



**Integrated  
Care System**

Nottingham & Nottinghamshire

# Dementia Wellbeing Pathway – Nottingham and Nottinghamshire

## Engagement Report

July 2021

## 1. Executive Summary

In Nottingham and Nottinghamshire, services are commissioned to assess, treat and support people with Dementia. The Mental Health Commissioners identified that there was a need to review the pathway and better understanding the views of patients, the public and carers to ensure services were meeting the needs of all those living and working with dementia, particularly during the Covid-19 pandemic.

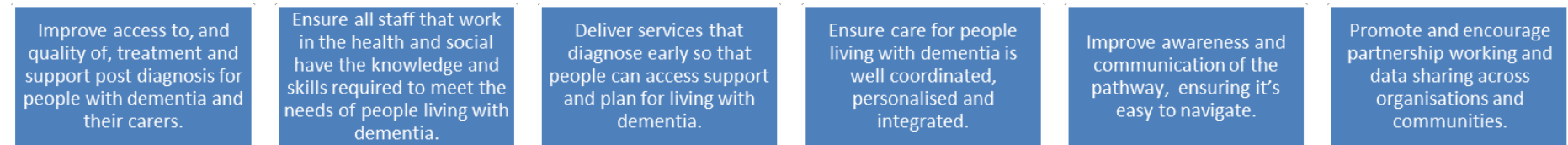
The Nottingham and Nottinghamshire Clinical Commissioning Group and Integrated Care System have engaged with community groups, service users, carers, health and social care professionals and the wider public to understand views and experiences of dementia services in our areas. The insights generated will inform the development of the future provision and an ICS Dementia Strategy.

This piece of engagement work commenced on the 17 May 2021 and concluded on the 16 July 2021.

The Engagement Team used various approaches to carry out the engagement using different methods including an online survey, focus groups, telephone interviews and attending forums and groups who were meeting either virtually or in a community socially distanced setting. A total of 349 surveys were received via the online survey.

### Recommendations

Outlined below are the key recommendations following analysis of the engagement.

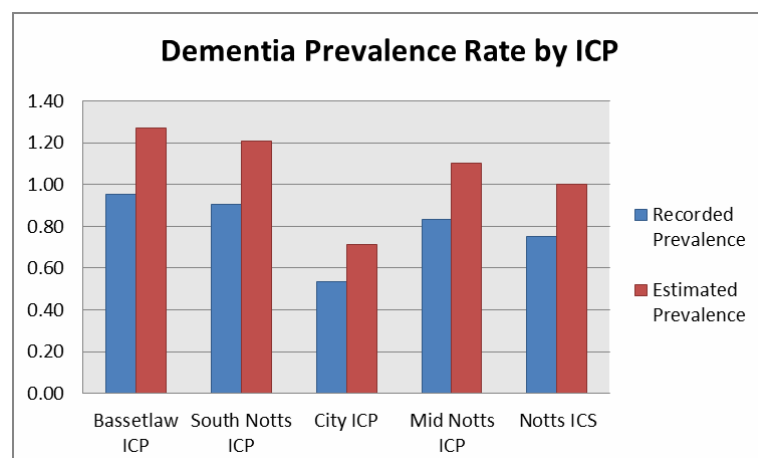


Thank you to all participants who took the time to complete the survey, for providing full details via telephone interviews and also to all who attended the focus groups to provide your feedback and experience and sharing your stories with us. Thank you to the community groups who allowed us to attend your specific sessions and to those who shared the information on any social media platforms. Thank you to all who provided

their personal experience and sharing your journeys with us. And finally, a special thank you to Christine Eagle who provided her personal story and experience. Should anyone have any queries or questions regarding the engagement report then please contact the Engagement Team at [ncccg.team.engagement@nhs.net](mailto:ncccg.team.engagement@nhs.net). Updates and progress around the implementation of the pathway will be available in due course on our website: [Current and previous engagement & consultations - NHS Nottingham and Nottinghamshire CCG \(nottsccg.nhs.uk\)](https://www.nottsccg.nhs.uk).

## 2. Background

People are now living far longer, but extra years of life are not always spent in good health. One in fourteen people over 65 and one in six people over the age of 80 has dementia. 70% of people in care homes have dementia or severe memory problems. There will be over one million people with dementia in the UK by 2025, and there are over 40,000 people in the UK under 65 living with dementia today<sup>1</sup>.



Locally, according to primary care data, 0.75% (8330) of the population has a Dementia Diagnosis with 1% (11079) of the population expected to have Dementia according to CFAS II estimates. Of those aged over 65 4.43% have a Dementia diagnosis. The number of over 65s across Nottingham and Nottinghamshire is projected to increase by 9% in the next 5-years<sup>2</sup>, with severity and the associated need also expected to significantly increase over the next 20 years<sup>3</sup>.

Following investment into the Memory Assessment Service in 2020/21, the priority for 2021/22 was to improve the post dementia diagnosis pathway. In January 2021 a Dementia Pathway Review was undertaken with particular focus on the post dementia diagnosis pathway, involving people with lived experience of dementia and system partners aiming to understand the key priorities. This review aimed to inform both the commissioning priorities for the dementia pathway and the

development of an ICS Dementia Strategy.

In May 2021, the Mental Health Team attended the CCG's Patient and Public Engagement Committee (PPEC) and provided an overview of the current services that are provided and the proposal for engagement to ensure that feedback informs commissioning the of the service in 2021 (outlined above).

The Mental Health Team will return to the CCG's PPEC in September 2021 to discuss the recommendations arising from the engagement and next steps and what this means for the pathway in the future.

<sup>1</sup> Trends in diagnosis and treatment for people with dementia in the UK from 2005 to 2015: a longitudinal retrospective cohort study (The Lancet Public Health, 2017)

<sup>2</sup> Projecting Older People Population Information (Oxford Brookes University, 2019)

<sup>3</sup> Projections of older people living with dementia and costs of dementia care in the United Kingdom, 2019–2040 (London School of Economics, 2019)

## **2.1 Aim and Objectives**

The aims for engagement are to understand current experiences of, noting improvements needed to be made thus informing commissioners when procuring services.

Key objectives that communications and engagement activities need to meet are:

- To provide patients, members of the public and carers with the opportunity to state what the services means to them and how they want to access early support
- To provide Primary Care Staff and Providers with an opportunity to feedback
- To provide Patients, members of the public and carers an opportunity to feedback their views
- To understand current demand and capacity
- To understand service users, experience particularly those experiencing health inequalities

## **3. Engagement Methodology**

The general principles to follow when implementing the communications and engagement:

- Engagement to follow best practice guidelines and conduct engagement in a timely manner to fit procurement deadlines to ensure business continuity.
- Engage people early within the process and not as an afterthought.
- Encourage participation with engagement for all interested ensuring reduction of barriers to engagement, especially those with protected characteristics and underserved communities
- Work with relevant partners to help promote and encourage participation with engagement activities. Partners include local councils and district councils, voluntary and community sector organisations, Self Help Groups, Primary Care Networks, Patient Participation Groups and Patient Leaders, and local community groups.
- Feedback outcomes to all those involved with the engagement and any commissioning decisions that have been directly influenced by this.

