

Guideposts Dementia Information Prescription Evaluation of its impact on care providers and service users



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The Report has been prepared for the purpose of developing an understanding of the effectiveness of the Dementia Information Prescription as a tool for health and social care staff working with people with dementia and people living with dementia and their carers. Deloitte LLP's judgement is based on an independent evaluation of the survey questionnaires which were distributed by, and returned to Guideposts, and then passed to Deloitte LLP for analysis and evaluation. The scope of the independent analysis has been limited by the number of survey responses and the information provided by the survey respondents. The completed questionnaires have been passed back to Guideposts.

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The scope of the independent analysis has been limited by the number of survey responses and the information provided by the survey respondents. The completed questionnaires have been passed back to Guideposts who retain ownership of them and are responsible for their security and any further use.

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Executive summary

Dementia is a progressive, terminal brain disease currently affecting an estimated 800,000 people in the UK, a number that is expected to reach one million by 2021. Caring for people with dementia has a considerable impact on public and private finances. While the NHS and social services across the UK spend around £15 billion on dementia services, two-thirds of people with dementia live in the community with an estimated 670,000 people acting as their primary carers, saving the State £8 billion per year. Dementia has suffered historically from poor awareness and understanding, combined with the stigma attached to both mental illness and old age, people fear dementia more than any other disease.

There is a growing consensus that early diagnosis combined with effective social, psychological and pharmacological support and intervention strategies are key to the successful management of dementia for both people living with dementia and their carers. In particular, there is a need to work constructively with primary care providers, especially general practitioners (GPs), to help them understand the availability and importance of effective post-diagnostic support for patients and carers. Indeed, with early intervention and access to the right services and support, people with dementia can continue to live well for many years.

Despite the increased publicity given to the need for early diagnosis, doctors still avoid diagnosing dementia because they feel that “nothing can be done” to help people who have been diagnosed. Indeed, diagnosis is not an end in itself, but a gateway to making informed personal life choices. It should also provide access to a full range of treatments, including medical and psycho-social interventions, and importantly, post-diagnosis support and services. However, despite explicit government policy that every person with dementia has the right to be diagnosed and offered relevant information and help, regardless of the severity of their condition, only 52 per cent of people have a formal diagnosis and many of these lack access to effective support.

Over the last few years, a number of approaches to post-diagnostic support have emerged, but to date there has been limited evaluation of their effectiveness. One approach, developed by the Guideposts Trust (Guideposts) in conjunction with carers, people with dementia and professionals who work with them, is the Guideposts Dementia Information Prescription (DIP). Launched in 2012, the DIP is the culmination of over eight years’ experience in providing support and advice to people with dementia and their carers. It is designed to be used by doctors and other health and social care professionals to provide local information on the support services available in their local area. It is also available directly to carers and people living with dementia and, importantly, is backed up by a local Helpline.

In recognition of the need for an evaluation of its effectiveness, Guideposts asked the Centre for Health Solutions (the Centre), an independent research hub of Deloitte LLP, to evaluate the DIP. In conjunction with Guideposts, the Centre developed a survey questionnaire to evaluate the usability, reusability and effectiveness of the DIP as a support tool. Conducted during January 2014, the survey was completed by 33 health and social care staff and 47 service users (people with dementia and their carers). One thousand people who had accessed and downloaded the Guidepost Trust’s Hints and Tips document were sent a separate survey to ascertain whether they would have found the DIP helpful. Some 115 people completed this second survey.

The Centre undertook an independent evaluation of the responses and identified overwhelmingly positive support for the DIP as an effective post-diagnostic support tool. In particular:

- eighty-seven per cent of the health and social care providers (including GPs) considered that the DIP is either very good or excellent as a post diagnostic tool for people living with dementia and that it helped them in providing support to people they were working with who had a diagnosis of dementia

- sixty-six per cent of the care providers felt better equipped as they consider the information is comprehensive and available in one place. Furthermore, it helps them to signpost patients to relevant support services (e.g. Age UK, Alzheimer's Society) and service providers (e.g. GPs, Dementia Advisor)
- the DIP is a user-friendly post-diagnostic tool with approximately 76 per cent of carers using it to find information on local healthcare support
- ninety-one per cent of people with dementia and their carers said they were likely or extremely likely to use the DIP again
- the information provided was seen as up-to-date relevant and the fact that the content reflects the local situation was identified as a real benefit by service users and care providers alike, with the majority of respondents planning to continue to use it
- a few users had some difficulties using the tool, stating that some of the local agencies that were signposted, were not particularly responsive. A few of the users also found the tool confusing because it was perceived as having too much content
- suggestions for improvement included the need for it to be more dementia friendly, especially to include more colour. Also, to advertise it in libraries and on council websites and to expand it to include information on local transport, mobility aid suppliers, social events and groups
- there were requests for more information on what to expect in terms of progression of the disease, where to get help as their situation deteriorates and also about living with dementia in care homes
- the majority of the 115 people who had accessed Hints and Tips felt that it would have been useful to have had the DIP available in GP surgeries but some people also suggested that they should be available in libraries, care homes, Citizen Advice Bureaux and pharmacies; indeed anywhere and everywhere people with dementia and their carers might access.

