



Evaluation of the York Dementia Friendly Communities Programme

by Janet Dean, Kay Silversides, Janet Crampton and Julie Wrigley

This report identifies the distinctive features of the York Dementia Friendly Communities programme, which promotes a range of innovative projects. It looks at how people with dementia have been involved in shaping the programme.

Evaluation of the York Dementia Friendly Communities Programme

Janet Dean, Kay Silversides, Janet Crampton and Julie Wrigley

How can the development of and support for dementia friendly communities be enhanced to inform future work and share learning with other organisations?

This evaluation of the York Dementia Friendly Communities Programme was carried out to help answer these questions.

The report identifies:

- the distinctive features of the York Dementia Friendly Communities Programme, which promotes a wide range of innovative projects;
- how people with dementia have been involved in shaping the York programme;
- the opportunity for York to integrate health and social care services and to focus on the wellbeing of people with dementia and their carers;
- the learning for others who are trying to build dementia friendly communities.

Contents

Executive summary	1
1 Introduction and methodology	3
2 Background to Dementia Friendly Communities	5
3 The York approach to Dementia Friendly Communities	7
4 Strengths and achievements	9
5 Barriers and challenges	13
6 What can we learn from York?	19
7 Conclusions and recommendations	28
Notes	32
References	32
Appendix 1: Detailed methodology	33
Appendix 2: Case studies	36
Acknowledgements	41
About the authors	42

Executive summary

This is a report of an evaluation of the impact of, and learning from, the Dementia Friendly Communities (DFC) Programme in York.

The objective of the evaluation was to enhance learning about the process of developing and supporting DFCs, inform future work in this area and share learning with other organisations.

The evaluation was carried out over a ten-month period from February to November 2014 using a range of approaches including face-to-face and telephone interviews with individuals, and an online questionnaire. In addition a range of meetings was observed, and it is on the basis of all these interactions that the following report is written.

In summary the evaluation found that:

- The approach in York of encouraging ‘many flowers to bloom’ has led to a range of small initiatives springing up, influenced by people with dementia and carers. We learnt of more coming on stream during the period of evaluation and since. The priority for the next stage will be to integrate these into a more strategic programme to ensure sustainability for the longer term.
- Sign-up at leadership level is evident, but the middle managers and teams which connect strategic objectives to frontline services need more support and investment before the City of York can truly claim to be dementia friendly.
- The spiritual, cultural and human assets of York should be utilised more to increase awareness, improve support, and complement already overstretched public sector resources.
- There needs to be greater focus on integration of health and social care for people with dementia. For example, the important role of GPs in enabling wellbeing through social prescribing and acting as a focal point of information and referral needs to be more consistently in place across the city.
- Organisations need to consider how to use relevant legislation to protect people’s rights and to enable people with dementia to engage in community life.
- It feels good to people with dementia, and their carers, to be seen as active participants in developments and informed contributors to a movement, with rights as well as needs.
- It is still difficult to engage with some individuals and smaller groups of people who are marginalised by their economic, social or environmental situations or their fear of stigma, as well as by the degenerative nature of their dementia.
- What most people want is the right to live as normal a life as possible for as long as possible
“People treat you differently after diagnosis even though you might not have changed.”

A participant with dementia at the York workshop

York is to be commended for the commitment already invested in becoming a more dementia friendly community. Awareness and training are becoming more embedded in to the flow of life in York, with many more training opportunities and positive media coverage. It is positive to see more schools and young people engaged in training opportunities and in regular contact with people with dementia. Being at the front of a wave has made people actively working for a dementia friendly York very aware of the

scale of the task and how much more needs to be done. Keeping people with dementia at the heart of future work is critical, and the net needs to continue to widen to include more people in more parts of the City. The biggest opportunity for York is in its chance to join up health and social care and to commission for the well-being of people with dementia in partnership with a wider range of organisations.

1 Introduction and methodology

This is a report of an evaluation of the impact of, and learning from, the Dementia Friendly Communities (DFC) programme in York. The work was commissioned by the Joseph Rowntree Foundation and carried out by a consortium of Dean Knight Partnership Ltd, Qa Research and 2020 Commissioning. The objective of the evaluation was to:

- enhance learning about the process of developing and supporting dementia friendly communities;
- inform future work in this area;
- share learning with other organisations.

The evaluation has a direct link to national policy on dementia, and specifically to the Prime Minister's challenge of March 2012 to encourage towns and cities across the UK to become dementia friendly communities (DFCs). York, supported by programme and small grants funding from the Joseph Rowntree Foundation, was in the first wave of places aspiring to become dementia friendly. This evaluation was commissioned to identify positive outcomes as well as persistent challenges, and to spread the learning across the UK and beyond, and also across the many agencies in the public, private and voluntary sectors who are contributing to DFCs.

The initial questions which the evaluation sought to address were:

- How effective have the initiatives been overall, within the resources available?
- What has been the influence on/challenge to local perceptions and understanding of the experience of living with dementia?
- What examples are there of practical influence or outcomes (beyond attitudes and perceptions) e.g. on quality of life, inclusion, range of options, etc.?
- What evidence is there of benefits to local partner organisations (e.g. commercial or cost-saving benefits; improvements in customer service; positive outcomes for organisational objectives)?
- How have people with dementia been involved in the projects?
- What can and should JRF and other key partners learn from the projects?
- What more could or should be done to create DFCs in York?

As part of its proposal the evaluation team suggested some additional questions:

- What are the indicators of a dementia friendly community that are visible? Which are hidden?
- How well has the idea of a DFC been communicated, and how well has it been understood?
- Who are the custodians of DFCs for the future, on an ongoing basis? Can DFCs be a reality, more than an initiative, and how will that happen, be funded, and made mainstreamed?
- How does York link to the regional and national networks?
- How do the projects enable people with dementia and their carers to co-create DFCs?
- What are the success measures for the future – in 5, 10, 20 years' time what will be happening?

The evaluation enquiries were primarily, but not exclusively, directed at people in York who had some connection with the Dementia Friendly Communities Programme. The evaluation framework (see Appendix 1) aimed to put people with dementia at the heart of the investigation and to include carers, supporters and family members where appropriate. Key stakeholders were partners across public, private, voluntary and community sectors and people leading funded projects. Those working in services,

businesses and projects which were used by people with dementia and their carers and supporters were also surveyed as part of the evaluation.

The evaluation was carried out over a ten-month period from February to November 2014. It included 15 structured in-depth interviews with close stakeholders and structured interviews and conversations with people with dementia, some accompanied by carers, who were also interviewed. Structured interviews and conversations were also held with a carers support group, and with people with dementia, their carers and volunteer and paid workers who were involved in projects funded through JRF small grants. These included the Harmony Café, Musical Connections, Secret Garden and Silver Songbox. Members of the evaluation team also attended a variety of meetings and events, such as meetings of the York Dementia Action Alliance (DAA) and the Yorkshire and Humber Dementia Action Alliance, to observe proceedings, ask questions or facilitate discussions. A survey which respondents were able to complete online received 36 responses. The evaluation report uses direct quotations from interviews and from the survey, and draws on the content of published progress reports, statistical analyses and media and press coverage. In November 2014 the evaluation team held a half-day workshop to test initial findings with a group of stakeholders, including people with dementia, which was attended by 23 people including people with dementia, carers, and professional staff and volunteers.

Drawing on earlier work for JRF by Janet Crampton, Janet Dean and Ruth Eley in 'Creating a Dementia Friendly York' (www.jrf.org.uk/publications/creating-dementia-friendly-york) the Four Cornerstones analytical tool was used to assess how York's progress towards becoming dementia friendly affected all aspects of the lives of people with dementia, their carers and supporters. Full details of the methodology and the survey instruments and models used are in Appendix 1.

2 Background to Dementia Friendly Communities

National developments

The concept of dementia friendly communities has grown out of a longer established age-friendly movement, which is supported by the World Health Organisation (www.who.int/ageing/age-friendly-world/en). Over the last decade, awareness has developed of the impact of increasing longevity resulting from long-term improvements in general health and medical advances. The increased prevalence of dementia, though not a consequence of old age, means that the number of people with dementia is continuing to grow, with projections of around 1 million people by 2025 (www.alzheimers.org.uk/statistics). In the UK a National Dementia Strategy (*Living Well with Dementia*) was put in place in 2009 (www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy). Emphasis on earlier diagnosis focused attention on the growing number of people with dementia remaining at home in their communities for longer.

The Joseph Rowntree Foundation commissioned research in 2011 to explore the concept of the dementia friendly community, with particular reference to York (Crampton, *et al.*, 2012). Its relevance was reinforced in the Prime Minister's challenge of 2012 which included an ambition to establish 20 dementia friendly communities in the UK by 2015,¹ all of which are stimulated and supported by the growing number of regional and local Dementia Action Alliances.

By February 2015 more than 82 places across England had committed to become dementia friendly (www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020/prime-ministers-challenge-on-dementia-2020). This was complemented by significant progress in raising awareness through the creation of 1 million dementia friends, the engagement of large businesses and the progress towards establishing dementia friendly standards and awards.

The implementation of the 2014 Care Act in 2015 created a duty to provide for the wellbeing of people in need of care, with an intention to prevent and delay the need for intensive residential and nursing services or hospital care. It also introduced a right to assessment for carers so they can continue to support people longer at home. The Care Act intends to prioritise community support and is therefore encouraging in terms of further stimulating the development of dementia friendly communities.

Alongside these initiatives, the statutory framework now includes responsibilities placed on local health & wellbeing boards and clinical commissioning groups and the annual national operating frameworks for the NHS. The government's *Vision for Adult Social Care: Capable Communities and Active Citizens* (Department of Health, 2010), emphasises the need for 'Empowered people and strong communities [who] will work together to maintain independence. Where the state is needed, it supports communities and helps people to retain and regain independence' (http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH_121508).

The Alzheimer's Society defines a DFC as '*A city, town or village where people with dementia are understood, respected and supported, and confident they can contribute to community life. In a dementia friendly community people will be aware of and understand dementia, and people with dementia will feel included and involved, and have choice and control over their day-to-day lives*' (www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1500).

At ground level, local Alzheimer's Society and other groups supporting people with dementia have begun to think about how people with dementia and their carers could be more involved in improving the quality of their lives, especially in early and middle stages of dementia. There has also been a growing awareness, facilitated by increasingly easy web access to information, of international movements, and innovative work in the USA, Japan and Australia, as well as in Europe (see Crampton, *et al.*, 2012).

An important accelerator in the development of dementia friendly communities is the collective voice of people with dementia. Facilitated by individual supporters and dementia activists, people with dementia have used the growth in the internet to connect with one another internationally. In the UK, JRF's support for the Dementia Engagement and Empowerment Project (DEEP) (<http://dementiavoices.org.uk/>) has been a significant driver in allowing the voices of people with dementia not only to be heard, but also to enable them to shape and redefine what they mean by dementia friendly communities.

The York context

The population of York in 2011 was 198,051 with 83,552 households.² Between 2001 and 2011 York grew more than Yorkshire and Humber or England (9.4 per cent compared with 6.2 per cent and 7.2 per cent (www.york.gov.uk/info/20037/statistics_and_information/79/census)). It is estimated that in 2014 there were around 2,725 people living with dementia in the city and its surrounding villages, and this number is expected to rise to 3,209 by 2020. During 2013/14, almost £6 million was spent on supporting people with dementia (www.york.gov.uk/downloads/download/1699/adult_social_care_local_account).

York has a strongly performing modern and mixed economy, and is an internationally recognised centre of excellence for education, with two universities. The city has an outstanding built and natural environment, with iconic world-class heritage and a wide variety of cultural opportunities. Overall crime rates demonstrate sustained improvement, income levels are relatively high, deprivation is reducing and there is a good general level of health (www.york.gov.uk/info/20037/statistics_and_information/79/census).

In Yorkshire and Humber 89 per cent of the population identified themselves as White, whereas in York the White British population was 90.2 per cent. The highest non-white group in York was Chinese, at 1.2 per cent of the population.

In its council plan City of York Council acknowledges that the provision of adult social care services will present as one of the biggest challenges in response to the change in York's demography. The population of older people in York is set to grow by 20.5 per cent in the next nine years. The number of residents aged over 65 will increase from 33,000 to 40,000 by 2020. The council helps around 6,175 older people to live independently in their own homes and more than 760 people are supported in residential or nursing care. Last year, York saw a 3 per cent rise in the number of residents receiving adult social care and this trend is expected to continue to grow over the next 10 years.

