

Living Well with Dementia:
A Participation and Engagement
Programme for People with Dementia
and their Carers

Development and Evaluation Report

March 2015



Karen Picking & Associates
Innovative Development for Healthcare Improvement

**NORTH EAST
DEMENTIA
ALLIANCE**

North of England
Mental Health Development Unit

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Executive Summary

This report outlines the developmental process and evaluation outcomes of a pilot Participation and Engagement programme for people with dementia and their carers, designed and delivered in the north east of England from June 2013 to December 2014. The programme was commissioned by the North East Dementia Alliance and developed through a collaboration with the North of England Mental Health Development Unit (NEMHDU) and leadership experts Karen Picking & Associates.

1. Background

According to the Alzheimer's Society, there are currently around 800,000 people living with dementia in the UK, with one in three people over 65 expected to develop some form of dementia during their lifetime.¹ Described as the 'biggest health crisis facing the world today',² in recent years the health and wellbeing needs of people diagnosed with dementia have received increasing attention at a policy, clinical and academic level. However critics argue that many people living with dementia continue to be let down.³

In 2012 the UK Prime Minister announced a *Challenge on Dementia*,⁴ to deliver major improvements through additional research funding, continued development of health and social care services, and the creation of 'dementia friendly communities'. This commitment was reinforced in February 2015 when a further *Challenge on Dementia 2020* outlined aspirations for research and service improvement for the next five years.⁵ In addition, the December 2013 G8 dementia summit saw a pledge to double government investment in dementia research to £132million by 2025, as part of an internationally agreed commitment to developing a cure and improving the quality of life for people living with dementia.⁶

In 2013 the North of England Mental Health Development Unit (NEMHDU) was approached by the North East Dementia Alliance (NEDA) to work together to develop a regional 'Participation and Engagement' initiative for people with a dementia diagnosis and their carers. The overall aims of the programme were to:

- Help people to become more involved in their own individual care planning
- Increase participation and encourage involvement in the wider design and development of services

Working in partnership with leadership specialists Karen Picking and Associates, the project involved the design, delivery and evaluation of two pilot programmes; one in the south of the region (May-July 2014) and one in the north (October-December 2014).

2. Development and Evaluation Process

A multi-stage approach was taken to the development and evaluation of the pilot programme. This included:

1. Literature review of the current landscape of user and carer involvement in UK dementia services.

2. A series of developmental 'expert knowledge sharing events' to gather the views and experience of stakeholders including people with dementia and their carers, clinicians and other frontline workers, policy leads and academics.
3. Ongoing evaluation of the programme throughout the pilot phase including initial data gathering, paper-based individual session evaluations and a final course evaluation.
4. Qualitative, semi-structured follow-up interviews with programme participants 6-12 weeks after the pilot phase, to explore their experiences in more depth.

This report outlines both the developmental process and findings from the various evaluation elements.

3. Literature Review: Key Findings

As part of the pre-programme development phase, a literature review was undertaken to examine the contribution of both academic and 'grey' (not formally published) literature to our understanding of user and carer involvement in UK dementia care, including any reported outcomes of existing intervention programmes.

Living with dementia: The subjective experience

Dementia research has traditionally held a biomedical focus on finding a cause, cure or other mechanism to control symptoms. It is only within the last few years that the person with dementia, and those caring for them, have become a research focus in their own right. The 'user movement' in dementia care is in its infancy, with much work to be done before terms such as 'participation', 'empowerment' and 'social justice' become as prevalent in dementia as they appear in many other long term conditions.⁷ However, the lack of progress in finding a biomedical way to prevent deterioration has led to growing interest in non-medical treatment such as cognitive and psychosocial interventions.⁸

The research literature has seen a recent shift towards greater emphasis on the individual, subjective experience of people living with dementia and those who care for them. Authors have for example begun to explore quality of life indicators specific to dementia,⁹ ideas around identity and self-concept,¹⁰ experiences of the care process, levels of emotional burden and coping styles.¹¹

User and carer involvement in dementia care

Perhaps the most useful and comprehensive discussion of current user and carer involvement in dementia care has been provided by the Joseph Rowntree Foundation (JRF), as part of the charity's *Dementia & Society* discussion stream. In 2012, JRF published a mapping report which was identified by the authors as the first systematic attempt to explore the current scope and future needs of existing user involvement projects in the UK.¹²

The authors note that the user movement in dementia care is growing in size and momentum yet is still in its infancy, with the small number of projects that do exist undertaking similar activity to other areas of health but on a much smaller scale. The groups identified were in varying stages of development but were

often new and still in the process of becoming established. Individual involvement was often tentative, in part because many people were still coming to terms with their diagnosis and were unsure of the extent to which they wanted to participate in collective influence outside of their own personal circumstances.¹³

In 2012 the Mental Health Foundation also published a useful literature review of the involvement of people with dementia in services, campaigns and research.¹⁴ The findings provide valuable qualitative insight into the motivations, outcomes, facilitators and barriers associated with involvement activity from the participant's viewpoint. Identified involvement benefits included peer support, a sense of belonging and increased understanding about the diagnosis, as well as the 'collective strength' created by group membership.¹⁵ Elsewhere, reported benefits include increased confidence and self-esteem, the development of skills and strong friendships, feelings of pride and the inclusivity of being part of an international 'dementia family'. However the costs of involvement have also been highlighted, including fatigue, the loss of personal time and often substantial travel requirements.¹⁶ Furthermore, questions have been raised about the future development of the user movement in dementia, particularly around whether user-focused initiatives can move from being seen as a luxury 'add-on' to an integral part of service provision within the current economic climate, and whether an increase in public resources will be made available to sustain and support its growth at a service-level.¹⁷

Methodological issues and research gaps

In its current form, the evidence base related to user involvement and user experience in dementia care holds a number of limitations. Key issues include:

- An overall lack of research into the subjective experience of people with dementia and the developing user movement, although this is increasing over time.
- What research does exist is generally confined to the 'grey' literature. While this is not a criticism in itself, it prevents findings from being subject to peer review and reduces discussion with academic stakeholders.
- Existing studies tend to be small-scale, qualitative and with varying degrees of methodological quality, which can make it difficult to draw conclusions about effectiveness.
- Recorded outcomes tend to provide a short-term picture of benefits and costs to the individual participant. Longer term outcomes and organisational/service-level impact both appear as valuable areas for future exploration.

There is a clear need for continued documentation and evaluation of attempts to involve users and carers in the design and development of dementia services. This is crucial to expanding the existing evidence base and providing examples of best practice, discussion of the barriers and challenges, and other key learning that may be of benefit to other projects and contexts.

4. Programme Development: Expert Knowledge Sharing

Following the literature review, development of the pilot programme's content and structure involved two key aspects. Firstly, an 'expert reference group' knowledge sharing event was held in July 2013 which brought together clinicians, service leads and other key stakeholders to gather knowledge and share ideas about what the 'ideal' programme might look like. Secondly, the perspectives of people with a dementia diagnosis and their carers were gathered through a series of discussions with existing, community-based dementia groups. Discussions in both of these forums centred around five key topics: 1: Course Outcomes, 2: Course Content, 3: Participation and Recruitment, 4: Delivery and Logistics, and 5: Support Requirements. These discussions are summarised as follows:

Course outcomes - Participants described a range of desired outcomes of the ideal dementia engagement programme. Ideally, by the end of the course participants will have built on existing abilities to develop:

- **Knowledge of dementia services and providers** and an understanding of what a 'good' standard of care looks like.
- **The skills required to help shape services and challenge provision**, including the ability to present issues in a constructive way and articulate the needs of self and others.
- **Personal outcomes** including ability to overcome personal care barriers, confidence, problem solving strategies and practical skills that will make a difference to day-to-day life.

Course content - Discussions highlighted the following aspects as core course content for the ideal programme:

- **Individual-focused** content including the identification of individual skills and goals which can be used as a reference point to re-visit as the programme develops.
- **Knowledge-focused** content including the structure of local, regional and national dementia services and where involvement opportunities exist or could be created.
- **Skills-focused** content including listening, communication, influencing, negotiating, assertiveness and presentation skills.

Participation and recruitment – expert input suggested that:

- Course participants should have a **specific dementia diagnosis** or be a carer of someone with a dementia diagnosis and a **desire to engage with service development** activities in order to create change.
- Recommendations for the identification and recruitment of participants included the use of a diverse **range of recruitment techniques** to attract under-represented groups, and **engagement with existing organisations** to promote the programme.

Delivery and logistics - The following factors were raised as crucial to programme delivery:

- **Location** – move away from a venue-based approach (e.g. hotel or conference centre) towards something more **familiar, tailored** and **dementia-friendly** – the **physical environment** will be crucial to the programme's success.
- **Structure** – move away from large group sessions towards something more individualised, such as a combination of group **'master classes'** and individual/ small group coaching.

- **Duration and timing** – move away from full day sessions in favour of **shorter but more frequent** ones; perhaps a **'light' version** of the course that requires less commitment than existing leadership programmes.

Support requirements – discussions highlighted the following:

- Recommendations for *pre-course support* included ensuring that the venue, course materials and transport links are **dementia-friendly** and asking individual participants about their **personal support requirements** at an early stage.
- Recommendations for support *during the course* included the development of clear, **practical guidelines** provided well in advance; using a **range of methods/styles** of communication including visual and spoken forms and communication/**staying in touch with participants between sessions**.
- Recommendations for support *after the course* included supporting participants to **explore routes** to how they could use their developed skills (and perhaps **supporting organisations** to make the most of the skills offered).

Findings from the pre-programme development phase were used to inform the aims, content, delivery and recruitment strategy of the pilot programme.

5. Programme Content and Delivery

The programme was designed based on learning from the development stages as well as practical delivery considerations. The basic structure consisted of two main aspects: core learning (elements considered fundamental to the programme's aims), and a flexible element (tailored to individual participant need).

The course was structured around 5 main delivery elements:

Introductory session Introduction to the programme, getting to know each other, finding out individual needs, aspirations and suggestions for bespoke course elements.

Day 1 Getting to know you, Overview of dementia services, Individual skill identification, Skill building.

Day 2 Sharing knowledge and information on local services, Listening skills and being heard, Managing conflict, Effective communication in meetings.

Day 3 Focus on individual goals and aspirations, Mapping a service journey, How do I/we want to be involved and influence, Where and how can I/we do this.

Day 4 Next steps to achieving personal goals/targets, Emotional and physical wellbeing, Developing a Wellbeing Plan, Reflection and personal journeys.

A total of 31 participants were recruited to the two cohorts (20 carers and 11 people with a dementia diagnosis), using a flyer distributed to stakeholder networks via the North East Dementia Collaborative as well as targeted advertising to care professionals. Eligibility was deliberately kept broad; the criteria

consisting of living in the general geographical area of the pilot, being available to attend all of the sessions, and either having a recent diagnosis of dementia or having an unpaid caring role for someone with a dementia diagnosis. Participants received written confirmation and a follow-up telephone call to confirm attendance and help with any travel arrangements.