Overall, there was extremely strong and positive support for the DIP and its use as a post-diagnostic support tool from care providers and service users alike with suggestions for improvement that should be relatively easy to deliver. The overwhelming feeling from reading each response was the strength of demand for such information and how much it was needed and valued. Furthermore, that ease of access and the fact that the DIP is regularly updated and customised to each locality, is of paramount importance.

The political and provider consensus is that post-diagnostic support is critical to the effective management and care of people with dementia and their carers and therefore no longer up for debate. What now needs to be agreed is how to provide that support. This evaluation suggests that the DIP is an effective way of delivering the required support.

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Part 1. The importance of early diagnosis, information and support

The scale and extent of the challenge

Dementia covers a range of progressive, terminal brain conditions which affect an estimated 800,000 people in the UK (both diagnosed and undiagnosed) a figure that is set to rise rapidly over the coming years as the UK population ages. Dementia causes a decline in multiple areas of function including memory loss, reasoning, communication skills and the ability to carry out daily activities. Around twenty-one million people in the UK have a close friend or family member with dementia. People fear dementia more than any other disease with 39 per cent of over 55s fearing alzheimer's disease the most, compared to 25 per cent who worry most about cancer.

There are four major causes of dementia: alzheimer's disease (about 55 per cent), vascular dementia (about 20 per cent), dementia with lewy bodies (about 15 per cent), and frontotemporal dementia (about 5 per cent). Dementia is strongly associated with ageing, although genetically inheritable early onset dementia does occur in small number of people under the age of 65. The prevalence roughly doubles every five years over the age of 60. Evidence suggests that while early diagnosis is critically important, the UK does not perform well compared to other countries.

People with dementia require a complex mix of health and social care with patients regularly moving across organisational boundaries. The effectiveness of care depends on co-ordination and co-operation between the NHS, social services, care homes, the voluntary sector and carers. Stigma and negative attitudes towards mental illness and old age further exacerbate the problem. Estimates put the current costs of dementia to the UK at £23 billion including the costs of social care, healthcare and unpaid carers. However, much of the direct health and social care spend is in response to crisis, in the later stages of the disease.

A research study identified that of the top 25 causes of years of life lost in the UK due to premature mortality between 1990 and 2010, Alzheimer's disease and other dementias had risen from 24th place to 10th, accounting for 2.6 per cent of total years of life lost across the top 25 causes. Although dementia is currently incurable, medicines and other interventions can lessen symptoms and people may live with their dementia for a further 7-12 years after diagnosis. Contrary to common perceptions, there is a great deal that can be done to help people with dementia.

The National Dementia Strategy for England and Prime Minister's Dementia Challenge

In February 2009, the Department of Health (Department) published a five year national dementia strategy: *Living well with dementia: a national dementia strategy for England* (the Strategy). This set out the Government's intentions to improve care and support of people with dementia and was developed in response to critical findings in reports by the National Audit Office and the Alzheimer's Society which demonstrated the scale of the challenge of dementia and the inadequacy of the NHS and social care response to it.

The Strategy covered the five years from February 2009 to 2014 and comprised 17 objectives based around three broad themes of improving awareness and understanding, timely diagnosis and living well with dementia. Following the 2010 election, the Strategy was adopted by the incoming coalition government, who affirmed the need for its implementation and, in March 2012, the Prime Minister published his personal challenge for dementia, which outlined key areas relating to dementia aimed at giving impetus to the progress being made under the Strategy.

The Prime Minister's Challenge was presented as a national programme of action to deliver sustained improvements in health and care, create dementia friendly communities, and boost dementia research. In part these areas were informed by the objectives in the Strategy; however it also outlined other priorities for action. In launching the Dementia Challenge, the Prime Minister described dementia as "a national crisis". While the Prime Minister's Challenge has provided a welcome political focus on dementia, the national Strategy remained the current government policy until February 2014.

Progress in improving services for people with dementia

The Department's progress report, *Dementia – a state of the nation report on dementia care and support in England* (November 2013) provides the latest update on the quality of dementia care in England. It found that the very best services are excellent and shows what is possible, but the worst services show that we still have some way to go. The message however was clear – we can and must do better.

In terms of progress, identifying and assessing people with dementia in hospitals has improved, and the number of prescriptions of antipsychotic medication have reduced. However only half the people in England estimated to have dementia have received a formal diagnosis (52 per cent). The diagnosis rate varies from 39 per cent in the worst performing areas to 75 per cent in the best. There is wide variation across the country in how long people wait before being seen by a memory service. The availability of post-diagnosis support also varies significantly. Of those diagnosed with dementia, 47 per cent feel excluded from their community. They often experience anxiety and depression and three-quarters do not feel society is geared up to deal with dementia. Sixty-two per cent of people with dementia living alone are lonely, and the fact that it can sometimes be hard to access services, only adds to this isolation.

The need for timely diagnosis and post diagnosis support

Timely diagnosis of dementia really matters. It is key to helping people with dementia, their families and carers get the support they need (social and psychological, as well as pharmacological), to plan for the future and to make informed choices about how they would like to be cared for. Indeed, with early intervention, and access to the right services and support, people with dementia can continue to live well for many years.

