different systems. It would appear at this point that CRS is bearing the brunt of this, as a recent brief audit has revealed holes in the CRS data set. This has been recognised and moving forward, consideration should be made of how to reconcile these two data sets, either ensuring that Navigators recognise the importance of entering CRS data as well as RiO data, or finding a way of limiting data entry to one system.

3.4.1 GP confidence in practice

The GP survey asked GPs about their knowledge of and experience of interaction with BDWS, as well as self-ratings for confidence in practice in relation to working with people with dementia. It is important to note that the second round saw higher levels of respondents than the first round of survey. This could be considered as a result in itself, as people are generally more likely to complete a survey about a service they know and interact with. In both rounds, almost all respondents were aware of BDWS.

Table 2: Are you aware of the Bristol Dementia Wellbeing Service

Are you aware of the Bristol Dementia Wellbeing Service?				
	Round 1 (2015)		**Round 2 (2016)**	
Answer Options	Response Percent	Response Count	Response Percent	Response count
Yes	93.33%	14	100%	30
No	6.87%	1	0%	0
answered question		15	30	
skipped question		0	0	

Awareness of the service is therefore high amongst survey respondents, as is understanding of roles and how to contact the service.

Table 3: Do you know what BDWS does?

Do you know what we do?				
	Round 1 (2015)		**Round 2 (2016)**	
Answer Options	Response Percent	Response Count	Response Percent	Response count
Yes	80.0%	12	93.33%	28
No	13.33%	2	0%	0
Unsure	6.67%	1	6.67%	2
answered question		15		30
skipped question		0		0

Table 4: Do you know how to make contact?

Do you know how to contact or make a referral to us?				
	Round 1 (2015)		**Round 2 (2016)**	
Answer Options	Response Percent	Response Count	Response Percent	Response count
Yes	86.67%	13	100%	30
No	6.67%	1	0%	0
Unsure	6.67%	1	0%	0
	answered question	15		30
	skipped question	0		0

In terms of level of contact with the different elements of service, the most contact is reported as being with Dementia Practitioners, and the percentages reporting this remain very similar in the two rounds of survey. There are signs of a slight increase in trends with regards to contact with Dementia Navigators with no-one reporting they didn't know about them in the follow-up survey, and the vast majority reporting that they use them sometimes or often. Again, we need to consider that in the original survey, only 10 of the original 15 respondents answered this section, and that number reduced according to type of service. Most responded to questions around the Dementia Practitioner, slightly less (8) to the dementia navigator and only 4 to the access point and memory clinic questions. It is possible that people who did not know about the service in question failed to respond to questions about that service. In the follow-up survey, all 29 out of the original 30 responded, demonstrating a more positive understanding of the service.

Knowledge about access points remains quite high in the follow-up, with 41.38% reporting that they didn't know about it. 24.14% also reported that they did not know about the core memory clinic.

Responses to the questions about how helpful the service has been show that the Dementia Practitioners and Navigators have always been seen as "very helpful", but that the percentages thinking this has increased, especially with regards to Dementia Navigators (from 38% to 63%). Access points and memory clinics again have a majority saying that they have made no contact. Overall, the service is reporting as having positive impact on helping GPs to effectively manage people with dementia and their family and carers, and the vast majority would recommend the service.

The data on confidence in practice with regards to working with people with dementia shows very little change in self-reported confidence and knowledge. In terms of positive change, whilst in the original survey 1 person (7% of the sample) reported feeling no confidence at all in providing care for someone with dementia, no-one reports this in the follow-up. However, the two people who reported feeling "extremely confident" in the original survey are no longer represented in the follow-up survey. It is very difficult to identify any significant shift in confidence or knowledge from the two rounds of survey, and it is suggested that more work should be done to identify any impacts that interaction has had on the confidence and working knowledge of GPs, and what could be done to improve that knowledge and confidence.

4 Synthesis of findings

Having established the findings from the different types of data, the evaluation framework then allows us to synthesise this data, pulling together the strands across type of data to consider progress against the aims and objectives.

Aim1: To help people with dementia access the services they need

Objectives:

- We will offer a personal tailored plan throughout each individual's lifetime
- We will provide a single point of contact
- We will provide an urgent response
- We will provide a dementia navigator for everyone diagnosed with dementia
- We will enable people to build and access local support networks
- We will work with families and people using the service to plan ahead.