Engagement was undertaken via:

- Survey
- Telephone interviews with carers and health and social care professionals
- Focus Groups
- Specific Community Meetings – Eastwood Memory Café, Young on Set Support Groups, Ashfield District Council Coxmoor Golf Sessions for Patient and Carers and a meeting the Alzheimer’s Society including patients, carers and Dementia Support Works
- Attendance at Nottingham University Hospitals Dementia, Frail Older People and Palliative Care Patient and Public Involvement Meeting
- Attendance at East Midlands Academic Health Science Network Patient and Public Involvement Senate

The CCG are committed to actively engaging and listening to the views of service users and carers within the community. The key communications and engagement activities that will take place include:

- GP communication – via GP Teamnet, emails to Practice Managers and Clinical Directors and Primary Care Network Managers (also include Locality Directors)
- Patients, members of the public and carers communication also via service providers, CVS, Ethnic Community Groups, third sector organisations, Local Authorities (including District/Borough councils), NHS Trusts (including Institute of Mental Health at Nottingham University), charities, local community groups, East Midlands Academic Health Science Network and Healthwatch.
- Patient, member of the public and carers engagement via focus groups
- Materials available in alternative formats upon request.
- Social media promotion and information available on the CCG Website
- Press release containing a case study/patient story
- Information in local CVS, Council, System Partners and CCG bulletins
- Equality Impact Assessment to ensure process is inclusive and adjustments made to Communication & Engagement Plan as appropriate

An activity log has been collated to identify as and when the engagement was undertaken and notes all information from telephone interviews, publications, press releases and group attendances.

#### **4. Findings**

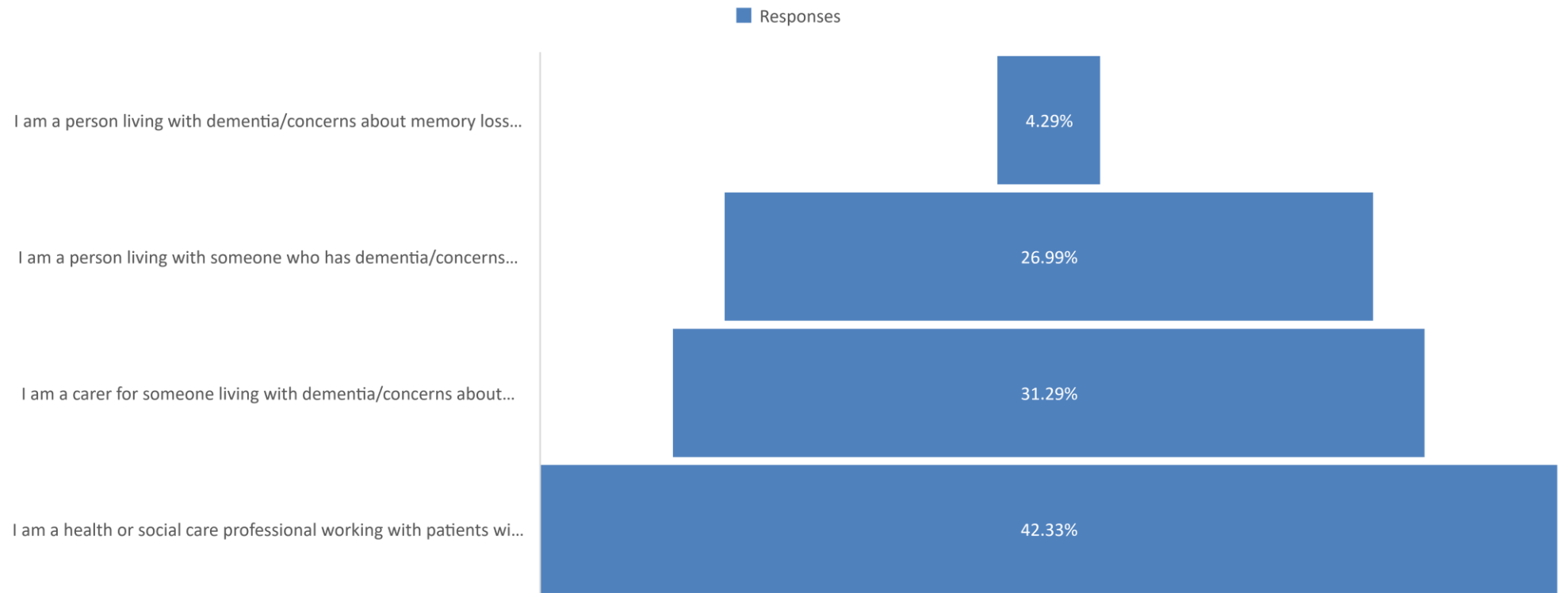
The findings below are split into the categories of survey results, telephone interview, focus groups and also attendance at a community groups.

Thematic analysis was conducted for the survey results. The main themes are highlighted within the report. Further information is also available on our website at: [Current and previous engagement & consultations - NHS Nottingham and Nottinghamshire CCG \(nottsccg.nhs.uk\)](https://www.nottsccg.nhs.uk)

#### **4.1 1 Survey Results:**

The survey ran from 17 May 2021 up to including the 16 July 2021. In total 349 responses were received. An outline of responses and graphics of the results and comments received are outlined below:

## Which of the following statements best describes you? Please chose one option only.

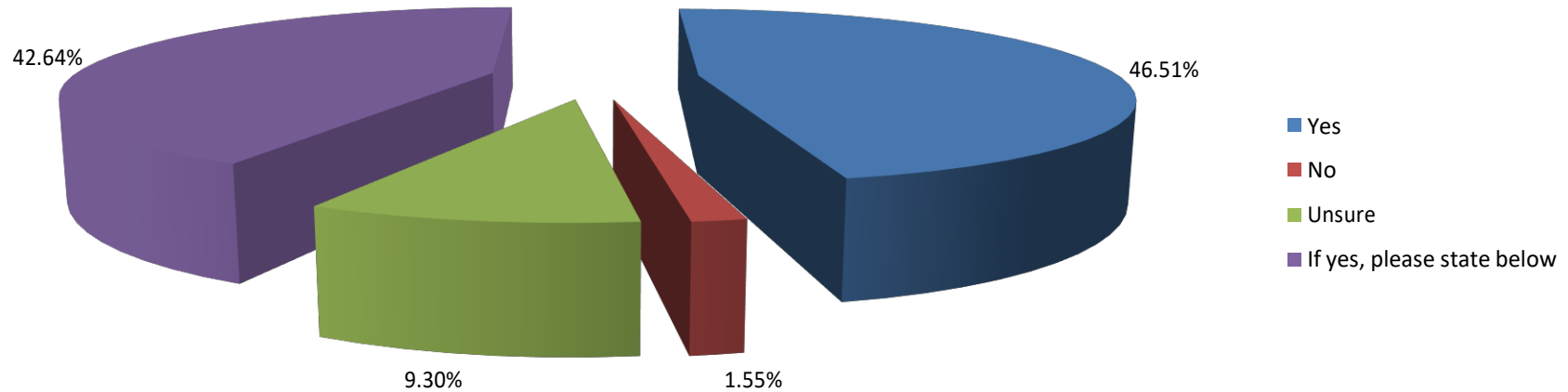


Other respondents included: -

- Volunteers (including working with veterans and charity volunteers)
- Friends
- Relatives
- Community and Voluntary Sector Colleagues