Despite the increased publicity given to the need for early diagnosis, doctors still avoid diagnosing dementia in their patients because they feel that “nothing can be done” to help them. This is despite government policy which holds that every person with dementia has the right to be diagnosed and offered the relevant information and help, regardless of the severity of their condition.

GPs have a vital role to play, not only in providing a timely diagnosis of dementia but also in ensuring that well-planned and co-ordinated community services are in place to help the person once they have been diagnosed. The benefits of a timely, high quality diagnosis of dementia for the person, their families and carers are compelling. Diagnosis is not an end in itself, but provides an essential gateway to making informed life choices. For example, it should provide information and access to a full range of treatments, including medical and psycho-social interventions, and importantly, post-diagnosis support and services.

Once someone has received a diagnosis of dementia there is a range of different types of support they and their families will need. If the condition is already advanced, some will be in need of health and care support straight away, while others may not have reached that point yet. However, everyone will need support, advice and help to understand what it means to have dementia, what they can do to live as well as possible with the condition, and how to plan for the future.

Examples of post-diagnosis help and support include:

- information about available services and sources of support
- a dementia adviser to facilitate easy access to appropriate care and advice
- peer support, such as befriending services, to provide practical and emotional support, reduce isolation and promote self-care.

The availability of treatment, care and support varies significantly across the country. Indeed, various surveys have shown that many people feel nothing happened after a diagnosis. This shows more immediate support and information is needed.

“Information about the condition and what to expect all the way through – a roadmap of sorts – would have been helpful in making the right decisions about my husband’s care. Instead, I have muddled through and provided his care by instinct rather than informed help. [This] has caused a great deal of stress on me and inevitably on him.”

A person with dementia

“We needed a ‘what now’ pack of essential information.”

A carer

An implementation plan is being developed by Public Health England, NHS England, the Association of Directors of Adult Social Services (ADASS), the Local Government Association (LGA), NHS Improving Quality, NHS Choices and other partners to support areas to improve post-diagnosis support. This work aims to make clear ‘what good looks like’ in terms of post-diagnosis care and improve our understanding of the level of care currently available. It will also seek to understand the support local commissioners need, and enable clearer expectations for patients and carers.

There is currently no national measure of the provision of post-diagnosis support. To track progress, work is underway to develop an indicator as part of the NHS outcomes framework which will aim to measure the effectiveness of post-diagnosis support in helping people with dementia to live independently for longer and improve their quality of life.

Carers play a fundamental role in caring for people with dementia

When someone is diagnosed with dementia, it has a profound impact, not just on them, but also their family and others in their life. As a person's needs increase, family carers can become the most important source of support for them. In turn, it is vital that carers are also supported. There are around 670,000 people in England acting as the primary carers for people with dementia. Carers for people with dementia save the nation nearly £8 billion every year. Estimates suggest that one in three people will care for a person with dementia in their lifetime.

Given the nature of dementia and the effect it can have, such as changing a person's personality, carers can experience distress over many years of caring. They can care for over 10–15 years, with the person with dementia needing increasing amounts of physical and emotional support 24/7 from the carer, often with little outside help. Most family carers want to be able to support the person they are caring for at home, but they sometimes need more assistance in terms of information and advice on caring for someone with dementia while also looking after their own health.

In spring 2013, a survey of carers of people with dementia found that:

- over half (52 per cent) of the carers reported difficulties in obtaining a diagnosis of dementia for the person they cared for
- less than half said they had not been given information on legal issues and managing money
- many had learned about Lasting Power of Attorney too late
- many carers, particularly those caring for someone in the later stages of the illness, felt ill-equipped to deal with more agitated behaviours that might develop. More than two thirds (68 per cent) said they had not received training or advice on this issue

- eighty-two per cent of carers said that caring had adversely affected their ability to work.

The survey also asked carers if during the process of getting a diagnosis, they felt their concerns had fully been taken into account – only 21 per cent of respondents felt they had. Supporting carers is clearly equally important and needs to be part of the care and support package for people with dementia.

The Dementia Action Alliance launched a 'Carers Call to Action' on 20 November 2013 setting out goals to bring about real change for carers. It calls for a society where carers of people with dementia:

- have recognition of the unique experience of caring for someone with dementia
- are recognised as essential partners in care – valuing their knowledge and the support they provide to enable the person with dementia to live well
- have access to expertise in dementia care for personalised information, advice, support and co-ordination of care for the person with dementia
- have assessments and support to identify the on-going and changing needs to maintain their own health and wellbeing
- have confidence they are able to access good quality care, support and respite services that are flexible, culturally appropriate, timely and provided by skilled staff for both the carers and the person for whom they care.

This message has been acknowledged by the coalition government and underpins the work on the national dementia awareness campaigns that have taken place in recent years, and on the emphasis on early diagnosis contained in the Prime Minister's Challenge On Dementia.

A review of one approach to post-diagnostic support

The focus of this report is on post-diagnostic support and, in particular, support provided by a post-diagnostic support tool, the Dementia Information Prescription (DIP). The rest of this report details the methodology and results of the Deloitte Centre for Health Solution's review and evaluation of the Guidepost DIP.

