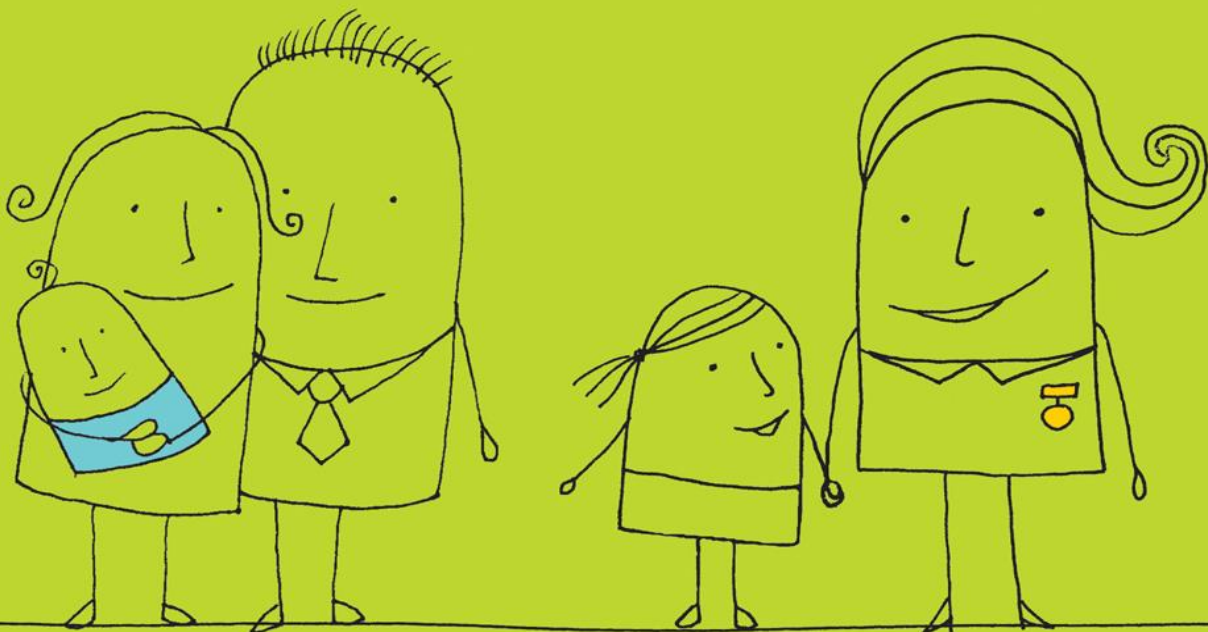


Patient and Client Council

Understanding the care experience of people with dementia

Year 1 – Scoping Exercise

March 2017



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1. Introduction

1.1 Dementia – a definition

Dementia is the term used to describe a group of conditions that affect the brain and cause a progressive decline in the ability to think, remember and learn.¹ The most common cause of dementia is Alzheimer's disease, which accounts for more than 50% of dementia. Other forms include: vascular dementia, Lewy bodies disease and frontal lobe dementia.²

Throughout this paper the term 'dementia' will be used to cover all these conditions.

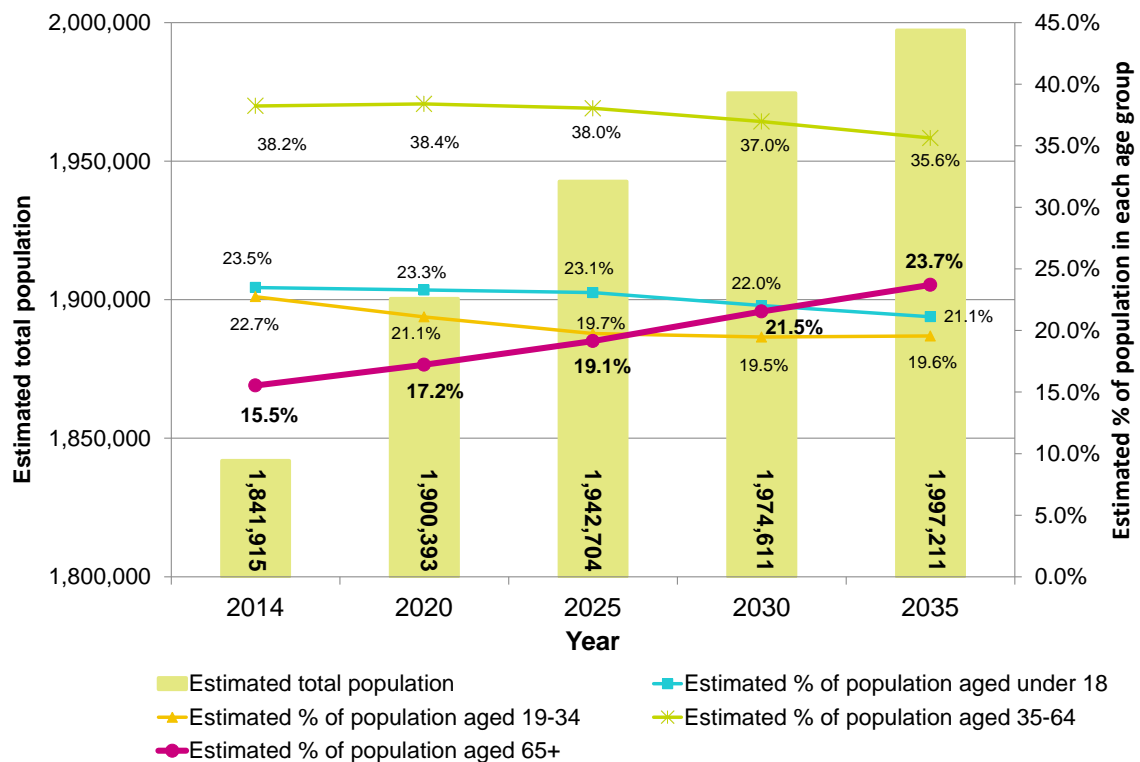
Symptoms of dementia can include: memory loss, confusion, speech difficulties, mood and behavioural changes, and problems with self-care and other aspects of daily living.³ There are some treatments that alleviate the symptoms, but there is no cure for dementia and it is a terminal illness. It is an increasingly common diagnosis and the prevalence is rapidly growing each year as the population lives longer.⁴