- Charities
- Deaf Community Link Workers
- Local Authority Colleagues

## Have you seen a change in their symptoms during the past year?

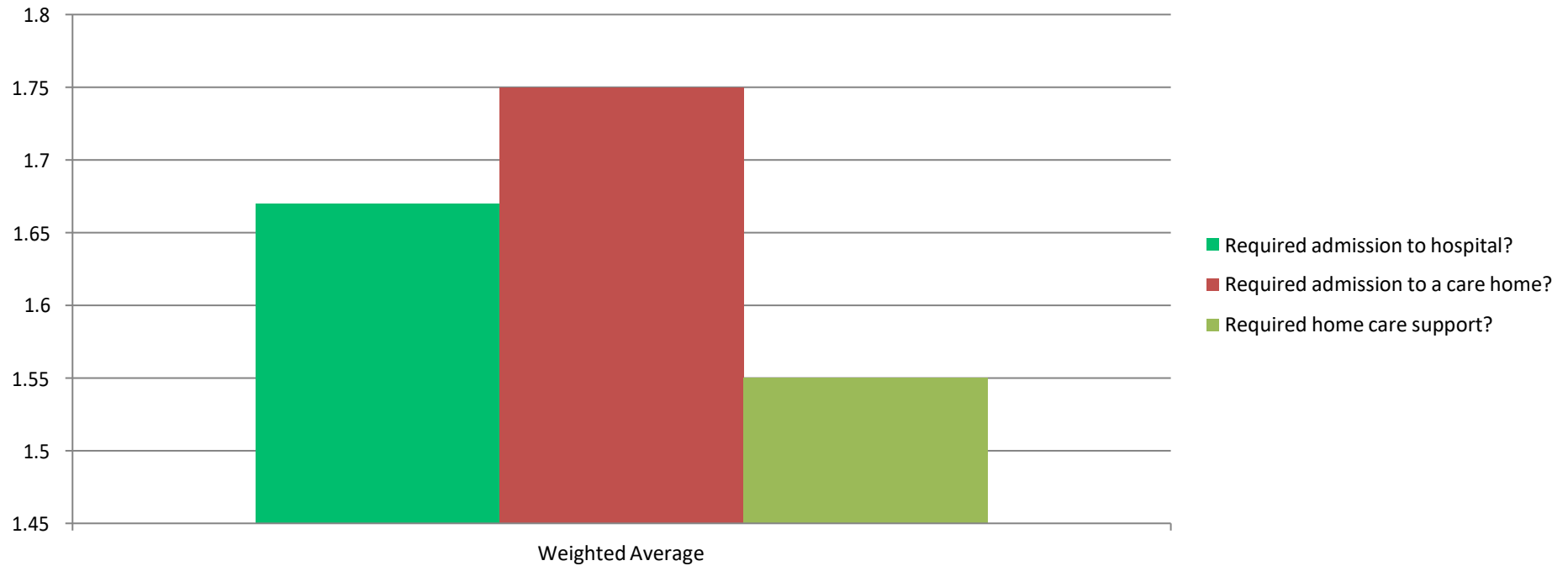


### Key Themes Identified: -

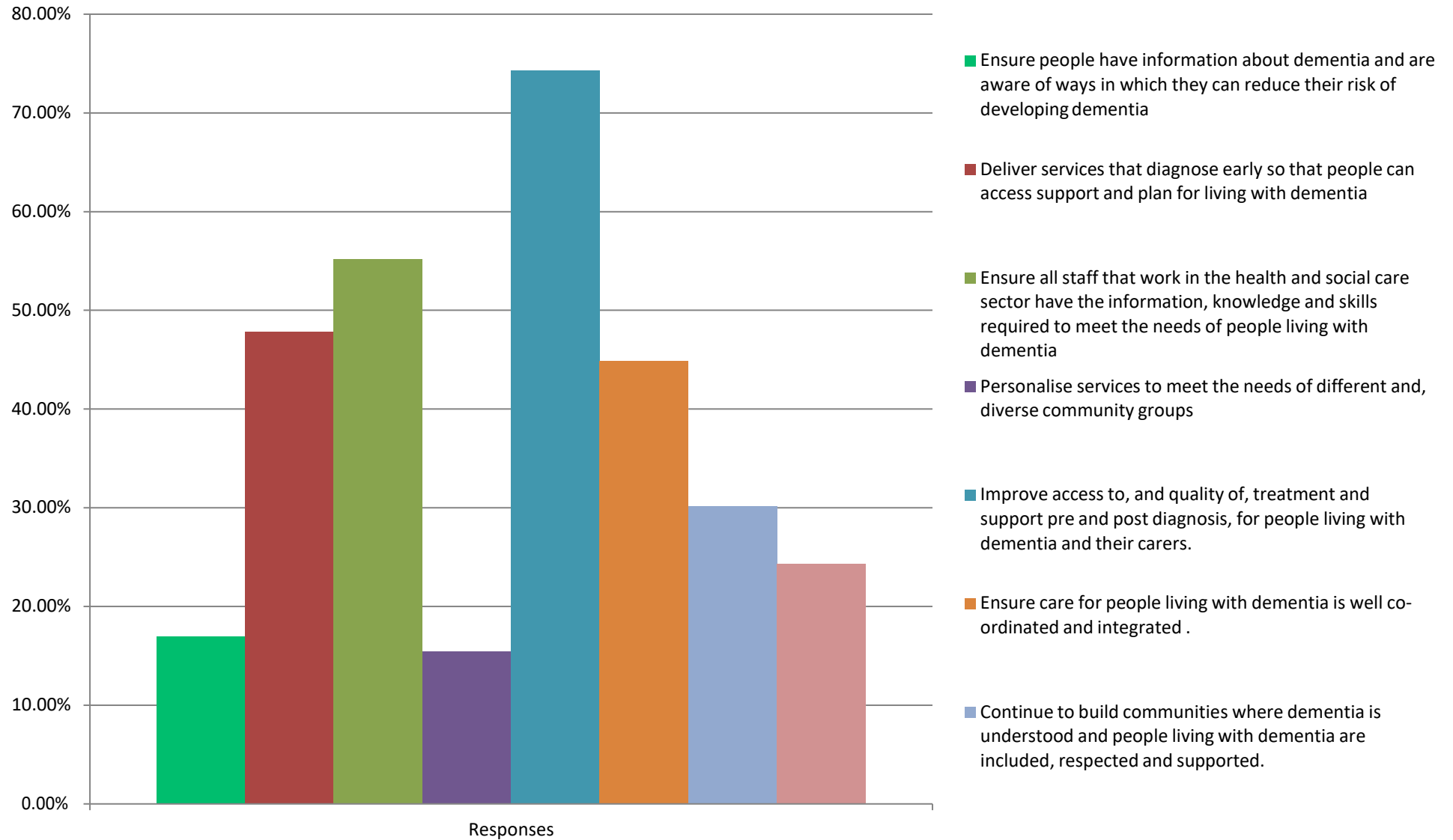
- Mental Health Issues
- Physical Ability
- Increase in Confusion and Memory Loss
- Accessing to services has caused increase symptoms
- Behaviours