Part 2. Evaluation of the Dementia Information Prescription

Over the past few years, while a number of approaches to post-diagnostic support have emerged, to date there has been limited evaluation of their effectiveness. One of these support tools, developed by Guideposts, is an online support service based around an information prescription. This was launched in 2012 following several years of experience in providing support to people with dementia and their carers. This part of the report explains the evolution of the Dementia Information Prescription and the results of the evaluation of its effectiveness.

The Guidepost Dementia Information Prescription

In 2005, Guideposts established a Dementia Information Service for Carers. This service operated regionally across the South East of England and provided a Helpline and information leaflets. An information website was piloted in Oxfordshire called Dementia Web, built in partnership with the Oxfordshire branch of the Alzheimer's Society. Its design and purpose was to enable carers and people with dementia to have easy access to accurate information on local services.

The success of this information service led to Guideposts establishing Dementia Web sites in eight local county areas in Bath and North-east Somerset, Gloucestershire, Oxfordshire, Warwickshire, Leicestershire, Essex, Bedfordshire and Kent. Local coordinators, embedded in each area, researched and populated the sites with local information.

In 2012, a simplified version of the county sites was produced, the DIP. The DIP provides information based on the most asked questions as identified by carers using the Guideposts Dementia Information Helpline. To date, 28 DIPs have been produced.

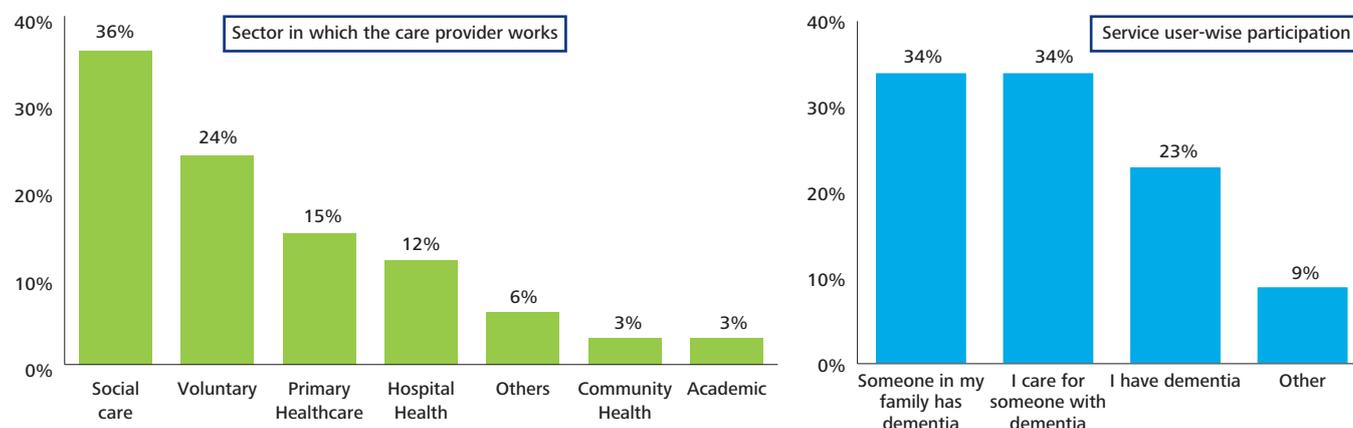
The Dementia Action Alliance post-diagnostic group has recognised the potential usefulness of the DIP, and together with Guideposts, approached the Deloitte Centre for Health Solutions to provide an independent assessment of the DIP. The Centre, which has strong research credentials in relation to dementia and was also engaged in a programme of research into better care for frail older people, agreed to help design the survey questionnaire(s) (Appendices A – C) and to provide an independent evaluation of the survey results. This part of the report presents the results of this evaluation.

Methodology

The Centre and Guideposts developed two survey questionnaires to obtain an understanding from people who have actually used the DIP. The aim was to discern how effective the DIP is in terms of its appropriateness, usability, reusability and acceptance. The surveys were provided to health, social care and voluntary sector care providers (Appendix A); and service users, predominantly people living with dementia and their carers (Appendix B). The survey was returned by 36 care providers and 47 service users. Figure 1 provides a breakdown of the survey participants.

Figure 1. Profile of the respondents to the survey

33 professionals, 47 service users participated in the survey of the usefulness and effectiveness of the DIP



- The greatest participation came from care providers working in social care (36%) followed by the voluntary sector (24%) and primary care, mainly GPs (15%).
- The majority of the service users who participated are carers (34%) and people with dementia in their family (34%) and dementia patients (23%) themselves (a number of people answered that they had someone in their family with dementia and were also carers).

Feedback from care providers

Care providers used the DIP mainly as a post-diagnostic tool (Figure 2) and consider that it improves their understanding and confidence in signposting people to other support services (for example, dementia advisors and dementia support groups such as the Alzheimer’s Society). Many mentioned that they always take a stock of copies with them when visiting patients as they are confident it will prove helpful.

Sixty-six per cent of care providers said that they felt better equipped as a result of having access to the DIP and 28 per cent said that they were partially better equipped (only six per cent of respondents said they didn’t feel any better equipped). Most commented on the fact that the information is very comprehensive, relevant, and up-to-date. A key issue for respondents was that it was available in one, easily accessible place.

“I was really impressed with the structured guide to support people in different parts of their life. I found it important when talking to service users that I could offer information and guidance on a variety of areas that may be important to them, both specific to their dementia and generally.”