The key themes in these objectives relate to whether the service is suitably responsive to need and whether it is providing particular types of service mechanism (single point of contact, wellbeing plan, urgent response, DN). Overall, the evaluation data shows that people within the service are receiving access to a Dementia Navigator and subsequently a wellbeing plan that is shared with the GP. The single point of contact is in existence, through the access point, although this remains an area that GPs may be less sure about in terms of availability and use. Urgent response rates appear to be satisfactory. Evidence from the interviews shows open discussions around planning and need, and support to make those decisions. They also show that the Dementia Navigators are providing the information needed for people to access support networks if wished for or desired, although it might always be possible for this to happen. The Dementia Navigators themselves are also providing a very important support network.

Aim 2. To provide the right treatment and support options at the right time, so a person with dementia can stay at home for as long as possible

Objectives:

- We will offer a personal tailored plan throughout each individual's lifetime
- We will provide an urgent response
- We will provide a dementia navigator for everyone diagnosed with dementia
- We will support people with significant behavioural and psychological symptoms through more intensive care and support

- We will work with families and people using the service to plan ahead
- We will regularly update the plans in review meetings with our Dementia Navigators and Dementia Liaison Co-ordinators
- We will encourage carers to look after their own health and wellbeing and take breaks.

Again, as pointed out in relation to Aim 1, wellbeing plans are being completed and people within the service are receiving access to a Dementia Navigator. Urgent responses are also being dealt with through the Access Point. There is evidence that the plans are being updated with the people who use services, although we do not have data to evidence review meetings with Dementia Navigators and Liaison Co-ordinators. There is evidence from interviews that carers are being supported to look after people through crisis situations, although there is no data as such to evidence intensive care and support. This does not mean that it is not happening. Carers are being supported by their DN, and respite is an important issue to many, and central to people being able to continue caring. It is clear that DNs are doing their best to help provide advice and guidance on accessing respite, although it is difficult to find and access.

Aim 3: To enable people with dementia to remain active citizens

- We will engage and educate the community
- We will enable people to build and access local support networks
- We will raise awareness and tackle myths about dementia.

In terms of enabling people with dementia to remain active citizens, Dementia Navigators are clearly helping to facilitate support networks to enable people to remain active, as far as possible and as far as desired. It is of course extremely difficult to track whether the service is having an influence on reducing stigma, as any shift can have multiple layers of attribution. The interviews found that people recognise a change in attitudes towards dementia, with increased comment and coverage in the media leading to it being less “taboo” a subject. However, there remains the feeling from carers that there is a lack of understanding about what living with dementia and caring for someone with dementia really means, other than memory problems.

In addition, the Community Development Coordinators (one per locality) have engaged with the local community, providing education to local organisations and businesses, with the aim of making generic services dementia-friendly.

The service also has a Befriending Manager who receives referrals for befriending, recruits and trains volunteer befrienders and provides a match based on need. This might be someone who supports the person with dementia to continue cycling, or an artist who has encouraged a person with dementia to rekindle their interest in painting.

Aim 4: To provide high quality integrated person-centred care:

- We will provide a single point of contact
- We will offer a personal tailored plan throughout each individual's lifetime
- We will provide a dementia navigator for everyone diagnosed with dementia
- We will enable people to build and access local support networks
- We will help GPs become dementia-care experts
- We will work with local hospital trusts and neuro-psychiatric services to develop a fully integrated service.

As noted for aims 1 and 2, the service is providing a single point of contact, wellbeing plans and Dementia Navigators who are helping people access local support networks. There are some very small signs of an increase in knowledge and confidence amongst GPs in terms of working with people with dementia and their families. The interviewees appear to feel that the GPs are "not specialists", and whilst some may be helpful, they do not really know what support is available or what is needed.

Aim 5: To provide high quality advice and support for other providers, especially primary care on assessment and management interventions

- We will provide a single point of contact
- We will help GPs become dementia-care experts
- We will work with partner agencies to maximize support and reduce the potential for crisis
- We will work with partners to deliver optimal palliative care as recommended by the European Association for Palliative Care.

It is clear that BDWS is providing a single point of contact and is working with GPs to help them develop their skills in working with people with dementia. As noted above the current evidence base shows slight change in these skills, but this is a long-term impact which needs to be considered again in future evaluations. There is evidence of partnership working with other Mental Health services in Bristol, especially around crisis care, but the evaluation currently has no evidence around palliative care provision (which does not mean that it is not happening).

Aim 6: To promote support and inclusion for people with dementia and family/carers using the service

- We will work with the community to build a dementia-friendly city
- We will raise awareness and tackle myths about dementia.