In the 2011 Census, only 4.1 per cent of York's population stated they had bad or very bad health, lower than regional or national figures. There are 18,224 carers in York which is lower than the regional or national figures. But although York's residents overall enjoy better health than the national average, there are still inequalities between different parts of the city. People's background and income still have the most significant influence over a whole range of outcomes, including educational attainment, employment, and health.

3 The York approach to Dementia Friendly Communities

Throughout this evaluation reference is made to the York programme, although this may suggest a more cohesive set of activities than is actually the case. JRF supports both the Bradford and York Dementia Friendly Communities work within its Dementia Without Walls Programme which is an umbrella for other work across the UK and supports national work on engagement and empowerment of people with dementia.

The York approach, which emerged following an initial scoping project (Crampton, *et al.*, 2012), appears to be in a looser form than the parallel Bradford Programme which is jointly funded by Bradford Council. In Bradford, JRF's role is that of co-funder, whereas in York it is more that of facilitator, although its small grants funding is significant. JRF staff include an overall programme manager for Dementia Without Walls, and a community development manager who, as part of her role, has represented JRF on the York Dementia Action Alliance and the DAA steering group. JRF also funds interim and associate staff to support its York committee in its allocation of grants and to provide support to funded groups. There are three distinct but connected strands of work.

Supporting partners to deliver a dementia friendly York

The interest in and awareness of dementia friendly communities which JRF has helped to generate in York has been picked up by the York Dementia Action Alliance (DAA). The initial focus was primarily on awareness training funded by City of York Council and provided by local organisation Dementia Forward, to secure specific buy-in from organisations across the private, public and voluntary sectors. Events promoting this work and celebrating its success had a positive impact on creating a sense of momentum about the DFC programme, although changes in roles and responsibilities and a delay in finding a chair for the DAA has meant that the pace seemed slower during the evaluation period. During this time, the number of York DAA members was around 49, with more than 2,000 people designated as dementia friends after initial awareness training. The DAA was initially convened by the commissioning manager from City of York Council but late in 2014 its first independent chair was appointed.

The dementia grants programme

JRF began funding small dementia projects within its wider York committee in 2013, and has awarded 28 grants worth in total more than £92,000. Projects funded have ranged from music, art, gardening, cycling and croquet groups, to the Harmony Café run by University of York students, the Yorkshire Film Archive, Tang Hall Community Centre and Inspired Youth. All have been within a framework of Dementia Friendly Communities.

Creating a dementia friendly organisation within JRF/JRHT

As part of demonstrating its commitment to Dementia Friendly Communities, JRF and JRHT have embarked on a programme of work to become more dementia friendly as an organisation. Issues being considered include how people with dementia are treated at work, how carers of people with dementia are identified and supported, and how JRF and JRHT services can become more dementia friendly. This initiative is being separately evaluated, with a report due to be published in autumn 2015.

Other relevant activity

In addition, within the Dementia Without Walls Programme, in 2011 JRF funded the Dementia Engagement & Empowerment Project (DEEP), initially a one-year project that aimed to investigate,

support, promote and celebrate groups of people with a dementia diagnosis across the UK that were trying to influence services and policies affecting the lives of people with dementia. The project found that engagement was at an early stage for most people with dementia, and the number of groups involved in leadership and lobbying was low. However there was potential to support people with dementia through further networking and support for groups. Following a report on its initial year (Williamson, 2012) JRF has funded Innovations in Dementia to continue to develop the DEEP network of involvement and empowerment groups of people with dementia across the UK.

City of York Council and Vale of York Clinical Commissioning Group are responsible for commissioning community health and social care services in York. Selby and York Alzheimer's Society receives funding to provide a range of services including adapted sports activities, Singing for the Brain, Reading Aloud, peer support groups and dementia cafes. From 2013, Dementia Forward provided dementia awareness training and promoted the DFC initiative widely among organisations and businesses in the city. From 2014 it has been commissioned by Vale of York Clinical Commissioning Group and North Yorkshire Partners to provide a care navigator role, dementia advisors and a dementia cafe to support people with dementia in York.

The council has embarked on a major transformation called the Rewiring Public Services Programme with a detailed programme which aims to introduce a new model of adult social care (www.york.gov.uk/info/200793/innovation/1478/rewiring_public_services). This relies less on hospital based care and care homes and more on care delivered at home and in local neighbourhoods. There is also an emphasis on preventative work, general health and wellbeing and stronger more resilient communities.

4 Strengths and achievements

The York Dementia Friendly Communities Programme has many successful features, which reflect a wide range of engagement with, and benefit for, people with dementia and their carers and supporters. York has already established a reputation as a dementia friendly city and attracts interest from across the world, as well as regionally and nationally. These are some of the key strengths identified during the evaluation.

Awareness and training

Respondents felt that there had been improvements in awareness of dementia, that there was a lot of media coverage, and more people were talking about dementia. People cautioned, however, that it is a 'marathon not a sprint', and there is a long way to go.

They also felt that there was more evidence that people were looking beyond the label to the person. It is not the word (whether Alzheimer's or any other kind of dementia) that is important, but the attitudes and behaviours that are directed towards the person behind the word.

People also felt that there was better awareness and understanding of dementia friendly communities. There was a sense that greater awareness of dementia was resulting in an actual willingness to help, illustrated by the following examples:

"My husband had started to look for his mother and the house that she used to live in, which was now a building site. He walked down there one day and became distressed and confused, a builder spotted him and took him to the local doctor's surgery who were able to contact me and I went to collect him."

Carer, York

"We have lived in our present house for the past 14 years, are on very good terms with our neighbours and I've got to know the people who work in our local shops and post office. We've told some of our neighbours about my dementia and they have been very supportive with offers of help, which we haven't as yet required."

Person with dementia

As a first point of contact, GPs are vital, and there was a sense in York that there had been an improvement (although not consistently so) in referrals, suggesting GP awareness is improving. There were views that some people now get a good response and helpful support following diagnosis. Dementia Forward has recently been commissioned to provide a 'care navigator' role, signposting people with dementia and their carers to a range of support services. While there is still too little direct experience of this service to draw conclusions, there was a general feeling of improvement in this area.

The impact of the Dementia Friends Programme appeared to be high in York, with people recognising the 'working to become dementia friendly' stickers in many places from the local Tourist Information Centre, to the back of ambulances. The work of Dementia Forward in delivering awareness sessions was well received, although people felt more was needed.

It was impressive to see City of York councillors doing dementia friends awareness sessions and including the dementia friends logo in a strapline on their emails to increase awareness further.

A range of other awareness raising activities and events have taken place including *A Night to Remember* (a fundraising concert for the Alzheimer's Society). Ian Donaghy who was heavily involved with that has also written a book *Dear Dementia* (Donaghy, 2014) which is listed in the Reading Well Books on Prescription scheme (<http://readingagency.org.uk/adults/news/reading-well-books-on-prescription-for->

[dementia-booklist.html](#)). Other creative and literary examples include a play *Dementia and Me* by York's Real People Theatre Company. A blog called (<https://whichmeamitoday.wordpress.com>) written by a person with dementia from York has also received publicity, including a personal thank you from Julianne Moore during her acceptance speech for the Oscar she received for *Still Alice* (www.theguardian.com/film/2015/feb/10/still-alice-alzheimers-accurate-dementia-sufferers-verdict) a film based on the book of that name by Lisa Genova.

Doorstep sellers and cold callers are a major cause for concern for carers of people with dementia. North Yorkshire County Council trading standards service has done good work on doorstep crime, raising awareness of dementia among staff. It has led the dissemination of this learning throughout a further 160 local authorities who are promoting the idea of 'protective neighbouring', which highlights financial abuse as well as criminal scams.

Overall, people felt that York's profile in raising awareness about, and training people in, dementia friendly communities had been high and there was a need to keep it up. One suggestion we heard was that it might be timely to have a dementia march to increase awareness further.

Intergenerational work

Work in schools and with young people has shown some real innovation and creativity. As one respondent put it 'small seeds have had a big influence'. The video of a performance by pupils at Joseph Rowntree School was part of the Genius York! initiative sponsored by City of York Council, and has been used in schools across the city. The film is available on YouTube and has had views and interest from as far afield as Australia (www.youtube.com/watch?v=LSAzAeBvh-E). Students also wrote and performed their own play *Breaking Thoughts* at the NHS Expo in London (www.youtube.com/watch?v=7dLvlQCOEUU). Both projects were based on face-to-face meetings between the students and local people with dementia.

The beginnings of good intergenerational activity have been supported by JRF project funding. The Harmony Café is a well-established monthly event for people with dementia, their friends and families, which brings together students from York University to offer musical entertainment and social activities at St Aelred's Church, Tang Hall. People come from all areas of York.

Inspired Youth, a social enterprise which engages young people in film making and artwork, has formed a partnership with the Harmony Café to engage people with dementia in creating some fresh images and narratives of what living with dementia is like. The project includes three short films featuring people with dementia which provide an insight into how it is possible to live well with dementia. The films are accompanied by a poster/portrait campaign (<https://astorylikeours.wordpress.com>).

Musical Connections work in care homes and schools provides further evidence not only of raising awareness about dementia but actually breaking down barriers between younger and older people.

Dementia friendly businesses and organisations

Respondents said that people in York seemed more dementia friendly in some shops and other places. There was a sense that employees benefit from the satisfaction of doing their jobs better. The evidence collected from people with dementia and their carers suggested that there was more of a 'can do' attitude, that staff conveyed the message that 'nothing is a problem and 'it's fine, we can sort it out'. One person with dementia explained how she had visited the Visit York information office on a couple of occasions when she had become disoriented, and had been very well supported by the staff there.

"I have been in there [Visit York information office] when I have been a bit confused and they have been very kind...very helpful...I know that they have a sticker in the window."

Person with dementia

Groundbreaking work pioneered by British Transport Police to raise awareness of dementia is now being replicated at stations on the East Coast Main Line. This involves training colleagues to become dementia

friends and dementia champions and building travel confidence in people with dementia and their carers. Other work around transport has included the commitment shown by local taxi company Fleetways, by ensuring that their drivers have dementia awareness training.

Ward 37, an acute ward at York Hospital, has been developed into a dementia friendly environment and this work is spreading throughout the hospital community to other acute wards and patient services such as shops and the chaplaincy. From the hospital's perspective, there is an acknowledgement that, although this work may have happened anyway, the DFC agenda has given the activity a real push and has illustrated that dementia affects the whole hospital. The preventative benefits of DFCs are also acknowledged in terms of helping to prevent or delay the need for acute care.

The Aroma Café in Haxby, a York suburb, is supported by the Methodist church as a community resource which supports a carers' group and volunteering by people with dementia in the café. It has also been a good practice example for promoting the concept of dementia friendly communities around Haxby, with supermarkets, banks and other local traders taking part in awareness and training activities. The work in Haxby has received considerable attention from the media, and has featured in Time Magazine alongside examples of innovative practice from across the world (www.haxbyandwiggintonmethodistchurch.org.uk/blog/wp-content/uploads/2014/03/Time-Magazine-March-3rd-2014.pdf). JRF also made a short film about members of the Haxby community who use the café (<https://vimeo.com/98042224>).

Drawing and building on cultural and community assets

York is a city rich in cultural and community assets and there is evidence that people are starting to draw on them to support the creation of a dementia friendly York.

Very significant work, which has been recognised regionally and nationally, is being done by City of York Council sports and leisure services. Activities which are particularly suitable for older participants (over 50) are clearly identified and there has been a programme of awareness raising and materials produced to help coaches work in an inclusive way with people with dementia.

York Minster is engaging positively with the York Dementia Friendly Communities Programme, with dementia featuring in sermons and dedicated training for its 198 staff and 500 volunteers. Staff are now looking at the Minster environment, including signage, and have embarked on outreach work to encourage people with dementia from communities outside the city centre to visit the building for guided tours and talks.

JRF's York committee's small grants allocation has enabled groups and individuals to retain or develop skills and interests in a range of cultural and leisure activities or to connect better with their community. Art, music and social activities have been offered and created a new set of resources and relationships for people with dementia across the city.

The use of the Yorkshire Film Archive's memory bank has been particularly successful and has been applied in a wide variety of community and residential care settings.

Early attempts to use of York Museums Trust resources such as the Castle Museum have provided insights into what people with dementia enjoy and the fact that the physical environment is critical to successful visits. This project (working in partnership with Here Now Dementia) involved 'dementia testing' York Castle Museum with a group of people with dementia, and provided recommendations on how to make the museum a more dementia friendly place. Art classes held at a local church demonstrated some success, and some learning about the different dynamics of mixed groups of people with dementia and carers, and groups of people with dementia on their own. Particular challenges are highlighted in Section 5.