A social work student

Over a third of respondents had used the DIP more than 10 times (Figure 3). The DIP was used mainly as a post-diagnostic tool either immediately after diagnosis or as an ongoing form of support (Figure 3).

Most care providers considered that the DIP was a either very good or excellent resource for people living with dementia and their carers (Figure 4). Furthermore, in providing them with relevant up-to-date information, it allowed them to be more responsive to service users’ needs.

“Service-users find it very useful to have a directory which is able to provide a very wide range of information in one user friendly document.”

A dementia support worker

“I have been using this tool as a template and through conversation with service users we have been able to choose the information and support that would provide the most help to patients. I could then cut and paste and offer them a less daunting document of information. I wondered about the colour and format of the document and whether it could be a more accessible, dementia friendly, format?”

A social care worker

Figure 2. Care providers timing of use of the DIP

Care providers used the DIP mainly as a post diagnostic tool and consider that it improves the understanding and confidence of the patient and carer and reduces the reliance on GPs

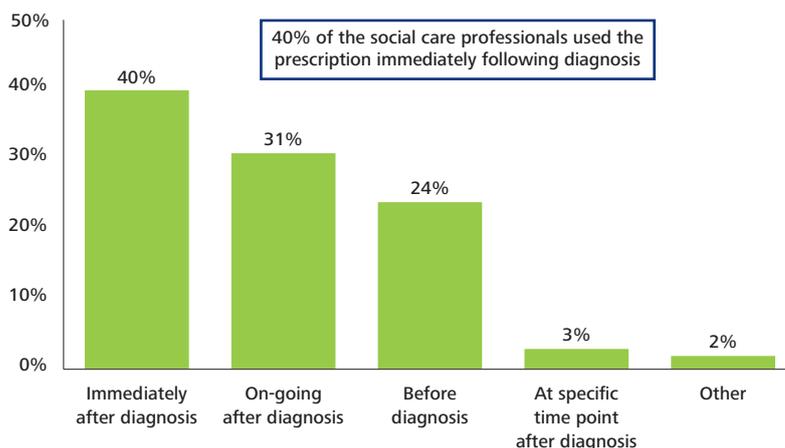


Figure 3. Frequency of use of DIP by care providers

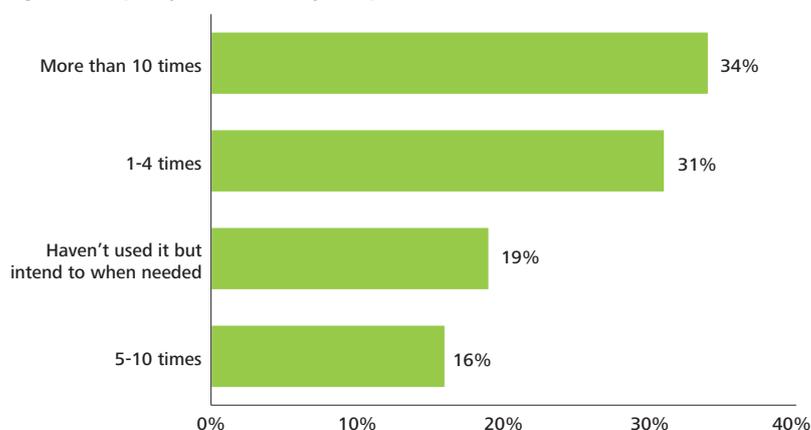


Figure 4. Care providers’ views on the effectiveness of the DIP in supporting people living with dementia and their carers