### During the Pandemic has your relative/friend/patient with dementia/concerns about memory loss:-



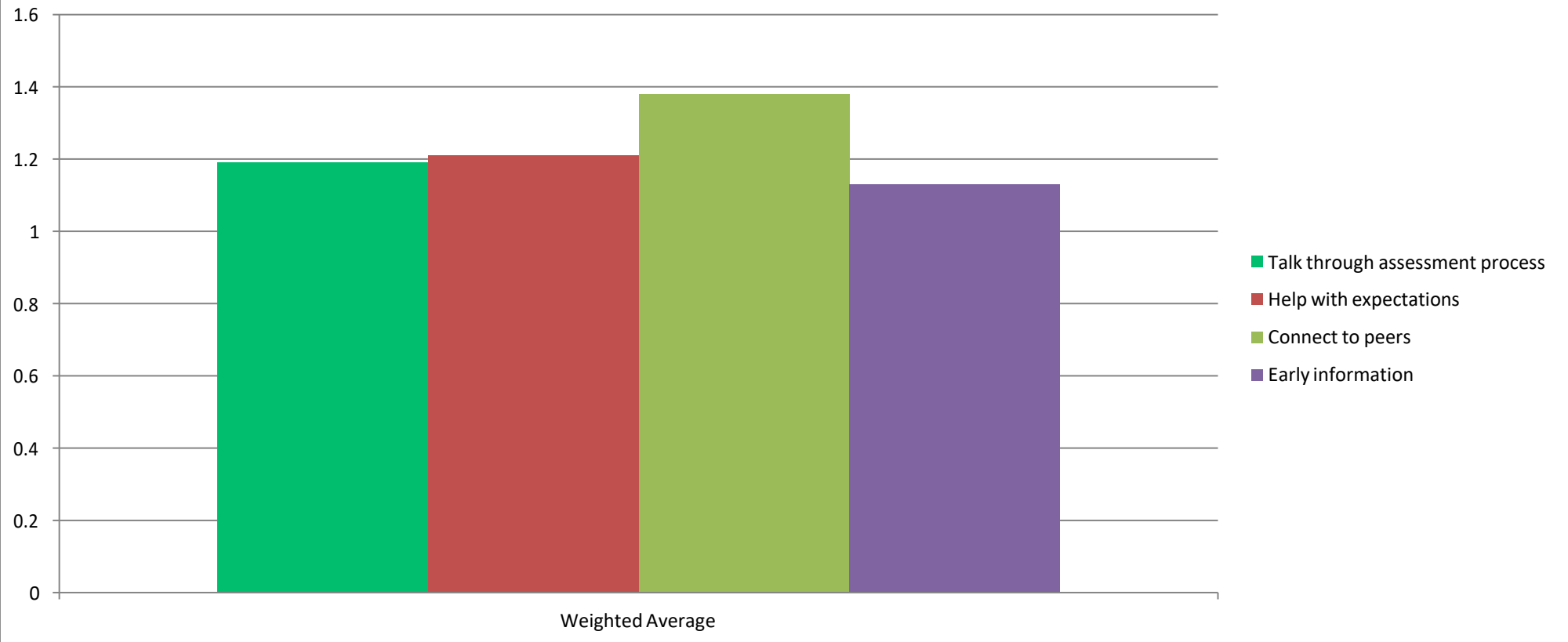
## Please mark your top three priorities, and tell us why they are important



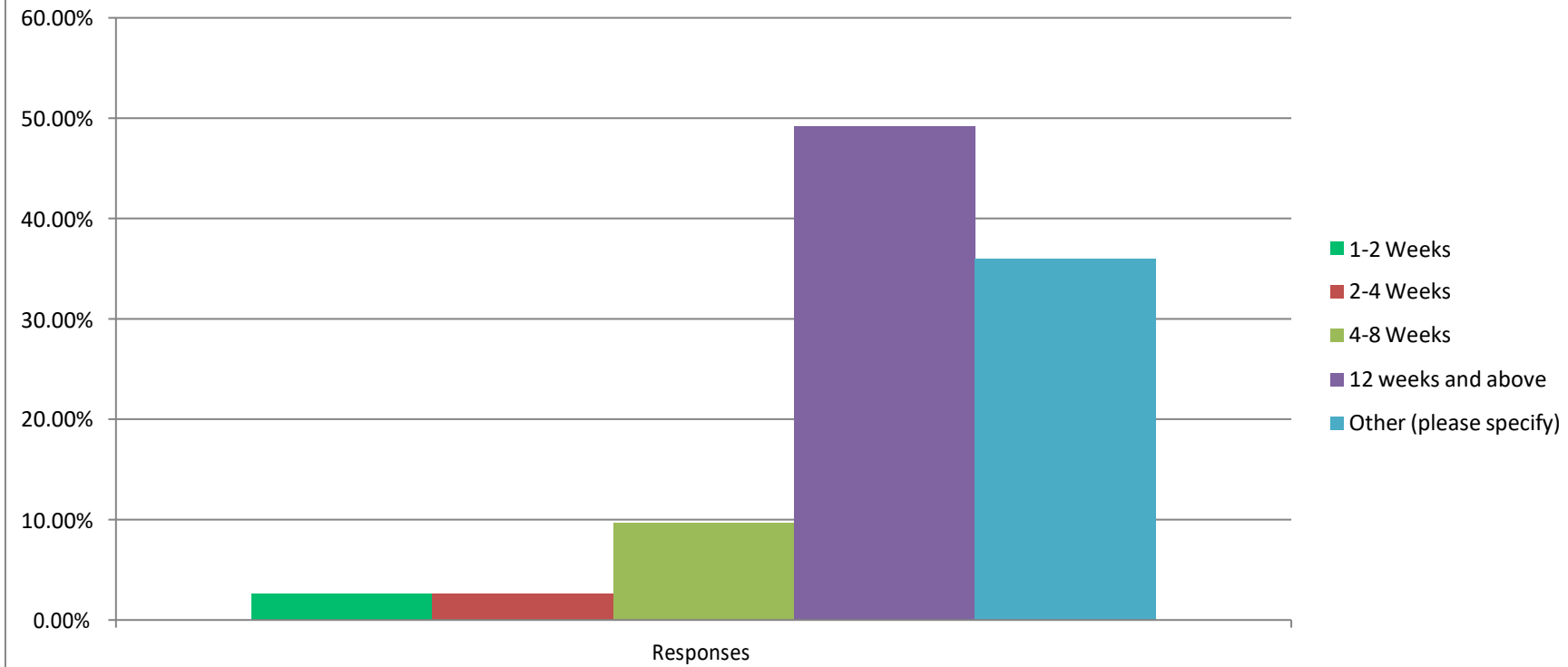
Participants were also asked to provide feedback on what other priorities needed to be considered – These were coded and themed from the open-ended questions and are outlined below: -

