



Dementia and Digital

**Using technology to improve health and wellbeing
for people with dementia and their carers**

A Tinder Foundation Research Project

September 2016



Table of contents

- [Forewords](#)
 - [Helen Milner](#)
 - [Professor Dawn Brooker](#)
- [Executive Summary](#)
- [Key Findings](#)
 - [Barriers](#)
 - [Delivery](#)
 - [Health and wellbeing outcomes](#)
 - [Benefits of digital in a clinical setting](#)
 - [Recommendations](#)
- [Introduction](#)
 - [People with dementia and their carers](#)
 - [About Tinder Foundation](#)
 - [This project](#)
 - [Our approach](#)
- [Findings](#)
 - [Barriers](#)
 - [Health and wellbeing](#)
 - [Impact in a clinical environment](#)
 - [Dementia case study: Joyce](#)
 - [Devices](#)
 - [Internet use](#)
 - [Carer case study: Ken Brown](#)
 - [Engagement](#)
 - [Delivery of digital skills training](#)
 - [Health professional case study: Christine Roworth-Gaunt](#)
- [Recommendations and next steps](#)
- [Appendix 1 - Survey respondents, demographics and wellbeing scores](#)
 - [People with dementia](#)
 - [Carers of people with dementia](#)
- [Appendix 2: Acknowledgements](#)

Forewords

Helen Milner

Chief Executive, Tinder Foundation



Dementia, digital and doing things differently

At Tinder Foundation, we believe everyone should be able to benefit from digital - especially people who are most isolated and most excluded. That includes many of the 850,000 or so people in the UK with Dementia - and their carers.

Godfrey, 68, was knocked sideways by his Alzheimer's diagnosis. He describes the disease as like 'living life in slow motion'. He stopped socialising, and shut himself away. One day, one of our UK online centre research partners visited his care home, and were showing some YouTube videos of Frank Sinatra on a tablet. He went over to see what was happening.

Now Godfrey can Skype his son or daughter with just a touch of a button. He can look up his favourite musicians, and find new music. He's become a fan of Seasick Steve, and his Grandson in Australia thinks he's 'cool'. He's ordering his prescriptions online now, and he's found out more about Alzheimer's disease - so he feels more in control. He's also joined some specialist groups so he's getting out and about more.

In Godfrey's own words, *"You don't realise what you can do until you try it out, and it has really helped me stop feeling sorry for myself, snap out of my depression and start looking forward to things again."*

At Tinder Foundation, we believe digital skills really can help people with memory loss live better, more fulfilling lives. This small, in-depth research project follows on from our three year Widening Digital Participation programme (funded by NHS England), which has helped people to take charge of their health by improving their digital skills. Our aim has been to reduce health inequalities - recognising the significant crossover between those who are digitally excluded and those at risk of poor health.

We wanted to build on these findings to expand our specific understanding of the role of basic digital skills and community-based support in improving the health and wellbeing of families affected by dementia. This report measures the impact on both people like Godfrey who have dementia, and their carers. It also scopes out the challenges and barriers to engagement and delivery, and how we can make technology work well for these audiences.

Carers deserve as much of our time and support as the people they care for, and have equal prominence in this report. With so much on their plates already, they were often reluctant to

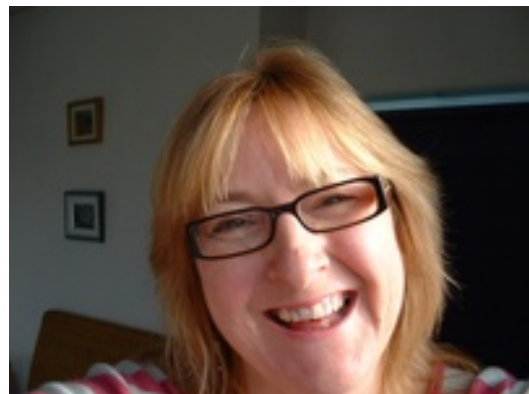
add basic internet skills to their growing lists. However, once engaged, they found digital technology to be a lifeline as a way of them creating space in their lives for themselves, accessing support, saving time on everyday tasks, and helping the people they care for find both coping strategies and memories.

Digital doesn't solve any problems all by itself. But it can help us do things differently, and in doing so make a difference to health, wellbeing and quality of life. We're looking forward to continuing to work with the NHS, with frontline health and care professionals, and with organisations that support people with memory loss and their carers, to ensure these benefits can be realised as widely as possible.

Professor Dawn Brooker

Director of the University of Worcester Association for Dementia Studies

The Association for Dementia Studies at the University of Worcester is committed to building evidence-based, practical ways of working with people living with dementia and their families, that enables them to live well. We believe that technology increasingly has a significant part to play in supporting health and wellbeing. For that reason we were delighted to contribute to the Tinder Foundation research to acquire a greater understanding of people with dementia and their carers - and the support they currently receive in terms of digital skills and the potential of technology to address any unmet needs.



There are currently around 850,000 people with dementia and around 670,000 informal carers of people with dementia in the UK. Dementia is an umbrella term for a variety of diseases and conditions which result in cognitive impairment. The most common form is Alzheimer's disease, which accounts for around two-thirds of diagnosed cases. Although memory loss is often a core feature of dementia, other symptoms may include subtle changes of mood, personality and perception, the inability to plan and carry out familiar tasks, and impaired reasoning and communication skills.

Technology has the potential to enhance many aspects of both the lives of people living with dementia and their carers, including supporting them to manage some of the difficulties they might be facing. Research shows that technology can help people manage their everyday lives, engage in social and leisure activities and promote independence. Carers can benefit from online support networks and access to information as well as improvement to their quality of life. Moreover carers have reported that using the internet can save time and money, aspects which are often put forward as barriers.

Prevalence of dementia is higher with increasing age and can be exacerbated by other physical health conditions. Some people with dementia may also have other conditions and disabilities such as a learning disability - particularly those with Down's syndrome who are at increased risk of developing dementia. There are over 100,000 people with dementia who also have a visual impairment.

Of the 12.6 million people in the UK who do not have basic digital skills a significant number are disadvantaged by disability, age and poor health and this is often related to low income levels and education. This means that some people living with dementia may be digitally excluded not just because they don't have the skills, but also because they cannot physically access the technology in the first place.

On-going assessment of changing need and support requires considerable expertise and knowledge not just of what technological solutions are available but how to best meet the needs of people living with dementia. The Tinder Foundation research has provided considerable insight into the challenges of using technology such as laptops, smartphones and tablets to getting on the internet as well as identifying strategies and solutions.

The NHS Widening Digital Participation programme also demonstrated that digital inclusion can help people improve their health and wellbeing. Developing and maintaining digital skills whilst being supported by an integrated and flexible person-centred health-care system is not only a powerful tool, I believe it is essential to help people to live well with dementia.

Executive Summary

Tinder Foundation is the UK's leading digital inclusion charity, with a vision of a world where everyone can benefit from digital technology. The organisation is committed to supporting people in some of the hardest-to-reach communities to improve their lives through promoting digital literacy. It does this by working with a 5,000-strong national network of hyperlocal UK online centres, which provide people with the support they need. Since 2010, Tinder Foundation has supported more than 1.9 million people to improve their digital skills.