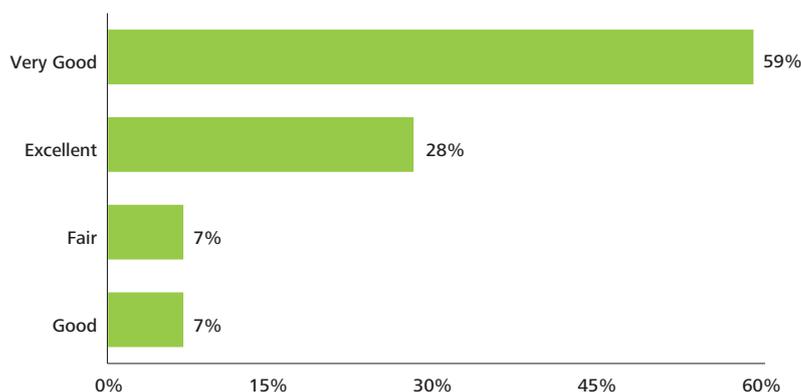


Figure 5. Service user's views on reusability of the DIP

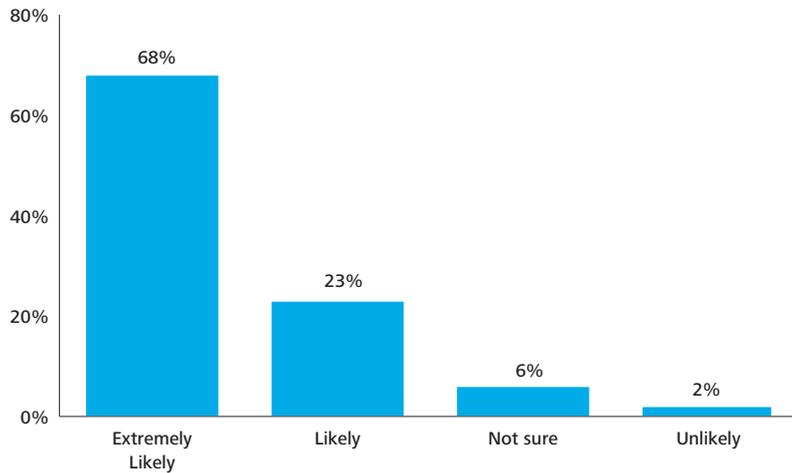


Figure 6. Feedback from service users on ease of use of the DIP

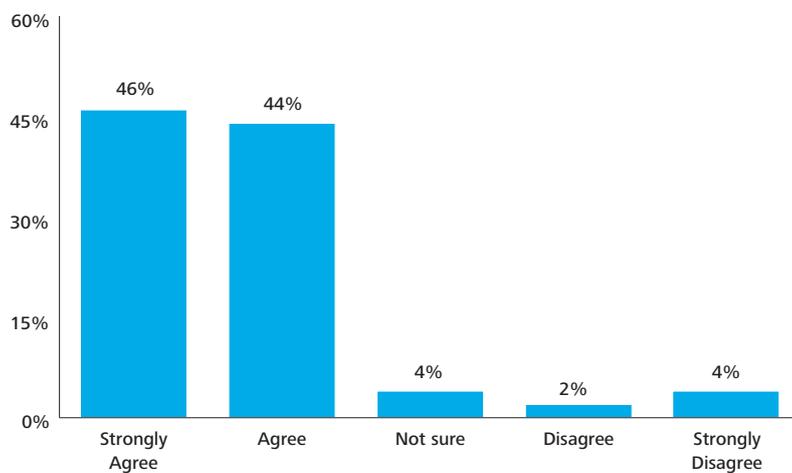
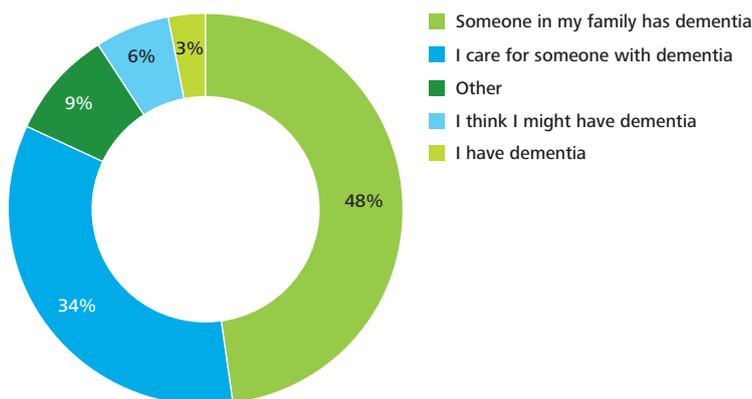


Figure 7. Characteristics of the people who had used Hints and Tips and who responded to the survey questions



"I think the format is excellent and especially that we can print it out in hospital" **A Hospital doctor.**

On reusability, the feedback was again very positive, with most care providers intending to always use it (66 per cent), use it most times (13 per cent) or intending to use it sometimes (22 per cent). These latter respondents indicated that this was dependent on their case load and how many of their patients had a dementia diagnosis. No-one responded that they would rarely or never use it.

Finally, on the question as to suggestions for improving the content or design, only a few respondents answered this question. Others simply reiterated their support and impression that it was an excellent tool. Of the half a dozen who suggested areas for improvement, these were to:

- include a section for social clubs/activities groups
- add a contents list and make headings clearer
- have more colour to make it a more dementia-friendly format
- make it even more person-centred
- make it available in libraries
- make it more easy to find on the council's website.

Two respondents suggested that this type of tool could be used for other conditions – for example for stroke survivors.

Feedback from service users

Service users comprised two distinct groups, people with dementia and the carers of people with dementia, all had been identified by the above group of health and social care providers who had given them the survey questionnaire to complete and return to Guideposts (47 completed surveys were returned). Understanding the views of people with dementia and carers was enhanced by sending a separate questionnaire to 1,000 people who had accessed the Guideposts Trust's Hints and Tips webpage (Appendix C). One hundred and fifteen survey responses were returned.

Seventy-four per cent of service users said they used the DIP to find help and local support and 24 per cent said that it had been partially helpful. On being asked if they intended to use it again, the majority of service users said they would (Figure 5).