Dementia mostly affects people over the age of 70 and is uncommon in people under the age of 60, but it can appear, though rarely, in people in their 40s or younger. Research shows that after 65 years the prevalence of dementia doubles with each additional five years of life.²

1.2 An ageing population

The population in Northern Ireland is getting older and people are living longer. The average age of death has increased over the last 30 years from 70.1 years in 1982 to 76.4 years in 2012.² Northern Ireland statistics and Research Agency (NISRA) projects that approximately 20 years from now (2035) those aged 65 and over in Northern Ireland will account for 23.7% of the total population, which is approximately half a million people. This represents an increase of 65% compared to 2014 population data (Figure 1.1.).⁵

Figure 1.1: Estimated population and breakdown of percentage of population by age group from 2014-2035



Source: NISRA. Northern Ireland Population Projections 2012-2062

At present, it is estimated that in Northern Ireland there are 19,000 people living with dementia. However, the ageing population in Northern Ireland could see the numbers of people diagnosed with dementia rise to 23,000 by 2017 and around 60,000 by 2051.² It is important that high-quality dementia care is delivered for the increasing number of people across Northern Ireland.

1.3 The Patient and Client Council and dementia

The Patient and Client Council (PCC) 2016/17 business plan states the following:

The Patient and Client Council will seek to understand the care experience of people with dementia. It is envisaged this project will extend beyond 12 months

The Patient and Client Council will conduct a scoping exercise to understand what the issues are for people living with dementia in health and social care.

The Patient and Client Council will report the findings of the scoping exercise.

The PCC included the above objective to explore the care experience of people living with dementia as it recognised that this is an area that is important to patients and carers and the wider public. While the PCC has not completed a specific project in relation to dementia, issues relating to dementia care have been raised in previous PCC research projects.* Some of the key areas of concern identified in our previous work are: treatment and care, respite, support for carers, and dementia awareness and understanding of dementia amongst Health and Social Care (HSC) staff.

The PCC has also been able to identify concerns related to dementia services through our Complaints Support Service. Common themes in the complaints we have dealt with in this area include: issues around capacity and decision-making, lack of involvement of family members of people with dementia, hospital care, and nursing and residential home care.

* See Carer's Priorities (November 2016), Care When I Need It (March, 2013), The People's Priorities (November, 2011), Respite (short breaks) (August, 2011)

2. Methods

The PCC is aware that dementia is an area that has been widely explored and reported on in recent times. In order to avoid duplication of work that has already been completed, the PCC decided to undertake a desktop scoping exercise to identify the context in Northern Ireland in relation to:

- a. Policy
- b. Research programmes
- c. Audits and research reports on dementia care in Northern Ireland
- d. Organisations and groups with a focus on dementia
- e. Other opportunities for engagement with people with dementia and/or their carers.

In addition, the PCC engaged with people with dementia and their carers to gather their experience using:

- a. Dementia discussion groups
- b. A review of blog feedback

3. Desktop exercise - the context in Northern Ireland

The desktop exercise identified significant work around dementia care undertaken in Northern Ireland in recent years. The work includes development of policy and a dedicated research programme, and publication of audit findings and research projects. In addition, a number of groups and organisations with a dedicated focus on dementia were identified, as well other opportunities for people with dementia and/or their carers to be engaged in shaping health and social care.

3.1 Policy

Examples of recent policy and service delivery programmes relating to dementia include:

- Dementia Strategy (2011)²
- Transforming Your Care: a review of Health and Social Care in Northern Ireland (2011)⁶
- Dementia Learning and Development Framework (2016)⁷
- Health and Wellbeing 2026 (2016)⁸

Dementia Strategy (2011)²

The aim of the regional strategy for dementia, *Improving Dementia Services in Northern Ireland*, was to provide clear strategic direction in Northern Ireland in order to improve services for and support people with dementia and their carers, particularly in the context of the anticipated increases in the numbers of people with dementia in the future. The strategy set out a holistic model for supporting people living with dementia. It consisted of 44 recommendations under seven specific themes: reducing the risk or delaying the onset of dementia, raising awareness, promoting early assessment and diagnosis, supporting people with dementia, supporting carers, legislation and research.