As part of its broader aims, Tinder Foundation is committed to understanding the needs of people with dementia and their carers. This focused, short-term piece of research was carried out to track the social and digital barriers facing people with dementia and their carers, understand how the UK online centres network is already helping to overcome these barriers, and discover what more can be done at a local and national level.

The work was carried out between January and April 2016 and followed the emerging findings from the NHS Widening Digital Participation programme, led by Tinder Foundation between 2013 and 2016. The programme aimed to improve the digital skills and digital health literacy of groups most affected by health inequalities - including people with dementia and their carers.

To do this piece of research, we engaged with and provided small grants to five community partners from the UK online centres network that run activities for people with dementia and/or their carers. We asked them to run focus groups with the audience as well as promote an online survey through their networks. These partners were:

- Age UK South Tyneside, South Tyneside
- Canada Water Library, Southwark Council, London
- Denby Dale Centre, West Yorkshire
- Lincs Training, Lincolnshire
- OASIS Community Centre, Nottinghamshire.

In addition to these UK online centres, we partnered with the Association of Dementia Studies at University of Worcester and Crossroads Care Rotherham to tap into their expertise in working with people with dementia and their carers.

Through these research findings we will work with UK online centres and other partners to continue to advocate for the role digital can play in helping people with dementia and their carers live well with the condition, sharing best practice and resources across our network and beyond.

Key Findings

Barriers

1. Health and wellbeing indicators are lower amongst people with dementia and their carers.

Office for National Statistics (ONS) and SWEMWBS scores (a mental wellbeing scale) are lower amongst these groups than the national averages - indicating just how isolating and difficult dementia is for those experiencing it, and their carers.¹ Facing the challenge of change is often its own barrier.

2. Like many new users of the internet, online safety is of particular concern amongst people with dementia and the condition appears to compound these anxieties. This particularly relates to money, and the fear people have of forgetting or sharing personal details.

3. Access to technology and/or the internet at home does not translate into using it if support is not available. Home access to the internet alone is not enough to increase the beneficial use of the internet amongst people with dementia and their carers. Community support is essential - but support services must be tailored to the needs of people with dementia and their carers.

4. Working with carers and family members is the key to engaging with people with dementia and it's important to get the right message across. Carers and family members often feel that developing digital skills and investing in IT equipment will not benefit people with dementia, and it can be difficult to challenge those attitudes. However, by working directly and closely with carers and family members, UK online centres have been able to engage them and convince them of the benefits of digital for those they care for.

5. Age-related, physical barriers can also stop people using technology. It's essential to overcome any physical barriers with adaptive equipment to ensure technology can be used successfully by people with dementia.

"I struggle to get motivated to learn any new skills and I get very anxious about doing things like online shopping as I worry about ordering the wrong thing or too many of one thing."

¹ SWEMWBS: The Warwick-Edinburgh Mental wellbeing Scale was funded by the Scottish Executive National Programme for improving mental health and wellbeing, commissioned by NHS Health Scotland, developed by the University of Warwick and the University of Edinburgh, and is jointly owned by NHS Health Scotland, the University of Warwick and the University of Edinburgh.

Delivery

6. Tablets are the most effective devices on which to deliver digital skills and digital health training for people with dementia. The touch-screen interface seems to be more intuitive and immediate for people with memory problems than the more remote operation of a keyboard and mouse.

7. Personalising interfaces can help people with dementia recall key processes. Stripping back the home screen and using pictures of friends, family or familiar places past or present as visual prompts, can help people remember how to get to favourite programmes and apps.

“We try to simplify and personalise the way people with dementia access technology - removing any superfluous icons, tiles etc. and adapting the remaining ones so that there is a simple association between the icon and an activity.”

8. Using a “multi-sensory approach” to assist with engaging with learners with dementia has the greatest impact. The use of familiar smells and visual prompts from a learner’s past, including photos, has proven successful when introducing online activities and promoting the retention of information..

9. Digital equipment needs to be introduced ‘softly’. For people with dementia, some of the most popular online activities were games and puzzles, and these proved a great way to introduce digital technology, before going on to look at more complex activities like the use of digital health resources.

Health and wellbeing outcomes

10. Digital skills training has a profound impact on both individuals with dementia and their families. Family members could quickly see the benefits to be gained from digital reminiscence tools. Using technology to trigger memories and even record the results allowed them to capture moments of lucidity from the person with dementia - something many hadn’t seen for some time.

11. Access to online resources reduces isolation and increases wellbeing and personal confidence for people with dementia. The use of puzzles and games helps people with dementia feel they are keeping their brain active, and improves their sense of confidence and independence. The use of reminiscence tools, such as YouTube videos, engages individuals with hobbies, memories, people and places - improving their sense of wellbeing.

"It's brilliant just to see my grandchildren. I used to see them once a year, now I can see them almost every day and I feel part of the family again."

12. Technology and going online is a lifeline for carers of people with dementia. The internet is a place for carers to connect with others, helping them access key information and resources - about dementia and dementia care. Things like online forums and Skype also helped reduce isolation and provided much needed respite. Digital skills also helped carers with limited time achieve everyday chores like booking appointments, ordering shopping and filling in forms, and even helped them - often as older people themselves - to manage their own health conditions.

13. Attending sessions at a UK online centre has range of health benefits for people with dementia and their carers. Making social connections and getting out of the house were important side effects of the training, and benefitted both people with dementia and their carers. People with dementia reported feeling more mentally active and involved in their communities, while carers described feeling more relaxed, less stressed and much less isolated.

Benefits of digital in a clinical setting

14. Digital health training improves relationships with health professionals. Confidence has been shown to improve when learning about dementia online, with individuals stating that they feel that their GP understands them more, and they're better equipped to understand and participate in conversations about treatment.

"I feel that I can talk to my GP as an equal. I am able to get my point across and we are now managing things together. I feel that I have got some sort of control back and I'm not going to lose that again."

15. Digital technology can be successfully integrated into assessment of and care planning for people with dementia. Embedding the use of digital resources at the discharge stage from dementia wards can create a 'digital care plan' to support ongoing clinical care. This combination supports both patients and carers, and can help healthcare workers achieve better outcomes with and for the families they work with.

Recommendations

Our research has helped us to put together the following recommendations for how digital technology and local support can be developed to help people with dementia and their carers to realise a wide range of benefits.

Tinder Foundation will:

- Ensure that its online resources, including the ongoing redevelopment of Learn My Way and its courses, continue to implement and build on best practice accessibility requirements
- Support UK online centres to provide opportunities for dementia carers to learn on their own
- Develop both on and offline resources to support the UK online centres network in working with people with dementia and their carers
- Work with UK online centres to develop specific resources and courses for people with dementia and their carers to learn basic digital and digital health skills
- Promote and support the provision of outreach work by UK online centres to reach the most isolated.