"It lists organisations and contacts that otherwise you wouldn't know existed." **A carer**

"I think it is well put together, lots of useful information and telephone numbers." **Someone with dementia**

"So good to use and up-to-date, such a useful document." **A carer**

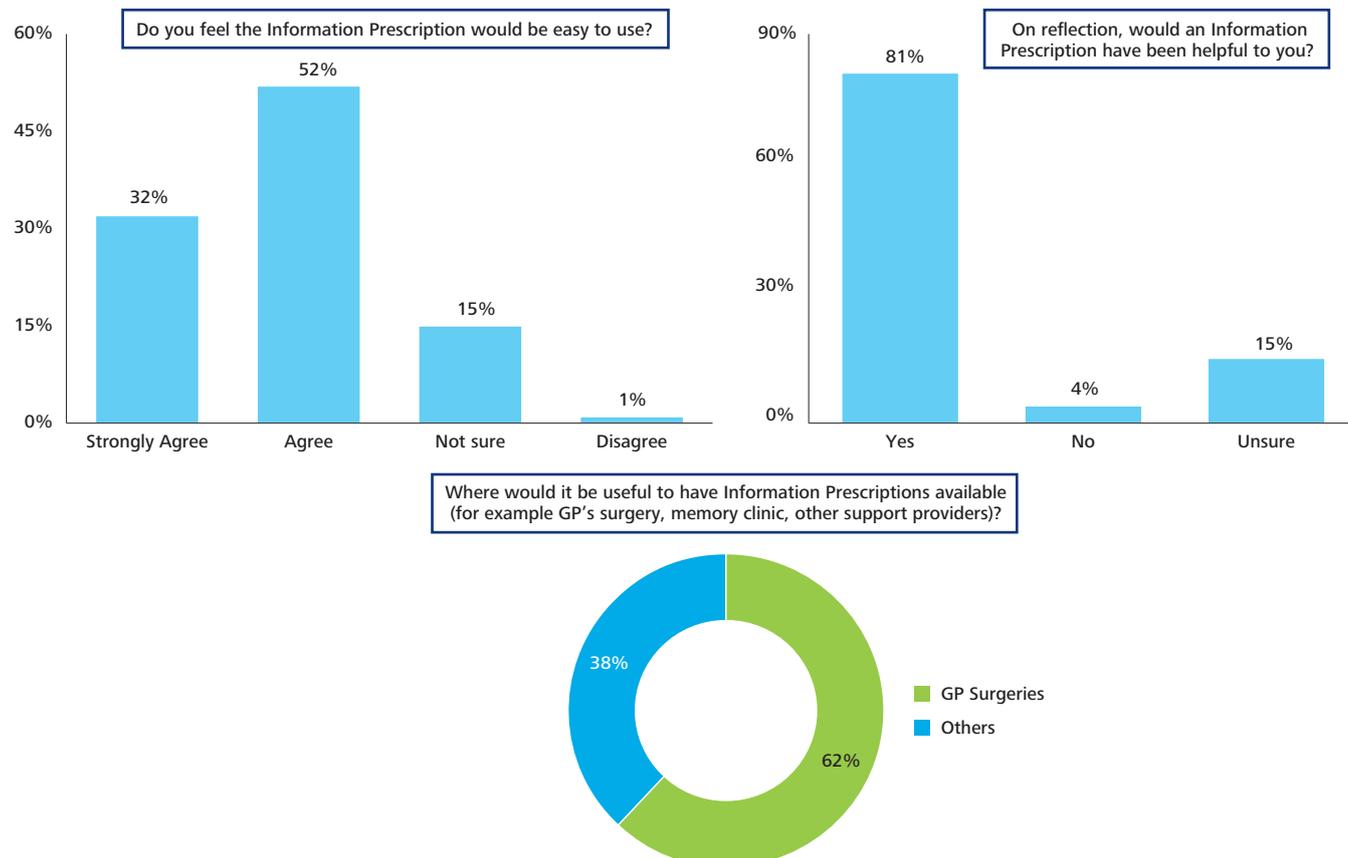
The majority of service users said that they agreed or strongly agreed that the DIP was easy to use (Figure 6).

"I am a committee member for Braintree Branch of Parkinson's UK. We discussed the DIP and all present agreed it would be a useful reference to have."

Over the last few years many people who accessed the Guideposts website have downloaded the Hints and Tips information sheet. In order to understand whether the DIP would have been useful to these people, Guideposts and the Centre designed a separate survey questionnaire (Appendix C). This was sent to 1,000 people, 115 of whom returned the questionnaire. The characteristics of the respondents are detailed in Figure 7.

Over 80 per cent of respondents who had used Guideposts Hints and Tips said that the DIP would have been very useful to them and that it would have been easy to use (Figure 8). Importantly, 62 per cent of respondents thought the DIP should be readily available in GP surgeries; others suggested that it should be available in a variety of settings where they might seek information and support. These included formal care settings like memory clinics and hospitals but also libraries, supermarkets, Citizen Advice Bureaux, Age UK branches, council websites etc.

Figure 8. Feedback on the DIP from people with dementia and their carers who have previously used Hints and Tips



Overall, the general tone of the feedback was extremely encouraging. Several respondents suggested that colour should be used to make it more dementia-friendly and indeed that it could be designed to resonate more with people with dementia. Figure 9 details a number of the more common suggestions.

Summary and conclusion on evaluation

The overwhelming view of care providers and service users is that the DIP is valued fulfills an important role. Most service users mentioned that the need for robust, reliable, up-to-date, post-diagnostic support and information was critically important to them and that the DIP met their needs in this respect. While there were some suggestions as to how it could be improved most found it easy to use and accessible. A key aspect of the DIP that care providers mentioned was that the information was up-to-date which gave them confidence in having the much needed conversations with people with dementia and their carers. Care providers also saw the DIP as an important tool to use with people who suspect they, or someone they care for, may have dementia.