Session facilitators were drawn from the delivery partners (North East Dementia Alliance, NEMHDU and Karen Picking & Associates), plus a range of external speakers who were chosen according to the knowledge and skills required for each specific topic. Topics for each programme were selected depending on the objectives of the participants. Sessions involved a variety of different learning methods including presentations, small group work and whole room discussions. Care was taken to choose 'dementia friendly' venues for each cohort, based on recommendations by the North East Dementia Alliance and site visits by the development team. Each day session was no longer than a maximum of 5.5 hours, including a number of refreshment breaks and the availability of a separate 'time out'/relaxation area for those who wished to take some time away from the session.

A demographic overview of programme participants can be found in Figure 6.1 (page 29).

6. Programme Evaluation: Key Findings

Evaluation data was collected across the course of the programme through a combination of initial baseline data, individual session feedback forms and a final post-course evaluation questionnaire. In addition, 17 course participants (61%) took part in a follow-up qualitative interview with a member of the NEMHDU research team 6-12 weeks after the course had ended.

Key findings are as follows:

- Both quantitative and qualitative elements of the evaluation showed a very positive response to the programme.
- Satisfaction with the programme was rated on average as 'good' or 'excellent' on seven different aspects measured, including session content, course tutors, overall quality of the programme and how well participants' individual support needs were met.
- The programme was rated on average as 9 out of 10, when participants were asked how highly they would recommend it to other people with dementia and/or their families.
- There were marked improvements in self-reported understanding of specific topics covered throughout the two cohorts (such as shared decision making, local services, and personal budgets). In addition, respondents reported improvements in knowledge and/or confidence in a number of broader areas, including how to give feedback about services, confidence gathering the views of others and discussing care with professionals.
- Over 4 out of 5 respondents reported that the course had helped them towards achieving their individual goals identified at the start of the programme. A number of additional, unanticipated effects were also reported including increased assertiveness, a more positive outlook and increased understanding of coping mechanisms.

Peer networking and developing friendships was regarded as a highly valued element of the programme. It proved most beneficial to those who it was specifically targeted at; namely those with a recent diagnosis of dementia (or those caring for someone with a recent diagnosis). Those at later stages of the illness appeared to gain less in terms of acquired knowledge and skills, yet still reported some benefits. In addition, some of the peer-to-peer knowledge shared across these two groups was reported to be of great value.

7. Discussion and recommendations

The reported findings have highlighted both successes and challenges of the piloted programme model. Having acknowledged that the idea for the programme arose from a noted gap in the current level of service user and carer involvement in dementia care planning and evaluation within regional services, and a commitment to improvement, it is clear that the pilot programme has responded to an otherwise unmet need amongst people with dementia and their carers - that being the reported gap in information and support following diagnosis. Were the Living Well with Dementia programme to become an integral part of the post-diagnosis support offered, this may help to facilitate an ongoing dialogue between programme participants, service providers and commissioners. This would also go some way to meeting a number of the aspirations set out in the Prime Minister's *Challenge on Dementia 2020*.¹⁸

Participants on the programme reported the benefits of social interaction and peer support, not only during the programme but also in friendships and networks maintained beyond the programme. This reflects the benefits of involvement reported elsewhere, including increased confidence and self-esteem, the development of skills and strong friendships, feelings of pride and the inclusivity of being part of an international 'dementia family'.¹⁹ It is worthy of note that the Living Well with Dementia programme is already receiving attention amongst healthcare professionals across the North East and potentially further afield, having been included as a case study in the report *Dementia 2014: A North East Perspective*²⁰ and the service mapping elements of each cohort being fed into the North East Clinical Network for Mental Health, Dementia and Neurological Conditions at a commissioning event in March 2015.

It is however our opinion that there is a current mismatch between the drivers of this type of initiative, which can often seem to be the system's need to have people involved in the development and monitoring of service provision, and service user and carers' drivers to be more involved in their own care. It was made clear by those attending the course that their main drivers were around increasing their own skills and knowledge in order to have better outcomes for either themselves or those that they care for. Only a small proportion of those people would then become involved at a local service level and an even smaller proportion of those would become involved at a strategic/developmental level within the system. The main drivers for this programme, therefore, should be those which drive better personal, clinical and social outcomes. This will naturally lead to a large group of skilled and knowledgeable individuals, from which system leaders will emerge.

Recommendations featured in the main report include:

1. The presentation of findings to commissioners and providers of dementia services across the North East.

2. Exploration of the possibilities to pilot an 'embedded' Living Well with Dementia programme early into the diagnostic pathway.
3. Exploration of funding possibilities to spread the implementation of the participation and engagement programme.
4. Further research into the longer term impacts of the programme for participants and organisations.

1. Introduction

1.1 Dementia: A growing global health issue

According to the Alzheimer's Society, there are currently around 800,000 people living with dementia in the UK, with one in three people over 65 expected to develop some form of dementia during their lifetime.²¹ As improved healthcare enables the population to live longer, dementia represents a steadily growing global health issue. Described as the 'biggest health crisis facing the world today',²² the 2013 World Alzheimer Report has argued that by 2050 the total number of older people with dementia-related long term care needs will have reached 277 million globally.²³ In the UK alone, the latest figures estimate that by 2021 the number of people with dementia will have reached around 1 million. The annual cost of dementia to the UK is currently estimated at around £23 billion, with the care carried out by unpaid family carers valued at around £8 billion.²⁴

'Dementia is now a public and political priority in a way that it has never been before.'
(Alzheimer's Society, 2012a:6)

In recent years the health and wellbeing needs of people with dementia have received increasing attention at a policy, clinical and academic level. However, as the literature review section of this report highlights, the 'user movement' in dementia care is in its infancy and there is a notable lack of research into the effectiveness of social interventions or user involvement initiatives in dementia. It is hoped that this report will add to the small but growing literature base by providing an account of the development and evaluation of a Participation and Engagement Programme for people with dementia and their carers, funded by the North East Dementia Alliance and piloted in the north east of England during 2013.

1.2 Improving services for people with dementia: A national approach

Over the last decade, dementia has become a key health focus for UK policymakers. Following the Department of Health's (DH) 2001 publication of the National Service Framework (NSF) for Older People,²⁵ in 2007 the first national dementia-specific resource guide, *Strengthening the Involvement of People with Dementia*, was published.²⁶ This coincided with the Mental Capacity Act 2005's introduction of safeguards and procedures which signified a move towards greater focus on an individual's right to independence and respect during the care process, including those with a dementia diagnosis.²⁷

Following this milestone, a series of published reports further developed national discussion around the challenges posed by dementia and identified the need to significantly improve dementia services.^{28,29,30} In 2009 England's first national dementia strategy, *Living Well with Dementia*, was published.³¹ Based on a national consultation, the strategy set out 17 objectives with an aim to improve the lives of people living with dementia, from early diagnosis through to effective end-of-life care. One of these (Objective 5) focused specifically on the development of learning and peer support for people with dementia and their carers. Elsewhere in the UK, Scotland, Wales and Northern Ireland have developed their own dementia strategies as well as additional high profile documents including the 2009 *Charter of Rights for People with Dementia and their Carers in Scotland*.³²

Building on this momentum, in 2010 the UK coalition government published an outcomes framework to support implementation of the national dementia strategy,³³ however not all of the original objectives were prioritised and Objective 5 was amongst those not carried forward as a priority. In England the Dementia Action Alliance (DAA) was created, made up of a range of statutory and non-statutory organisations, and went on to publish a National Dementia Declaration which outlined seven outcomes that people with dementia want to see in their lives.³⁴

Despite the growing policy focus, a recent report by the Alzheimer's Society argues that many people with dementia continue to be let down:

'Despite the significant spend on dementia, this is not being developed effectively and too many people are not provided with good quality care and support that meets their needs and aspirations. Furthermore, the quality of care varies considerably across geographical areas.' (Alzheimer's Society, 2012)³⁵

In 2012 the UK Prime Minister announced a *Challenge on Dementia*,³⁶ to deliver major improvements in care and research by 2015. This included a commitment to the provision of additional research funding, to the continued improvement of health and social care services for people with dementia, and to the creation of 'dementia friendly communities' by working with organisations within local communities that come into regular contact with people with dementia and their families.

Despite this pledge dementia remains an area of intense debate, with attention being drawn to the lack of research funding when compared to higher profile areas of health such as cancer.³⁷ Ahead of the G8 dementia summit held in London on 11th December 2013, the Alzheimer's Society joined other international charities in calling for a collaborative global action plan for dementia research, significantly increased funding to support it, and assistance to 'attract, develop and retain the best scientists, clinicians and care professionals'.³⁸ Following this, at the G8 summit the UK Prime Minister announced plans for the UK to become an international leader in the field of dementia research, and committed to doubling the government's investment in dementia research to £132million by 2025. This formed part of an internationally agreed commitment from Health Ministers to invest in greater innovation and ambition in order to develop a cure and improve the quality of life for people living with dementia by 2025.³⁹

More recently, in February 2015 the UK Prime Minister issued his second *Challenge on Dementia 2020*,⁴⁰ which builds on the initial 2012 proposal by setting out the government's aspirations for the next five years. Alongside research, prevention, improved service access and enhanced training and awareness, there is a continued focus on developing dementia friendly communities. Of particular interest in the current context is the document's emphasis on the need for meaningful care following diagnosis; to include information on post-diagnosis services, access to relevant advice and support and appropriate support for carers.

1.3 Developing dementia services at a North East regional level

Of the seventeen objectives set out in England's 2009 national dementia strategy, *Living Well with Dementia*,⁴¹ seven key priority areas were identified in the north east:

1. Good quality early diagnosis
2. Improved community support services
3. Improved quality of care in general hospitals
4. Housing support, housing related services and telecare support
5. Living well with dementia in care homes
6. Improved 'end of life' care for people with dementia
7. Reduced inappropriate prescribing of antipsychotic medication

The North East Dementia Alliance (NEDA) has played a key part in taking these priorities forward. Set up in 2008, part-funded by the Department of Health and hosted by Newcastle University, NEDA forms a partnership of health, social care, voluntary and private sector organisations concerned with the effective implementation of the national dementia strategy in the north east.⁴² It aims to drive improvements in health and social care for those with dementia, undertake research and enable the development of dementia friendly communities in the region. Involving people with dementia is crucial to their work, which shares the priorities described above as well as focusing on the improvement of care and support to those living with dementia in minority communities.⁴³

Within the north east, dementia also forms part of the formal strategic clinical networks. A dementia work programme sits within the mental health, neurological conditions and dementia strategic network, which is currently developing its own outputs to influence dementia services and commissioning across the region. It is hoped that learning from this pilot process will feed into this overall programme of activity.

1.4 Living Well with Dementia in the north east: A participation and engagement programme

In 2013 the North of England Mental Health Development Unit (NEMHDU) was approached by the North East Dementia Alliance to work together to develop a 'Participation and Engagement' initiative for people with a dementia diagnosis and carers of people with dementia. The overall aims of the programme were to:

- Help people to become more involved in their own individual care planning
- Encourage involvement in the wider design and development of services

The idea for the programme arose from a noted gap in the current level of service user and carer involvement in dementia care planning and evaluation within regional services, and a commitment to improving these levels of involvement. The project involved the design, delivery and evaluation of two pilot programmes; one in the south of the region (May-July 2014) and one in the north (October-December 2014).