Tinder Foundation advocates for change on a wide scale, gathering support from health services and support organisations in order to achieve this. Working in partnership with local and national government, Community Commissioning Groups (CCGs), health professionals and dementia-focused organisations, we want to:

- Promote best practice in terms of website accessibility for people with dementia, with a particular focus on the provision of health and support services online
- Build sustainable relationships with dementia and carer support organisations nationally to promote the UK online centres network and establish referral routes in both directions
- Foster a culture of information sharing and trust between health professionals, dementia and carer support organisations and UK online centres at a local and national level
- Support health professionals to become 'digital champion' volunteers to support people with dementia, and signpost them to support
- Continue to promote the [health pages of Learn My Way](#) to support relationships between patients with dementia and healthcare professionals.

Introduction

People with dementia and their carers

Dementia is a term used to describe a set of symptoms including memory loss and problems with judgement, understanding and thinking speed.² Dementia is common, with an estimated 850,000 people living with the condition in the UK in 2015.³ Furthermore, two thirds of people with dementia are supported at home by unpaid carers - a further 670,000 people - and the number of carers is predicted to increase dramatically over the coming years.⁴ People with dementia and their carers experience poorer health and wellbeing outcomes which leads to social exclusion, loneliness and isolation for a significant proportion of the UK's population.

40% of people with dementia have felt lonely recently, with less than half feeling part of their community and 72% living with another medical condition or disability as well as dementia.⁵ Crossroads Care Rotherham, a partner in this research project, advised us that a lack of insight into their illness often leads to a refusal of services by people with dementia as they cannot see that the carer needs support. This, coupled with a lack of understanding as to why they can no longer participate in certain activities, clubs, groups or work contributes to a loss of self esteem and self worth alongside feelings of isolation, as well as feeling ignored and invisible.

Carers of people with dementia are often older which means that there are additional health and wellbeing considerations for this group of people. One in five people aged 50–64 are carers in the UK. 65% of older carers (aged 60–94) have long-term health problems or a disability themselves, with 69% of older carers stating that being a carer has an adverse effect on their mental health and one third of older carers saying they have cancelled treatment or an operation for themselves because of their caring responsibilities.⁶ Crossroads Care Rotherham highlighted a number of other issues relating to carers of people with dementia, including isolation and a loss of lifestyle leading to feelings of resentment, oppression and depression. In addition, there is often a reluctance to accept help, particularly with male carers, and a lack of support groups which lead to a further deterioration of health and wellbeing.

An estimated 12.6 million adults (23%) in the UK lack basic digital skills, and 10.2% of adults (5.3 million) have never used the internet.^{7,8} Older people are disproportionately represented within these groups and, as dementia is most prevalent within older age groups, this means

² <http://www.nhs.uk/conditions/dementia-guide/pages/about-dementia.aspx>

³ <https://www.alzheimers.org.uk/dementia2014>

⁴ <https://carers.org/about-caring>

⁵ <https://www.alzheimers.org.uk/dementia2014>

⁶ <https://carers.org/about-caring>

⁷ Go ON UK (2015) "Basic Digital Skills, UK Report 2015"

⁸ ONS (2016) "Statistical Bulletin: Internet Users 2016",

<https://www.ons.gov.uk/businessindustryandtrade/itandinternetindustry/bulletins/internetusers/2016>

that people with dementia are more likely to be digitally excluded. Our own research shows that digital exclusion is a key issue amongst carers too.⁹ With information and services increasingly moving online, there is a challenge to ensure everyone can access what they need so that the digital divide doesn't deepen social exclusion for people with dementia and their carers.

"Those who suffer social exclusion are at least four times more likely to be digitally disengaged than those who are more socially advantaged."¹⁰

Digital exclusion is closely linked to other measures of social exclusion, meaning that statistically, digitally excluded people tend to be at greater risk of poor health.¹¹

People with dementia and their carers feature as groups cited in the National Information Board's report 'Personalised Health and Care 2020: A Framework for Action'.¹² The report describes how the Department of Health, NHS England and the HSCIC (in partnership with the voluntary and independent sectors) would support initiatives to develop and provide technology and data services which support new ways of delivering care services.

In 2014, the NHS published its Five Year Forward View. The report included the intention that *"the NHS will become a better partner with voluntary organisations and local communities"*, as part of a move towards enabling people to better manage their own health.¹³ Additionally, in December 2015, Baroness Lane Fox made a number of recommendations to the NHS National Information Board to increase take up of internet enabled services in health and care.¹⁴ This included a commitment to reaching the 'furthest first' – making sure those with the most severe health and social care needs, who are the least likely to be online, are the priority in new digital tools being used across the NHS.

9

http://www.tinderfoundation.org/sites/default/files/research-publications/unpaid_carers_report_final_sml.pdf

¹⁰ Price Waterhouse Coopers (2009) "Champion for Digital Inclusion, The Economic Case for Digital Inclusion"
http://parliamentandinternet.org.uk/wp-content/uploads/Final_report.pdf

¹¹

<https://www.statslife.org.uk/science-technology/2445-mind-the-gap-the-digital-divide-and-digital-inclusion>

¹²

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/384650/NIB_Report.pdf

¹³ NHS (2014) Five Year Forward View

<https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>

¹⁴ <https://www.gov.uk/government/news/martha-lane-fox-sets-out-her-digital-proposals-for-the-nhs>

About Tinder Foundation

Tinder Foundation is a leading digital inclusion charity, with a vision of a world where everyone benefits from digital technology. The organisation is committed to supporting people in some of the hardest-to-reach communities to improve their lives through promoting digital literacy and it underpins its work with research excellence. The organisation works with a 5,000-strong national network of hyperlocal UK online centres, which support people in disadvantaged communities. Since 2010, Tinder Foundation has supported over 1.8 million people to improve their digital skills.

The UK online centres network is a diverse collective of local and grassroots organisations which provide a range of support services – including digital skills – to their communities. The network includes '[specialist networks](#)' for centres that have a particular expertise in working with older people and carers. UK online centres all adapt their programmes and support to the needs of local people, for example through running outreach sessions at accessible locations within the community and tailoring learning to individuals' needs and motivations. Learners supported by the UK online centres network tend to be resistant to formal educational programmes and this informal approach helps to break down barriers to learning. In addition, in total the UK online centres network supports over 17,500 volunteers who help people in their communities to develop digital skills.

In total the UK online centres network supports over 17,500 volunteers who help people in their communities to develop digital skills

This project

This Tinder Foundation project was a focused, short-term piece of research carried out to gain a better understanding of barriers to social and digital inclusion facing people with dementia and their carers, including the role that digital can play, and the ways centres are currently supporting these people. The work was carried out between January and April 2016.

A number of findings emerged through the three-year Tinder Foundation [NHS Widening Digital Participation](#) programme around the challenges and successes of engaging with and delivering digital skills training to people with dementia and their carers, amongst others. The overall programme helped more than 220,000 people to improve their digital health

skills, recognising the huge crossover between those who are digitally excluded, and those at risk of poor health. The project aimed to provide people with digital skills to allow them to take charge of their own health. We wanted to build on these findings to expand our understanding of the role of digital skills and community-based support in improving the health and wellbeing of people with dementia and their carers.