The Secret Garden project run by Here Now Dementia (www.herenow.org.uk/#projects) with support from United Response has provided an opportunity for some previously isolated people with dementia to make new friends and to feel less lonely. The project provides a supportive environment for people to continue to enjoy gardening and the therapeutic benefits that this can bring. People with dementia who

attend the group have developed some close friendships and there is a real sense of peer support and making the most of each other's strengths. One participant described how she was supported by another member of the group:

"I find writing difficult so [name] helps me...she's like my secretary!"

Person with dementia

Clement's Hall is a relatively recently lottery funded resource which has become a focus for community events in the south of the city. It hosts 'Food and Fun', a social event for over 50s which includes people with dementia and their carers, and is supported by City of York Council and York Older People's Assembly.

A recent update of way-finding and signage in York, particularly in the city centre, has drawn on advice from the York Dementia Friendly Communities work and from people with dementia, including the new Minds and Voices group.

York has good networks, especially in the cultural, arts, sports and community sectors, and where the Dementia Friendly Communities Programme has become known people with dementia can be connected to a wide range of resources.

People with dementia at the heart of the programme

There was a view from those interviewed that 'York is ahead of the game in involving people with dementia' in planning, initiating, implementing and evaluating attempts to create a more dementia friendly environment. By building on the engagement of people with dementia and their carers in the original scoping project, this approach has now become embedded, with people with dementia advising on project applications and grant funding, speaking at conferences and events and participating in further research, such as the work on women and dementia led by Innovations in Dementia and the University of York (www.dementiawomen.org.uk).

People from York with dementia have also in some cases achieved national influence. Wendy Mitchell's blog 'Which me am I today?' (<https://whichmeamitoday.wordpress.com>) is well known and she has recently appeared on the BBC 2's Victoria Derbyshire programme (www.bbc.co.uk/news/health-31773339). The short JRF film of Peter and Avril Jones has been shown nationally and internationally (<https://vimeo.com/9804222436>).

There are acknowledged challenges in this area. Sometimes people with dementia and their carers who are willing to become involved can find themselves being the 'usual suspects' at most events. As the programme has progressed, however, new people have been encouraged to take part and have been supported through the work which began as York Dementia Forum and which is now called Minds and Voices (www.herenow.org.uk/item/york-dementia-forum). This has involved a group of people with dementia working with dementia entrepreneurs Emily Abbott and Damian Murphy. Minds and Voices is demonstrating even at this early stage the ability to engage with single people and those who might otherwise not have a voice.

5 Barriers and challenges

Despite the progress in York, or indeed because of it, there remains a fair amount of concern and frustration at the lack of impact in certain other respects.

Low impact on carers

There were a range of negative views from carers and other respondents that the impact of dementia friendly communities on the ground might not be as great as people, and particularly carers themselves, might have hoped.

Opportunities are still being missed to help people who are developing dementia and their carers to understand what might happen in the short and longer terms. This is a time when the importance of general wellbeing and staying connected to the community could be stressed and connections made to dementia friendly activities and resources.

Carers raised the issue of the multiplier effect of dementia on pre-existing conditions or co-morbidities such as Parkinson's, heart disease, cancers, physical disabilities and sensory loss. They often found that services did not see the person they cared for as a whole person i.e. dementia services did not address the impact of other conditions, and services specialising in other conditions were not dementia friendly.

Carers also spoke about the specific experiences of younger people with dementia or those with more unusual forms of dementia (e.g. Pick's disease). It is often difficult to find age-appropriate support or support that can cater for some of the markedly different manifestations of behaviour which can occur with different types of dementia.

The concept of a dementia friendly community was viewed positively in relation to the early stages of dementia, but carers felt that direct practical support for them as dementia progressed was important. This was not a primary focus of DFCs as far as they were concerned.

“Anything which makes life easier for a person with dementia is to be celebrated, this includes memory cafes, singing groups and social groups etc. My concern is the lack of increase in help and support for carers. All the above require the carers to take their [family member] and stay with them, when a lot of carers actually need a break, whether a couple of hours or a day or a weekend just to recharge batteries.”

Service provider, York

Alongside support for increased confidence, greater independence and self-determination of people with dementia, the real and perceived risks that carers fear need to be addressed. Carers were more likely to consider the role of police, fire and rescue and banks as crucial in creating a dementia friendly community, with their capacity to respond to crises such as a missing person, a house fire or financial abuse.

Engaging with specific individuals and groups

People with dementia have been very prominent in the development of the dementia friendly communities programme in York. The number of people engaged is still relatively small, however, and typically involves people with dementia either accompanied by or at least supported by a carer.

It has, until recently, been quite difficult to engage with people with dementia who are living on their own. Loneliness and isolation is a real challenge for single people as research in York has shown (Collins and Wrigley, 2014). Diagnosis may come later for single people as they may not have sufficient regular contact with people to track the development of the symptoms of dementia. This might mean that more single people are referred directly into specialist dementia services, particularly if there are no carers or supporters around them.

We know that older people are as likely to be living alone as with a partner or family member, and about one third of all people with dementia in the UK live alone (Mirando-Costillo, *et al.*, 2010). Single people also face other barriers more often, both economic, in terms of lower disposable income and access to transport, as well as personal and social barriers in terms of advocacy and support to access services. This has the effect of compounding their isolation, especially if confidence is lost in the early stages of dementia.

Respondents also highlighted other groups who seemed to be 'hidden' in York in relation to dementia friendly communities. The Lesbian Gay Bisexual and Transgender (LGBT) community was felt to be missing from the picture, and this may have to do with persistent attitudes among older LGBT people that they will be excluded and discriminated against in relation to their dementia. York seems to be a relatively friendly LGBT city, and it might be helpful to raise awareness and engage more and younger LGBT people in dementia friendly communities work to help to secure more support for LGBT people with dementia.

Respondents also expected to find better links to the community of people in York with a learning disability, some of whom are more at risk of developing dementia, and many of whom share experiences with people with dementia. This relationship is emerging through the work of United Response and The Krumbs Café but is still quite new.

Engaging with people with dementia through small projects

Despite the many positives achieved through funding small projects in York, not least exploring innovative ideas for what dementia friendly communities might mean, there has been a persistent challenge to engage people with dementia through this route. Some observations here might have to do with the timing of the evaluation work as many of the funded projects had not been running for very long when the fieldwork was done.

There was a fairly consistent message, however, about the difficulties of launching a project 'cold' into the community. More time is needed to establish a relationship in a particular area and to build up links with people, getting to know key 'movers and shakers' who can help with referrals and connect the project to existing networks and individuals.

"It is harder for the small independent projects to have a profile – we don't have the time to go to all of these networking things."

JRF grant receiver, York

In autumn 2012 York Museums Trust funded an eight-week pilot art project at York Art Gallery for people with dementia and their carers. Working with a community artist, each week featured a different art or craft, from portrait painting to felt-making. This initial work developed into a partnership with Here Now Dementia to deliver art workshops (the Artbus project), held in a local church as the art gallery closed for major redevelopment. The approach of offering specific sessions for people with dementia suffered from low referrals and challenges around mixed groups of people with dementia and carers. An example of the sort of challenge encountered was that of a carer who was upset by the work produced by her spouse because she felt it emphasised his loss of skill. The person with dementia on the other hand felt pleased with what he had produced. For the artist facilitator it felt difficult to encourage people with dementia to work freely because some carers were inclined to want to do the work for them.

Another issue – transport – featured in many conversations with stakeholders and people with dementia and their carers. For some, participation is simply not possible without the provision of timely, safe and appropriate transport, sometimes expressed as simply as the need for clear timetabling and signage, that enables people to access the places, activities and services they want to maintain their interests and normal lives. Those providing activities and services reported real challenges in getting people to venues when people with dementia were unable to use public transport, as the following quotes illustrate.

“Everyone involved did more than they were paid for in the end...the atmosphere was brilliant it was just frustrating...we needed more people. Social services ring me up and ask if I have got anything going on but they need more than three months’ notice to make arrangements for client and transport etc. Transport was a problem, we paid for [name] taxi otherwise she wouldn’t have been able to come.”

JRF grant receiver, York

“Often people would like to attend activities but are put off because of difficulties in getting to the venue. Often people with dementia have difficulties accessing public transport”.

Service provider, York

The short-term nature of many of these grant-funded projects was a challenge that organisers needed to consider and plan for, so that longer term plans were not prejudiced by the relatively time-limited nature of seed funding. Some communities such as Haxby, Acomb and Heworth/Tang Hall have a continuing focus on becoming dementia friendly communities and there are key actors in those areas who are involved in supporting work over the longer term. There is a pressure on resources which short-term project funds may not resolve, and the need to understand how capital investment, revenue funding and volunteering capacity can support ongoing activity is an important development activity.

People expressed disappointment that some communities – Huntington was named as an example – appeared not to support dementia friendly communities projects, despite the older population being significant, but respondents could not say why this might be. What it suggests is that a ‘many flowers bloom approach’ will not guarantee a response even if there is a need and this may not be effective in the longer term.

There is a continuing need for projects, voluntary agencies, and private and public services to work together more, to enable people with dementia to gain better access to the activities and services they want to use. For example, on the one hand there is an excess of demand and a waiting list for Singing for the Brain, and on the other a shortage of referrals to Silver Song Box – two quite similar activities. This appears to be because voluntary organisations find it difficult to collaborate and cross-refer. This uneven use of resources is wasteful and unhelpful for people with dementia, some of whom may have a relatively short window of time to take advantage of projects on offer.

“His name is on the waiting list for Singing for the Brain, these things are all great but I don’t know how long I’m going to be waiting...time is of the essence really.”

Carer, York

Information sharing and communication

Sharing information is seen as a broad challenge, with data protection and data sharing still being a barrier to creating dementia friendly communities. One example from Age UK is that they have a long waiting list, including people with dementia, who would like to use their befriending service, but they do not have the capacity to respond and are not able to share their list with other organisations who might be able to help. Organisations need to collaborate and find a way of asking people if they can share their details across organisations in a safe but effective way.

There are also persistent barriers and some quite negative perceptions between organisations and sectors in York, which work against creating a dementia friendly community, and leave people with dementia in the middle.

“I think the health and social care services in York are very poor. In my experience there is pitifully little communication between the services (and third sector providers), let alone any genuine working together.”

Service provider, York

More needs to be done within health, social care and housing to ensure that communication is as dementia friendly as possible and sensitive to the situations of individuals especially where, as in more than one quoted instance, arrangements had been made to communicate via registered attorneys acting on behalf of people who had lost capacity to act for themselves.

There had been a sense of information being 'scattergun' and a danger of duplication because agencies and organisations were not communicating effectively (one carer reported that they found out about Silver Song Box from a JRF report, and that took a lot of finding.)

At the time of writing, the link to York Community and Voluntary Service adds another agency for people with dementia and their carers to have to understand and deal with.

"There should be somewhere where people with dementia and carers can visit to find out where are the places I can go if I want a taxi or an optician. Dementia Forward provide information and newsletters but information generally is a bit dispersed."

Stakeholder, York

This sort of frustration is now being addressed by the Connect to Support website which is attempting to remove confusion and provide an information hub for public, staff and providers (www.connecttosupport.org/s4s/Wherellive/Council?pageld=417).

Also, the profile of York DAA was fairly low and there was some confusion about its identity, e.g. is it Dementia Without Walls or York Dementia Action Alliance? Respondents to the online survey, including businesses and organisations, were less likely to be aware of York DAA than of the Alzheimer's Society and Dementia Forward.

"Dementia friendly communities are fine for those who know about it but what does it mean if you don't know where to look? Where is the central place to go to on diagnosis, how do you access this? When someone dies you're given a pack of info on all the things you need to do - where is this for dementia?"

Carer, York

"I also suggested that there was a need for something like a 'community pack'. Each resident would have access to a community pack which would firstly give one contact name and number, but also have a list of all the activities and agencies in that area. All areas would be served by a central co-ordinator and all activities and agencies would have to register with the central team in order to cascade their service...I wish I'd had a community pack when I was diagnosed, as I would have learned sooner about the support available to me when I most needed it."

Person with dementia

Dementia friendly stickers do not guarantee a dementia friendly city

There is a lively yet unresolved debate in York about whether labelling people and resources with the word 'dementia' is helpful or not. There is a risk of spending more time on the debate than on creating a dementia friendly city. Generally it appeared that people would prefer not to label, but at the moment it is probably practical to do so until York is further along in its journey of raising awareness of and developing dementia friendly communities.