DHPSS Transforming Your Care: a review of Health and Social Care in Northern Ireland (2011)⁶

Transforming Your Care (TYC) indicated a number of key areas to address in regards to dementia. These included:

- To improve regional standards of care, especially for dementia;
- The need for greater provision of services for older people at home and in the community given the decline in the number of nursing homes and the growth in cases of dementia;
- To address the issue that people with dementia stay longer in hospital than other people undergoing the same procedure, which can have a detrimental effect on the symptoms of dementia;
- To improve the quality and availability of respite care for people with dementia;
- To undertake research on how best to shift services from hospital settings closer to home.⁶

Dementia Learning and Development Framework (2016)⁷

The Dementia Learning and Development Framework aims to support HSC staff to deliver better care to people living with dementia, their families and carers in Northern Ireland. The framework recognises that training and education, both general and specialist, across all staff levels and sectors of HSC services are integral to the development of the recommendations made in the Dementia Strategy (2011). The framework states how important it is for staff to be mindful of the fact that it is not only older people who experience dementia, but that younger people and people with a learning disability can also be affected.

The Dementia Learning and Development Framework is presented in 13 thematic subject areas that include: dementia awareness, communication, diagnosis, person-centred care, and working in partnership with families and carers. The framework is structured under four 'Tiers' that define knowledge and skills specific to the role and responsibilities of various HSC staff, ranging from Tier 1 to Tier 4. Tier 1 is relevant to all staff and the framework outlines the baseline level of dementia knowledge for everyone working in a HSC setting. Tier 4 requirements target specialist HSC staff working at an advanced level of expertise.

The purpose of the framework is to provide a structure for dementia-specific training and education to ensure that all staff working within health and social care across the statutory, voluntary and independent sectors have the skills and knowledge they require to recognise

and respond appropriately to the unique needs of a person living with dementia and their carers.⁷

Health and Wellbeing 2026 (2016)⁸

In October 2016, the document *Health and Wellbeing 2026* set out the current Health Minister's direction for HSC services in Northern Ireland. This included a focus on dementia. *Health and Wellbeing 2026* states that the Department of Health (DoH) plan to expand the range of information and interaction available to people online, including the development of a new patient portal to allow service users to secure online access to their own health and care information. A target was set that the new patient portal should be in place for dementia patients within the next 12 months. In the area of technology, data and healthcare, a programme of work to improve the use of health analytics focused on dementia patients is due to start in 2017.⁸

3.2 Research programmes

The Research and Development Division of HSC, in collaboration with Atlantic Philanthropies, issued a call for research to address the increasing prevalence of dementia in Northern Ireland and the burden it places, and will place, on HSC staff and resources, and on the quality of life and wellbeing of service users and their wider network of carers.

Priorities identified as part of the research programme included: staff and staff training, quality of care, information and communication, management of behaviours and management of symptoms. The first open call for proposals was issued in June 2013 and the call closed in September 2013. Eight applications were submitted, three of which were awarded funding (£987,228.52 awarded in total). A second call was issued in February 2014 and closed in May 2014. A consultation event was also held on 6th March 2014. At this stage eight applications were received, four of which were awarded funding (£1,282,651 awarded in total).⁹ Each of the seven research projects that were funded are still active at the time of writing this report (March 2017).

3.3 Audit and research reports on dementia care in Northern Ireland

Audit of dementia care in acute hospitals in Northern Ireland⁴

Between November 2014 and January 2015 an audit was carried out in all 12 acute hospitals in Northern Ireland that admit adults in order to measure the quality of dementia care in this setting.⁴ It was intended that the findings of the audit would allow for tailored recommendations to be made for dementia care in the acute hospital setting specific to Northern Ireland, adding to the direction on actions to improve dementia care already provided by the regional dementia strategy.

The audit made a number of key findings:

- None of the 12 hospitals reported having a dementia care pathway in place, or in development. The report recommended that developing Integrated Care Pathways (ICPs) for dementia should become a priority as a way of adopting a systematic approach to care provision.
- Key workers for dementia within the hospital provide information and advice to people with dementia and their family/carers. Some 83% (10/12) of hospitals had a named officer with designated responsibility for the protection of vulnerable adults, including people with dementia. In addition, 75% (9/12) of hospitals had a social worker or other designated member of staff responsible for working with people with dementia and their carers.
- Advocacy services can play an important role in helping people with dementia to better understand issues, make decisions and give their input. 67% (8/12) of hospitals had access to an advocacy service with experience and training in working with people with dementia.
- One in five people with dementia admitted to hospitals in Northern Ireland from home are currently being discharged to residential care/nursing homes.

The audit also found that more could be done to improve dementia education and training for healthcare staff in Northern Ireland's acute hospitals; to increase staffing levels on wards that admit people with dementia, and to create suitable ward environments tailored to the needs of people with dementia.⁴

Access Research Knowledge (ARK) ageing programme reports^{10, 11}

ARK Northern Ireland has published reports outlining results from the Northern Ireland Life and Times (NILT) Survey specifically related to the public's attitudes and knowledge of dementia in Northern Ireland. The surveys were conducted in 2010¹⁰ and 2014¹¹.

The findings from the surveys identified that the percentage of people who knew a person with dementia rose from 45% to 61% from 2010 to 2014, with a strong link to the age of respondents in both years, i.e. older respondents being more likely to have answered positively.