In particular, the aim of this research was to:

- Give us more detailed information about the makeup of this audience currently receiving support in UK online centres and other national networks
- Deepen our understanding of the effects of dementia - both early and later stage - on the health and wellbeing of patients and those who care for them
- Identify any unmet needs of dementia patients and carers relating to skills training, information and guidance
- Inform us of what UK online centres and specialist centres are currently doing (in-house or with partners) to support the needs of this audience and allow us to understand their current capacity to do so
- Inform us of the role of potential partners locally and nationally in support of this audience
- Identify challenges facing centres and partners currently working with this audience, and what can be done to overcome these
- Identify scalable grassroots innovation in working with this audience
- Support Tinder Foundation to build its expertise and partnerships which will help us provide better support to people with dementia and their carers.

Our approach

We engaged with and provided small grants to five community partners from the UK online centre network that run activities for people with dementia and/or their carers. We asked them to organise focus groups with the audience as well as promote an online survey through their relevant networks. These partners were:

- Age UK South Tyneside, South Tyneside
- Canada Water Library, Southwark Council, London
- Denby Dale Centre, West Yorkshire
- Lincs Training, Lincolnshire
- OASIS Community Centre, Nottinghamshire

In addition to these UK online centres, we partnered with the Association of Dementia Studies at the University of Worcester, and Crossroads Care in Rotherham. Through their expertise, they provided: support in refining the methodology and data collection methods in an advisory capacity; specialist insight from their experiences of working with people with dementia and their carers; and support to distribute an online survey within their national networks and support in encouraging people to complete it.

Data collection methods for this research included:

- Semi-structured interviews with partners;
- Focus groups with people with dementia and their carers;
- Online surveys for people with dementia and their carers including the ONS Wellbeing Scale and, where appropriate, the 7-point Warwick-Edinburgh Mental Wellbeing Scale (SWEMWBS);¹⁵
- A summary of the relevant findings from the NHS Widening Digital Participation programme.

¹⁵ The Warwick-Edinburgh Mental wellbeing Scale was funded by the Scottish Executive National Programme for improving mental health and wellbeing, commissioned by NHS Health Scotland, developed by the University of Warwick and the University of Edinburgh, and is jointly owned by NHS Health Scotland, the University of Warwick and the University of Edinburgh.

Findings

Barriers

There are a number of age-related, physical barriers that need to be overcome when supporting people with dementia and their carers to use digital technology.

- 58% of survey respondents with dementia reported some kind of physical difficulty that would affect their use of technology, including finding it difficult to hold a device, type or interact with a screen
- 42% also reported some kind of hearing difficulty that would affect their use of technology and 25% highlighted visual difficulties that would affect their use of technology.

These difficulties were much less pronounced amongst the carers we surveyed, but still prevalent. The reported use of assistive technology to overcome these barriers amongst study participants is lower than those that report the barriers which suggests that awareness of the available tools is low.

Many people with dementia have a lack of interest in and motivation to learn about the internet and digital technology. This often stems from a lack of confidence, including a fear of doing things wrong, as well as a sense that they have no need to use digital technology. People with dementia involved with this study told us:

"I am not interested in using digital technology at all. I don't like computers. They scare me."

"I have basic skills but think it may be helpful to learn more things. But I struggle to get motivated to learn any new skills and I get very anxious about doing things like online shopping as I worry about ordering the wrong thing or too many of one thing."

"I have got this far without needing computers so I don't think I would ever try. I am happy without them."

There is a sense amongst some carers and support organisations that there is no point in addressing digital exclusion for people with dementia due to their inability to retain new information.

"A lot of people I work with with dementia have no interest in learning computers or in how technology at all. Many can't even use their mobile phones anymore. They simply cannot remember how to use them."

Carer, OASIS Community Centre

"If people do not already have skills in technology they appear to be either uninterested or not prepared to attempt new things or new challenges once they have a diagnosis of dementia. In fact many really do not seem to be able to learn these skills past this point (from our experiences). Many seem to have problems even using a mobile phone let alone a computer or tablet sadly. Once people have got the onset of dementia it is almost totally unlikely that they will even try to gain new skills and will probably not be able to retain the necessary knowledge or understanding to progress to doing things which would be of value to them sadly."

OASIS Community Centre

Although this feeling is borne from direct experience, there is a counterargument from many UK online centres that have successfully engaged people with dementia around digital skills, even those at the advanced stages of dementia. The benefit of this engagement is often improved wellbeing outcomes through attending sessions, rather than improved digital skills outcomes alone.

"Use of technology and related activity has had a positive impact even on the people with advanced dementia. Even though there is an acceptance with themselves and their friends, families, carers and support networks that knowledge and any learning is unlikely to be retained, as long as the sessions are fun and interesting the fact that they had a good time does appear to stick and the vast majority want to take part the next time a session is on."

Age UK South Tyneside

As with many new users of the internet, online safety is of concern amongst people with dementia and the condition seems to compound these anxieties. This predominantly relates to worries about money, scams and keeping card details safe. Due to the isolation encountered by people with dementia, there is a lack of considered advice and guidance and people have been particularly affected by media coverage around the subject. 71% of those surveyed reported that they did not know enough about staying safe online and this means that there is a lack of confidence to develop their digital skills. Study participants with dementia told us:

"I hear news reports about people losing money or scams and I am worried to answer questions on screen."

"I have heard about people being robbed by computer and not knowing until much later. I keep reading about viruses. I was warned in the bank about online banking with other banks so I am worried."

Carers are time poor and do not have the opportunities for dedicated sessions to allow them an opportunity to learn on their own. Carers do not have the free time to attend sessions and learn basic digital skills and, even when they do, caring responsibilities prevent effective learning. During digital skills training sessions, the responsibility of looking after the person with dementia often hampers the learning journey of the carer. A UK online centre told us:

“Carers often need to help the person they are caring for with accessing the technology and this can be time consuming and frustrating as a person loses the ability to do so much for themselves or loses the confidence to do so.”

Health and wellbeing

Measures of health and wellbeing were lower amongst the study participants with dementia and their carers. This echoes the background evidence from Alzheimer’s Society cited in the introduction.

- Of those people with dementia surveyed: 47% self-reported their health as ‘Good’; 26% as ‘OK’; and 26% as ‘Poor’.
- For carers, 68% self-reported that their overall health was good, leaving a significant proportion that did not perceive this to be the case.

In addition, average scores from the ONS wellbeing scale of those surveyed showed that people with dementia and their carers were less satisfied, less happy, feeling less worthwhile and more anxious than national averages.^{16, 17, 18} For those carers surveyed, the average SWEMWBS metric score was 21.18, below the population average of 23.61 obtained through the Health Survey for England (2011) and in the bottom 20-40% of responses.^{19, 20}

Digital health training has a positive impact on both individuals with dementia and their families. Family members see the benefits to be gained from digital reminiscence tools and the resources have been used to capture moments of lucidity from the person with dementia that the family may not necessarily have seen. A project participant with dementia told us:

“Now instead of asking my daughter to book me a doctor’s appointment, I have learnt how to book one online. I have a little book I keep notes in to remind me how to do things and what buttons to click on.”