- Consideration of Access to Services
- Carers Support
- Community and Voluntary Services and Community Groups
- Integration of Services to ensure that the patient journey is aligned, and systems are working in partnership
- Training of all staff in all settings to ensure that they are equipped to support patients and carers

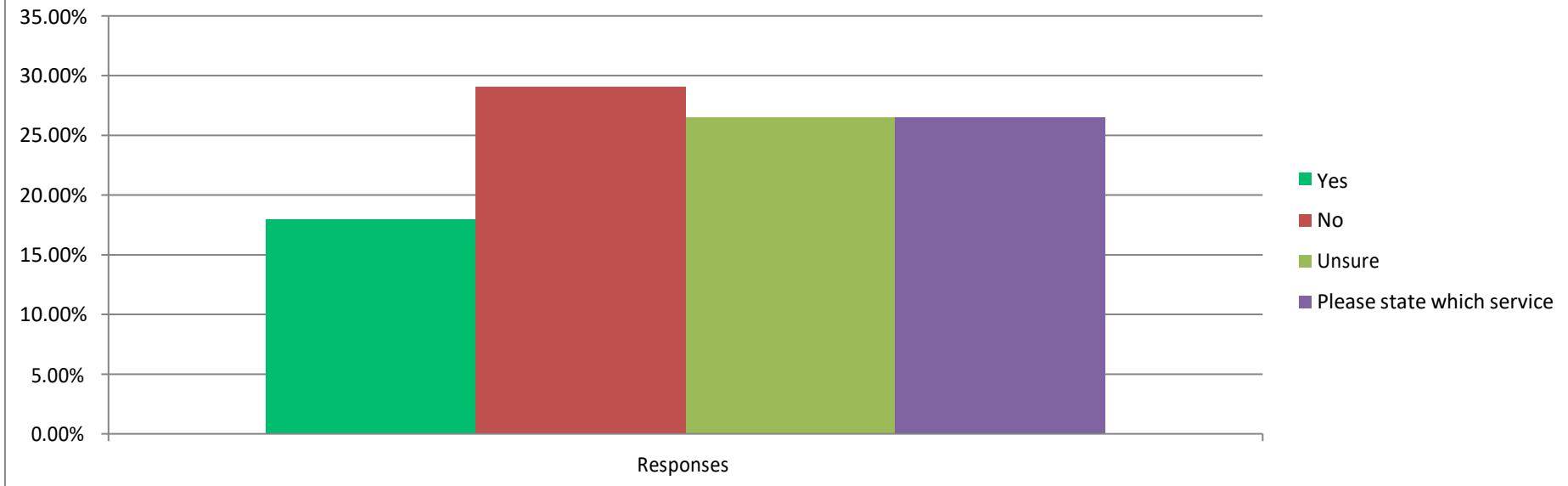
In your opinion as a carer/paid carer or Health Care Professional, do you feel support pre-diagnosis would be helpful to:-



## What was the duration of the time between realising there was an issue and wait to seeking support and diagnosis?



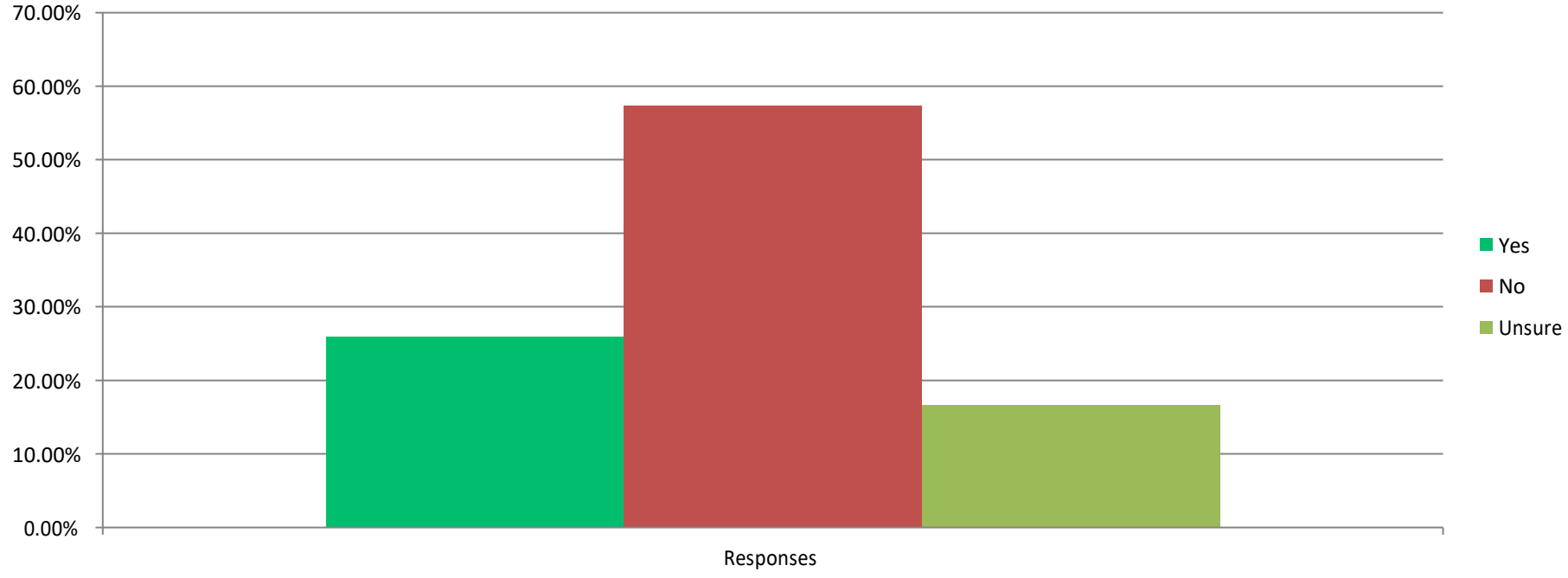
After the dementia diagnosis, were you or your friend/relative/patient provided with information about who to contact for advice and support? Which service was this provided by



Comments received around Service Provider: -

- Mental Health Team
- Alzheimer's Society
- Social Care Services
- Memory Cafes
- Social Prescribers
- Acute Settings