The 'Working towards becoming dementia friendly' stickers (www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2136) carrying the forget-me-not logos which businesses and organisations can display are seen as both positive and negative. Their value is more in raising general awareness of dementia than providing any guarantee about the service or organisation itself – in fact it does not do this. A view was expressed that in the longer term there is the

potential for an endorsement scheme by people with dementia and carers to recommend services, which would have real economic benefits and engage businesses more effectively.

Some people with dementia and carers said that some services which promoted themselves as dementia friendly did not actually come across as such. Yet other shops, businesses and organisations which were already known to be dementia friendly do not have the promotional logo. In York, Marks & Spencer and Barnitts (despite its crowded shop floor, customer service to people with dementia, and their carers, was considered excellent) were specifically mentioned. There were also positive reports from people with dementia about York's 'official' dementia friendly organisations, such as Visit York. People felt strongly that the 'dementia friendly' logo is not a guarantee – what people with dementia need is for ordinary things to work well'.

"Recently, I have seen a few signs saying that shops and organisations in my area are 'dementia friendly' but haven't seen very much evidence of it in practice when I go places with my mother who has Alzheimer's".

Carer, York

Given the importance of transport which is highlighted above, the following extract shows how even those organisations who have adopted a high profile approach to training staff will still find it difficult to guarantee a good service until there is a better underlying awareness of what people with dementia (and all of us who value good customer service) actually need.

"I got on the wrong bus at the weekend...however, sometimes I get confused by numbers and I think one number is another. Some of our buses don't stop at every stop. I rang the bell as usual, got up and went to the front of the bus, and it went sailing past my stop. I panicked and rang the bell again and said to the driver that I needed to get off...I said I'd got confused with the numbers and would he mind stopping on this occasion. He was downright rude and no way was he going to stop the bus until he got to his destination two miles further on. He was even rude when I got off and said I should take more notice next time...York is aiming to be a 'dementia friendly' community. Most bus drivers are brilliant in York but the driver was obviously off work the day he was supposed to have training... I may have been someone who hadn't ventured out for weeks. After that experience I may not have ventured out for many more weeks."

Wendy Mitchell's blog (<https://whichmeamitoday.wordpress.com>)

There has been an emphasis on training of businesses and organisations in the early part of the dementia friendly communities programme in York. Dementia Forward confirmed that it had delivered 73 education sessions to more than 3,000 people, and this has created a core of awareness among a diverse range of organisations including opticians, solicitors and department stores, as well as public and voluntary bodies like the ambulance service. The majority of organisations that are members of the York Dementia Action Alliance and which therefore have dementia friendly communities action plans are public or voluntary organisations, with around a third being private sector, although with increasing numbers appearing on the high street. Awareness training is seen as important; it removes barriers, increases knowledge and alters attitudes and behaviours and respondents felt encouraged at progress but they were also clear that there was more to do in York.

The programme has not had a sufficient impact on public services

There is a sense of disappointment in York about the extent to which the DFC programme has had an impact on and influenced public services, notably health, social care and housing.

Generally the NHS and social services refer people with dementia into other parts of the NHS, or to other public services, or for dementia-specific activities run by specialist organisations (like Alzheimer's Society or Dementia Forward). This suggests a low level of awareness of the support which might be

gained from 'social prescribing' by, for example, suggesting different leisure, social or cultural activities. The JRF small grants programme has been used to develop some of these social prescribing opportunities, but there have been real difficulties in getting health and social care professionals to recognise and refer to them. Even among specialist health workers in the community, the term 'dementia friendly communities' is not widely known and its meaning not understood.

"Better links need to be made between services that provide care/activities for people living with dementia."

Service provider, York

During the evaluation fieldwork period the Vale of York Clinical Commissioning Group was involved in detailed consultation for its integrated operational plan 2014– 2019 (Vale of York Clinical Commissioning Group, 2015) and a tender for the procurement of mental health (including dementia) and learning disability services (www.valeofyorkccg.nhs.uk/current-work/mental-health-and-learning-disabilities). However their contribution to the dementia friendly communities programme was not as visible as it perhaps might have been. The positive work being done in York Hospital is referred to earlier in this report.

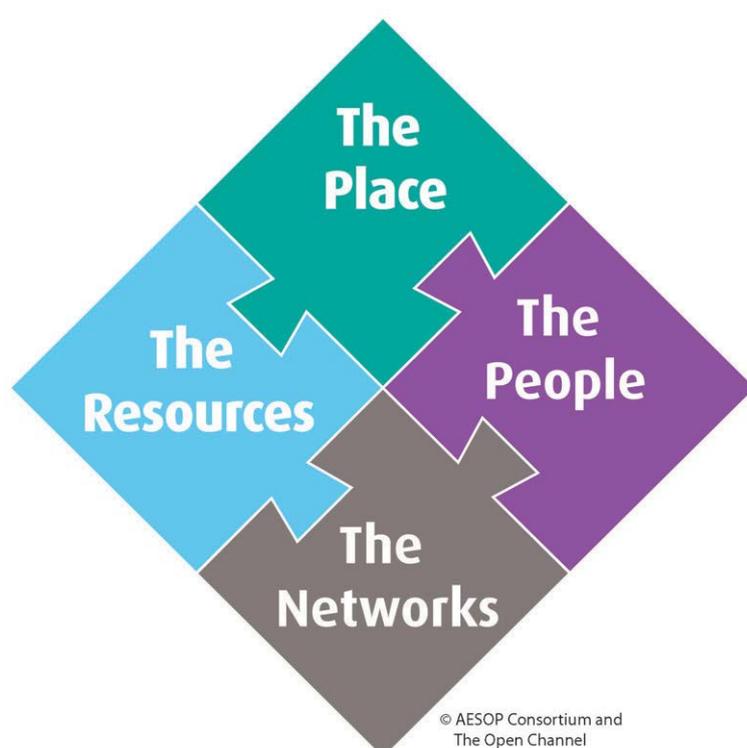
People with dementia specifically, and their carers and supporters, told us they wanted more volunteer and work opportunities following diagnosis, and that these were hard to come by. They wanted to know why public sector organisations in particular did not see volunteering and work as part of the wider commissioning of services for people with dementia. There are opportunities for more imaginative thinking here.

6 What can we learn from York?

In earlier research (Crampton, *et al.*, 2012), Janet Crampton, Janet Dean and Ruth Eley, developed the four cornerstones model as an analytical tool to assess how dementia friendly a community might be. This was based on observations that dementia friendly communities are multi-faceted and deficits in one area could still have a significant impact on people's experience and quality of life even if other aspects were positive.

The four cornerstones model has been used to help to draw out wider lessons from the evaluation of the York Dementia Friendly Communities Programme.

Figure 1: The four cornerstones model



Lessons about place

In the 'place' cornerstone all aspects of a person's home environment, their neighbourhood, and access including transport are considered. In relation to the ten elements of a dementia friendly community identified by the Alzheimer's Society in their recognition scheme they map on to a good physical environment, appropriate transport and maintaining independence by delivering community based solutions.

Key messages which have emerged from the York evaluation and which have wider resonance, are:

Inequality of access including transport is a barrier to DFCs

It is important to take account of the physical and mental challenges that people with dementia may face in getting out and about and consider how these create barriers to experiencing a dementia friendly community. The barriers might be about the challenges of using public transport, or continuing to drive,

or they might be about difficulties with going to new places, or finding their way round buildings. The evaluation team met people at locations of their choice and tried to make sure that any barriers to access were removed. There are indications that commissioners and service providers are systematically trying to address these issues for people with dementia as a whole group, or in different areas. For example, City of York Council took advice from a dementia design expert when refurbishing the King's Square area, and more recently people with dementia have been involved in the redesign of York's signage and wayfinding system. A spokesman for the council stressed that opportunities are being taken as they arise and cited the brief for the new Burton Stone Community Hub which includes dementia friendly principles as one current example but said that 'there is more to be done'.

Some further thought about how to increase access to transport for people with dementia is needed, including better advice and shared experience about continuing to drive, access to volunteer transport 'buddies' and more community transport in rural areas. Some community activists and 'dementia entrepreneurs' were organising this directly, sometimes it appeared out of their own pockets, as a way of ensuring that people with dementia could participate.

Faith groups have physical resources

York is a city with enormous spiritual resources, and there is a growing awareness and engagement among faith groups. Examples of positive community leadership include the Methodist Church's support for the Aroma Café and the wider DFC work in Haxby, the Catholic Church's support for the Harmony Café at St. Aelred's Tang Hall, and York Minster's engagement broadly across the DFC programme.

York has a spiritual significance of national and international importance. It could do more to harness the resources of faith groups across the city to actively support the realisation of a dementia friendly York. This would contribute greatly to supporting the work of community groups and to providing quiet spaces for people with dementia and their carers, breaking down barriers such as loneliness and isolation.

"Surrounding villages need support. Churches may be able to contribute with premises and volunteers, though they would need help to establish."

Workshop participant

The pace could be slowed with quiet spaces

The fast pace of everyday life can be one of the biggest barriers for people with dementia, so championing aspects of a 'slow movement' was seen as positive. Ideas expressed ranged from more time and patience with customers to places to go and things to do which are quiet and unhurried – whether these be walks, or cafes or places of worship. People suggested that initiatives needed to be kept small and local, effective and appropriately paced. Ordinary contact needs to be just that, ordinary and normal and not specially designed around other people's concepts of dementia. Parks, gardens, walks and street furniture could be promoted as a way of everybody slowing down, and this would help people with dementia to feel part of a more inclusive environment.

"There needs to be more 'thinking space'. Places to just 'be', not to have to 'do'."

Volunteer, York

Lessons about people

The 'people' cornerstone considers how carers, families, friends, neighbours, health and social care professionals (especially GPs) and the wider community respond to and support people with dementia. It is also concerned with how people with dementia themselves engage in, influence and help to create dementia friendly communities. In relation to the Alzheimer's recognition criteria, it covers challenging stigma and building awareness, empowerment and recognising the contribution of people with dementia, and shaping communities around the views of people with dementia.

Key lessons which were highlighted in York about people were:

General awareness needs to grow but a rights movement is emerging

In York a new forum for people with dementia, called Minds and Voices was formally established at the end of the fieldwork phase of this evaluation. It provides an opportunity to increase the influence of people with dementia on asserting their right to live in a dementia friendly community and to shape and influence what happens in York in the future. A network of 'dementia entrepreneurs' who have worked in and around the dementia friendly communities programme is working with Minds and Voices to support its development.

The relationship between the concept of a dementia friendly community and a 'rights movement' is interesting. For some a DFC is about making a place easier to live in for a person with dementia, for others the notion of inclusion is more explicitly about rights. Dementia has only relatively recently become something which people are prepared to discuss, and for some it is still a matter which bears a great deal of stigma and shame. But given the progress that has been made through the disability rights movement, and the challenge to age discrimination, there are suggestions that it could be time to consider the particular needs of people with dementia as an equality issue. Other campaigns have much to offer people with dementia in terms of learning and shared experience. These include movements which have led to legislative change (as enshrined in the Equality Act for instance) as well as changes in social awareness (such as Age UK work on ageing, Time to Change on Mental Health) (www.time-to-change.org.uk).

In York, there are good levels of awareness about this issue, and people with dementia, their carers and supporters were positive about the opportunities for empowerment. This was not always seen as a matter of introducing a system, or institutionalisation, but more about an organic inclusion of people with dementia in everyday life. One example of this was a suggestion that a small corner of the library might be given over as a place where a group of people with dementia could meet for a coffee and a chat.

"There's more evidence that people are looking beyond the label – 'Still me!' – It's not the words dementia or Alzheimer's that's important, it's the attitudes and behaviours behind the words."

Person with dementia at York workshop

Some people did question whether in fact the assertion of the distinctive rights of people with dementia is a stage we have to go through – so that we consciously and formally describe dementia friendly communities so they eventually become normalised, as is happening with access for people with disabilities.

A question raised by the evaluation is whether the use of the term dementia friendly communities is helpful. Clearly, not everybody wants the dementia label, but it is difficult to know how to raise awareness without it at the moment.

Dementia has different consequences for women

Over the course of the evaluation, awareness has been raised of the particular experience of women in relation to dementia, and a conference was held at York University in November 2014 exploring the issue.

Women's longer life expectancy increases the prevalence of dementia among them, and women also find themselves caring more regularly than men, not only for spouses and partners, but also for parents and relatives within the wider family. Male carers are often supported earlier and with more resources than female carers. Women with dementia may be more isolated because of the reluctance or inability of their (male) carer to network in the way that female carers might.