Attending sessions at UK online centres has a range of health and wellbeing benefits for carers of people with dementia. Carers and healthcare workers reported that they felt better physically since the sessions started and all felt an overall increase in wellbeing, due to more

¹⁶

<http://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/bulletins/measuringnationalwellbeing/2015to2016>

¹⁷ Actual wellbeing scores for those surveyed can be found in Appendix A.

¹⁸ The 7-point SWEMWBS scales was not used for people with dementia as, on the advice of the Association for Dementia Studies, the questions used can be difficult for some people with dementia to answer.

¹⁹

http://www2.warwick.ac.uk/fac/med/research/platform/wemwbs/researchers/interpretations/wemwbs_population_norms_in_health_survey_for_england_data_2011.pdf

²⁰ NEF Consulting’s SWEMWBS Wellbeing Data Comparator Tool:

<http://www.nefconsulting.com/wp-content/uploads/2014/08/SWEMWBS-wellbeing-data-comparator-to-ol.xls>

physical exercise getting to and from the centre, being more mentally active and becoming involved in community activities that lead to socialising with other carers. Carers also described feeling more relaxed, less stressed and much less isolated. One carer told us:

“Being better informed leads to a better quality of life – even if it just provides peace of mind.”

Being able to access health resources online enables carers with limited time to manage their own existing conditions more effectively. Through better management of health conditions, wider improvements in wellbeing outcomes occur. A carer told us:

“Since becoming a diabetic I am more aware of sugar and have learned to look for what is in food by reading the label. The diabetes site shows you what to look for and gives recipes. Also YouTube have examples of recipes. BBC website is also good for recipes. Exercise routines are shown on the site as well. I feel better for doing little stretches every day and I am walking with my wife [who has dementia] now to keep her fit as well.”

Staying in touch with friends and family using the internet reduces isolation of carers and supports their role as carers. 76% of those surveyed use the internet for social media, while email and Skype were also frequently used. Carers told us:

“Using Skype to talk face to face with others is great and it lets me pass the tablet so others can speak to my mother who has dementia and they can see how she is doing.”

“I obviously find my laptop and iPhone are my lifelines as I can hardly go out at all. I need them for communication with friends and family as well as for ordering things I need. I don’t have transport either so lots of things are very difficult for me.”

Impact in a clinical environment

Digital health training for people with dementia improves relationships with health professionals. Confidence has been shown to improve when learning about dementia online, with learners stating that they feel that their GP understands them more as a result of being able to have more equal conversations. A dementia patient told us:

“Before I didn’t mention [to my GP] all [the] things that were happening because I thought it was just silly. Having read on the Dementia UK [website] about symptoms, I have confidence to discuss with doctors and nurses without being silly.”

And Martin Simpson, Centre Manager from Age UK South Tyneside, provided further insight from their focus group activities with people that had been learning digital skills:

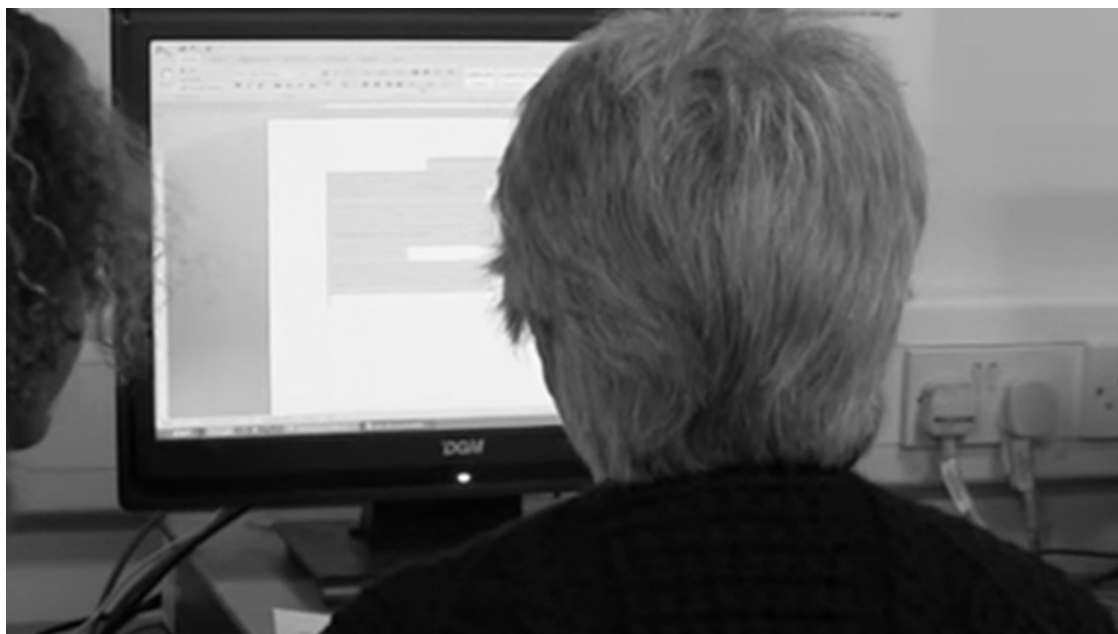
“Everyone [at the focus groups] felt more informed about their condition(s) and felt better able to know when something felt wrong so they needed to ask for help. Out of

the 22 people across the two focus groups 18 felt they were better able to talk to health professionals about specific symptoms or medium to long-term expectations with more confidence. 15 of these now feel that they get a lot more respect, particularly from their GP, because they are more informed. This is actually more prominent with the people with dementia themselves."

Digital technology can be successfully integrated into assessment of and care planning for people with dementia. mHabitat, as part of the NHS Widening Digital Participation programme, has embedded the use of digital resources at the discharge stage from dementia wards so that a bespoke digital care plan can be carried forward for patients.

Dementia case study: Joyce

Joyce is a 69 year-old retired nurse who lives alone. Her husband died recently and her family are scattered all over the world. She has a few friends but most of them have moved into sheltered accommodation so she doesn't see them now as much as she used to. She was diagnosed with Dementia 14 months before a local UK online centre, Age UK South Tyneside, began working with her.



Joyce has always been very social and now feels very much alone. She tries to keep in touch with people, particularly family, as much as possible but struggles with the differing time zones and quality of the calls when phoning abroad and is also concerned about the cost of the calls. She has a pension but is just above the threshold to obtain extra benefits so has found it difficult to make her money stretch from month to month. Although her job as a nurse gave her an understanding of Alzheimer's, since her diagnosis she has had very limited information and support, and was scared that she might deteriorate with little or no ability to maintain her quality of life, becoming more isolated and cut off from other people.