As is noted in Aim 3, it is extremely difficult to track changes in awareness and stigma within a whole city, and even more difficult to attribute any change to one particular service. However, working with Alzheimer's Society as a partner, the service is not only a service provider but a campaigner. Awareness is being raised through the activities of the Alzheimer's Society, as well as the work that practitioners undertake through primary care services at community level and the important role of the Community Development Coordinators in each team in engaging the local community and working with minority communities who traditionally do not have equity of access to services

Aim 7. To support the development of the workforce and volunteers providing the service with the right attitudes and skill mix

Objectives:

- We will raise awareness and tackle myths about dementia
- We will recruit volunteers who can provide peer support both for individuals and their carers.

The BDWS is committed to employing people who show positive attitudes towards people with dementia and their carers and are prepared to work towards general awareness raising in the community. The interviews included evidence of the benefits felt by accessing peer support that is either provided by, or signposted to by the service.

5 Conclusions

Overall, there is clear evidence of satisfaction with the service from people using the service as well as people delivering the service. For people delivering the service, the set-up has been challenging, but many of the challenges have been overcome, working with a flexible atmosphere with a culture of **"doing things differently"**. For people using the service, the BDWS provides back-up, the important function of someone **"being there**" when needed to provide information and support and also facilitates access to networks of support and services. Key Performance Indicators show that the service is heading towards meeting, or is meeting, targets and the Friends and Family test reports high levels of satisfaction, although with low numbers of respondents over the year.

In terms of the evaluation itself, it is important to take into consideration that the data used is still reporting on very early days in the service, and needs to be further established so that the analysis can work with data from higher levels of respondents and with clarity on some of the KPIs. There has, however, been additional data collected that was not originally planned for, such as the process evaluation, which has proved extremely valuable to this first year evaluation.

The evaluation points towards some important areas that the service managers should consider in the next year:

- The growing gap in Social Care provision could prove a future difficulty and needs to be considered in terms of how the BDWS will either seek to fill those gaps, or work to find ways of collaborating to fill those gaps experienced by people seen by the service.
- The area of GP interaction requires further data to be able to really understand what is working, however, there are hints that this interaction is difficult and it would be good to understand why and what can be done to facilitate such relationships.
- Growth in GP knowledge and confidence is not clearly evident in the existing data, and again, this is an area that requires further data collection to be able to know more about if and how GPs are learning from the BDWS.
- There are some signs that there are ongoing complications around the roles and boundaries of the Dementia Navigators and Dementia Practitioners in terms of what is expected of them and what they feel they are required to do. Again, this links to the point around Social Care gaps, and the interaction with GPs.
- Data from carers is currently being partially collected through CRS, but the records are incomplete. The interviews provide useful data and will be repeated, however, a full data set on carer assessments and experience would be extremely useful to the evaluation.

As is noted above, there is a need for better input and information about the experiences of GPs as the survey provides little information, but anecdotally there is positive feedback and a clear shift in support from GP to Dementia Navigator from the interviews. This is a very important link so it is important to understand more about this interaction. In terms of social networking and quality of life, the questionnaires coupled with the interviews demonstrate how vulnerable this population is to social isolation and loneliness and how the service is starting to make inroads into supporting people to connect where possible, as well as providing an important link through the support of the Dementia Navigators.

5.1 Proposal for future evaluation

This first year evaluation points towards plans for the future evaluation. As noted above, particular issue points have been identified: GP involvement/interaction, how issues with social care are impacting on the work of DN/DPs, how the understanding of the role of the DN is spreading amongst stakeholders, and GP confidence in practice/learning from BDWS. Going forward, we will gather data to be able to monitor and evaluate what is happening in relation to these issue points. Some of this data (for example stigma and also GP confidence-building) need to be considered over a longer time-frame and should be built into the timeframe for a further 12 or 18-month evaluation.

The interviews provided an extremely useful source of data and the proposal would be to ask if interviewees from this round would consider being a panel of interviews to be re-interviewed on a 6-monthly basis. It would also be very useful to use this group for the questionnaire asking about quality of life and social isolation, to be able to compare over time.

The GP survey will continue as part of the CQUIN process, but as well as that, we also need to develop a mechanism for assessing the experience of GPs. A round of interviews with GPs would be extremely valuable at this point to answer some of the queries raised in this evaluation, and provide a basis for building on GP related data going forward.

And finally, a particularly important piece of work going forward needs to be around the impact of the service on acute hospital admissions of people with dementia. This is a complex piece of work, but one which can be put in place, now that the service and data collection is established.