Despite quite a high proportion of people knowing someone with dementia, the respondent's understanding of dementia was quite mixed. For example, most participants recognised that dementia is a disease of the brain (94% in 2010, and 87% in 2014). However, approximately 25% of respondents in both years thought that dementia was a normal part of ageing.

The surveys also identified that the public have a low awareness of the risk factors for dementia and participants' responses also suggested that there may be a lack of understanding regarding the rights of people with dementia. For example, around one third of respondents felt that 'there is little or no benefit to be gained from telling someone they have dementia' and that 'people who have just been diagnosed with dementia are unable to make decisions about their own care'.

While the authors summarised that the results of the surveys demonstrate a need to challenge attitudes, and improve understanding and awareness, they did highlight encouraging findings such as the significant majority of respondents who felt that people with dementia should be involved in activities in the community.

Living and Dying with Dementia in Northern Ireland⁶

In April 2015, Marie Curie and the Alzheimer's Society Northern Ireland published a joint report that found that people living with dementia in Northern Ireland faced barriers to high-quality end-of-life care in three key areas: identification and planning, inequality of access and quality of care. The report concludes that these barriers must be removed, and the

way in which care and support are currently provided must improve in order to ensure that people with dementia are supported to live their lives as they wish for as long as possible. In addition, when it comes to end of life, people with dementia and their carers should also be able to access appropriate care, advice and support.⁶

3.4 Organisations and groups with a focus on dementia

There are a number of organisations and groups within Northern Ireland with a dedicated focus on dementia. These include:

Alzheimer's Society NI

The Alzheimer's Society is a dementia support and research charity for anyone affected by any form of dementia in England, Wales and Northern Ireland. The Alzheimer's Society provides information, advice and support to people affected by or worried about dementia through their Helpline, online forum and community-based services. The Alzheimer's Society provides a range of local services in Northern Ireland, including social groups and support groups for people with dementia and carers; advocacy services; befriending services; dementia training and workshops for carers.

Dementia NI

Dementia NI is an independent membership organisation that was set up by people living with dementia. Dementia NI was set up to give people living with dementia a platform to influence how society views dementia. Dementia NI aims to raise awareness about dementia and challenge stigmas; promote the rights of people living with dementia; provide training, education and awareness to organisations and the public on how to live well with dementia, and support people with dementia to lobby and raise awareness in their own right. Dementia NI offers a safe and secure environment for people living with dementia to come together with support staff and volunteers. Anyone with a diagnosis of dementia can become a member of Dementia NI.

Age NI

Age NI is the leading charity for older people in Northern Ireland. Age NI offers a range of services including advice and advocacy, older people's networks, campaigning to influence policy, fundraising and care services. *My Life, My Way* is an Age NI project providing support to older people with dementia and their carers in the Belfast and Northern HSC Trust areas. The aim of this project is to promote the personal autonomy and decision-making of hard-to-reach, older people with dementia who are isolated and at high risk of disempowerment.

3.5 Other opportunities for engagement of people with dementia and/or their carers

The views of people with dementia and their carers have made an important contribution to policy making and service delivery across the UK. While not all the examples that follow involved participants from Northern Ireland, they will nonetheless help to shape and inform practice and research priorities for dementia care in Northern Ireland.

Informing policy and service delivery

In Northern Ireland, the DoH sought the views of people with dementia and their families to help inform the regional strategy for improving dementia services. In recognition of the challenges involved in gathering these views, the department funded research by the Alzheimer's Society. The *Listening Well* report describes the findings of work in which one-to-one interviews, focus groups, and a group listening event with people with a diagnosis of dementia and carers were used to ensure the authentic involvement of people with dementia in the development of the dementia strategy for Northern Ireland. The report made recommendations based on what people told them: to raise awareness of dementia among HSC staff and among the wider public; to improve the experience of receiving a diagnosis of dementia, including early assessment and early diagnosis, communication and information; to improve access to information, support and advocacy after diagnosis, and further research.¹²

The Dementia Learning and Development Framework for supporting HSC staff to deliver better care to people living with dementia was also informed by the experiences of people with dementia and their carers. The expert steering group that came together to develop the framework consisted of a wide range of individuals from HSC, local charities, university academics, carers and people with a diagnosis of dementia.⁷

Northern Ireland Innovation Lab, in conjunction with key partners, held an event in June 2015 attended by 80 participants including: carers, people with dementia, healthcare professionals, General Practitioners (GPs), staff and managers from care homes and residential homes including private sector, people working in the voluntary and social sector, charities, researchers from academic institutions and designers. The purpose of the event, which ran over five days, was to 'co-design effective care for persons living with dementia and help find solutions to the challenge posed by the DoH'.

Outcomes from the project included identification of six gold standards:

- Prevention: promoting understanding, sustaining relationships, citizenship and social inclusion embedding dementia into real life.
- Personhood: giving people the information they need to help them maintain quality relationships while maintaining personal identity. An enabling and supportive environment where people feel valued and understood.
- Diagnosis: comprehensive, accurate and as quickly as possible.
- Early intervention and treatment: distinct, discrete dementia service informed by people living with dementia, recognising the role that society plays - citizenship, dementia-friendly communities.
- Living well at home: multidisciplinary teams involved in a holistic assessment of a person with dementia and their carer. Ensuring that sufficient resources are in place to deliver high-quality care and choice to enable the person to remain at home for as long as possible. Each person should have an identified key worker who will be a point of contact for a person with dementia and their carer.
- Living well in supported living and care homes: whole systems approach where people are valued and enabled to live life to the max. Where there is community ownership and flexibility, including commissioning.