Age UK were running a pop-up event in a local GP surgery, focusing on working with people with dementia. Joyce was in the waiting area and was interested in how Age UK might be able to help her. Age UK demonstrated using tablets to access health information, booking GP appointments and ordering prescriptions followed by a quick Skype demonstration to communicate with another session they were running in another surgery. Joyce was able to have a go herself and realised just how easy it was to use and the potential of using digital to improve things for herself. Age UK arranged to come and teach her how to use a tablet in her own home, initially using one of their own devices. Because Joyce was worried about her memory and being able to use the

device independently, Age UK 'skinned' the device - replacing the main screen with a much simplified version with limited options, personalized to Joyce, so that she could easily associate tiles with what she wanted to do.

Using the tablet, Joyce was quickly able to search for local groups that could help her. Even though she had been given contact numbers, she wasn't fully aware of the support available to her. She contacted the local branch of the Alzheimer's Society, and has since become a regular at their dementia-friendly café. She also signed up to their "Singing for the Brain" group, as well as physical activity groups such as dancing and bowling. She's also joined one of Age UK's walking groups both for exercise and for the social aspect. Age UK helped her set up accounts for email, Skype and Facebook, all of which she now uses regularly. She got in touch with a local group of women and they now have a weekly online game of Scrabble. She's also now got a routine to email and Skype her family and says that she can now "watch my grandchildren grow up".

"It's brilliant just to see my grandchildren. I used to see them once a year, now I can see them almost every day and I feel part of the family again."

Joyce has also registered for e-booking with her GP, allowing her to easily book appointments and order repeat prescriptions online. She says the quality of her GP appointments has also improved, as she's able to use the internet to find out about her condition and how to control symptoms, and feels she can discuss her health in more depth and from a much more informed position. She feels much more positive and, because she is keeping active, she feels more in control of her condition and is more aware of what help is available as her condition deteriorates.

Joyce told us: "I feel that I can talk to my GP as an equal. I am able to get my point across and we are now managing things together. I feel that I have got some sort of control back and I'm not going to lose that again. Before I was worried that I would just get worse, end up in a home and then I wouldn't be me any more. I have found so many positive people and now I am determined to make the best of things."

Devices

The use of digital technology is low amongst people with dementia and there are particular challenges with using devices. For example, remembering what different icons or keys mean, the misplacement and forgetting of usernames and passwords, and getting used to screen layouts on different devices have all been highlighted as issues. The majority of study participants with dementia stated that they did not use any type of device. Four survey respondents with dementia used assistive technology to help them use digital devices, with three people using it to see the device display better and one person to assist with holding the device and typing.

Table 1: Use of devices by the people with dementia surveyed as part of this project and for how long they've been using them

Device type	I do not use it	Less than 1 year	1 - 5 years	5+ years
Computer - desktop	75%	6%	6%	13%
Computer - laptop	53%	24%	12%	12%
Computer - tablet	58%	37%	5%	0%
Smartphone	75%	25%	0%	0%

Table 2: Use of devices by the carers of people with dementia surveyed as part of this project and for how long they've been using them

Device type	I do not use it	Less than 1 year	1 - 5 years	5+ years
Computer - desktop	30%	0%	10%	60%
Computer - laptop	8%	12%	27%	54%
Computer - tablet	8%	23%	50%	19%
Smartphone	13%	23%	37%	27%

Internet use

Carers use digital technology and the internet more than people with dementia based on the study participants, and community venues are important to both groups for supported access.

- All of the dementia carers surveyed said they use some form of technology at home (78% for people with dementia), with half also using it at a local community venue (28% for people with dementia).
- 50% of carers and 47% of people with dementia surveyed accessed the internet at a local community venue. A further 14% of carers and 13% of people with dementia accessed the internet at a local library.

- Only 39% of carers thought that it would be useful if someone could come to their home to help them access the internet, but this figure was much higher (94%) for people with dementia.

This is symptomatic of the fact that there is less support for people with dementia to learn basic digital skills as they may not be able to retain the information, but it also related to the way carers often use digital technology, particularly at home, as respite from their caring responsibilities. There has been anecdotal evidence from this study that carers may not wish to share this activity with the person for which they care as they see it as a personal escape for them, separate from their caring role.

The internet provides access to information on dementia and support networks for carers, but people with dementia are less likely to focus on their condition.

- 66% of carers surveyed use the internet to find out information on dementia (56% for people with dementia) and 52% to access support networks.

Websites such as NHS Choices, WebMD and Alzheimer's Society have been highlighted as particularly useful for advice on how to support family members living with dementia, anxiety and depression. People with dementia, on the other hand, have reported that the use of digital technology provides an escape from thinking about their condition and an opportunity for living in the 'here and now' rather than focusing on what's going to happen to them. A study participant with dementia told us:

"I want to concentrate on today, not on my illness and how it affects my life. Since I started to learn how to use a tablet, I feel as though now I can sit for an hour and forget about anything other than the games I am playing or the videos I am watching."

"Using dementia as the hook never works."

Martin Simpson, Age UK South Tyneside

The most common use of the internet amongst study participants with dementia was centred around games, puzzles and contact with others, but there is a desire to learn more practical uses to increase personal independence.

- 56% of study participants that had used the internet reported that they did so to play games with 39% using social media.
- A third of respondents had never used the internet.

Online shopping and banking (or the general managing of money) featured heavily as things that people would like to do next with the internet, alongside access to health and council services, online support forums and researching family history. Route planning tools, including Street View, were also reported as useful resources for people with dementia and

their carers so that they could plan visits to unfamiliar locations or settings. Study participants with dementia also told us:

"I would like to be able to research about my condition and keep in touch with friends and family."

"I have seen people looking at their family history and would like to try it myself. I would like to make more friends online so I have started to try Facebook."

Home access to the internet allowed carers to complete many tasks that they would otherwise struggle to do. 96% of carers surveyed stated that they used the internet at home, with 62% using online banking and many stating that they make GP appointments online would like to do online shopping in future. Carers told us:

"As a carer I feel personally that technology like computers, iPads and the internet are great as you can find places for help, support and if you're struggling to be able to get out with the person you are caring for you can do online shopping, book appointments etc."

"[The internet is] my lifeline! Communication is easier and cheaper. Completing an OU

Carer case study: Ken Brown

Ken and Val Brown from Hull are in their late sixties and have been married for 47 years. In November 2014, Val was diagnosed with vascular dementia. Soon after, her appetite deteriorated and Ken became concerned. With support from local UK online centre, Inspire Communities, they've been able to get online, learn about the condition and find ways to adapt.



Before Val's diagnosis, she started to experience some of the symptoms associated with dementia, but at the time they weren't recognisable. Ken says: "There were problems possibly a year before Val was diagnosed. I think she had an idea that things weren't right but kept it hidden. It's possible that she didn't have any idea what was going on; some days it was good and some days it was bad."

Prior to Val's diagnosis she had a healthy appetite, and she and Ken shared the cooking in their house. But since her diagnosis Val was eating less, or rejecting meals altogether. Ken felt concerned that this was another symptom of dementia, or even something else more serious.