This report outlines findings and discussion points from the developmental stages and subsequent evaluation of the programme, which has drawn on the shared knowledge and experience of a range of

experts including service users, carers, clinicians, academics, researchers, policy leads and frontline workers.

1.5 Delivery partners

1.5.1 *NEMHDU's background and strategic activities*

The North of England Mental Health Development Unit (NEMHDU) is a social enterprise based in the North of England. NEMHDU's mission is to improve the mental health and social wellbeing of local communities by:

- Working alongside statutory and independent organisations to develop and deliver their strategic objectives, increase their efficiency and capacity and deliver recovery-focused outcomes.
- Working alongside service users and carers to develop an active role in their care as well as the development of health and social care services.

NEMHDU's work aims to ensure that service users, families and carers are able to play an active role in the development and evaluation of effective, recovery-focused services.

NEMHDU has a ten year track record of delivering leadership programmes for people with lived experience of mental health problems and their carers. Whilst this has been predominantly adult focused, two exciting new aspects of this ongoing programme are the young leaders programme, developed alongside Young Minds, Change UR Mind and Youth Focus North East, and this pilot Living Well with Dementia programme.

1.5.2 *Karen Picking and Associates*

Karen Picking & Associates are a collaboration of healthcare development specialists with leading edge knowledge, skills and expertise in the fields of leadership and organisational development. They are leaders in the development of both service user and clinician-focused leadership programmes and have worked alongside NEMHDU in the development and delivery of their service user and carer leadership development programmes for a number of years.

2. Development and Evaluation Methods

A multi-stage approach was undertaken to developing and evaluating the Participation and Engagement pilot programme. This included a series of ‘expert knowledge sharing’ events to inform the programme’s development; individual session and final course evaluation questionnaires; and a qualitative follow-up phase 6-12 weeks after the completion of each cohort.

This section provides a brief overview of the development and evaluation process; further details can be found at the start of individual sections.

2.1 Pre-programme development

1. *Literature review of existing knowledge on dementia interventions and user involvement*

As part of the pre-programme development phase, a scoping exercise was undertaken to explore the contribution of both academic and ‘grey’ literature to our understanding of user and carer involvement in dementia care, including any reported outcomes of existing involvement programmes. Key findings are presented in Section 3.

2. *Programme development: Expert knowledge sharing*

Development of the pilot programme’s specific content and structure involved two key aspects. An initial ‘expert reference group’ knowledge sharing event, held in July 2013, brought together 30 clinicians, service leads and other key stakeholders to gather knowledge and share ideas about what the ‘ideal’ programme might look like. Following this, the perspectives of people with a dementia diagnosis ($n=20$) and carers ($n=18$) were gathered through a series of discussions with existing, community-based dementia groups. Key findings from the expert knowledge sharing phase of the project are presented in Section 4.

2.2 In-programme and immediate post-programme evaluation

Given the nature of the pilot programme as the first attempt to deliver a dementia-specific participation and engagement initiative in the region, it was considered important to give participants an opportunity to feed back after each individual session, as well as collecting pre- and post-programme information. The evaluation process was made up of a series of related elements:

3. *Initial programme data collection*

A brief questionnaire was developed and used to guide individual discussions with participants at the beginning of their involvement. This was used to record brief demographic information, reasons for taking part and individual goals that the person wanted to achieve, as well as any concerns, support requirements and/or specific topics that the participant would like to learn about. Participants were also asked to rate their current knowledge and confidence in a number of areas (e.g. knowledge of local services, confidence in gathering/presenting the views of others), as a baseline for the post-course evaluation.

4. *Individual session evaluation*

Brief individual session evaluation forms were used to gather immediate feedback after each part of the programme, by asking participants to rate specific aspects of the session (e.g. length, content, hand-outs, overall quality) and say a few words about the aspects that they liked most and least. Participants were also asked to rate their understanding of the session topics 'before' and 'after'.

5. *Post-programme evaluation*

A self-report final evaluation questionnaire was given to participants at the final session. This tool was designed primarily to examine overall client satisfaction with various aspects of the programme, and also to briefly explore individual perceptions of any outcomes in terms of knowledge and/or skills developed, goals attained or any changes to wider aspects of the person's wellbeing.

All of the tools developed were designed to be brief. They combined closed questions and ratings scales with opportunities for open-ended qualitative response. Participants were offered support to fill in the questionnaires if needed. Individual session evaluation forms and the post-programme questionnaire had the option to be anonymous, although participants were able to record their name should they wish to discuss their comments in more depth with a member of the team.

Questionnaire responses were subject to quantitative and qualitative analysis. Findings are presented alongside the interview analysis in Section 6.

2.3 Qualitative follow-up phase

6. *Follow-up interviews with programme participants (n=17)*

A qualitative follow-up phase took place during November 2014 for cohort 1 and January 2015 for cohort 2, to explore in further depth the subjective experiences of programme participants. 19 course participants (61%) expressed interest in taking part in a follow-up interview with the NEMHDU research team. Of these, 17 respondents were available and happy to take part upon follow-up. A range of options were offered in order to remain flexible to individual circumstances, however all participants opted to be interviewed face-to-face at their own home. Interviews were undertaken by a member of the NEMHDU research team who had had minimal input into the programme itself, in order to maintain a level of externality for participants.

A semi-structured interview topic guide was developed based on key themes and understanding drawn from earlier stages of the programme's development and evaluation. Topics explored included experience of the programme, any impact on participants' knowledge, skills or wider wellbeing, and any ways that the skills or knowledge developed had been used in the 2-3 months since course participation. Interview notes were then analysed thematically by the research team and sorted into key themes and areas of discussion.

Figure 6.1 (page 29) provides a demographic overview of those who took part in the pilot programme and the different evaluation elements.

3. Programme Development: Literature Review

3.1 Scope of the literature review

As part of the pre-programme development phase, a literature review was undertaken to examine the contribution of both academic and 'grey' literature to our understanding of user and carer involvement in dementia care. Two key questions were considered:

- What is the current landscape of service user and carer involvement in UK dementia care?
- What are the reported health, wellbeing and wider outcomes of existing dementia intervention programmes?

The scoping exercise examined both local and national programmes including evaluation studies, primary research and previous reviews by academic institutions. The remainder of this section highlights some key emerging themes, issues and recommendations from the available literature.

3.2 Dementia research: The current context

3.2.1 *Research funding and priorities*

Over the last decade, public awareness and understanding of dementia has progressed considerably. Despite the increasing international spotlight on dementia and its significant annual cost to the global economy however, attention has been drawn to a lack of research funding compared to higher profile areas of health such as cancer research.⁴⁴ Ahead of the G8 dementia summit held on 11th December 2013, the Alzheimer's Society joined other international charities and key organisations in calling for a collaborative global action plan for dementia research, significantly increased funding to support it, and assistance to 'attract, develop and retain the best scientists, clinicians and care professionals'.⁴⁵ Following this, at the G8 summit David Cameron announced plans for the UK to become an international leader in the field of dementia research, and committed to doubling the government's investment into dementia research from £66million next year to £132million by 2025. This formed part of a global agreement for co-ordinated action on dementia, in which the UK will take the lead in exploring innovation in 'social impact investment'.⁴⁶

While the UK and international commitment to dementia research investment is clearly increasing, at present there remain many gaps in the existing evidence base, both in relation to medical and psychosocial interventions and also specific to user and carer involvement in dementia care. Dementia research has traditionally held a biomedical focus on finding a cause, cure or other mechanism to control symptoms. While this is perhaps understandable, it is only within the last few years that the person with dementia, and those caring for them, have become a central focus in their own right. As we will see as the literature review develops, the 'user movement' in dementia care is in its infancy, with much work to be done before terms such as 'participation', 'empowerment' and 'social justice' become as prevalent in dementia as they appear in many other long term conditions.⁴⁷

3.2.2 Cognitive and psycho-social interventions in dementia

Despite over two decades of active research into a biomedical cure or preventative treatment for dementia, the international research community have made little progress in finding a way to significantly prevent deterioration. In the understanding that - when discovered - the cost of medical treatment is likely to be prohibitive, particularly as the prevalence of dementia is set to increase as people live longer, there has been growing interest in non-medical treatment such as cognitive and psychosocial interventions.⁴⁸

While few such interventions have been subject to robust evaluation until very recently, positive findings have been emerging since the 1960s, when use of the Reality Orientation approach was observed by researchers to create a shift from hopelessness to hopefulness in people with dementia.⁴⁹ Since then a range of different techniques have been developed and piloted including reality orientation, cognitive stimulation and family interventions. Despite promising findings of a positive effect on both people with dementia and those caring for them, early reviews of the evidence pointed to vast methodological issues in the evaluation of such techniques and only a few examples of randomised controlled studies (RCTs), which are generally considered to be the 'gold standard' of evaluation research.⁵⁰ In addition, the majority of early studies were US-based and it is not clear how findings could be translated to the European context.

A range of methodological and ethical issues have prevented researchers from undertaking large-scale, randomised controlled trials of psychosocial interventions, particularly in light of the applied setting and differences in service context even within fairly small geographical areas. Baseline measures can be difficult to establish, variables cannot always be controlled, replication is difficult and there are substantial ethical dilemmas involved in potentially withholding treatment from those who form part of the required 'control' group.⁵¹ The lack of an internationally accepted evidence base is argued to have formed the key barrier to psychosocial interventions for dementia moving forward, as evaluations have largely remained small-scale and fragmented in their approach.⁵²

In response to this problem, in 1999 a European network of dementia researchers, INTERDEM, was established to support the development of large scale, high quality pan-European research collaborations to move forward the evidence base. To date the network has shed light on issues around European variations in the quality of dementia care, stigma and timely diagnosis, and is currently working to develop pan-European guidelines and quality indicators for psychosocial interventions.⁵³ A subsequent increase in randomised controlled trials have led to promising findings that illustrate reality orientation and reminiscence therapy to have cognitive benefits comparable to anti-dementia drugs, as well as wider quality of life benefits.⁵⁴ Cognitive stimulation therapy (CST) has been trialled in a number of European countries including Spain and Italy and is now recommended in the UK as part of NICE guidelines for the management of dementia.⁵⁵ Cognitive rehabilitation, an innovative approach during which the practitioner assists the person with dementia to achieve personal goals by using their strengths to compensate for dementia-related impairment, has also recently been trialled, with findings pointing to improved satisfaction and goal performance.⁵⁶

Elsewhere, research into the positive benefits of a range of other non-medical treatments including physical activity, conversational strategies, educational interventions and even aromatherapy is also underway.^{57,58,59}

Findings of the positive benefits of peer support groups, including increased coping and a reduction in the need for formal counselling, are also emerging.⁶⁰ Overall the research base on social interventions has improved dramatically in recent years and continues to accumulate, although authors assert the need for a ‘continued flow and development of creative ideas’ which can then be evaluated and refined.⁶¹

3.2.3 Care outcomes and the subjective experience of dementia

As the evidence base on the effectiveness of psychosocial interventions continues to grow in momentum, the individual, subjective experience of people living with dementia and those who care for them has also arisen as a central research topic.