Key areas for action were highlighted as: a whole systems regional model; creation of a Dementia Alliance; a 24-hour helpline; awareness and communication, and economic modelling/costing the system.¹³

The Public Health Agency (PHA) in Northern Ireland is also running a project on dementia. It is currently engaging with patients, their families and carers as part of the 10,000 Voices project, with a particular focus on the issue of delirium.

In England, the DoH commenced a 'listening programme' in November 2014 to gather the views and experiences of people who have been recently diagnosed (within two years) with dementia. The findings from the programme, which closed in January 2017, will be used by the DoH to help identify what changes are needed at a local level in relation to delivery of services and support. In addition, the DoH said it would also be using the information gathered to inform the formal review of the Dementia Challenge 2020 Implementation Plan to assess whether the policy and actions are actually making a difference to people's day-to-day lives.¹⁴

Informing priorities for dementia care research

The James Lind Alliance has recognised that there is often a mismatch between the research being carried out and the research evidence needed by patients and clinicians every day. In an attempt to address this it facilitates Priority Setting Partnerships that bring patient, carer and clinician groups together on an equal footing to identify treatment uncertainties that are important to both groups. It then works with these partnerships to jointly prioritise the uncertainties and produce a 'Top 10' list of jointly agreed uncertainties as research questions to be presented to funders.

The top 10 research priorities as agreed by the Dementia Priority Setting Partnership are highlighted in Table 1.1. The priorities were launched at the Alzheimer's Society's Research conference on 27th June 2013.

Table 1.1: James Lind Alliance Top 10 Priorities for Dementia Research¹⁵

	Priority
1	What are the most effective components of care that keep a person with dementia as independent as they can be at all stages of the disease in all care settings?
2	How can the best ways to care for people with dementia, including results from research findings, be effectively disseminated and implemented into care practice?
3	What is the impact of an early diagnosis of dementia and how can primary care support a more effective route to diagnosis?
4	What non-pharmacological and/or pharmacological (drug) interventions are most effective for managing challenging behaviour in people with dementia?
5	What is the best way to care for people with dementia in a hospital setting when they have acute healthcare needs?
6	What are the most effective ways to encourage people with dementia to eat, drink and maintain nutritional intake?
7	What are the most effective ways of supporting carers of people with dementia living at home?
8	What is the best way to care for people with advanced dementia (with or without other illnesses) at the end of life?
9	When is the optimal time to move a person with dementia into a care home setting and how can the standard of care be improved?
10	What are the most effective design features for producing dementia-friendly environments at both the housing and neighbourhood levels?

4. Discussion groups and blog – key issues for people living with dementia in health and social care

The discussion groups organised by the PCC were held in conjunction with existing third sector community and voluntary groups (Alzheimer's Society and Dementia NI).

Participants were a mix of patients, clients and carers with direct and current experience of the specific health and social care issues being examined. A group was held in each HSC Trust area with the intention that should there be particular locality issues these may be identified.

The purpose of the discussion groups was to engage with both service users and carers to understand the key issues for people living with dementia in health and social care with the view of informing any further work undertaken by the PCC in this area. The groups took a less formal approach than a traditional focus group format by using only a few open questions from the facilitator to prompt participants to share their expertise and input into the discussion. Rather than holding a stand-alone focus group, the intention of collaborating with the community and voluntary sector was to enable a panel of participants to be established to facilitate reciprocal exchange of information.

In addition to the discussion groups, the PCC posted a blog in January 2017 discussing the PHA's #STILLME dementia awareness campaign. PCC asked for feedback from the public on how health services could be improved to better meet the needs of people with dementia. Comments made on the blog were gathered and are presented alongside the findings from the dementia discussion groups.

A total of 43 people took part in the five discussion groups across the HSC Trusts in November 2016. Participants included 28 people with a diagnosis of dementia and 15 carers. In addition, 13 people provided comments to the PCC blog on dementia and one person, who was unable to attend a group, provided a written account of their experience.

Key Findings

Although the number of participants who took part in the project was relatively small there was consistency of the issues that were raised across groups. There are a number of key findings relating to dementia care experience that people identified. These were:

- Issues with diagnosis and lack of immediate support;
- Need for ongoing support in health and social care;
- Unique challenges faced by those with young onset dementia;
- Carers require support;
- Role of community and voluntary organisations; and
- Need for continued awareness-raising and better understanding.

4.1 Issues with diagnosis and lack of immediate support

KEY QUOTES:

“Absolutely no preparation, nothing. To get a one-liner and then said goodbye ... I thought it was so bad and so horrible. For someone to go and then he gets a diagnosis, it’s soul destroying, and then you are the wife, the husband, or the partner, whatever, and you have suffered terribly hearing this but you cannot show this and there has been nothing for the people, no feedback.”