The evaluation team encountered more female carers, probably due to the tendency for females to find themselves in the caring role (although it could also be the case that male carers do not find groups of female carers meet their needs). One particular case is a woman who had taken on the primary caring role for her boyfriend's father. It was not clear why she had taken on this role, whether it had been a

pragmatic decision or related to gender expectations. The carer had found it very difficult to access support and it is interesting to speculate about how this would have differed if her boyfriend had taken on the role.

York is not different from other parts of the UK – it has an ageing population where women survive longer into frail old age than men, and experience dementia more frequently. Nor is it different in continuing to have an older generation of women who are more used to traditional caring roles than some younger generations might be. But the work done by York-based academics, dementia activists and creative artists in focusing on women and dementia has created a network of people with an opportunity to raise awareness of this particular aspect and to continue to highlight what women in particular might want from a dementia friendly York, which could be replicated elsewhere.

The role and contribution of carers is vital

Asserting the rights of people with dementia can present a challenge for carers, especially where close family relationships are involved, and there are differing perceptions of risk between the person with dementia and their carers. This calls for careful handling by professionals, volunteers, the wider family and community.

Some carers were most concerned about the real pressures of daily life, especially in the middle and later stages of dementia. This can lead to a tension between raising awareness and challenging stereotypes and being honest about the terrible impact that dementia has on the lives of both the person with dementia and their carers and family. There is some frustration that the Dementia Friendly Communities work, in focusing on how to enable the continuation of life in the community, underplays the impact of the disease as it progresses, at the expense of carers.

“There needs to be more understanding of the role of carers. Living with dementia and working with dementia are different things. Until you have to spend every night sleep-deprived for the last three months, you don't understand. I understand that we want to make dementia less frightening but it is still a difficult disease and I worry we are hiding those later stages.”

Carer, York

What carers want and need is practical help – a frequent request was for places in shops and cafes where you can leave a person with dementia and be sure they are safe while you pay for something or try on clothes. Carers often feared that a person with dementia might get lost if and wanted more practical signage than a dementia friendly sticker. Another regularly identified area was the need for support in a crisis.

There is more to be done to understand and respond to the needs of carers in order to secure their effective support for people with dementia over the longer term. Fair access to care and eligibility criteria will need to be reconsidered in York as they will across England and Wales, as the Care Act now includes self-funders as being eligible for guidance and advice from local authorities.

More support is needed from general practice

There were reports of wide variation in GP practice in diagnosis and referral of people with dementia in different parts of York (*'you're better off living in the north of York than the south'*, said one stakeholder). Individuals reported that some GPs avoided diagnosis for as long as possible and after diagnosis only referred people to NHS services without a wider assessment of the personal, social and community needs of a person with dementia.

More could be done, through the clinical commissioning group (CCG) with its links into health and wellbeing partnership work, to raise awareness among GPs of the concept of a dementia friendly community, to see a person with dementia as a whole person and to prioritise continuing general health and wellbeing and social connectedness as well as specific treatment and support for dementia symptoms.

Vale of York CCG is working with Dementia Forward to develop awareness among GPs (and practice staff) of the range of dementia services on offer. Vale of York CCG also has plans to develop its website to give GPs easier access to information on local dementia services.

Lessons about resources

The 'resources' cornerstone considers if there are sufficient services and facilities for people with dementia and whether these are appropriate to their needs and supportive of their capabilities. How well can people use the ordinary resources of the community? In relation to the Alzheimer's recognition scheme criteria they are closely related to maintaining independence by delivering community based solutions, early diagnosis and personalised and integrated care as the norm and businesses and services that respond to people with dementia.

The lessons which were identified in relation to resources were:

There is a need to invest long term in community support for people with dementia

More work is needed in York to identify how community support – which can harness voluntary capacity – can contribute to rebalancing the health and care system for people with dementia.

There were consistent concerns about public spending constraints and the potential impact this might have on people with dementia. Some people felt that the focus on dementia friendly communities might fall away as other political priorities emerged leading up to the General Election in May 2015; at national level the focus has indeed been more on the challenge of meeting the overall costs of health and social care.

The continuing focus of commissioners – in health particularly, but also in social care – is on health and social care solutions. The lack of consideration of the personal, emotional, and social needs of people with early stage dementia was seen as a problem. Commissioners do not yet seem to have real confidence that creating dementia friendly communities could lead to savings or improvements in the care and support of people with dementia, despite the Alzheimer's Society highlighting the difference in cost of caring for someone at home compared with residential care (www.alzheimers.org.uk/dementiauk). The perception is that the Vale of York CCG is proving slow to consider investing in community schemes which might address loneliness, isolation or wider wellbeing issues, although as this evaluation was being finalised, the CCG was undertaking a major re-procurement exercise for learning disability and mental health provision, which includes dementia. Given that this is reported to have a very strong focus on innovation, partnership and third sector development, it will be interesting to see what comes out of this process.

Some respondents commented on the failure of commissioning bodies to manage and stimulate the market in alternative forms of support for people with dementia, such as sport, leisure or cultural activities, or to think about how practical support with shopping, gardening, or managing household waste, could enable people with dementia to live well in the community for longer. There is no doubt that the dementia friendly communities programme is having an impact on the strategic thinking of health and social care commissioners. An example is the Connect to Support initiative which offers a platform for new providers to promote themselves and stimulates the market for care and support, although this has come at the end of our evaluation and it is not possible to evaluate levels of success or impact.

There are pockets of innovation and creativity in York which are clear to see, for example sport and leisure services are becoming increasingly dementia friendly, but as yet they are not widespread in their impact on people with dementia. The innovative library/café at Sycamore House is a combined NHS and City of York Council service aimed at people with mental health needs, but open to general community use. It is not, however, a resource aimed at people with dementia, which seems to be a missed opportunity to include them in an integrated service.

People who are diagnosed with dementia early are often keen to continue working or to take up volunteering, but we saw little evidence of pro-active working practices outside JRF. One local firm had included supporting staff in its DAA action plan and the Aroma café has a volunteer with dementia. On

the other hand a blogger with dementia revealed little support from an NHS employer (<https://whichmeamitoday.wordpress.com>) so the evidence suggesting that workplaces are dementia friendly environments is slim. However, the recent launch of Alzheimer's Toolkit for Employers (www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2979) is a key step forward nationally and York DAA is offering free training and support for employers to develop an action plan. Most businesses and public sector organisations who engaged with the DFC programme saw the issue as about customers. Large public bodies might make a bigger investment in dementia friendly communities if they reviewed their people development policies, and health and social care could offer work and volunteering opportunities to people with dementia as an alternative to low level or community support.

Effort is needed to connect DFC initiatives to mainstream work

Despite initial energy and high profile success with the delivery of dementia friendly awareness training by Dementia Forward, this momentum has not been continued consistently across the business or public sectors. The Dementia Action Alliance has taken time to establish itself, with a changing membership and the recent appointment of a new Independent chair. Its voice is not heard loudly across the city and does not appear to influence significant players, particularly in health and social care, to really explore the potential of dementia friendly communities as a tool to aid service transformation. Our research found little strategic understanding of the connections between dementia friendly communities and the Better Care Fund, though the local authority and its partners would argue that it is integral to their joint planning and that dementia friendly communities are a city-wide priority, pointing to the continuous awareness training since 2014 run by the council's workforce development unit and the push to encourage all council employees to become dementia friends. On the other hand, a JRF-funded project to establish Tang Hall Community Centre as a hub for people with dementia struggled to attract interest or support from health and social care commissioners despite being championed by a neighbourhood worker employed by the council.

In other places there is evidence of more success in widening the net of engagement in businesses and organisations to include all sectors, and particularly in connecting to programmes of activity which support people with dementia alongside mainstream programmes, such as in arts and cultural services in Leeds. It is perhaps surprising that, despite the evident success of mainstream initiatives in sport and leisure in York, that these have not served as a template for other services to become dementia friendly, in the council and across other public and private organisations in the city, for example to connect people with dementia to cultural volunteering opportunities.

Dementia friendly – inclusion or exclusion?

In thinking about the resources which are available in a Dementia Friendly Community and in seeking to remove barriers to participation, the evaluation has reflected with respondents on the pros and cons of 'dementia only' activities, services and resources. In York, we found a positive balance of demand and provision between groups and activities specifically for people with dementia, and opportunities for people with dementia to have access to the same facilities and resources as everybody else. This did not mean there was a consistent or comprehensive offer of appropriate resources to suit everybody's needs and aspirations.

Linked to the rights issues we discussed above, it should be a starting point that people with dementia should be able to access mainstream services and resources in a Dementia Friendly Community alongside everybody else – this is, in essence, the core meaning of the term. At the same time, people with dementia should also of course have the right to choose to engage in specific 'dementia-only' activities as well.

Lessons about networks

The 'networks' cornerstone considers whether those who support people with dementia communicate, collaborate and plan together sufficiently well to provide the best support and to use people's own 'assets' well. It also considers the networks of people with dementia and their carers and supporters. In mapping across to the Alzheimer's Society recognition criteria, shaping communities around the views of people with dementia and their carers, and befrienders helping people to engage with everyday life are

relevant here, although there is perhaps less emphasis in the criteria on networks at different levels of neighbourhood and across communities.

In York the key lessons for networks were:

People with dementia need to network

In York, face-to-face networking is effective in pockets where people have built up relationships over time, such as through the Harmony Café and Singing for the Brain groups. Although a few people have connected on a long-term basis through the JRF Dementia Without Walls programme and through networking at conferences and events, these do not appear to sustain relationships as regular networking groups do in other parts of the country.

More systematic networking, as a way of people getting together to share their experiences of dementia, has begun to emerge through the embryonic York Dementia Forum, which has recently become part of the DEEP network and renamed itself Minds and Voices. The work of DEEP has shown how powerful bringing together people with dementia can be, and it will be an asset for York to have a regular forum for people with dementia, if this is what Minds and Voices can become.

We know that in other places and across the UK and the world people with dementia network extensively using social media. This can be a very inclusive and liberating method of communicating for many people with dementia, and it facilitates inter-generational communication and networking very well. There has been positive experience of the use of iPads in the JRF-funded small project work.

For the many people with dementia who may not respond to social media, and for whom telephone and written communication have become problematic, personal networking is often preferable. Besides being fun, networking is often practically useful, challenging and empowering, and is part of a socially engaged life which helps people with dementia to retain their capabilities for longer.

Professional networking is crucial for a dementia friendly community

Professional networking in York appears to be stronger at the top and bottom of the system, and weaker in the middle, where it might matter most. There is more that could be done through the DAA to strengthen networks between health and social care commissioners and providers. However there was a lot of change in personnel in the city council during 2014, which meant that new relationships were still being formed.

At a neighbourhood level, people do know other professionals working in the area, although work is needed to make this more than something that rests on personal knowledge. Attempts such as those being led by Tang Hall Community Centre, to build a community of people who can help the area become more dementia friendly, are hampered if a key individual is absent, putting pressure on volunteers or those with a wider geographical remit to fill gaps. At the moment ideas are more prevalent than action. We observed better results where there is shared knowledge and ability to act between middle managers, assessment and care staff who have authority to make decisions about people as individuals. Where this is not evident, people fall between the gaps.

York has recently been announced as one of 11 integrated care pilots, so there is a real opportunity to demonstrate effective joint working across the health and social care system. This relies not just on health and social care commissioners agreeing what to do, but on providers across all sectors, including private and voluntary, being able to deliver what is commissioned. If joint forward planning to avoid crises improves, this will contribute to York being more dementia friendly, as lack of integration is a real barrier to people with dementia and their carers.

Dementia Forward has been commissioned to provide a 'care navigator' role to support the joining up of information at each stage of the dementia journey. This is already impacting on some people, though it depends on people being referred into 'the system' on diagnosis.

Personal and organisational networking help to build the DFC ‘movement’.

Being part of a wider regional, national and international movement has been significant for the York programme. The establishment of a national Dementia Action Alliance of organisations committed to creating and supporting dementia friendly communities, and the roll-out of regional and local DAAs on the same model has created a network of organisations, practitioners, activists and policy-makers able to share and explore new ideas about what makes a Dementia Friendly Community and how to work towards making it a reality.

JRF’s Dementia Without Walls programme manager has been influential in the work in York since its inception, and has brought regional, national and international networks and contacts back into the programme to its benefit. In 2013 JRF’s appointment of a community development manager boosted its capacity to connect York to the wider dementia friendly movement. Connections have been made with a wide range of individuals and groups, and these have often involved people with dementia and their supporters as well as professional and voluntary staff. A particular link has been made with Bruges, a European city with many of the characteristics of York in its historic character and its demography, and the programme manager has played a significant role in European work through the European Foundations’ Initiative on Dementia network, taking a lead role in identifying good practice examples in several other European countries.