The care outcomes for those living with dementia is a major issue. A state of care report published in November 2013 by the Care Quality Commission (CQC) highlighted that people with dementia continue to have the poorest outcomes in hospital, including higher death rates, more emergency admissions and longer stays when compared on average to similar people without dementia. Concerns have also been raised about the quality of care in nursing homes, where around 80% of residents have a dementia diagnosis and are more likely to be admitted to hospital with problems such as urinary infections than residents without dementia.⁶² For those who live in the community, social isolation, loneliness and living alone are highlighted as key issues for people living with dementia.⁶³

The research literature has seen a recent shift towards greater emphasis on the subjective experience of people living with dementia. Authors have for example begun to explore ideas around identity and self-concept, how this is retained in early-stage dementia and its links to mood and quality of life.⁶⁴ Von Kutzleben et al. (2012) undertook a systematic literature review of studies into the subjective experiences of people with dementia and concluded that needs do not differ significantly from other chronic conditions, with ‘coming to terms’ with the condition and ‘maintaining normality’ as the major themes observed across the six studies included in the review. In terms of professional health care needs, counselling and the need for continuous, accompanying support were highlighted as central to people’s reported needs.⁶⁵ Research has also begun to explore the subjective experience of carers, including their role in the care process, levels of emotional burden and coping styles.⁶⁶

In 2010 the Alzheimer’s Society published a report into quality of life outcomes for people with dementia.⁶⁷ Based on findings from a mixed methods study which included qualitative interviews, focus groups and a postal survey of people with dementia, including participants from ‘seldom heard’ groups, the report identified ten quality of life indicators that summarise what people reported to be central to their quality of life. In order of importance they are: Relationships or someone to talk to; environment; physical health; sense of humour; independence; ability to communicate; sense of personal identity; ability or opportunity to engage in activities; ability to practise faith or religion; and experience of stigma. Importantly, the study highlighted that people with dementia, including those at more severe stages of the condition, are able to express their views about what is important to their quality of life and many of the domains identified are similar to outcomes desired by the general population. Despite being a progressive condition that severely affects a person’s cognitive functioning, the authors argue that there are significant opportunities available to improve people’s quality of life, which is defined by environmental and wider factors rather than being

dictated by the diagnosis itself. The importance of regular, meaningful social interaction and its positive impact on quality of life is also highlighted.

3.3 User and carer involvement in dementia care

3.3.1 *The user movement in dementia: Mapping the UK picture*

Perhaps the most useful and comprehensive discussion of current user and carer involvement in dementia has been provided by the Joseph Rowntree Foundation (JRF), as part of the charity's *Dementia & Society* discussion stream. In 2012, JRF published a mapping report based on findings from the 'Dementia Engagement and Empowerment Project' (DEEP), identified by the authors as the first systematic attempt to explore the current scope and future needs of existing user involvement projects in the UK. The study involved a range of methods including a mapping survey, follow-up interviews and a national event to share knowledge and best practice.⁶⁸

The study's final report outlines the range and scope of user involvement projects across the UK and highlights what existing groups and projects feel they need in order to develop further. The authors note that the user movement in dementia care is growing in size and momentum yet is still in its infancy, with the 'language of involvement' less common in dementia than for other diagnoses and disabilities. The small number of groups and projects that do exist undertake similar activity to other areas of health but on a much smaller scale. The groups identified were in varying stages of development but were often new and still in the process of becoming established. Individual involvement was often tentative, in part because many people were still coming to terms with their diagnosis and were unsure of the extent to which they wanted to participate in collective influence outside of their own personal circumstances.⁶⁹

The report illustrates that the focus of most existing projects include a mixture of influencing work, peer support and social activities. Reported 'influencing' activities included national lobbying and meeting with government representatives, local lobbying of services, involvement in professional training and education, sitting on advisory boards, and awareness-raising activities including media work and speaking at events. The majority of groups were supported by larger, pre-existing organisations and involved both staff and carers as well as people with a dementia diagnosis. The focus of individual groups was generally local, with a preferred informal approach to membership and their chosen scope of influence.

Barriers to the user movement's future development identified during the study included funding constraints and the challenge of involving hard-to-reach groups such as those with later stage dementia and those from Black, Asian and minority ethnic communities. In addition, the findings highlight that people need time to come to terms with their diagnosis, and access appropriate information and support for their own individual situation, before feeling confident or able to take part in wider influencing activities. At a group level, while only a few projects were identified that had reached the stage of influencing policy and practice, a number expressed that they wanted to know more about such opportunities, as well as how to more effectively involve harder to reach groups. The idea of creating a national network of dementia support groups was welcomed, however people found it difficult to visualise how it would work in practice.⁷⁰

The DEEP study made a number of specific recommendations in relation to how support for the dementia user movement could be improved, including the development of involvement plans at CCG and dementia alliance level, allocation of resources to build capacity in the local community, and the promotion of positive stories of involvement to the local and national media.⁷¹

3.3.2 Involving and empowering people with dementia: An overview

In 2012 the Mental Health Foundation published a useful literature review of the involvement of people with dementia in services, campaigns and research,⁷² which formed an additional component of the 'Dementia Engagement and Empowerment Project' (DEEP). 36 studies from the UK and international literature were identified and selected for inclusion from the years 1996-2011. The authors noted that the relevant studies primarily used qualitative methods (21 out of 36 articles), with a small number of mixed methods studies and the remaining 11 papers made up of literature reviews, evidence summaries and guidance documents. Sample sizes tended to be small, ranging from 1 to 308 participants.

The findings provide valuable qualitative insight into the motivations, outcomes, facilitators and barriers associated with involvement activity from the participant's viewpoint. Clare et al. (2008) for example outlined the involvement benefits for seven members of Dementia Advocacy and Support International (DASNI) using interview and survey data. Reported benefits included peer support, a sense of belonging and increased understanding about the diagnosis. In addition, the 'collective strength' created by membership of the advocacy network was described by participants to foster resilience and enable members to challenge stigma and change attitudes and practice in the wider context.⁷³

Other authors have explored the motivations behind activism for people with dementia, including feelings of exclusion and paternalism, and a desire for development and personal growth following the initial shock of diagnosis.⁷⁴ Subjective benefits described by participants include increased wellbeing and feelings of self-worth, as well as the groups providing an enjoyable learning experience.⁷⁵ One Canadian study of the Alzheimer's Society of Canada (ASOC) explored benefits from the organisational viewpoint as well as volunteers and support group members. Staff interviewed described a range of societal-level benefits including breaking down stigma, giving hope and encouraging others to seek early diagnosis.⁷⁶ Furthermore, a UK study of the development of People who Rely on People (PROP), a young-onset dementia project in Doncaster, outlined a range of practical service-level benefits including the design of care plans, patient information leaflets and advance directive templates, and sitting on interview panels.⁷⁷ Facilitators of PROP's success described by Chaston et al. (2004) include the provision of training and support to volunteers, the use of informal meetings with short agendas, and social activities to create lasting relationships and a strong group identity.

In the policy development arena, Weeks et al. (2011) provide a comprehensive discussion of both the benefits and costs of involvement for people with dementia, based on findings from a study of the Scottish Dementia Working Group (SDWG).⁷⁸ Substantial achievements were noted including the shaping of national policy, improvements to education and training through lectures and the production of DVDs, as well as key actions to challenge stigma and raise awareness through media work and public speaking. The authors noted that individual motivations appeared to change over time; originally being focused on

learning about the condition and accessing peer support, but shifting towards wider motivations around making a difference and campaigning for change as group members became more experienced.

Reported benefits observed by Weaks et al. (2011) included increased confidence and self-esteem, the development of skills and strong friendships, feelings of pride and the inclusivity of being part of an international 'dementia family'. However the report also makes clear some of the costs involved to participants. These included fatigue, the loss of personal time and often substantial travel requirements. The recruitment of new members and the retention and support of existing members were identified as key challenges to the longevity of the SDWG.

These barriers reflect earlier Canadian findings (ASOC, 2006) which describe financial concerns, conflicting time pressures and transport problems as key concerns for group members. In addition, a staff survey highlighted limited training or support for volunteers and this was suggested as a key area for future development – for example by training staff in supporting volunteers, fielding media and public speaking requests and supporting volunteers to prepare presentations. A number of recommendations were made to improve the experience of volunteers with dementia, including:

- Development of strategic direction and policy goals that focus on inclusion
- Securement of funding to cover volunteer expenses and allow paid staff to provide support
- Provision of support and training for both staff and volunteers
- Greater provision of information about volunteering opportunities
- Greater involvement of people with dementia in advocacy and lobbying roles

Organisational-level barriers to involvement identified by authors elsewhere include assumptions and prejudices about what people with dementia are able to contribute, low priority given to meaningful involvement within services, and a lack of training available to enable staff to support the active involvement of people with dementia.⁷⁹

Furthermore, questions have been raised about the future development of the user movement in dementia, particularly around whether user-focused initiatives can move from being seen as a luxury 'add-on' to an integral part of service provision within the current economic climate, and whether an increase in public resources will be made available to sustain and support its growth at a service-level.⁸⁰

'Collective involvement and empowerment has real value not only for people with dementia but the services they use, the communities they live in, and the policies that affect their lives. For this value to be sustained and built upon commitment and resources are needed to support and develop existing groups as well as building capacity by supporting new groups to be set up and develop.' (Williamson, 2012: 73)

The JRF are building further upon the DEEP project as part of a new work programme titled 'Dementia Without Walls' (2012-2015). With the support of partners including JRF, the Mental Health Foundation and

Alzheimer's Society, part of the programme aims to help build capacity of existing groups, develop new projects and undertake influencing activity.

3.4 Research gaps and considerations

This section has highlighted that research into social aspects of dementia, including the effectiveness of psychosocial interventions and the development of the expanding user movement, is accumulating and expanding. In particular, work led by the Joseph Rowntree Foundation and other key third sector partners including the Alzheimer's Society has made considerable progress in mapping and reviewing the current picture and making recommendations for future development.

In its current form, the evidence base related to user involvement and user experience in dementia care holds a number of limitations that have been discussed here. In summary, key issues include:

- An overall lack of research into the subjective experience of people with dementia and the developing user movement, although this is increasing over time.
- What research does exist is generally confined to the 'grey' literature. While this is not a criticism in itself, it prevents findings from being subject to peer review and reduces access to the academic audience, prompting researchers to call for greater funding to enable third sector organisations to publish in peer reviewed journals.⁸¹
- Existing studies tend to be small-scale, qualitative in approach and with varying degrees of methodological quality. While authors argue that qualitative techniques and small samples might be the most appropriate and accessible way to engage people with dementia in research, this can make it difficult to draw conclusions about the effectiveness of initiatives or compare across different projects.⁸²
- Recorded outcomes of user involvement projects tend to provide a short-term picture of benefits and costs to the individual participant. Longer term outcomes and organisational/ service-level impact both appear as valuable areas for future exploration, particularly given that funded involvement initiatives often have wider service-level aims in addition to what might be gained by individual participants.