Going forward it will be necessary to keep the information updated and to continue to monitor how it is being used and obtain feedback on its use. The survey responses provide a real sense of how people feel once they, or someone they care for, receives a dementia diagnosis. Indeed it was evident that many people, especially those who had used the Hints and Tips website, felt scared, vulnerable and lacking in the information and support needed to help them navigate the dementia journey. It was encouraging therefore to see that they felt that the DIP could have made a difference to them.

Figure 9. Feedback on use of the DIP and recommendations as to how it could be made even better



Appendix A: Survey for health and social care service providers

The Dementia Information Prescription is currently being evaluated and we would really value your feedback to improve the quality and content of the Information Prescription.

We would be grateful if you could answer the following questions and return by 24th January 2014

Thank you

1. Which sector are you employed by:

- Social care
- Primary healthcare
- Mental Health
- Community Health
- Hospital Health
- Voluntary
- Academic
- Other (Please state) _____

2. What best describes your professional role? (e.g. GP, Social Worker, Information advisor)

3. How often have you used the Dementia Information Prescriptions?

- 1-4 times
- 5-10 times
- More than 10 times
- Haven't used it but intend to when needed

4. Has the use of the Information Prescription benefitted you in your profession?

- Yes
- No
- Partially
- Please provide any comments on how/why

5. Do you feel better equipped to provide post-diagnostic support with the provision of an Information Prescription?

- Yes
- No
- Partially
- Please provide any comments on how/why

6. In your view how effective or otherwise, has the Information Prescription been for the user? Please score your answer:

1. Excellent
2. Very Good
3. Good
4. Fair
5. Poor

Please provide any comments on reasons for your response:

7. Currently and moving forward will you continue to use the Information prescription?

1. Always
2. Most Times
3. Sometimes
4. Rarely
5. Never

Please provide a brief reason for your answer:

8. Do you have any feedback/suggestions for improvements on the content or design of the Information Prescription?

Thank you for taking the time answering our questions

DATA PROTECTION ACT 1998: We will keep the information you give us on this form safe.

Your information is protected by law. This means that:

- We only use it for the purpose we give on the form
- We only share it with people who need to see it
- We only keep it for so long as we need to; and
- You have the right to see the information we hold on you.

Appendix B. Survey for health and social care service users

Feedback Form (Conducted through forms handed to patients/carers and through the survey monkey tool)

The Dementia Information Prescription is currently being evaluated and we would really value your feedback to improve the quality and content of the Information Prescription.

We would be grateful if you could answer the following questions and return by 24th January 2014

Thank you

1. Please tell us about you:

- a) I have dementia
- b) I think I might have dementia
- c) Someone in my family has dementia
- d) I care for someone with dementia
- e) Other _____

2. Was the information provided in the Information Prescription useful to you in helping you to find local support?

- a) Yes
- b) No
- c) Partially

Please provide any comments on how or why:

3. Have you contacted any of the local support/services listed in the Information Prescription as a result of receiving the Information Prescription?

- Yes
- No

4. Which best describes the local services that you contacted (please tick all that apply)?

- a) Statutory
- b) Voluntary
- c) NHS
- d) Legal/Financial help
- e) Dementia Advisor
- f) Peer led support group
- g) Other (please specify) _____

5. If you have contacted a local service, did it meet your requirements at the time?

- Yes
- No

Please provide examples

6. Do you think it is likely that you will use the Information Prescription again as your situation changes?

- Extremely likely
- Likely
- Not sure
- Unlikely
- Extremely unlikely

Please provide any comments on reasons for your response

7. Was the Information prescription relevant to your needs?

- Yes
- No
- Partially

Please provide any comments on reasons for your response

8. Do you feel that the Information Prescription is easy to use?

1. Strongly agree
2. Agree
3. Not sure
4. Disagree
5. Strongly disagree

Do you have any feedback/comments on how it could be improved?

Appendix C: Survey of health and social care service users who have received hints and tips

1. Please tell us about you:

- I have dementia
- I think I might have dementia
- Someone in my family has dementia
- I care for someone with dementia
- Other _____

2. On reflection would an Information Prescription have been helpful to you?

- Yes
- No
- Unsure

3. At which point do you feel the Information Prescription would have been most useful?

- Before diagnosis
- Immediately after diagnosis
- On-going after diagnosis
- At specific times point after diagnosis (please specify)
- Other (please specify) _____

4. Where would it be useful to have Information Prescriptions available (e.g. GP's surgery, memory clinic, other support providers)?

5. Do you feel the Information Prescription would be easy to use?

- Agree
- Strongly agree
- Not sure
- Disagree
- Strongly disagree

Do you have any feedback/comments on how it could be improved?

If you have found the Information Prescription useful and would like to have one produced for your local area please contact us and we will produce one for you.

Yes I would like to be contacted _____

Name _____

Address _____

Phone _____

Email _____

Contacts

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Sources of other relevant information

National Dementia Information Line: +44 (0) 845 120 4048

www.dementiaweboxfordshire.org.uk

www.dementiaweb.org.uk

www.guidepoststrust.org.uk

Guideposts Trust and Dementia Information prescription

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Designed and produced by The Creative Studio at Deloitte, London. 34559A