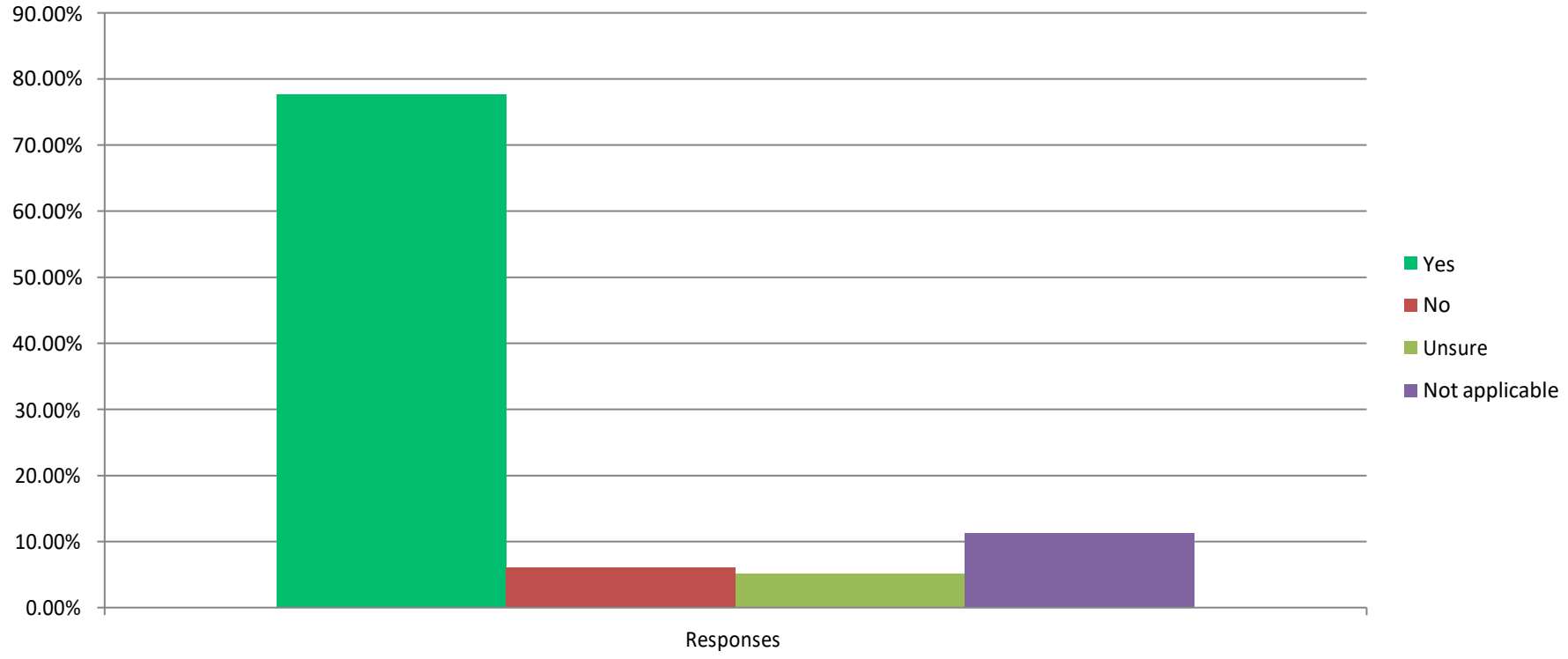
# Has there been a consistent person to help coordinate care and provide support/information and which service was this provided by?



Services provided by: -

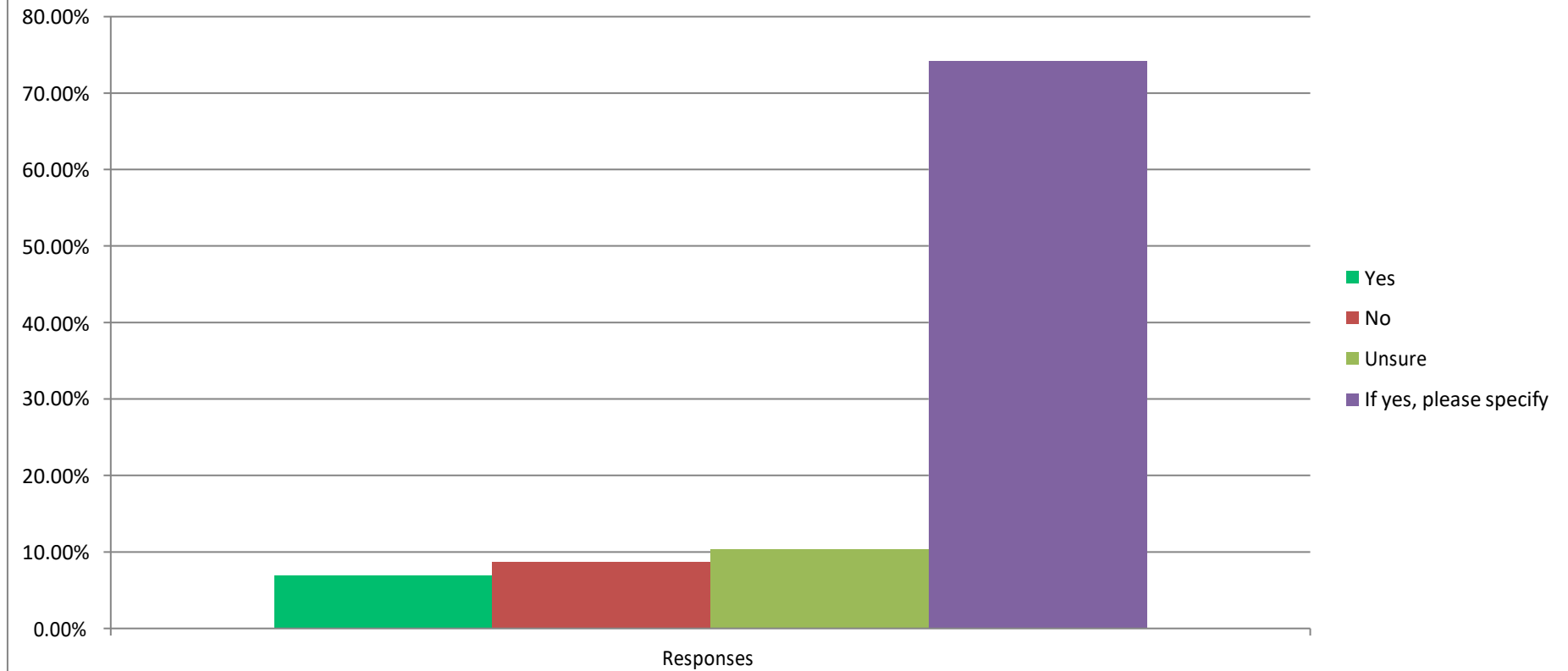
- Community Mental Health Team
- Alzheimer's Society
- Care Homes
- Social Care Settings
- Community and Voluntary Sector