There is a clear need for continued documentation and evaluation of attempts to involve users and carers in the design and development of dementia services, particularly where projects attempt new or novel approaches to user involvement. This is crucial to expanding the existing evidence base and providing examples of best practice, discussion of the barriers and challenges, and other key learning that may be of benefit to other projects and contexts.

Additional points relevant to the current context that have been identified as part of the review and may need to be addressed include: how to ensure ongoing support for participants after a programme's formal elements have run their course; issues around funding for volunteer expenses and ongoing training; maintaining an active and ongoing recruitment process; and how to overcome organisational-level barriers to ensure that the skills and knowledge gained by project participants can be effectively put into practice.

4. Programme Development: Expert Knowledge Sharing

This section explores how the pilot programme's content and structure developed through a series of 'expert knowledge sharing' events which were used to gather the views and experience of stakeholders including people with dementia and their carers, clinicians and other frontline workers, policy leads and academics. The key themes that arose through this element of the programme are likely to be useful not just to the current project but also to the development of future programmes.

4.1 The development process

Development of the pilot programme's content and structure involved two key aspects. Firstly, an 'expert reference group' knowledge sharing event was held in July 2013 which brought together clinicians, service leads and other key stakeholders to gather knowledge and share ideas about what the 'ideal' programme might look like. Secondly, the perspectives of people with a dementia diagnosis and carers of people with dementia were gathered through a series of discussions with existing, community-based dementia groups.

a) Expert Knowledge Sharing Event – July 2013

The initial knowledge sharing event took place on Monday 29th July 2013 at the Durham Centre, Durham bringing together 30 attendees who held a special interest in dementia care. Attendees held a range of roles within the region's NHS Trusts and social care services, as well representatives from the Department of Health, Northumbria University and a range of third sector organisations including Sunderland Carers' Centre, the Alzheimer's Society, Age UK, and Action on Dementia Sunderland.

Following an introduction to the initiative's background and aims, delegates took part in a series of interactive table discussions around different elements of the programme. Key aims were to understand the target audience, existing best practice and key issues, and to explore how leadership programmes already developed by the project team (including Mental Health Leadership and Youth Leadership courses) might be adapted or even re-invented to suit the requirements and preferences of the current client group. Mind maps, 'post-its' and extensive notes taken by table facilitators were brought together and used to begin mapping out ideas for the basic course aims, content and structure.

Delegates each took part in five table discussions on the following topics: Table 1: Course Outcomes, Table 2: Course Content, Table 3: Participation and Recruitment, Table 4: Delivery and Logistics, and Table 5: Support Requirements.

b) Service User and Carer Views – September to November 2013

Ideas and recommendations from the initial knowledge sharing event were collated and drawn into a potential course structure. This 'prototype' was then taken to existing community-based service user and carer groups, where it was used as a tool for reflection and discussion of the proposed programme. Participants were provided with an overview of the proposed programme and draft advertising flyer. A

semi-structured set of questions was used to guide discussions. The views of 38 people (18 carers and 20 people with a dementia diagnosis) were gathered during this process.

The views of these people were gathered in relation to their personal preferences which ranged from personal discussions with service users and carers within their own homes, to informal discussion groups within community setting familiar to that group.

4.2 Key findings and recommendations

Information from the stakeholder event and the service user and carer discussions was collated into five themed areas to help develop the pilot programme.

4.2.1 *Desired outcomes*

Participants described a range of desired outcomes of the ideal dementia engagement programme. Ideally, by the end of the course participants will have built on existing abilities to develop:

- **Knowledge of dementia services and providers** (including local, regional and national perspectives), and an understanding of what a 'good' standard of care looks like and how standards and access can vary.
- **The skills required to help shape services and challenge provision**, including the ability to present issues in a constructive way that will be heard, articulate the needs of self and others, negotiation skills, and the ability to gather the views, understand the needs and act on behalf of others.
- **Personal outcomes** including improved ability to overcome personal care barriers, resilience, confidence, problem solving strategies and practical skills that will make a difference to day-to-day life.

4.2.2 *Programme content*

Discussions highlighted the following aspects as core course content for the ideal programme:

- **Individual-focused** content including introductions, 'getting to know each other' exercises and the identification of individual skills and goals which can be used as a reference point to re-visit as the programme develops. Later sessions could include reflection on these goals, skills developed and the individual participant's journey through the programme.
- **Knowledge-focused** content including the availability and structure of local, regional and national dementia services and how they fit into the wider health and social care picture – including how to access services and where involvement opportunities currently exist and/or how new ones could be created. This could include a research element which requires participants to find out about services in their local area. Participants also requested practical information, such as will-making and power of attorney, knowledge of what 'good' home care looks like and support for carers.

- **Skills-focused** content including listening, communication, influencing, negotiating, conflict management, assertiveness, confidence building and presentation skills – based on existing approaches, experience and real-life examples that can be shared within the group. Participants could then be asked to put these skills into practice by documenting the use of their skills to achieve a particular goal, either in written or visual form.

A number of useful questions were also raised, for example whether the title ‘course’ might be off-putting to some potential participants. Another important question for consideration is around whether the content should be different for users and carers. Carers are also likely to be a very diverse group, so sessions are likely to require tailoring to individual circumstances.

Practical recommendations for content delivery included the importance of not using Powerpoint, and a general preference for close personal contact. Bright printing can be helpful, for example blue on a yellow background. Lots of good practice guidelines exist that may be helpful (e.g. Resources developed by Stirling University). Storybook-style approaches can work well, as a visual prompt/journey that the participant can refer back to. It was also recommended towards the end of the programme to bring different organisations in to the sessions, to inform participants about potential involvement opportunities.

4.2.3 *Participation and recruitment*

Discussions highlighted the following points:

- Course participants should have a **specific dementia diagnosis**, including dementia caused by Parkinson’s and MS, and a **desire to engage with service development** activities in order to create change. The team need to consider whether **carers** will take part as course participants or just in a supportive capacity (and what about the role of paid carers in addition to informal carers?)
- Recommendations for the identification and recruitment of participants included the creation of a **clear set of criteria** and clear objectives, and the use of a diverse **range of recruitment techniques** to attract under-represented groups and not just the ‘usual faces’. Recommendation to **engage with existing organisations** to promote the programme, including GP surgeries, charities such as Age UK and The Alzheimer’s Society, Community Mental Health Teams (CMHTs), memory clinics and local community-based faith, advocacy and support groups.
- Service user and carer participants felt that the programme should be available as soon as possible after diagnosis.
- In terms of **advertising** the programme, participants were keen to see clear, concise information, giving enough detail to entice people but not too much to confuse and put people off. The name ‘Living Well with Dementia’ was suggested as a strapline from the national dementia strategy. Any promotional material should include practical information such as the number of days you need to attend, who can attend and any costs involved.

- **Under-represented groups** were raised as a key issue, particularly related to the **stage of diagnosis**. It was commented that people in the later stages of dementia are likely to be more difficult to engage and there may be capacity issues, while those in the early stages offer the most potential for engagement but are often ‘cherry picked’ by existing interventions. Recommendation to use early to mid-stages as the focus for the pilot, then expand/adapt to later stages of diagnosis if this seems feasible based on learning from the pilot phase. As a **long term view**, it could be possible to develop **different levels of the course**, tailored to different abilities and/or stages of dementia diagnosis.

4.2.4 Programme delivery and logistics

The following factors were raised as crucial to programme delivery:

- **Location** – Recommendation to move away from the venue-based approach (e.g. hotel or conference centre) used in previous leadership courses, towards something more **familiar, tailored** and **closer to home**. It is essential that any chosen venue is **dementia-friendly** (even down to small details such as cups, chairs, door handles) – the **physical environment** will be crucial to the programme’s success. A stressful or unfamiliar environment may prevent people from contributing. Venues must be familiar, dementia-friendly and **easily accessible** by both public transport and car. City centre or on a main bus route preferable over an out-of-town location. Nursing homes that offer day services, Gentoo assisted housing, community centres or existing dementia café venues all suggested as possibilities – perhaps involve potential participants in scoping out a suitable venue, and/or discuss potential options at the pre-course taster session? Also important to have break-out rooms or **‘time out’ space** available, and to not require participants to travel too far from home. It was noted that a nice venue with good food would help attract participants.
- **Structure** – Recommendation to move away from large group sessions towards something more individualised, such as **one-to-one or small group work** (max. 6 attendees). A strong preference was articulated for a combination of group **‘master classes’** and individual/ small group coaching. **Buddying** could also be a useful approach, by pairing up those who are more able with participants who may need more support. It could even continue afterwards, as an outcome of the course. Recommendation to consider a ‘dementia café’ style approach, perhaps utilising existing support groups where members express interest in taking part. The structure may need to be altered depending on the stage of diagnosis and individual need. Taster sessions could be used as a two-way process to plan the sessions.
- **Duration and timing** – recommended movement away from full day sessions in favour of **shorter but more frequent** ones; perhaps a **‘light’ version** of the course that requires less commitment than existing leadership programmes? Attention to detail (such as bus pass time restrictions) is essential when planning event timings. Late morning is often the best timing for people with dementia, but it will vary across individuals. **Daily routines** are very important.

4.2.5 Support requirements

Discussion raised the following issues for consideration:

- Recommendations for *pre-course support* included ensuring that the venue, course materials and transport links are **dementia-friendly**; asking individual participants about their **personal support requirements** at an early stage (including physical, dietary and hygiene requirements); thinking about what systems need to be in place to gain **informed consent** and assess capacity; and ensuring that the pre-course information is easily understandable and has a strong '**human touch**' (e.g. face-to-face rather than just flyers/leaflets) and focus on two-way communication.
- Recommendations for support *during the course* included the development of clear, **practical guidelines** provided well in advance; using a **range of methods/styles** of communication including visual and spoken forms, communication/**staying in touch with participants between sessions**, support to 'dip in and out' of sessions where necessary, the potential need to employ **additional support workers** for the group sessions and the possibility of setting up some form of '**buddy**' system or utilising support from existing groups in between sessions. Funding will need to be available to cover the expenses of paid carers where required.
- Recommendations for support *after the course* included supporting participants to **explore routes** to how they could use their developed skills (and perhaps **supporting organisations** to make the most of the skills offered), creating ways to **link participants up** with existing organisations and networks, arranging a **post-course 'meet-up'** and developing a **de-briefing session for carers**. Recommendation that ex-delegates could inform delivery for the next cohort. **Pre-meeting support** opportunities may also be desirable, for example to help anyone who gets involved in forums or meetings to prepare for specific events (buddies could help with this?).

A summary of the pre-programme development discussions was sent out to the various individuals and organisations who had participated. The findings were then used to inform the aims, content, delivery and recruitment strategy of the pilot programme.

5. Programme Structure and Content

5.1 Programme structure and content

The programme structure and content was developed based on learning from the pre-programme development stages as well as practical delivery considerations. The basic structure of the programme consisted of two main elements: core learning which was considered fundamental to the programme's aims, and a flexible element which would be tailored to participant need as identified in the early stages of programme involvement.