Group 5c – Participant 5: Carer

“Well, whenever I think about it, we were told [family member] had vascular dementia, but [family member] wasn’t in the room, we were just told. So [family member] has never really been told that [they have] dementia.”

Group 3 – Participant 3: Carer

“Even after diagnosis I asked for counselling to be given and was told there wouldn’t be any point ... I would say that there needs to be more immediately after the diagnosis. There needs to be more, be that counselling, or this, or the other, because quite honestly the doc just gives the diagnosis.”

Group 1 – Participant 9: Carer

“Also, no leaflet information was given to us at the end of the assessment and diagnosis until we were contacted one month later by the CPN [Community Psychiatric Nurse] by telephone and later by the Dementia Navigator who was very helpful.”

Written correspondence - Participant 1: Person with dementia

In the group discussions many people relayed negative experiences of their diagnosis of dementia or the diagnosis of the person they care for. People highlighted both a lack of emotional and informational support to help them come to terms with and understand the diagnosis.

The way in which the diagnosis had been communicated was a key issue. Some people said that the professional who delivered the diagnosis of dementia was very “blunt” or “cold” and did nothing to prepare them or their carer in advance. In several cases the person with dementia or their carer said they were simply given the diagnosis, prescribed medication and sent away without further discussion, advice or support.

Two people with dementia explained how they became very depressed and isolated in the immediate period after their diagnosis to the extent of feeling suicidal. One individual said they felt “abandoned” after their diagnosis as they were sent home to cope with the news alone and received no further contact from HSC services for three months.

A couple of people made reference to the fact that they, as family members, had been told that their loved one had been diagnosed with dementia but it had never been communicated directly to the person themselves. A group coordinator from one of the voluntary organisations also emphasised this point and they believed it put families in an unfair position and left them in a dilemma as to whether to tell their loved one that they had been diagnosed with dementia.

Most people, when asked, said they were not provided with any information or offered any counselling or emotional support to help them understand or come to terms with their diagnosis or with the diagnosis of their family member. Some people believed they would have benefitted from such a service, with one participant stating how they felt it should be routine practice for a member of HSC staff to be in touch within two to three days to let people know there is help out there.

4.2 Need for ongoing support in health and social care

KEY QUOTES:

“Is there no way, you know, once somebody is diagnosed with dementia that it goes on their notes that follows on through. You know that they [health professionals] are aware before [person with dementia] enters the room, that this is a patient that has dementia?”

Group 3 – Participant 3: Carer

“I think GPs to start with need to be more informed, you know they might just know a bit about dementia or that, but I think there needs to be more information because it’s them you go to and that they can point you and say maybe you can do this.”

Group 5 – Participant 4: Carer

“The carers that come to [family member], they didn’t even realise that [family member] had Alzheimer’s, you know, so I had to inform the office and leave leaflets... they [domiciliary carers] want to get in and out as quick as possible, but that’s not always the case with somebody with dementia.”

Group 3 – Participant 2: Carer

“As a family we tried to care for [family member] as much as possible at home. We had a rota to look after [family member] but, in the end, we had to seek support from professionals to help us. When the disease advanced we were devastated to hear that [family member] and those suffering from this cruel disease have no other choice but to sell up.”

Blog – Participant 9: Carer

“I should have a visit from a psychiatric nurse, I have seen her once. She might have a workload, which I would understand but, nevertheless, I have had no support from them, Mental Health [services] or anything. I see a Psychiatrist on a three-monthly basis, the memory clinic, they compliment me but I work very hard just to stand still. I work hard every day.”

Group 1 – Participant 1: Person with dementia

Participants in the discussion groups reported mixed experiences of the support they received from HSC services in respect to dementia in the longer term. These discussions related to follow-up and further care in the hospital setting and ongoing support in the primary care/community setting.

Lack of awareness and understanding in the hospital setting

A lack of awareness and understanding from HSC staff was the predominant issue highlighted by participants when reflecting on their experiences within the hospital setting.

A number of individuals recounted experiences in the hospital setting where health professionals had not appropriately taken into consideration the impact of dementia. This related to both staff working at a specialist level and staff with whom participants came into contact for other health complaints. Participants described consultations where they struggled to understand the information being discussed, which left them feeling confused and upset, and consultations that had to be abandoned because the professional didn't have the skills to successfully conduct the assessment with someone with dementia.

On a practical level it was highlighted that having clear signage or navigators within the hospital setting would be very beneficial for someone with dementia. One participant with dementia described occasions when they had been sent by a Consultant to another ward or floor to get blood tests done and they had forgotten where to go and got lost.

For those participants who had experience of an inpatient stay the sense was that this was a particularly isolating experience. One person with dementia reflected that they had just kept to themselves and never "let on" to staff about their dementia. Another carer felt their family member was left sitting in a chair for long periods during a hospital stay but, because their dementia was advanced, they could not communicate this to their family, which they highlighted as a particular challenge for people with dementia.

Both carers and participants with dementia highlighted a need for a "flagging up system" to make HSC staff aware that a person has dementia in order to avoid confusion or awkwardness and to fast-track people to avoid them having to wait around in an unfamiliar environment when they attend the hospital for appointments.

Support in the secondary care/community setting

GP services, social workers, care homes and financial support were the main topics raised by participants when reflecting on the level of support in the primary care/community setting.