JRF has also provided opportunities for people with dementia and their carers to engage in networking, not only through the DEEP project, but also by including and involving people in conferences and events and in reflection and analysis throughout the York programme. There is a sense in which the York programme benefits from the impact of JRF’s wider work on Dementia Without Walls, which Bradford and other funded projects experience to a lesser extent.

In York, connections to mainstream work on ageing, mental health and dementia are less evident, so it is more difficult to see how the York DAA, for example, connects to and influences the partnership structures which sit under the health and wellbeing board. Therefore the extent to which the key statutory agencies and decision-makers within them have dementia friendly communities at the centre of their consciousness is uncertain. There is the opportunity to reaffirm these links and relationships with the new Vale of York CCG mental health and learning disabilities provider.

Despite dementia being identified as a priority issue for York in the Joint Strategic Needs Assessment ³, it was not clear how the York Dementia Friendly Communities Programme was considered as part of the response to that need. There seems to be a risk that if the concept of dementia friendly communities is not integrated into the mainstream of health and social care in York, as well as the rest of the community, it may be seen as peripheral and not sustained. At the time of writing Vale of York CCG had just published its integrated operational plan 2014–19 (Vale of York Clinical Commissioning Group, 2015) and was in the process of appointing a new mental health (including dementia) and learning disability services provider. The integrated operational plan includes a commitment ‘to work in partnership to develop dementia friendly communities to reduce stigma and improve early diagnosis and provide support to people to live independently for as long as possible’. It will be important for the new provider to work effectively with all organisations involved in creating a dementia friendly York to ensure that the good work continues.

Social capital and human scale support the creation of dementia friendly communities

There is a culture in York of bottom-up development which does flourish with little or no mainstream support. This may have to do with the strength of local capacity to organise and enlist support for community needs. York in aggregate has lower levels of social and economic deprivation than urban areas in West and South Yorkshire, although it has more pockets of deprivation than North Yorkshire. In York there were many ideas and initiatives, often coming through project bids, where people were seeing a need and coming up with a bright idea to address it. For some people – primarily those in the voluntary and community sectors – dementia friendly communities are not about commissioning services but about creating an environment in which social movement – local-grown, home-grown groups – can

flourish. This is particularly being driven by some individual and organisational ‘dementia entrepreneurs’ who have been supported by JRF, and they recognise the existence of a ‘dementia economy’ or a market for new dementia friendly products and services. New services such as Getting Along which supports couples living with dementia, and My Dementia, a course for people with a new diagnosis, are demonstrating demand for early support to enable people to define how they want to live with dementia. As people move from early to later stages of dementia, their needs change and other organisations may need to be involved. This means there does need to be a system of referral and movement that ensures that people get an appropriate response at any given stage. At the moment it appears that there is a disconnection between the bottom up ‘many flowers bloom approach’ and the top down commissioning of services for people with specific needs. What this fails to ensure therefore is that people are identified early and their needs are anticipated with time to plan both for a known outcome, and for inevitable crises as they arise.

Involve people with dementia and carers and supporters in defining and promoting dementia friendly communities

In York the DFC programme has operated with people with dementia at its heart since 2012 when the ‘Creating a Dementia Friendly York’ research connected with individuals and their carers. Sadly, several of these people have since died, although one carer has stayed involved and participated in this evaluation through his continuing interest. However there is now a fresh core group of individuals who are involved in many ways in the York programme; in evaluating bids for funding, in reflecting on progress; in auditing physical spaces; in making or reviewing films; in media interviews; in writing blogs; and in considering gaps which might be filled with new work. This is not a fixed group, although most if not all are involved in projects and groups funded by or connected to the programme, such as Singing for the Brain, the Harmony Café, and the Aroma Café Haxby.

Despite the positive engagement of these core individuals, wider connections with people with dementia have been difficult to make, especially with single people, and people from different ethnic or sexuality groups. However there are signs that this is beginning to happen through the new Minds and Voices group, which has joined the DEEP network. Having a focus for people with dementia to come together to share their experiences could ensure that people with dementia continue to be at the heart of dementia friendly communities.

Minds and Voices might also have an influence on sharing information and advice about how dementia friendly services and resources are in York. This would go beyond the current Alzheimer’s Society forget-me-not logo scheme. A ‘Trip Advisor’ type approach (www.ncl.ac.uk/press.office/press.release/item/new-mobile-app-will-find-dementia-friendly-places) – perhaps as part of a local dementia friendly York app – could enable people with dementia to rate shops, businesses and community facilities.

7 Conclusions and recommendations

In summarising the conclusions of this evaluation of the York DFC programme we have referred back to the evaluation brief and the additional issues raised in the proposal which were included in Section 2.

The York Dementia Friendly Communities Programme has been successful so far, with strengths in widening awareness and providing basic training, focusing on intergenerational work, developing dementia friendly businesses and organisations, drawing on cultural and community assets, and putting people with dementia at the heart of the programme. There has been less progress in other areas. These relate to support for carers, ability to engage with specific individuals and groups, engaging directly with people with dementia through the small projects, information and communication, unresolved issues about whether to 'label' dementia, and insufficient impact on public services.

Overall there has been good publicity about dementia and dementia friendly communities which has reached many more people and parts of the city. This is starting to influence and challenge perceptions and understanding of what people with dementia experience. There are some real pockets of excellence, especially in leisure and cultural activities, some organisations and some of the longer established projects. These have built real understanding of what people with dementia need to live a good quality of life. In terms of practical impact, there is evidence that some people's lives have been enriched, and their own confidence and capacity to determine their immediate future much enhanced. People are able to sustain lifelong interests, develop new ones, and make new friends, and carers have felt supported by opportunities for social engagement and time on their own. In York there is a particular opportunity for inclusion which is being demonstrated in some key areas (for example in over-50s sport and leisure provision), but which could and should be much more widespread across a wider range of cultural and spiritual organisations.

Organisations large and small have connected with the DFC programme in York; for larger organisations the benefits might be more reputational and seen in terms of wider corporate social responsibility than commercial or cost benefit or in direct benefit to people with dementia. There was no automatic correlation for business or organisations between involvement in the programme and improved impact. For smaller organisations, or specific services, the impact was more visible on improvements in customer service and for some organisations there was a positive sense of better referrals which might lead to more business. People with dementia and carers reported that involvement in the programme was less important than the ethos and values of the organisation itself.

People with dementia have been influential in shaping the York DFC programme from the start, with formal involvement in advising on grant allocations and helping to review performance and inform future strategy. Until recently, however, a few key people had been most influential and it has taken time to engage a wider group of people across the programme as a whole. The impact of this involvement is only just starting to emerge.

The formal tangible signs of a dementia friendly community might be seen as the 'Working towards becoming a dementia friendly community' stickers which are visible in a several key locations in York. In the city council's West Offices, a 'virtual' receptionist', in the form of a person-shaped noticeboard, provides a specific welcome for people with dementia. These tangible signs are welcome, but most people with dementia and their carers are looking for the human understanding that is displayed in patience, kindness and respect. In the city centre, and in the suburban areas and villages, people tend to know where is 'good' for people with dementia in terms of facilities and positive customer service. People said that it would be helpful to name the good services to let other people know where to go.

People thought that the idea of a dementia friendly community had been well communicated on the whole, and that it was reasonably well understood. What they hoped for now was a sustained focus on making the idea a reality. Many of the people surveyed or interviewed – stakeholders, volunteers and people with dementia and their carers – expressed some concerns about the future of the DFC initiative, in that they wanted it to be more than just an initiative. They hoped for health and social care

commissioners to support dementia friendly communities through long-term funding and they hoped that businesses would see the long-term benefits of improving their services to people with dementia.

The evaluation findings suggest that there is a strategic commitment to dementia friendly communities but the evidence of delivery is not yet widespread. Health and social care commissioning has been influenced and there are good signs that practice is changing to focus on the potential of dementia friendly communities to make long-term gains. There are concerns in York about the rivalry of different organisations working with people with dementia and a feeling that they need to collaborate more effectively. York has been identified as an integrated health and social care pilot area and there is a real opportunity for the learning from the DFC programme to have a positive impact on future health and social care commissioning.

York appears to link well to the regional and national networks, with strong connections to other cities around the UK and even beyond. JRF brings its own network of national and international contacts into the programme to share ideas and people with dementia and carers have connected with many other people at events and conferences, learning from and challenging one another. York has a high reputation in the UK for being at the forefront of DFCs and to some extent this is warranted, although the downside of being a trailblazer is that others can build on ideas and run ahead. People in York know that the work is far from done, and there is no room for resting on past success.

Although people with dementia and their carers have influenced the DFC programme in York, the next step is to enable and empower them actually to co-create DFCs, both in terms of their individual lives and the wider community. Personalisation of health and social care should mean the choice to use everyday services and community facilities to support a good quality of life – this might mean going to an adapted Zumba class rather than a memory café, or joining an inclusive community choir rather than Singing for the Brain.

A 20-year vision for dementia friendly communities in York could see people with dementia supported to live fulfilled lives for as long as possible in their own communities, drawing on the full range of social, cultural, environmental and spiritual resources that the city owns. York has a reputation, with its Quaker heritage, of more than 250 years of innovation in the support and care of people experiencing all kinds of mental health problems, and this should inspire the city to become truly dementia friendly. The leadership shown in the city over the past few years in terms of fairness, which has tended to concentrate on poverty, could now consider how to balance the needs of an ageing population, and how to deal with the continuing stigma around mental health issues which means that people with dementia often suffer a double discrimination.

The work that JRF has done in leading the way on dementia friendly communities should be more widely owned by the public, private and voluntary sector leaders who have influence and decision-making powers in York. There is already progress. The Alzheimer's Society and Dementia Forward have been able to develop and extend what they offer in terms of activities, sport, music and peer groups and advice, information and support. There is an opportunity now to consider, through growing awareness and involvement and the procurement of health and social care services, how some of the smaller innovative projects which have demonstrated their benefit could be commissioned as part of ongoing services for people with dementia. These projects not only offer more diversity, they also offer the opportunity for people with dementia themselves to decide what kind of community they would like York to be.

Recommendations

The city has made good progress, but there are more things that could be done to create a dementia friendly York. Concentrating on some key strategic areas will have the most sustainable impact.

Treat people as citizens

- People are not dementia, they are people, and the aim of a dementia friendly community is to enable people with dementia to be active citizens, able to choose the lives they want to live.

- There is a specific opportunity to consider how to support, through long-term funding, the York Minds and Voices group so that they can develop their priorities and provide a focus for understanding how to engage meaningfully and ethically.
- Organisations should explicitly apply the Equality Act (incorporating the Disability Discrimination Act) in responding to the needs of people with dementia. Assessment of need should take account of psychological, social and economic circumstances as well as health and care needs.

Tap into York assets

- The Dementia Action Alliance should praise and highlight what works – good, friendly, customer service, as well as more specific schemes. Could a local 'Trip Advisor' service recommend restaurants and other services that are good for people with dementia? Could York Mix, the local events and news website, host this?
- City of York Council is well placed to provide more volunteering opportunities, work, social activities and support, especially for people with dementia who are young and who feel young. There are specific opportunities during commissioning and procurement to consider what community services could be run by people with dementia, or use people with dementia as volunteers, such as in grounds maintenance, management of parks, sport and leisure services, libraries, community cafes, and peer support services.
- York's spiritual and cultural assets are enormous – if every place of worship, theatre, sports club or music venue were dementia friendly, people with dementia would feel welcomed and emotionally nourished. Spiritual and community leaders could make this happen.

Prescribe for wellbeing

- Even before diagnosis, GPs should provide more information on social support and general health and wellbeing, and on diagnosis they should make formal social prescriptions to maintain confidence and quality of life. Vale of York Clinical Commissioning Group (CCG) should ensure that people across the whole of York get positive support and referral leading up to, upon and beyond diagnosis.
- The CCG should make the most of the opportunities GPs have through knowing who their patients with dementia are, and what support they need. This would allow them to provide accessible and appropriate information about the range of services and resources available, and it would enable people to be referred not only to dementia services but also to broader community support. It would also provide a basis for commissioning preventative support which sustains inclusion and activity, and may delay the need for high level care or avoid crises and hospital admission.