The course began with a taster, or introductory, session which was specifically designed to engage with participants in the following ways:

- Enable participants to get to know each other and the facilitators
- Build personal confidence in the environment and with other people
- Decide whether ongoing participation was right for them
- Allow participants to express personal needs, wishes and aspirations
- Allow facilitators to decide on bespoke elements of the course content

Following this half-day introduction the course was structured around 4 main delivery days as follows:

Day 1 Getting to know you, Overview of dementia services, Individual skill identification, Skill building.

Day 2 Sharing knowledge and information on local services, Listening skills and being heard, Managing conflict, Effective communication in meetings.

Day 3 Focus on individual goals and aspirations, Mapping a service journey, How do I/we want to be involved and influence, Where and how can I/we do this.

Day 4 Next steps to achieving personal goals/targets, Emotional and physical wellbeing, Developing a Wellbeing Plan, Reflection and personal journeys.

Due to recruitment issues in the early stages of the pilot, the introductory session was amalgamated with Day 1 for the first cohort.

Session facilitators were drawn from the delivery partners (North East Dementia Alliance, NEMH DU and Karen Picking & Associates), plus a range of external speakers who were chosen according to the knowledge and skills required for each specific topic. Sessions involved a variety of different learning methods including presentations, small group work and whole room discussions.

All participants received a personalised, branded course folder for session notes and useful information.

5.2 Environment and logistics

Care was taken to choose 'dementia friendly' venues for each cohort. Locations were chosen based on recommendations by the North East Dementia Alliance, combined with site visits by the development team. The first cohort was delivered at the Middlesbrough Teaching and Learning Centre and the second at the Alnwick Garden. Both venues had free parking, were accessible by public transport and had suitable space to offer a separate 'time out'/relaxation area for participants to access should they wish to take a break from the session. Each day session was no longer than a maximum of 5.5 hours, including a number of refreshment and lunch breaks.

Before the programme began, all participants received written confirmation and a follow-up telephone call to confirm attendance and help participants with any travel arrangements. All participants were offered reimbursement of their travel expenses.

5.3 Recruitment of programme participants

A course flyer, which was developed during the pre-programme development phase, was distributed across various stakeholder networks via the North East Dementia Collaborative and their members. Eligibility for the course was deliberately kept broad; the criteria consisting of living in the general geographical area of the pilot, being available to attend all of the sessions, and either having a recent diagnosis of dementia or having an unpaid caring role for someone with a dementia diagnosis.

During the first round of recruitment 23 applications were received, however 20 of these were from paid care professionals despite the eligibility criteria being stated on the flyer. A second recruitment attempt was more successful, which saw the flyer being re-designed and the creation of a supporting guidance document for professionals describing the course, its intended participants and a request for paid staff to help reach this target audience. On this occasion 18 applications were received (for 12 places); 5 people with dementia and 13 carers of people with dementia.

The same revised recruitment method was used for cohort 2, including the focused use of professionals to support the recruitment process and reach the target audience. As a result 13 applications were received; 7 carers and 6 people with a diagnosis of dementia.

A demographic overview of programme participants can be found in Figure 6.1 at the start of the next section.

6. Programme Evaluation: Key Findings

This section presents findings from the various evaluation elements of the pilot programme, including individual session evaluation forms, a post-programme satisfaction and outcomes questionnaire, and a qualitative follow-up phase carried out 6-12 weeks after participants completed the programme.

6.1 Demographic profile of programme participants

Figure 6.1 below provides an overview of the demographic characteristics of the 31 people who took part in the pilot Participation and Engagement programme.

Figure 6.1 *Demographic profile of programme participants*

	Cohort 1 - Middlesbrough Teaching and Learning Centre	Cohort 2 - Alnwick Garden
No. of participants	5 people with dementia 13 carers	6 people with dementia 7 carers
No. of people with dementia/ carers attending together	10	12
Demographic characteristics Sex Ethnicity	9 Female; 9 Male All White British	8 Female; 5 Male All White British
Total no. of participants	18	13
Total across both cohorts	31 participants (11 people with dementia and 20 carers)	

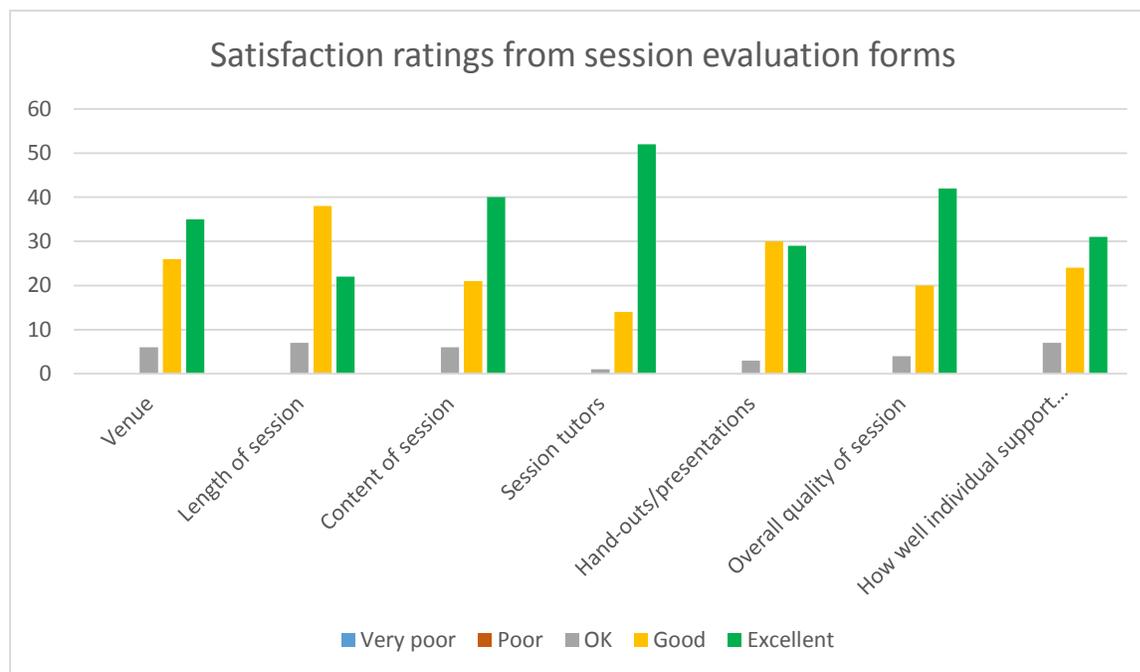
6.2 Satisfaction with the programme

The following findings are drawn from responses to individual session evaluation forms and end of programme evaluation forms across both cohorts. 67 out of a possible 86 (78%) individual session evaluation forms were received and 28 out of a possible 28 (100 %) end of programme evaluation forms were received. NB. Not all participants were able to attend all sessions.

6.2.1 Overall satisfaction ratings

Participants were asked to rate different aspects of the programme on a scale of 1 (very poor) to 5 (excellent). Figure 6.2 below provides an overview of satisfaction ratings from participants across the two cohorts. The most common response option for each element is shaded.

Figure 6.2 Satisfaction ratings of different aspects of the programme



As can be seen in Figure 6.2 above, the most common satisfaction rating was ‘excellent’ for five aspects of the programme: the session tutors, overall quality of the sessions, the content of the sessions, venue and how well individuals’ support needs were met. The session tutors in particular were rated highly, with over three quarters (78%) of participants rating them as excellent. The remaining two items (length of sessions and presentations/handouts) were rated as ‘good’ on average across the sessions.

6.2.2 Qualitative insight: Satisfaction and recommendations for improvement

The individual session evaluation forms asked participants to comment on what they liked most and least about each session. Participants offered a range of responses, some relating to individual speakers and/or topics, but there were consistent themes around people enjoying the friendly atmosphere and the willingness to share amongst participants and facilitators. In addition, the opportunity to learn from each other as well as from the speakers, and the opportunity to meet others in similar situations, featured in positive comments.

When participants were asked to comment on what they liked least about each session, these factors were often environmental such as room temperature, however there were some comments from participants on the first cohort about specific speakers and topics, which were taken into account when planning the second cohort. A number of people also commented that they didn’t like the course coming to an end!

6.2.3 Recommendation of the programme to others

At the end of each cohort, participants were asked how highly they would recommend the programme to other people with a dementia diagnosis, on a scale of 0 (would not recommend at all) to 10 (would highly

recommend). The range of responses to this questionnaire item can be seen in Figure 6.3, separated into the two cohorts.

The mean recommendation rating fell at 8.8 out of 10 for cohort 1, and 9.8 out of 10 for cohort 2. As can be seen in Figure 6.3, whilst very positive for both cohorts there was an improvement from cohort 1 to cohort 2. This may reflect changes to content in terms of individual speakers and length of presentations, made in response to feedback from the first group.

Figure 6.3 Recommendation of the programme to other people with dementia and/or their families

[Responses shown in actual numbers. 0 = would not recommend at all; 10 = would highly recommend]

	0	1	2	3	4	5	6	7	8	9	10
Cohort 1							1	2	2	5	6
Cohort 2										2	9

As part of the qualitative follow-up interviews, carried out 6-12 weeks after each cohort had ended, participants were asked for their overall opinions of the programme and any recommendations for improvement. There was overwhelmingly positive feedback on the programme overall, with the majority of participants commenting that they would wish for the programme to continue to be available beyond the pilot phase.

Recommendations for the future included follow-up sessions for those who have completed the programme in order to maintain the contacts and support network developed over the course of their involvement. Analysis of the qualitative responses suggested that the programme was perceived to have 'filled a gap' for people with dementia and carers alike, by providing an opportunity to connect with others in a similar position and to source information and contacts which could support them in responding to the challenges posed by a dementia diagnosis.

Participants also made a range of practical suggestions of topics for inclusion in future programmes, for example tips on safety in the home, managing personality changes and how to choose a good care home.