# Would you or your friend/relative/patient benefit from having access to a named person to help coordinate your care?





## Are there any changes to you would like to see in local Health and Social Care Dementia Services?

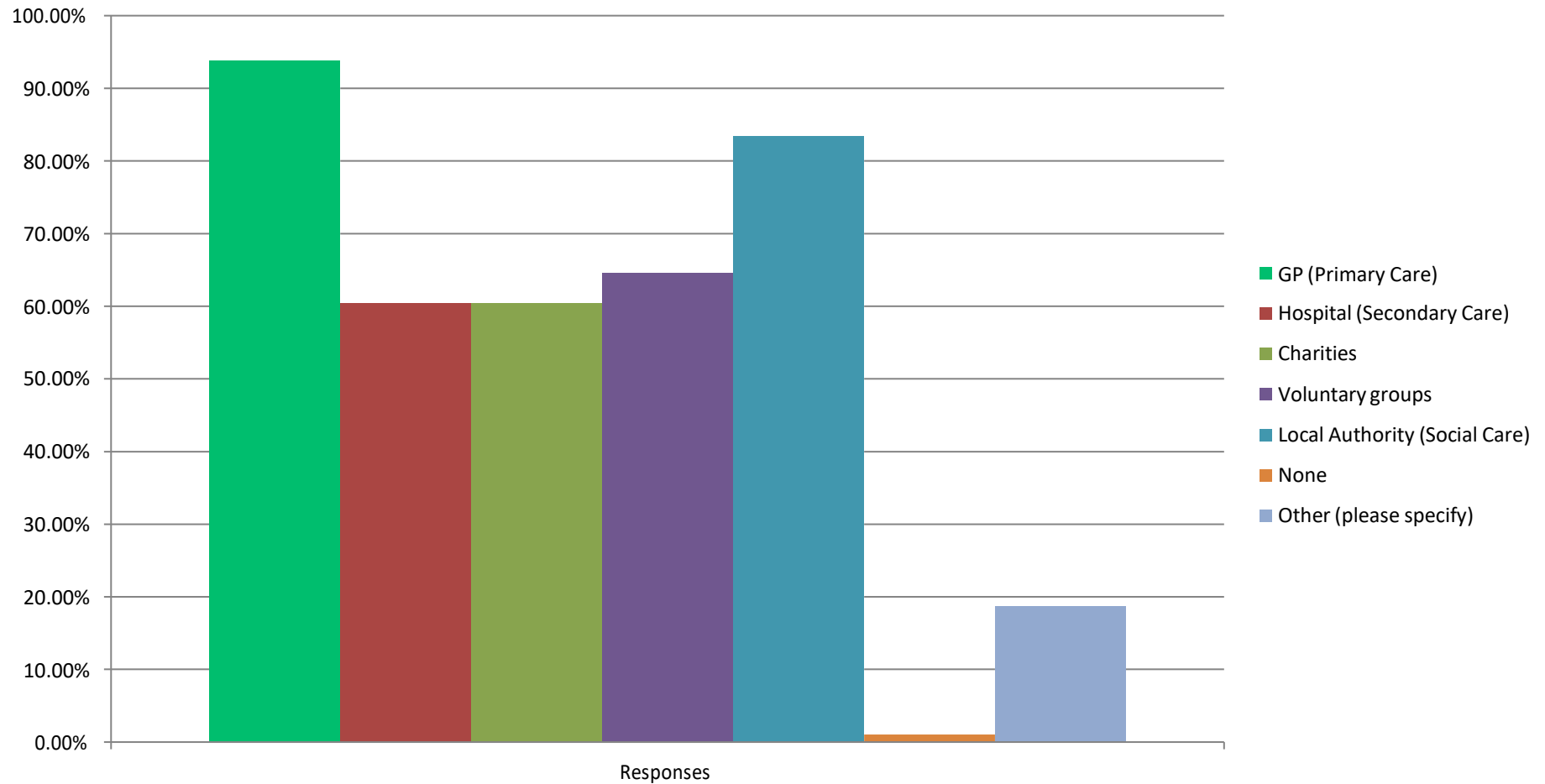


Comments Specified: -

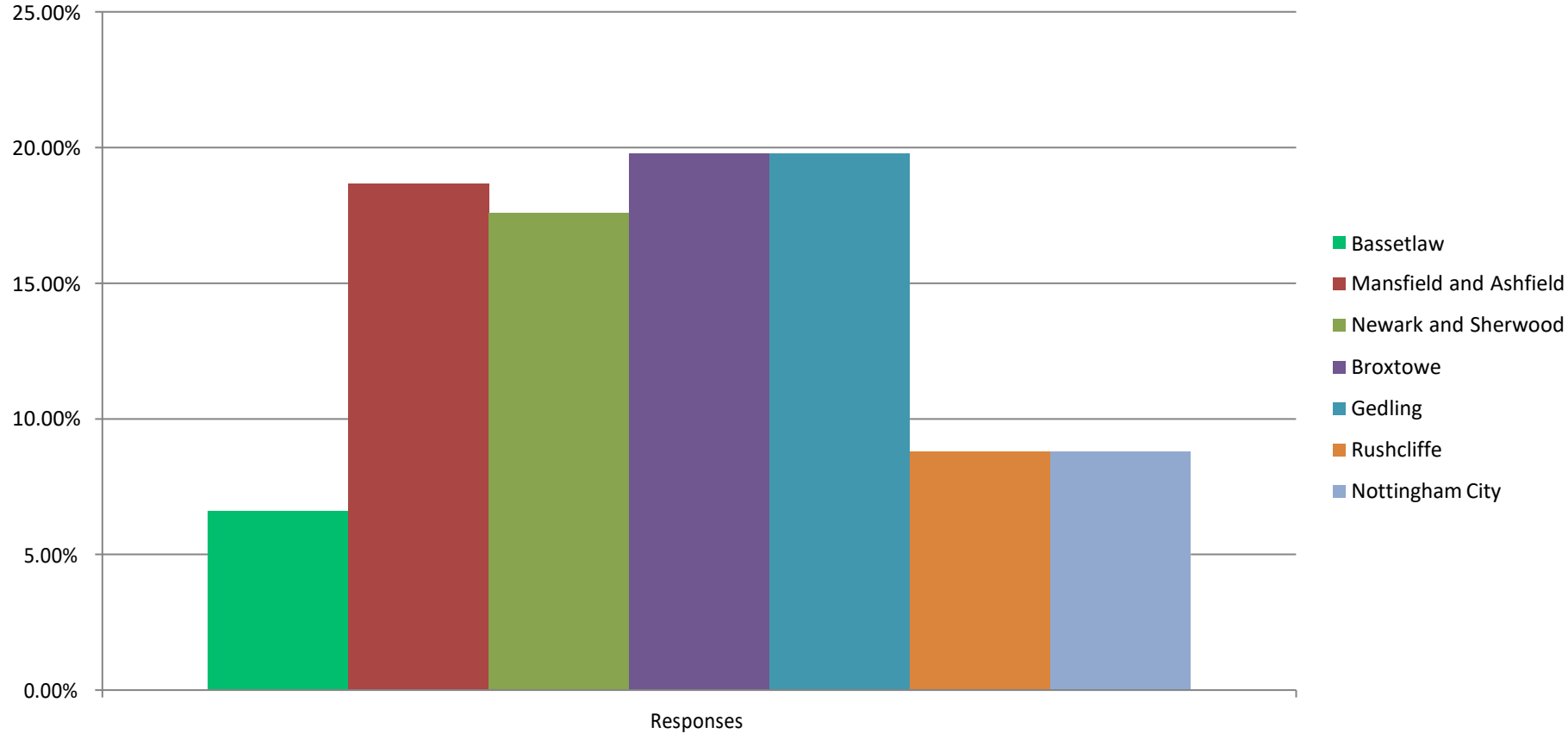
- More resources – Clear information about what is available and how you can access the support
- Integration of services – Working in partnership together
- More awareness and support for carers
- Admiral Nurse Services across Nottingham and Nottinghamshire