Connect the care and support

- There needs to be a focus on sustainability for the future – health and social care partners should grasp the opportunity of integration and use it to look for innovative ways to make dementia friendly communities a reality. This would help to deliver on aspirations to increase personalisation of care.
- Top-level commitment has to result in delivery on the ground and middle managers need to be able to make that happen. Providers should be commissioned to collaborate, not compete.
- York DAA needs to develop a clear plan and processes for following up on action plans – there are signs that the appointment of a new chair has led to a relaunch and opportunities to expand the membership.

Practical help for carers

- Carers should not lose out in the squeeze on resources – their support can help to reduce or stave off high care costs, but they also have the right to live their own lives. Practical support in the home, support to find the right social activities and befriending schemes which carers can find difficult to arrange, are essential elements of DFCs from a carer perspective, and need to be understood across the health and social care system as a joint responsibility.
- A safe place in each community, such as a local café or shop, would help to reassure carers if a person with dementia becomes confused when out on their own. Local councillors could be real dementia friends in supporting a simple initiative like this.

Last word

This evaluation of the York dementia friendly communities programme has demonstrated considerable work and progress over the last three years. It saw the city at the front of a wave of growing awareness of dementia and the importance and opportunity offered by becoming a more dementia friendly community. The timing of this evaluation has enabled reflection on learning from early work, but progress is ongoing and confidence growing, so that there is likely to be an acceleration of effort and impact in the next period. This will be sustained if there is a commitment to dementia friendly communities, not only within the commissioning of health and social care, but also in the delivery of everyday community services.

As one respondent said: *'Nothing's a problem – we can sort it out.'*

Notes

- 1 This target has been exceeded – there are a great many places that are working towards being designated dementia friendly communities e.g. Bradford, Torbay, Blandford, Plymouth, Leeds, Doncaster, Sheffield, with a dedicated website to help aspiring communities at www.dementiaaction.org.uk/joint_work/dementia_friendly_communities
- 2 All 2011 Census figures from www.york.gov.uk/info/200630/census/249/census
- 3 More information available at: www.healthyork.org/about.aspx

References

Collins, A. and Wrigley, J. (2014) *Can a neighbourhood approach to loneliness contribute to people's well-being?* Available at: www.jrf.org.uk/publications/loneliness-evaluation (accessed on 2 July 2015)

Crampton J., Dean J. and Eley, R. (2012) *Creating a dementia friendly York*. York: Joseph Rowntree Foundation. Available at: www.jrf.org.uk/publications/creating-dementia-friendly-york (accessed on 2 July 2015)

Department of Health (2010) *A vision for adult social care: capable communities and active citizens*. London: Department of Health. Available at: http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH_121508 (accessed on 2 July 2015)

Donaghy, I. (2014) *Dear dementia*. London: Hawker Publications

Mirando-Costillo, C., Woods, B. and Orrell, M. (2010) 'People with dementia living alone: what are their needs and what kind of support are they receiving'. *International Psychogeriatrics* 22(4), pp 607–617

Vale of York Clinical Commissioning Group (2015) *Integrated Operational Plan 2014-2019*. Available at: www.valeofyorkccg.nhs.uk/publications/5-year-plan (accessed on 2 July 2015)

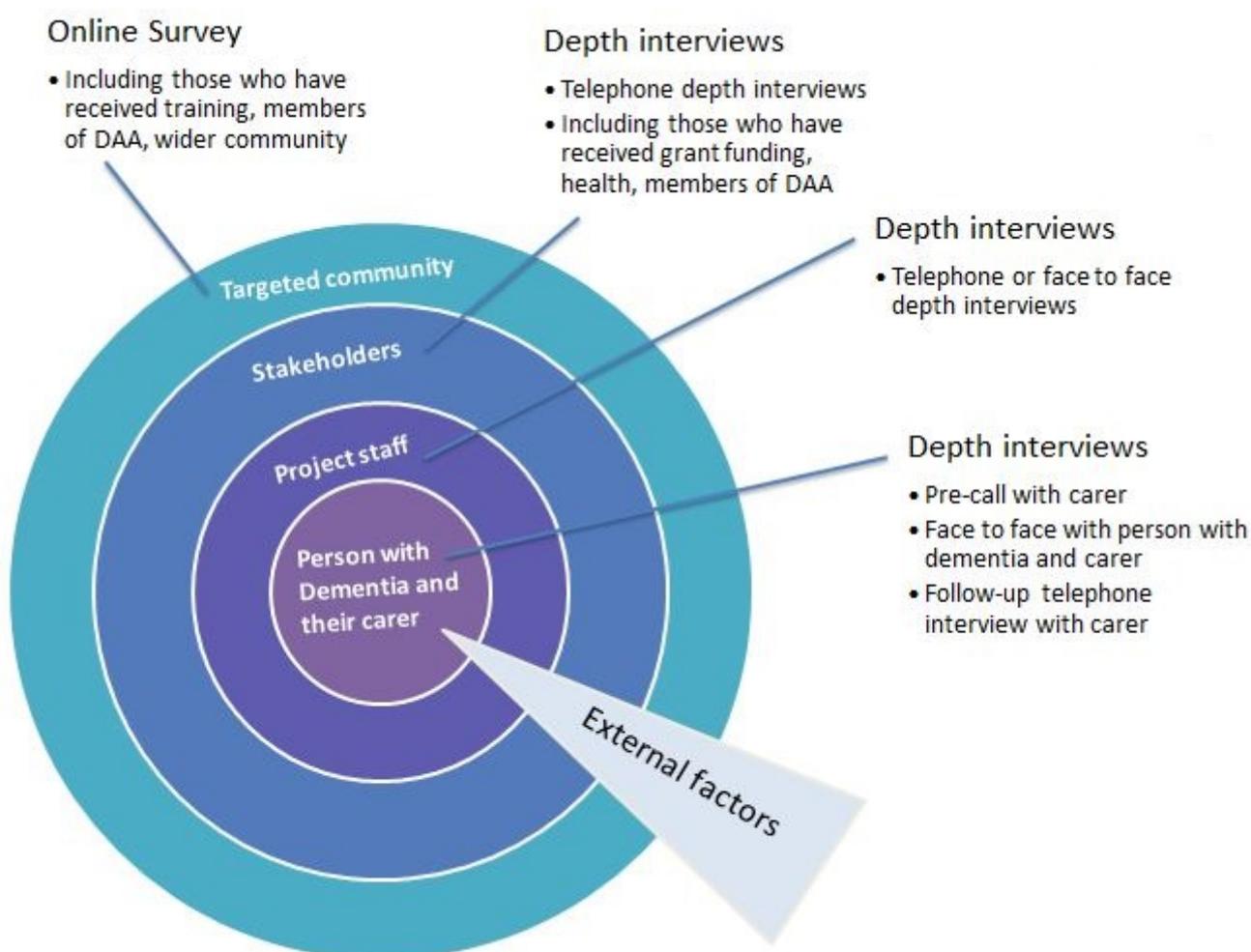
Williamson, T. (2012) *A stronger collective voice for people with dementia*. York: Joseph Rowntree Foundation. Available at: www.jrf.org.uk/publications/stronger-collective-voice (accessed on 2 July 2015)

Appendix 1: Detailed methodology

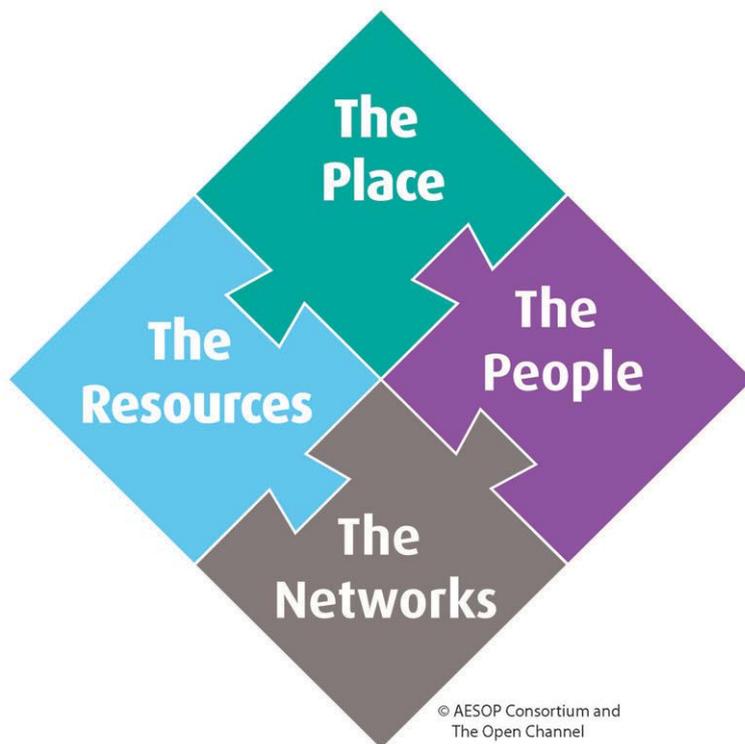
The design for both projects has been based on an evaluation framework which gathers evidence from the full range of stakeholders and participants using a range of appropriate techniques.

Our approach placed the person with dementia at the heart of the evaluation framework, on the basis that the primary beneficiaries of dementia friendly communities are people with dementia themselves. We then conceptually moved outwards from the person with dementia to identify stakeholders and potential respondents from within the family and caring relationships, health and social care services, the neighbourhood and community, the public service system as a whole, and the place with all its resources.

The following demonstrates this approach:



We have used the four cornerstones model developed by AESOP Consortium in their research for JRF which is a model which captures the key dimensions of any dementia friendly community with people with dementia at its heart.



This model has been used (with slight adaptation) by the LGA in the development of a toolkit for dementia friendly communities and is increasingly being adopted as a framework for building the capacity of partners to understand how to make communities more dementia friendly. AESOP Consortium in collaboration with The Open Channel (a leadership development brand co-owned by Janet Dean) has developed an accelerated learning programme based on appreciative enquiry and participatory involvement, learning and action for dementia friendly communities based on the four cornerstones model which has been piloted and is now being rolled out in other localities.

Scoping phase

We took as our starting point a range of stakeholders and potential respondents who were easily identifiable from within the current projects, including:

- people with dementia;
- carers, normally close family relationships;
- family members, and personal networks and supporters of people with dementia;
- health and social care professionals and providers in public, private and voluntary sectors;
- public, private and voluntary service providers of housing, transport, community safety, leisure, cultural, sporting, educational, faith and other neighbourhood services;
- commercial service and product providers including shopping, eating out, banking, insurance, legal services, communications and personal services (such as hairdressing) which impact directly on people's lives;
- other community services and resources which can enhance people's lives or create barriers – ranging from membership associations to online services.

Once we had identified the range of stakeholders/potential respondents and had a clearer understanding of the 'reach' of the projects we then decided on the most appropriate method to adopt, e.g. face-to-face, telephone interview or online survey invitation.

In-depth interviews

In the main, we have used individual face-to-face and small group methods of gathering qualitative data from people with dementia and their carers.

Attendance at meetings and observation

We also attended a variety of meetings and where we observed proceedings, asked questions or led group discussions.

Targeted survey

We have taken a different approach to gathering feedback from professionals and groups of commissioners, service providers or commercial and voluntary sector providers, JRF grant recipients and members of the Dementia Action Alliance. For these stakeholders, we used both small and larger groups or events for face-to-face contact, and (primarily) online surveys for research questions where we wanted to look at the scale of impact as well as the depth. The online survey link was distributed to wider networks by York CVS.

Analysis

The small group and individual in-depth interviews were audio recorded (with consent), transcribed and analysed to identify themes, and areas of consensus and disagreement were noted. If useful for illustrative purposes, direct quotes of the participants are included in the report. As a research team, we reflected on interview findings on an ongoing basis in order to ensure that our findings were consistent.

Responses from the targeted online survey were analysed using statistical software.

Ethical Issues

We have followed guidelines issued by the Social Research Association (SRA) and have abided by its research governance in terms of limiting our research only to the scope of the project and not straying beyond its boundaries, and acknowledging and making accountable our methodologies and our findings. For the research to be of benefit to society and the groups and individuals within it, we have ensured the highest standards of objective impartiality, neutrality, confidentiality and the privacy of the individuals who volunteered to be interviewed or otherwise take part in the research. We have sought consents where they are needed, or used proxies where appropriate without diluting or compromising the data, and have adopted a non-intrusive and sensitive style of conversational enquiry. All conversations and transcripts are confidential and de-personalised (with the exception of those instances where interviewees allow us to use their words as a direct quotation), and we will not divulge anything said to us in confidence.

Qa Research abides by the SRA guidelines and also those of the Market Research Society (particularly in relation to the administration and management of online survey research).