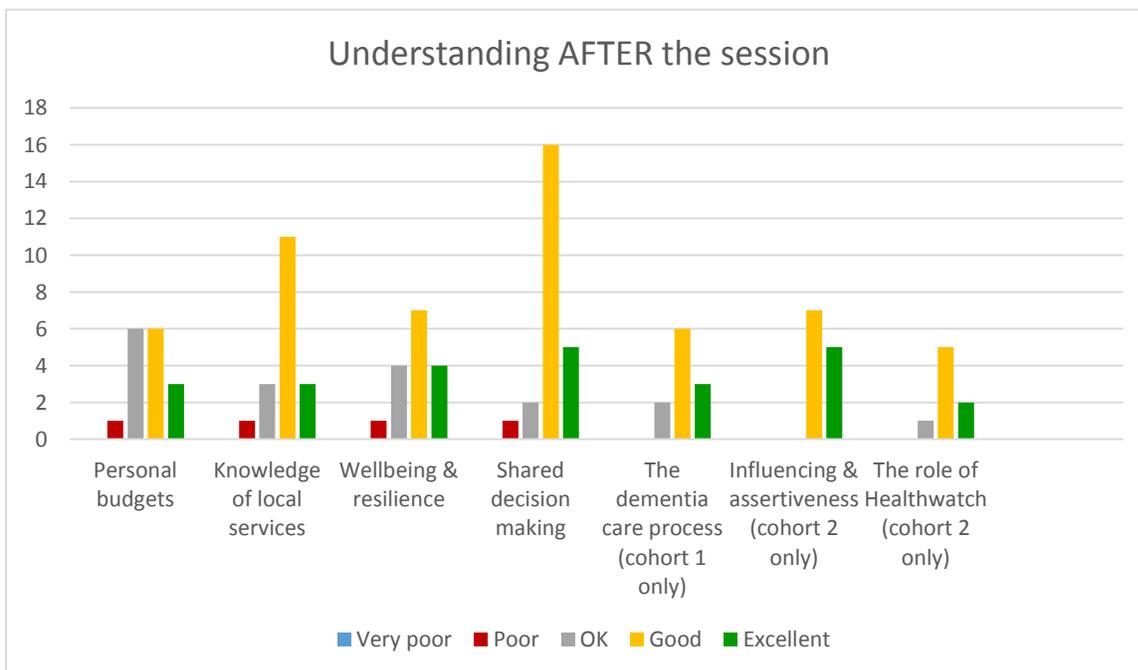
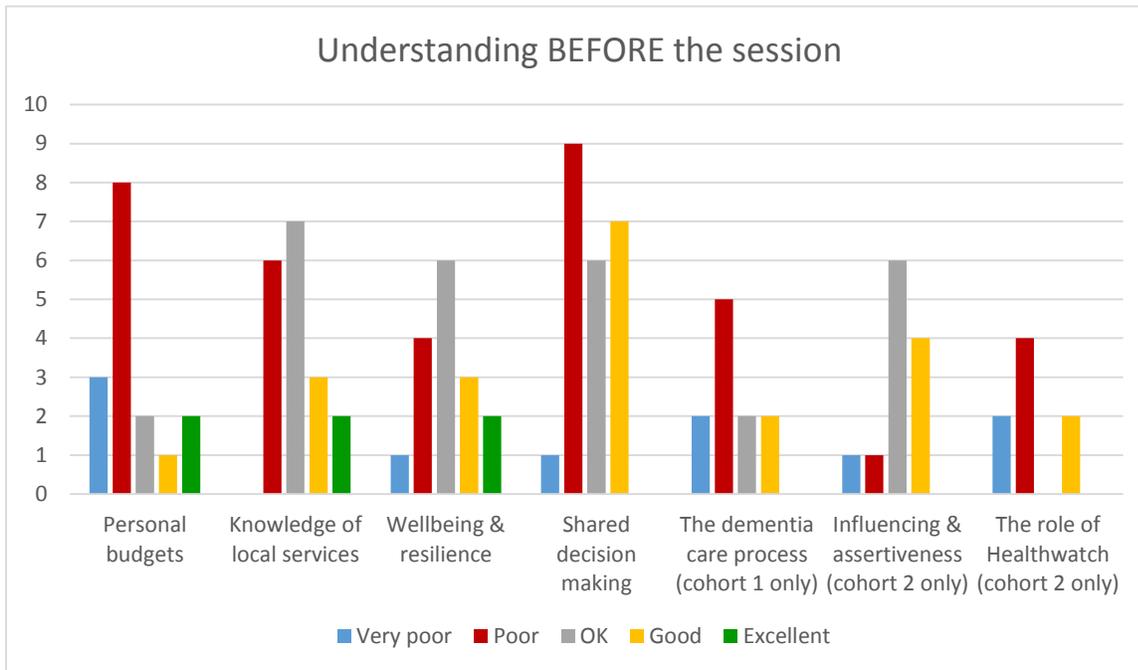
6.3 Knowledge and skills development

6.3.1 Understanding of specific topic areas

Participants were asked to rate their understanding of session topics before and after the various sessions, on a scale of 1 (very poor) to 5 (excellent). Specific topics included personal budgets, knowledge of local services, wellbeing and resilience, shared decision making, the dementia care process (cohort 1 only), influencing and assertiveness (cohort 2 only), and the role of Healthwatch (cohort 2 only). Responses,

collated across both cohorts, are shown in Figure 6.4. As can be seen in the graphs there was a substantial shift from the negative responses of Very Poor, Poor and OK, before the sessions, to the positive responses of Good and Excellent after the sessions.

Figure 6.4 Participant understanding of session topics before and after each session



6.3.2 Broader knowledge and skills development

As part of the post-programme evaluation questionnaire, participants were asked if they felt the course had helped increase their knowledge and/or confidence in a number of broader areas. Responses from both cohorts showed substantial improvements in both knowledge and confidence, as can be seen in Figures 6.5 and 6.6 below.

Figure 6.5 *Impact of programme involvement on participants' perceived level of knowledge*

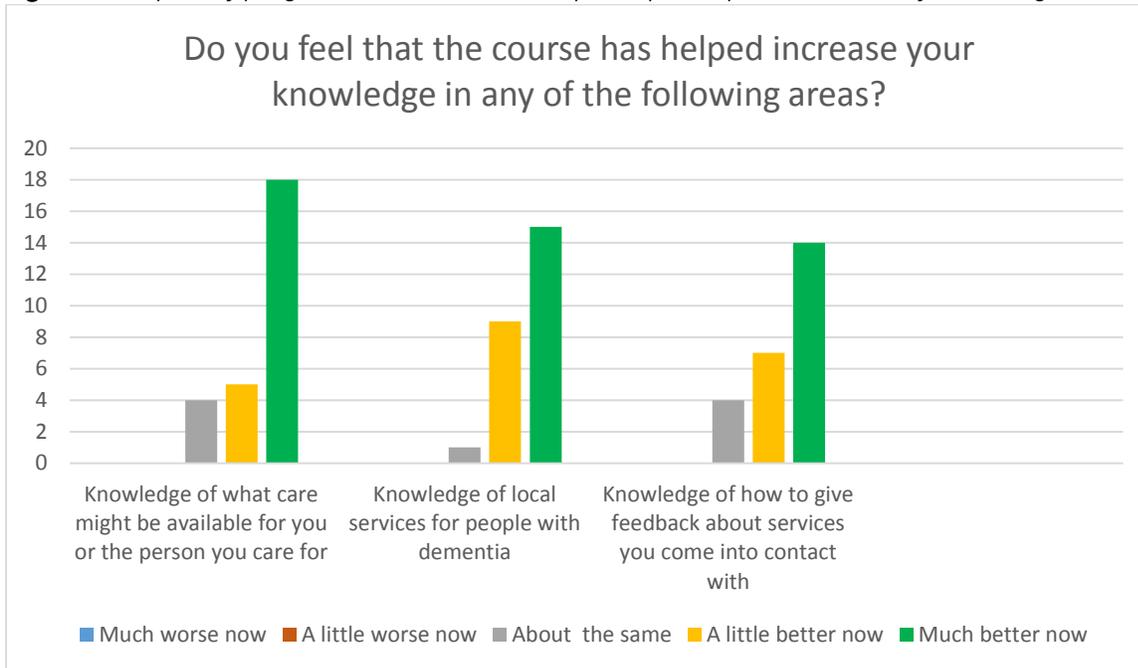
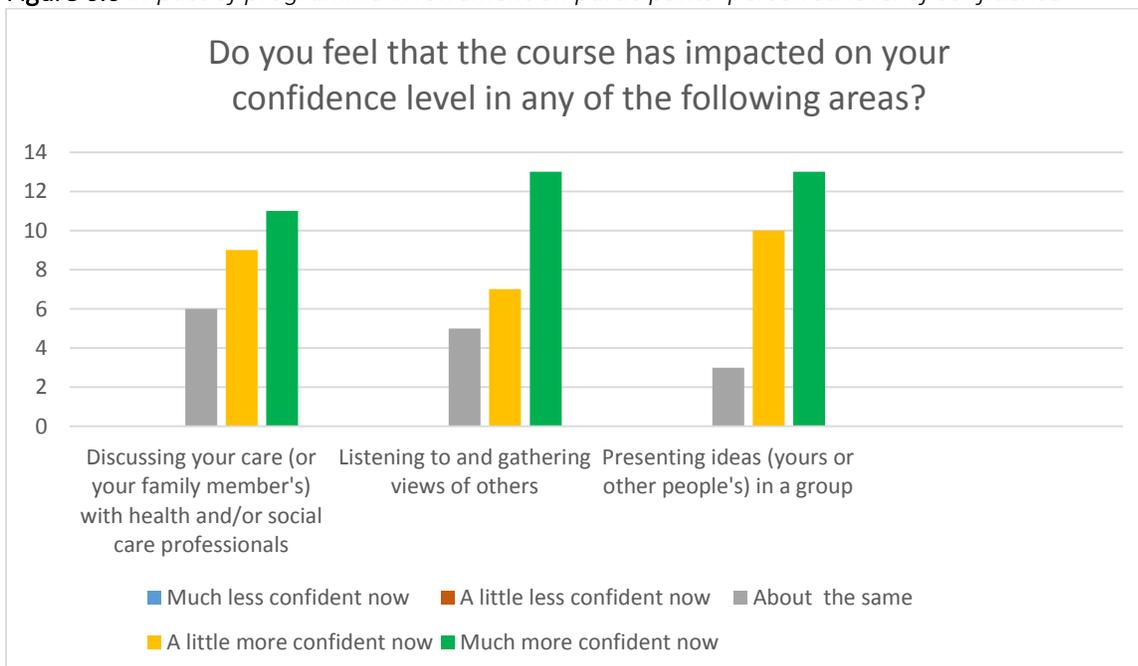


Figure 6.6 *Impact of programme involvement on participants' perceived level of confidence*



6.3.3 Qualitative insight

Qualitative feedback from the post-course interviews further supported the increase in confidence observed in the post-programme questionnaire findings. It was particularly noticeable amongst carers, who reported changes in the way they interact with professionals and becoming more proactive in seeking support. When interview participants were asked how they expected to use the knowledge and skills they had developed, responses included:

- Being more assertive and better prepared when speaking with health professionals
- Being able to seek the right support at the right time, by knowing who to go to and when
- Change in approach as a carer, through a better understanding of the diagnosis and knowledge of how to avoid conflict
- Communicating more effectively through improved understanding and confidence

6.4 Goal attainment and wider impact

6.4.1 Helping participants to achieve their asserted individual goals

At the start of each cohort, participants were asked to identify two or three goals that they hoped to achieve by taking part in the programme. A wide range of goals were identified, which fell into a number of recurring themes:

- Learn more about dementia and local services for people with dementia and their carers
- Identifying coping strategies
- Meeting people and sharing experiences
- Awareness raising of dementia amongst others, including health professionals

At the end of each cohort, participants were asked whether the programme had helped them towards achieving the goals identified at the start of their involvement. Of those who responded to this question (n=26, 84% response rate), more than 4 out of 5 reported that the programme had help them towards their goals. The overall range of response can be seen below.