GP services were one of the few primary care options accessed by most participants in the group discussions. However, many participants stated how they had only limited interaction with the GP regarding dementia, for example, only ringing up for repeat prescriptions. While some said their GP was very supportive, others felt the GP was poorly informed about dementia and was not well-trained in delivering dementia care.

With regards to social care only a few people said they received regular contact and a high level of support from a social worker. Other participants believed their social worker was not forthcoming with information on what support was available, such as grants and domiciliary care. A participant with dementia emphasised that people need to be told upfront what support is available rather than being asked what they need as most people don't know what they are eligible to access.

The need for improved communication between staff in the community was noted by one carer who explained that carers who were assigned to their loved were not informed of the diagnosis of dementia. The participant believed this had impacted negatively on the quality of care their family member had received as the carers did not understand why the person was sometimes aggressive or took longer to do things.

While most participants reflected negatively on the limited support they had received there was evidence to suggest that, in some cases, the system had worked well. For example, one participant with dementia described how they had been quickly put in touch with a social worker who they saw every four to six weeks. They were also able to schedule regular appointments with their GP, with whom they had an "excellent relationship". In addition, the participant also had weekly visits from AGE NI and attended a group through Dementia NI.

Most feedback regarding care homes related to concerns regarding the cost of care for people with dementia. This feedback mainly came from people who had responded to the

PCC blog. Another aspect of finances that was discussed within groups was related to difficulty accessing benefits. A couple of participants with dementia described form-filling and assessments as distressing and wondered why people with dementia were continually reassessed for benefits when their condition was progressive. In relation to cost of care and access to benefits, participants queried whether there was equity for people with dementia in comparison to those with other chronic and terminal conditions such as cancer.

4.3 Unique challenges faced by those with young onset dementia

KEY QUOTE:

“We weren’t offered any support at the beginning, mainly because [spouse] was considered young. No diagnosis was given but, after psychometric testing, etcetera, one guy did write us a report which basically said ‘we have no facilities in Northern Ireland for people of this age group’. So until [spouse] was 60 we didn’t get a diagnosis. It was only then that we could report back into the system.”

Group 1 – Participant 9: Carer

Two people with dementia spoke about their experience of being diagnosed with young onset dementia. In both cases, diagnosis was made at a relatively young age (45-54 years age group) and the participants stated that the system did not know how to deal with or treat younger people with a diagnosis of dementia. One individual felt they had fallen through a gap and didn’t know whether it was because dementia was considered an older person’s condition and services were only available for that age group, or whether it was because information was being withheld by HSC staff who didn’t want to explain to them what they were likely to face. The other participant, a carer, described how they were told clearly that services were not available for their partner.

It was the opinion of a dementia group coordinator that, while people may be presenting in their forties, fifties and sixties, they were not being diagnosed until many years later as there is no provision for diagnosing younger people. People felt that those years were a missed opportunity to actively treat and perhaps slow or stall progression of the condition.

One of the participants, who had young children, described the challenges and fears they had for the future as their condition progressed. They explained that, while they needed assistance, due to past experiences and a fear of their children being taken into care, they were worried about approaching social services and felt they had nowhere to turn.

4.4 Carers require support

KEY QUOTES:

“You went home and you just thought – have I to live with this person, keep them and watch them, you know?”

Group 5c – Participant 2: Carer

“I think you could do with like a ‘sit in’ service. You know, that people could go around and sit with people and talk to them and do something with them.”

Group 5a – Participant 3: Carer

“Much greater support for carers is needed to enable people who have dementia to remain at home. Bearing in mind that the majority of people with dementia are older people, it can be expected that a large number will be living with spouses who are also elderly and who may have their own health and/or mobility issues. Unless there is appropriate/significant support for such carers, it will not be possible for people with dementia to remain safely in their own homes.”

Blog – Participant 10

Many of the carers who participated in the groups said that their family member’s diagnosis of dementia came as a shock, even if they had been showing symptoms for some time. A couple of carer participants described how, if they had known the signs and symptoms of dementia when their loved one had first displayed them, they would have been able to cope better. For example, one carer believed that if they had known personality change can be a symptom of dementia then they would have been more sympathetic to their loved one.

For those carers who had tried to access information themselves, some said it was not always straightforward despite considering themselves quite computer literate. It was felt that for carers with limited time and limited resources information needs to be more readily available.

When asked what they would value most, carers identified caring services and respite as the two main areas. The caring services people referred to were ideas such as a 'sit in' service or a 'befriending service' for the person with dementia. Participants felt there were opportunities for formal carers to "branch out" and help people with dementia engage in more meaningful activities, such as going to the cinema or enabling them to get out to groups.

In one group, carers described the difficulty they had experienced in trying to book respite in advance and how they felt respite places were being held for crisis situations. They highlighted how this made it very difficult for carers to be able to plan in advance and felt this was something that could be improved. Only one carer mentioned having had a carer's assessment or even being aware of what it was.

As with the unique situation faced by people with young onset dementia, it was highlighted that younger carers may also face distinctive challenges as they most likely would not have experience of dementia. As such, they may have less understanding of the condition and how to cope. One participant described how it was only through involvement from Barnardo's, that their children had been able to access any support. This participant felt their experience highlighted the lack of knowledge regarding what support is available for young carers.