Ken and Val had been attending their local Memory Cafe at the Alzheimer's Society in Hull City Centre where they met Dave Edeson from Inspire Communities, a charity and registered UK online centre that runs a wide range of projects for local people, including the provision of advice on nutrition and healthy living. Dave asked Ken what types of food he was preparing for Val and asked him to complete a food diary over the course of a week. Dave discussed possible causes of Val's loss of appetite with Ken and together they researched different health conditions on NHS Choices.

Dave explained to us: “When you have dementia, your timeline gradually disappears; starting with the most recent memories, and eventually you can lose your recognition of people and events to the point where you feel you are back at the age of your childhood. We wondered whether there is any possibility that, as well as your memories reverting back to earlier days, other things also do – such as your taste in food. As adults we often change our tastes in food compared to what we liked as a child.

“We explored whether there is a health condition relating to loss of sense of taste or smell. Typing the words ‘loss of sense of taste’ into the NHS Choices search box brought up a number of options. Ken is pretty good with computers and knows how to use the internet, so he took away the links to these conditions and studied them himself.”

Ken says: “The links were full of advice and were very helpful. Val also has diabetes so I was able to look up information about that and about foods that she can and cannot eat.”

“NHS Choices did help to ease my mind. If it said that Val’s loss of taste had been another symptom of dementia, I would have been upset because it would have made me think that her deterioration was increasing. There’s still a chance that it is, as NHS Choices says anosmia - one of the links that I explored - can be caused by Alzheimer’s disease. But this is just one of many possible explanations and health conditions.

“The information that me and Dave found just made me feel much better about the situation. The internet means I’ve got somewhere to go, rather than sitting and thinking ‘what do I do now?’”

This has led Ken to feeling more positive about trying a range of new dishes, which has seen Val’s appetite has improved

Ken says: “I would say to anyone else in the same kind of situation or any others caring for family members or friends, go out and visit your local UK online centre and get online. It really does help to put your mind at ease and make you feel better - I’d definitely recommend it!”

The full case study can be found at:

<http://www.tinderfoundation.org/our-thinking/case-studies/ken-and-val-brown-life-full-flavour-thanks-online-world>

Engagement

Working with carers and family members is the key to engagement. Carers and family members often feel that developing digital skills and investing in IT equipment will not benefit people with dementia, and it can be difficult to challenge these attitudes. However, by working directly and closely with carers and family members, UK online centres have been able to engage them and convince them of the benefits of digital for those they care for.

The term ‘carer’ is not the preferred terminology and many carers of people with dementia do not see themselves as such. Through our survey:

- 65% of respondents stated that they see themselves as a carer while 31% do not and the remainder don’t know;
- Only 17% prefer the term ‘carer’, while 17% prefer the term ‘supporter’, 20% ‘partner’, 13% relative; and 23% ‘family member’.

This has implications for how digital skills training is presented to people in order that carers are fully engaged and see its relevance.

Delivery of digital skills training

UK online centres are providing support to people with dementia and their carers and recommendations are the most common way for people to find out about the support offered.

- 54% of carers surveyed had been to a UK online centre for help to access the internet, of which: 44% went on their own; 25% with a partner (which may be the person for which they care); 12.5% with a friend; and 6% with a paid carer.
- Only 27% of people with dementia that attend centres go on their own with 53% going with their partner or another family member, with the remainder going with a friend or other unpaid carer.

Recommendations from friends, family or dementia groups are the most common ways people find out about UK online centres, but this provides a challenge for those most at risk from social isolation as they may not have these networks through which to find out about support. There is an appetite amongst people with dementia and their carers to learn more about digital skills and access support at a local level, especially amongst those which have yet to use UK online centre support. One dementia patient told us:

“I would like to use the internet but have no one to teach me.”

Using a “multi-sensory approach” to engage learners with dementia has the greatest impact. The use of familiar smells and visual prompts from a learner’s past, including photos, has

proven successful when introducing online activities and promoting the retention of information. For example, Age UK South Tyneside reported that the use of a particular furniture polish in the room in which digital skills training was delivered was familiar to a learner with dementia; this familiarity promoted a higher level of engagement during sessions, as well as better retention of information between sessions.

Tablets are the most effective devices on which to deliver digital skills and digital health training for people with dementia. Finding the right device is crucial for the delivery of digital skills training and should be tailored to the individual. iPads were highlighted as more intuitive for users learning from scratch, whereas those with Android phones were more familiar with other devices. Digital equipment needs to be introduced in a 'soft way', such as the use of apps for games and puzzles, before moving on to digital health resources. A funded UK online centre told us:

"We have used tablets/iPads because this group of people seem to manage touch screen easier than laptops."

Volunteers trained to deliver digital skills training should have an understanding of health issues, as well as digital expertise. This approach has worked well in communicating the relevance of digital skills to people with dementia in the context of how it can support them with the condition.

Effective record keeping, data sharing and consistency of approach result in better digital skills learning and health outcomes. People with dementia form attachments to particular resources and people once they have started working with them so keeping a record of these is important so that anyone new coming in - carers, staff or volunteers - can pick up the learning journey with that person. However, Individual Care Plans have not always been as in-depth in terms of history as required and there have been issues around data sharing between relevant organisations which has made the tailoring of learning more difficult. A UK online centre that was funded through the NHS Widening Digital Participation programme told us:

"We generally work in a different way - spending a lot of time finding out about the background of a person as well as existing skills and interests. This personal history is then embedded into the way we teach skills. We also try to simplify and personalise the way people with dementia access technology - removing any superfluous icons, tiles etc. and adapting the remaining ones so that there is a simple association between the icon and an activity."

Health professional case study: Christine Roworth-Gaunt

Christine Roworth-Gaunt is a Senior Occupational Therapist for Leeds Memory Services, working as part of the Dementia Team. She was involved in the NHS Widening Digital Participation programme working with mHabitat, an Innovation Pathfinder, delivering outreach sessions in Digital Cafés and Memory Services initiatives.



Christine told us: “It’s all about bringing digital technology out into the community and working with people with memory loss. It’s all about them still being in charge of their lives. I’ll go out and do a full occupational therapy assessment with someone, and [sometimes] it comes in that that they’re having difficulties in accessing services [...] shopping, or generally sat there day in day out with nobody. I used to do it with my own iPhone, [but] now I’ve got a tablet it’s brilliant. I pop it in their hands, use the mobile WiFi units that we’ve got and we’re off and running. It’s wonderful to work with people. We’re getting so much out of it as therapists ourselves.”

“Technology has made a real difference to a lot of the people I work with.”

Online health resources have proved particularly useful for Christine’s patients. She says: “Anybody using our tablets, we actually point them towards NHS Choices, so they can have a look at things. People want information. When people don’t know fully what’s happening to them, they become frustrated and low in mood; they feel left in the dark. To get a handle on it and a sense of control is very important for people.”

It has also benefited Christine and her colleagues. “I promote independence at home in community, so anything that facilitates that is part of my job. A lot of people that we

see, particularly people who are in their 80s/90s, they're very socially isolated, probably with physical difficulties, so they can't get out and about easily. If you can bring them something that can enrich their lives and provide quality, that's brilliant.

"It's made a real difference to a lot of the people I work with. The referrals that we're getting through now from different colleagues in different professions mean that they know about what we're doing with digital and they're aware that we can go out and work with people. They're quite excited about it."