Yes = 21	No = 1	Not Sure = 4	Non-responders = 5
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6.4.2 Wider impact on participants and their families

As part of the follow-up interviews, programme participants were asked whether there were any additional, unexpected goals that the course had helped them to achieve. A range of additional outcomes were identified, including:

- Increased confidence and assertiveness

- Increased knowledge of where to go for help and support
- Knowledge of coping mechanisms
- “To get more out of my life and not let this get me down and feel helpless”

As part of the qualitative follow-up interviews, participants were asked whether the programme had had any wider impact on them and/or their family. This prompted a wide range of responses, often related to increased strength and a new, more positive perspective on their current situation. There were also some practical outcomes identified, as can be seen in the interview quotes/notes below:

- Learning that “it’s not their fault, and it’s not my fault”.
- “Since the course I have applied for and am now in receipt of attendance allowance.”
- “Feel much more positive since being on the course and more understanding from [their] perspective.”
- One participant with a diagnosis of dementia reported that the course was a significant factor in them giving up drinking – as well as now feeling much better this has also brought them back in contact with their family who are now in regular contact.
- “I have more confidence at the GPs now, much more assertive – it’s a generational issue, we were brought up not to complain or challenge.”
- “I came away stronger and learned more patience.”
- “It gave me a different outlook – people do care – they don’t all just leave you.”
- “I have more confidence to challenge and ask for information.”

6.5 Additional learning from participants: Service issues and existing support

6.5.1 Service issues raised by participants

Whilst not part of the formal evaluation of the programme it is important to reflect some of the wider issues raised by participants, to inform future development, commissioning and delivery of the programme.

Key issues raised included:

- A widely reported lack of information and contacts immediately following diagnosis. One carer described feeling ‘put off’ asking for information about where to get help, and was requested by a health professional, “if you find out, let us know”.
- Substantial variation and inconsistent experiences of GP, community and hospital services, including referral/waiting times, attitudes and level of knowledge.

Time spent on the programme with other participants was described to be hugely valuable for sharing experiences and learning from each other. The genuine friendliness, knowledge and support of the

facilitators was highlighted by a number of participants, who expressed feeling that they went ‘above and beyond’ to help people feel comfortable and able to participate.

The qualitative interview data suggested that participants who were caring for someone whose dementia was further progressed found the mix of people with dementia and carers in one group less helpful than those at earlier stages. The reason for this was that they wanted to discuss issues relating to later stages of the illness and felt unable to do so within the mixed group. On the other hand, those experiencing a more recent diagnosis and their carers felt strongly that the mixed group was an integral part of the learning experience. Their perception was that it was important to be able to attend the programme together, as they were at the beginning of a shared journey and wanted to be treated as equals. This perhaps highlights an argument for the need for complementary carer-specific support as the person they care for reaches the later stages of illness.

6.5.2 Comparison with other learning/support opportunities

Participants were asked whether they had experienced any other types of support for people with dementia or carers of people with dementia, and how the Living Well with Dementia programme compared. Some participants reported awareness of other support, with some having attended groups before while others either hadn’t felt the need to, or felt unable to access support due to their caring commitments.

In Middlesbrough, Carers Together and the Carers Association were referred to as places where carers could seek information and support. In terms of support groups for people with dementia, awareness was much lower and there was a feeling that little was available. Some criticisms were raised of existing groups. One was described as well-meaning but not actually meeting the needs of people with dementia, while another was criticised for separating people with dementia and carers into different groups and not treating them equally.

Within the context of this discussion, a number of participants commented on the benefits of being able to attend the Living Well with Dementia programme together (person with dementia and their carer), specifically stating that it was good to be able to learn together and that it boosted confidence to attend and take part. It was also felt that some existing groups were more of an informal social gathering, whereas the Living Well with Dementia programme had a focused programme of activities and information sessions.

7. Conclusions and Recommendations

7.1 Conclusions

The 2013 state of care report published by the CQC⁸³ highlighted that people with dementia continue to have the poorest outcomes in hospital, including higher death rates, more emergency admissions and longer stays when compared on average to similar people without dementia. It is conceivable that knowledge of how to access appropriate care and support services, for both people with dementia and their carers, could positively impact on these key pressures. The same report highlighted that social isolation and loneliness are key issues for people living with dementia.

Participants on the programme reported the benefits of social interaction and peer support, not only during the programme but also in friendships and networks maintained beyond the programme. This reflects the benefits of involvement reported elsewhere, including increased confidence and self-esteem, the development of skills and strong friendships, feelings of pride and the inclusivity of being part of an international 'dementia family'.⁸⁴ In addition, there were clear improvements in understanding of a range of key service and involvement-focused topics over the course of the programme.

Having acknowledged that the idea for the programme arose from a noted gap in the current level of service user and carer involvement in dementia care planning and evaluation within regional services, and a commitment to improving these levels of involvement, it is important to note the reported increases in confidence amongst participants and the increase in knowledge of how to give feedback about services. This in turn may be a sign of future potential success for the programme, and is worthy of further exploration of any longer term service-level and organisational outcomes.

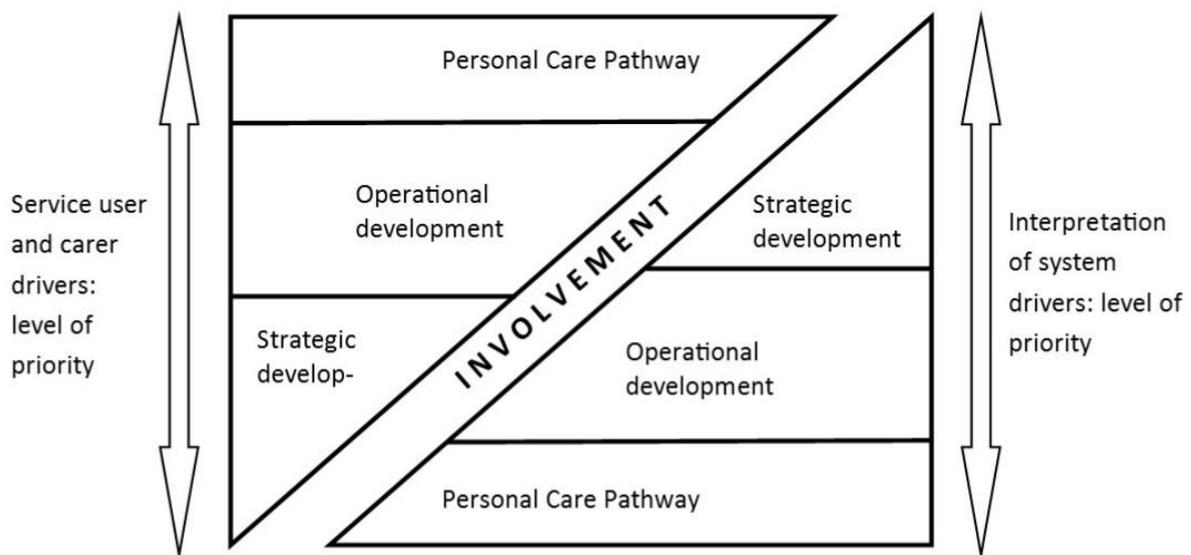
From the lessons learned from the development and delivery of these two pilot Living Well with Dementia programmes, it is clear that they have responded to an otherwise unmet need amongst people with dementia and carers of people with dementia - that being the reported gap in information and support following diagnosis. Were the Living Well with Dementia programme to become an integral part of the support offered to people receiving a diagnosis of dementia, and carers of people with dementia, it could be concluded that this would be likely to facilitate an ongoing dialogue between programme participants, service providers and commissioners. This would also go some way to meeting a number of the aspirations set out in the Prime Minister's *Challenge on Dementia 2020*.⁸⁵

Feedback from participants would seem to endorse the approach of targeting the programme towards people with a recent diagnosis of dementia and their carers, with a number of participants falling into that category commenting on the benefits of being able to attend the Living Well with Dementia programme together, either as a couple or as parent and son or daughter. On the other hand, carers of people with more advanced dementia felt less able to speak freely and gain maximum benefit from the programme; suggesting that at least some carer-specific support may be increasingly useful in the later stages of illness. While participants with more advanced dementia reported enjoying the programme, they were noticeably less able to give feedback on any acquired skills or knowledge – their satisfaction was more simply an enjoyment of attending and feeling involved.

It is worthy of note that the Living Well with Dementia programme is already receiving attention amongst healthcare professionals across the North East and potentially further afield, having been included as a case study in the report *Dementia 2014: A North East Perspective*⁸⁶ and the service mapping elements of each cohort being fed into the North East Clinical Network for Mental Health, Dementia and Neurological Conditions at a commissioning event in March 2015. Involvement and engagement of people with dementia and carers of people with dementia has become the North East Dementia Alliance’s top priority for 2015-16 and this programme will influence this work.

It is our opinion that there is a current mismatch between the drivers of this type of initiative, which can often seem to be the system’s need to have people involved in the development and monitoring of service provision, and service user and carers’ drivers to be more involved in their own care. The strategic drivers for the commissioning of this programme are similar to the interpretation of the strategic drivers which pervade the rest of the system, in that the desired outcome seems to be to increase the number of people with the knowledge and skills to meet the needs of the health and social care system to have people ‘involved’. This is visualised in Figure 7.1 below.

Figure 7.1 Comparison of strategic system drivers and personal drivers for service users and carers



It was made clear by those attending the course that their main drivers were around increasing their own skills and knowledge in order to have better outcomes for either themselves or those that they care for. In other words, ‘living well with dementia’. Only a small proportion of those people would then become involved at a local service level and an even smaller proportion of those would become involved at a strategic/developmental level within the system.

The main drivers for this programme, therefore, should be those which drive better personal, clinical and social outcomes, rather than those which drive the needs of the system. This is part of the rationale for suggesting this type of intervention should be routinely placed at an early part of the personal and clinical journey, i.e. immediately post-diagnosis. The system needs to commission this type of programme, not to

meet its own needs in terms of involvement and service development, but as a primary function to meet the needs of the individual participants in the early stages of their pathway. This will naturally lead to a large group of skilled and knowledgeable individuals, from which system leaders will emerge.

7.2 Recommendations

- 7.2.1 It is recommended that the North East Dementia Alliance present the findings of this report to commissioners and providers of dementia services across the North East with the aim of raising awareness of the need for and benefits of such a programme.
- 7.2.2 It is recommended that the North East Dementia Alliance support NEMHDU to explore the possibility of piloting an 'embedded' Living Well with Dementia programme into the diagnostic pathway immediately post diagnosis.
- 7.2.3 It is recommended that the North East Dementia Alliance explore the possibility of securing funding to establish a training programme to spread the implementation of the Living Well with Dementia programme, following an embedded pilot.
- 7.2.4 It is recommended that the North East Dementia Alliance pursue funding, alongside an academic partner, to research the longer term impacts of the Living Well with Dementia programme for participants - to include personal outcomes, engagement and demands on the system, system navigation and medium term wider system involvement. Service-level and organisational outcomes could also be of interest for future research.

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