4.5 The role of community and voluntary organisations

KEY QUOTES:

“I have been here [attending dementia group] so long... but I would say I have got more each time I come here, whether we giggle and we laugh, you know, I would say I get so much from that.”

Group 1 – Participant 3: Person with dementia

“It’s good to come here to talk to different people with same situation and to talk about their different experiences.”

Group 4 – Participant 2: Carer

Many people said that their biggest source of support, outside of family, were the dementia groups they attended. Both carers and people with dementia explained how, by attending groups run by the community and voluntary organisations such as Alzheimer’s Society and Dementia NI, they realised that they were not on their own and were able to share their problems with others.

Carers also explained that through simply hearing others speak at the groups about their own experience they were able to glean so much information. For example, being able to understand the likely progression of the condition from others further along the journey or becoming aware of practical support, such as grants or benefits and how to access them.

Participants repeatedly said that the groups run by community and voluntary organisations were their primary source of information, particularly when it came to aspects of planning for the future, such as information on capacity and power of attorney and end-of-life planning. Training on how to care for someone with dementia is provided by these organisations and carers spoke of finding these courses very valuable.

4.6 Need for continued awareness-raising and better understanding

Participants we spoke to recognised that while awareness of dementia is growing so is its prevalence. They felt strongly that there needed to be continued effort in raising public awareness and understanding to enable people to identify the symptoms of dementia so it can be diagnosed and treated as early as possible. One blog participant queried whether screening procedures could be put in place so as to “alert or reassure” people and increase the chances of early diagnosis.

While some people felt the PHA’s #STILLME dementia awareness campaign was “excellent” as it had stimulated discussion about dementia, there were mixed feelings from others who felt that, while the campaign was well-meaning, it “trivialised” dementia and was “disingenuous” because it did not reflect the “sheer misery and uncertainty” faced by people with dementia and the people who care for them.

Participants in one group in particular, who were volunteers in a dementia group, believed that as well as promoting awareness of the condition, awareness of the services available was also needed. They believed that to do this there needed to be better integration of services that are currently available for people with dementia or their carers. Their opinion was that while community and voluntary organisations, councils and HSC services all had interventions or services targeting dementia they were completely divorced from each other. Participants felt this needed to be addressed so that collective resources could be used to the full potential.

5. Conclusions

This scoping exercise identified a substantial body of work focused on improving services and supporting people with dementia and their carers in Northern Ireland, including policy such as the regional dementia strategy, the Dementia Learning and Development Framework as well broader policies that have included a focus on dementia, such as Transforming Your Care, and Health and Wellbeing 2026. A dedicated research programme including seven research projects with the aim of addressing the increasing prevalence and burden of dementia, and improving the quality of life and wellbeing of service users and carers has also been funded at a cost of approximately £2million.

A number of opportunities for engagement with people with dementia and their carers were also identified, the findings of which were used to influence policy making and service delivery in Northern Ireland. These included one-to-one interviews, focus groups, a group listening event with people with dementia and their carers, inclusion of people with dementia and their carers on expert steering groups and an Innovation Lab event.

Despite this comprehensive body of work conclusions from recent audit and research reports from within Northern Ireland suggest that even more needs to be done to challenge attitudes, and improve understanding and awareness of dementia; that improvements are needed in education and training for HSC staff and that barriers such as inequality of access need to be addressed so that the way in which dementia care and support are currently provided can improve.

The findings from the qualitative work undertaken as part of this scoping exercise would also seem to suggest that there are significant issues experienced by people with dementia and their carers that negatively impact on their experience of dementia care. Concerns raised by participants in this project include issues with diagnosis, such as the way it is communicated and the lack of immediate informational or emotional support to help people understand and come to terms with the diagnosis. The need for improved ongoing support in health and social care both in the hospital and community setting was also raised, as was the importance of the role played by the community and voluntary sector in supporting people with dementia and their carers. The unique challenges faced by those with young onset dementia was highlighted in this project and is an issue that

does not seem to be reflected in other published reports from within Northern Ireland. Better support for carers and the need for continued awareness-raising and better understanding of dementia, including dementia services, were further issues raised by the participants in this project.

6. Recommendations

A number of recommendations can be made from the findings of this report.

Recommendation 1

The Dementia Learning and Development Framework (2016), which provides a structure for dementia-specific training and education for staff within health and social care, has only recently been published and it is believed that the framework could be a major influencing factor in realising the recommendations made in the dementia strategy.

Once the framework is fully embedded the PCC will undertake another project to explore whether people's experience of dementia care has improved.

Recommendation 2

The unique challenges faced by those with young onset dementia and their carers were highlighted by participants in this project. This is a key issue that doesn't seem to be reflected in other published reports identified by the scoping exercise. Therefore, in 2017/18, the PCC will undertake a piece of work to highlight these issues.

Recommendation 3

There are learning points for HSC services within this report, which include the need to improve people's experience of diagnosis and their ability to access support both immediately and in the long term in the hospital and community setting. The need to acknowledge the important role played by the community and voluntary sector and to make better use of collective resources was also identified.

The PCC will endeavour to promote learning from this project by sharing findings with a range of stakeholders across health and social care.

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