Appendix 2: Case studies

Case study: Harmony Café

Harmony Café forms part of a broader programme of activities organised by Minds in Motion, a community group run by students at the University of York and Hull York Medical School. It provides an environment for people with dementia and their carers to socialise with one another and with the student volunteers.

The cafe runs for a couple of hours once a month on a Saturday afternoon at St. Aelred's Community Centre in York. It is free and includes a buffet and live music. The project works closely with York Alzheimer's Society which helps promote it via its Carer education groups. Many Singing for The Brain attendees also visit Harmony Café. The café is very well attended with upwards of 40 people each month. The co-ordinators believe, however, that there is more that could be done to promote the café.

"There is still a lot more scope to let people know about this. When I have spoken to other people in York, they say 'I wish I had known about it when my dad was alive'...It makes such a difference to all the people that turn up and is the main social event in these people's calendars – we could be doing more though..."

Harmony Café volunteer, York

The café provides a very positive environment and a great atmosphere. People with dementia and their carers clearly enjoy the opportunity to socialise and the live music. Student volunteers chat to participants during the café to gather suggestions and ideas for future activities and types of music that they would like to hear. A couple of carers of people with dementia who have since passed away still attend the café and value the opportunity to socialise and offer support to others. Carers appreciate the opportunity to have somewhere to go with their relatives where they know they can both relax. It is particularly valuable for family members who work during the week as there aren't many other opportunities on a Saturday.

"It's great, it is somewhere where I can come with mum on a Saturday when I'm not working and it's a place where everyone understands".

Carer, York

Case study: Dementia Forward

Dementia Forward was funded by City of York Council to provide the education and awareness raising element to underpin the development of dementia friendly York. Over 70 dementia education sessions have been delivered between 2012 and 2014 with around 3,000 individual attendees. It is evident from feedback from professionals and people with dementia/carers that the training provided by Dementia Forward has been of high quality and very well received.

“Dementia Forward has been the real powerhouse behind this.”

Stakeholder, York

As an aid to engaging businesses with York DAA, Dementia Forward worked with students at the University of York to make a film which demonstrates the benefits of working to become dementia friendly (www.youtube.com/watch?v=j-AVFrIA87E). The film features several York businesses and organisations that are working to become dementia friendly including a firm of solicitors, York station, and City of York Council sports and leisure services. The film emphasises that businesses do not have to do an awful lot to start on the road to becoming dementia friendly and that much of the approach is based in good customer service which has clear benefits for any business.

The awareness raising in York was the initial vehicle for developing and growing York DAA, and funding remains in place for an average of two awareness raising sessions per week. Some organisations have been reluctant to write and review formal action plans, and this may explain why membership of York DAA has levelled off to some extent. Since the appointment of a new chair to the York DAA steering group and the provision of administrative support from York CVS, the profile of York DAA has been higher and this is likely to assist in attracting further members.

Towards the end of the evaluation period Dementia Forward was commissioned to provide a ‘care navigator’ role, within York and Vale of York, signposting people with dementia and their carers to a range of support services.

Case study: Trading standards

North Yorkshire County Council trading standards services has been involved in the development of DFCs from an early stage and officers have been trained in dementia awareness. The team has a strong focus on safeguarding and is in the position of often being the only contact with outside agencies for some older people living alone. The team has developed ways of capturing video statements from people with dementia and using individual’s diaries which can sometimes evidence spending patterns.

Ruth Andrews, Head of Investigations and Safeguarding, is now the national lead for Trading Standards Doorstep Crime and has been able to share her team’s experience of supporting people with dementia with 166 local authorities. NYCC trading standards has developed strong links with the Alzheimer’s Society and a recent survey of local authorities revealed that only 18 per cent had a relationship with their local Alzheimer’s Society. The trading standards team is also working to raise awareness of doorstep crime among neighbours and within communities and to encourage ‘protective neighbouring’. Work is also being carried out at a national level to raise awareness and train staff in financial institutions to recognise the signs of doorstep crime and financial abuse which disproportionately affects older people, including those with dementia.

Case study: British Transport Police

British Transport Police at York station was one of the earliest organisations to take forward actions to make York dementia friendly. Initially, officers were concerned that from time to time they were encountering older people at the station who were confused and disoriented. Contact was made with the Alzheimer's Society with a view to getting them to help or come and 'collect' the individuals.

"The whole thing came from a briefing at the station, and we were asking, why are there all these people with dementia at the station? When I went to the Alzheimer's Society I was looking for a 'quick fix' – can we ring you? Can you come and get them"?

Fiona Andrews, British Transport Police

At the same time work was beginning in York to raise awareness of dementia and this early thinking developed from asking another organisation to take responsibility for people with dementia to thinking about how people with dementia could be supported and encouraged to use the station.

"It became apparent that the problem was not people with dementia but us as a society not understanding – my whole way of thinking changed."

Fiona Andrews, British Transport Police

Early activities included organising free day trips for people with dementia and carers to reacquaint them with train travel and offer reassurance that support is available. These trips were very successful and the work at York station has progressed since then with further dementia awareness training for station and travel centre staff (delivered by Dementia Forward) and the opening of a 'safe haven' within the chaplain's office.

The work at York station has made a significant impact in terms of influence. Stations in West Yorkshire, Doncaster and Hull have approached York for advice on how to implement their own plans to become dementia friendly. East Coast Trains has now also signed up to become a member of York Dementia Action Alliance. British Transport Police are looking at ways in which to embed dementia awareness learning, e.g. to form part of first aid training or perhaps as a topic within staff familiarisation days.

Case study: City of York Council sport and leisure services

City of York Council sport and leisure services have made significant progress in working with staff and local sports clubs to raise awareness about dementia and to work with clubs so that they can adopt an inclusive approach to people with dementia. They developed a document 'Coaching Adults with Dementia: Top Tips for Recreational and Community Coaches' which has been used in the Dementia Awareness Workshop for Sports and Leisure Settings (<http://www.sportscoachuk.org/sites/default/files/Coaching%20Adults%20with%20Dementia%20Top%20Tips.pdf>).

"The focus has been on ensuring clubs adopt a generally inclusive approach, being aware of dementia and showing patience if someone forgets the rules or turns up in the wrong kit – they are more likely to acknowledge that there might be another reason."

Older people's physical activity officer

The work focused on sports that tend to be popular with older people, e.g. bowls, tennis, golf and cricket. Eight sports clubs/leisure facilities attended the workshop. Two of these clubs have submitted action plans to York Dementia Action Alliance, with others working towards becoming dementia friendly after attending the workshop. The work has had influence outside York with other organisations expressing an interest in the workshop after hearing about it at conferences during 2014.

It continues to be a challenge to engage some clubs and organisations and the approach needs to be flexible.

"It took a bit longer to get off the ground than hoped. It's challenging – some clubs aren't certain why they need to be dementia friendly so it is about selling the concept...finding the positives that it can give to a club and focusing on being inclusive rather than specifically about dementia. A lot of them are volunteers and don't have much time."

Older people's physical activity officer

Work is continuing to develop a general club directory for York which will indicate clubs that have received dementia awareness training and/or are working towards becoming dementia friendly. Another strand to the work has included a partnership with Sporting Memories Network, a national initiative which uses sporting reminiscence alongside an opportunity to take part in organised and supported activity. The work ran for six months in different settings – a care home, a community venue and a sports club. The project was slow to take off in the community venue and sports club but reported more success in the care home setting.

Case study: JRF Dementia Without Walls Small Grants Programme

Some of the people with dementia (and carers) who did take part in some of the grant-funded activities spoke in very positive terms about the way in which their lives had been enriched by their involvement. It is well known that many people with dementia retain longstanding skills and interests but they can lose the confidence to participate as dementia progresses and the practical aspects of participation such as transport can be a barrier. The DFC small grants programme has enabled people with dementia to achieve a better quality of life socially and in terms of the therapeutic benefits of the arts. One carer described her father's involvement with Silver Song Box:

"He used to work in a bank, so he was always used to a very structured day....I would go and see him and just find him sitting...[Before] he did bowling, and used to play golf but all the men died and he lost his golfing friends and stopped going to these places. He used to sing and was in a choir in his 20s, and he does go to church, they sing part of the mass in Latin and he remembers some of this....it has given him a lot of confidence. He has been coming [to Silver Song Box] since January, has made a friend and he absolutely loves it."

Carer, York

"I would like to write a few lines in thanks for your efforts in bringing together the resources to allow [name] and myself to join with you and the rest of the team in the informal drawing lessons, we really enjoyed the lessons and the chat, you made [name] as happy as I've seen her for a long while, your care and understanding of her problems made each meeting a joy and something that we now sadly miss now the meetings have had to come to an end, we look forward to hearing from you again in the future, good luck with getting more funding."

Carer/participant, York

Where the grant-funded projects have been successful is in their ability through the individuals involved to demonstrate genuine inclusion and a commitment to maintaining normal, ordinary life for people with dementia. From discussions with people with dementia and carers it was evident that it becomes increasingly difficult to maintain an ordinary life as dementia progresses and these moments of normality are imbued with a new sense of importance.

"The priority needs to be making life normal"

JRF grant recipient, York

In addition, the activities of the grant-funded projects have provided a challenge to conventional notions about what people with dementia can do and enjoy. For example, the Musical Connections project which works in care homes has moved away from the conventional wartime songs and introduced a wide range of musical genres to engage people with dementia, e.g. heavy metal and reggae. The way in which this project works by linking with local schools also provides an opportunity to address stereotypical views of older people.

Acknowledgments

Our thanks to everyone with dementia and their carers who contributed to interviews, workshops and the survey.

Thanks also to the following people and organisations:

Age UK, York
Alzheimer's Society, York
Aroma Café
Arty Farty
British Transport Police
City of York Council (sports and leisure, adult social care, housing)
Damian Murphy
Dementia Forward
Galtres Care Home
Halifax Bank
Harrowell's Solicitors
Here Now Dementia
Home Instead, York
Jayne Gledhill
Joseph Rowntree Foundation
Joseph Rowntree Housing Trust
Musical Connections
NYCC Trading Standards
Silver Song Box
Specsavers
The Retreat
University of York – Minds in Motion
Vale of York CCG
Visit York
York Carers Forum
York CVS
York Hospital
York Minster
York Older People's Assembly
Yorkshire & Humber Dementia Action Alliance

About the authors

Janet Dean is a director of Dean Knight Partnership and provides expert advice for national and local government and charities. For 20 years she worked as a director in local government in London and Yorkshire and as a non-executive director in the health and housing sectors. She is co-author of *Creating a Dementia Friendly York* published by JRF in 2013.

Kay Silversides is a social researcher with 15 years' experience in designing and conducting qualitative and quantitative research, and service/programme evaluation studies on behalf of a range of public and third sector clients. Areas of research include older people and ageing, and children and families.

Julie Wrigley is a social researcher experienced in qualitative and quantitative research and evaluation methods. Julie also has extensive voluntary experience over the past 20 years, with young people, those with special educational needs, those in the youth criminal justice system and carers.

Janet Crampton is a health and social care consultant with over 20 years' experience in national and local government. She was a former national programme manager at the Department of Health and lead commissioner for older people's and dementia services and was part of the team that developed the National Dementia Strategy 2009. A governor of South Tees Hospitals NHS Trust, she chairs their Independent Review Panel, and is also chair of Northallerton Dementia Action Alliance. She is co-author of *Creating a Dementia Friendly York* published by JRF in 2013.

The Joseph Rowntree Foundation has supported this project as part of its programme of research and innovative development projects, which it hopes will be of value to policy makers, practitioners and service users. The facts presented and views expressed in this report are, however, those of the author[s] and not necessarily those of JRF.

A pdf version of this publication is available from the JRF website (www.jrf.org.uk). Further copies of this report, or any other JRF publication, can be obtained from the JRF website (www.jrf.org.uk/publications) or by emailing publications@jrf.org.uk

A CIP catalogue record for this report is available from the British Library.

All rights reserved. Reproduction of this report by photocopying or electronic means for non-commercial purposes is permitted. Otherwise, no part of this report may be reproduced, adapted, stored in a retrieval system or transmitted by any means, electronic, mechanical, photocopying, or otherwise without the prior written permission of the Joseph Rowntree Foundation.

© Dean Knight Partnership Ltd

First published August 2015 by the Joseph Rowntree Foundation

PDF ISBN 978 1 91078 301 6

Joseph Rowntree Foundation

The Homestead

40 Water End

York YO30 6WP

www.jrf.org.uk

Ref 3131



Inspiring Social Change