Read the full case study at

<http://nhs.tinderfoundation.org/index.php/case-studies/christine-roworth-gaunt/>.

Recommendations and next steps

Key to Tinder Foundation's approach is combining research expertise with practical action. As a result of the findings of this research, there are a number of recommendations to take forward. These relate to how UK online centres support and address the barriers facing people with dementia and their carers, as well as considerations for how to integrate this support in to the wider provision of services at a local and national level.

Tinder Foundation will:

- 1) **Ensure that its online resources, including the ongoing redevelopment of Learn My Way and its courses, continue to implement and build on best practice accessibility requirements and tools.** In light of the range of physical, visual and hearing impairments experienced by people with dementia and their carers, it is essential that these are considered and addressed when designing resources to assist with the delivery of basic digital skills training.
- 2) **Support UK online centres to provide opportunities for dementia carers to learn on their own.** Due to the intensity of caring for someone with dementia, it is essential to have dedicated sessions for carers where they can focus on their learning. We will need to encourage centres to provide caring support where possible for the person with dementia, who may also be attending at the same time.
- 3) **Develop on- and off-line resources to support the UK online centres network in working with people with dementia and their carers.** These resources will include handbooks, similar to those developed for the [support of unpaid carers](#), as well as guidance on how to identify and engage with carers, choose appropriate devices and promote the wellbeing benefits of digital skills training for people with dementia.
- 4) **Work with UK online centres to develop specific resources and courses for people with dementia and their carers to learn basic digital and digital health skills.** These resources will include, but not be limited to, courses around using online forums to access online support networks and tools for dementia patients to assist with the retention of information, including standardised notebooks to record usernames, passwords and information about icons.
- 5) **Encourage and support the provision of outreach work by UK online centres to reach the most isolated.** This will address the limited time available to carers for attending sessions and the fact that many people with dementia have highlighted the need for home support to access the internet.

Changes also need to take place in health services and support organisations across the dementia care sector. Tinder Foundation will work in partnership with local and national

government, CCGs, health professionals and dementia-focused organisations, to achieve the following:

- 6) **Promote best practice in terms of website accessibility for people with dementia, with a particular focus on the provision of health and support services online.** This should concentrate on the physical, visual and hearing impairments experienced by people with dementia.
- 7) **Build sustainable relationships with dementia and carer support organisations nationally to promote the UK online centres network and establish two-way referral routes.** It is clear that referrals and signposting from dementia and carer organisations are key to people with dementia and their carers accessing support from UK online centres. Through effective partnerships at a local and national level, these referral routes should be formalised and opened up to promote an integrated, sustainable approach to dementia care.
- 8) **Foster a culture of information sharing and trust between health professionals, dementia / carer support organisations and UK online centres at a local and national level.** Due to the importance of having consistency when working with people with dementia, it is necessary to enable this - both in approach and people - within learning journeys. This requires the addition of learning preferences into individual care plans as a record of successful approaches at the individual level.
- 9) **Support health professionals to become 'digital champions' for people with dementia.** Provide training and resources for those directly involved with the care of people with dementia so that they can assist with the digital inclusion of patients within the context of their own condition and health needs.
- 10) **Continue to promote the health pages and courses of Learn My Way to support relationships between patients with dementia and healthcare professionals.** The strong evidence of the health and wellbeing benefits of using Learn My Way health resources demonstrates the value of learning about digital health. This builds on the foundations laid by NHS Widening Digital Participation and supports its continued legacy beyond the end of the funded programme.

Appendix 1 - Survey respondents, demographics and wellbeing scores

People with dementia

19 responses, 9 of which were completed on behalf of the person with dementia:

- 47% respondents live with partner; 26% in a care home; 21% living with friends/family; and one person lived on their own
- 37% respondents aged 65-74; 32% younger than 65; and the remainder 75-94.
- 42% diagnosed 1-2 years ago; 32% diagnosed within the past year; 16% 2-5 years ago; 10% more than 5 years ago.
- 39% have Alzheimer's disease; 33% have vascular dementia; 11% have dementia with Lewy bodies. One person reported having early onset dementia; one reported 'Progressive non fluent aphasia' and some reported a combination of vascular dementia and Alzheimer's disease.

ONS wellbeing scores for people with dementia that were surveyed:

- Average score across respondents in relation to satisfaction is 4.53 lower than the national average of 7.7 (so less satisfied)
- Average score across respondents in relation to feeling worthwhile is 4.42 lower than the national average of 7.8 (so less worthwhile)
- Average score across respondents in relation to happiness is 4.89 lower than the national average of 7.5 (so less happy)
- Average score across respondents in relation to anxiety is 4.11, higher than the national average of 2.9 (so more anxious)

Carers of people with dementia

32 responses in total:

- 10% of respondents have spouse or partner with dementia; 26% have a family member with dementia; 45% state 'supporting someone with dementia'; 19% have previously cared for / supported someone
- 13% live alone at home; 42% live with their partner; 39% live with family;
- 39% younger than 55; 42% 55-64; 13% 65-74; 6% 75-84
- 10% have been caring for someone for less than a year; 32% for 1-2 years; 26% for 2-5 years; and 19% for more than 5 years

ONS wellbeing scores for the carers of people with dementia that were surveyed:

- Average score across respondents in relation to satisfaction is 5.97 lower than the national average of 7.7 (so less satisfied)
- Average score across respondents in relation to feeling worthwhile is 6.97 lower than the national average of 7.8 (so less worthwhile)
- Average score across respondents in relation to happiness is 6.32 lower than the national average of 7.5 (so less happy).
- Average score across respondents in relation to anxiety is 3.68, higher than the national average of 2.9 (so more anxious)

Appendix 2: Acknowledgements

Tinder Foundation would like to thank a number of organisations and individuals without whom this project would not have been possible.

Thank you to all of the staff, tutors and volunteers at participating UK online centres and other partners who provided support to people with dementia and their carers, as well as being actively involved in the project evaluation. This includes all of those involved with the NHS Widening Digital Participation programme.

In particular, we would like to thank the following key contacts:

- Helen Rowntree, NHS England
- Bob Gann, NHS England
- Martin Simpson, Age UK South Tyneside
- Rich Avison, Lincs Training
- Steve Williams, OASIS Community Centre
- Noreen Edery, Denby Dale Centre
- Charlei Rees, Denby Dale Centre
- Liz Bent, Crossroads Care Rotherham
- Shirley Evans, Association of Dementia Studies
- Dawn Brooker, Association of Dementia Studies
- Alicia Ridout, mHabitat
- Liz Whale, Southampton Libraries

The author wishes to express his gratitude to colleagues James Richardson, Abi Stevens, Sam Taylor, Alice Mathers, Emily Redmond, Sharon Wagg, Laurence Piercy, Kelly Lothbrook-Smith, Rob Shapiro, Holly Bagnall-Bell, Ben Brown, Craig Salisbury and Anna Osbourne.

Author: Tom French

Comments to: research@tinderfoundation.org