## Where would you like to see dementia information and support provided? Please tick all the apply.



To allow us to generate a geographical population map we require some information of where you live. Please chose ONE of the following areas:



## Telephone Interviews

Throughout the course of the engagement period of total of 7 telephone interviews took place. These were with carers, health care professionals and members of the public. Breakdowns of the feedback from those interviews are outlined below: -

- The dementia journey is hard for patients, carers and health care professionals especially around people at the End of Life and patients who are frail and have co-morbidities
- Referrals often exclude other problems that patients are having including behavioural issues which doesn't always get managed in the right way especially in care homes where the staff are not trained to deal with these specific situations – also intense wandering
- Placements often breakdown which causes distress to patients, carers and other residents in the care home setting
- There needs to be recognition for the quality of life for patients
- Medication should be used as a last resort as this doesn't always fit with what patients need or want
- There needs to be support for staff and adequate training – Staff need in-depth knowledge around this specific area
- There should be resources in place for care home staff
- Pathways and systems are not responsive to patient and carers needs
- Reviews need to be every 28 days not annually as patients deteriorate rapidly and needs are not always met
- There needs to be integration between health and care systems to ensure that this joined up for the patients
- There is little practical support and help available
- Monthly support is provided by a Dementia Support Worker but sometimes this isn't enough for what is required
- Leaflets and information have been provided around day centres, but these have moved to remote access which isn't always accessible for everyone – Information needs to be contained in one place for ease of access and kept up to date
- The system is disjointed and there is no holistic view for people
- Gedling Borough Council have provided information about what and when people can access but this should have been done sooner
- People cannot access support and services until a patient is in the system and a formal diagnosis has been received which can sometimes be a lengthy wait which is not supportive of the patient and the carers
- There needs to be a clear pathway around accessing services – NHS 111 and Walk in Centres are not helpful for patients and carers as they are not always the most accessible for a patient with dementia as unfamiliar settings and causes upset
- Educational training for carers is essential
- There needs to be integration of services without financial pressures
- There needs to be support mechanisms in place for carers and groups for carers to come together to support each other
- Admiral nurses provide support for people but these need to be available across patch

- There needs to be informed knowledge and support across GPs/Hospitals and Care for patients and carers
- There needs to be adequate training for all staff across primary, secondary and within care home settings
- Financial constraints – Care home settings are affordable for those from affluent areas but what about those that do not have the means available to fund for appropriate care
- What about support for those in assisted living accommodation
- There needs to be funding for the voluntary sector to support patients, carers, families, etc
- Health inequalities – work as one system and ensure that the family are consulted at all stages
- Attitudes of staff – They need to have compassion, dignity and respect at all levels towards patients, carers and families
- Patients are sometime reluctant to go into care homes – Need to identify what support is available for carers and let people know
- Look at what information is already available in the Region and what work has been done about implementing research
- Support groups – These are not always the best for some patient and carers who may have behavioural issues to consider

### Feedback from Community and Representative Groups

<p>What do you feel are the key priorities for the dementia pathway?</p>	<ul style="list-style-type: none"> <li>• Have a person or place where you can access information about dementia other forms of information such as leaflets, access to information online.</li> <li>• Care plans need to be personalised not everyone has the same issues or strand of dementia</li> <li>• Continuing pathway from diagnosis with a named contact to go to. Carers find it stressful not knowing who to contact along with looking after the person with dementia.</li> <li>• Communication, digital, face to face and regular reviews.</li> <li>• Pre dementia screening for patients after the age of 74 CCG looking into this with online pre screening</li> <li>• Access to services across County and City</li> <li>• Training of Health and Social Care Staff</li> <li>• A defined pathway for carers and patients to follow</li> <li>• An individual care plan for each patient</li> <li>• Support for carers post diagnosis – toolkit for them to follow from diagnosis to EOL care</li> <li>• Carer in crisis – access to intensive home support</li> <li>• Annual review by a Nurse or GP for the patient</li> <li>• Training for GPs, Nurses, Carers, Care Home Staff</li> <li>• Dementia Champions within GP surgeries</li> <li>• Pathway for young carers via Dementia UK</li> <li>• Look at pathway for working age dementia patients – not discharging them after 6 months more of a long-term support.</li> <li>• Keeping up with activities to stimulate the brain</li> <li>• Consider digitally excluded patients and carers keep face to face appointments</li> </ul>
--	--

	<ul style="list-style-type: none"> <li>• More joined up services – possibly a one stop shop</li> </ul>
In addressing these priorities what benefits would there be to you, your family and local communities?	<ul style="list-style-type: none"> <li>• Memory Café and Carers Hub have been key to deliver help and advice to many dementia patients and carers.</li> <li>• Communication more regular reviews</li> <li>• Contact with GP practice to raise concerns initially about relative who displays possible signs of dementia. Receptionists can discretely call GPs to inform them of their concerns.</li> <li>• Local Dementia Cafes, Facebook forums and WhatsApp keep carers informed.</li> <li>• Pre-screening would help with tackling issues earlier and gaining help and support before issues become bigger</li> <li>• Training of Health and social care staff would benefit carers and patients giving the right support and advice at the right time. Having an individual care plan would stop the carer telling their story over again</li> <li>• Having a dementia champion within a GP practice who is trained to assist the carers and patients would give some support.</li> </ul>
What are the challenges of addressing these priorities?	<ul style="list-style-type: none"> <li>• Boarder accessing service issues with County and City and larger areas such as different CCGs. Communication issues between different areas and different pathways. This should resolve some of the issues between City and County if the ICS develops a more integrated care pathway between health and social care.</li> <li>• Communication is key involving partnerships such as HMRC, DWP and Social Care</li> <li>• Access to GPs and completing regular reviews on patients of a particular age and dementia patients</li> <li>• Admiral Nurse pilot in Nottingham City looking at how these work in social care – additional admiral nurses to look after the specialists needs.</li> <li>• Training of GPs, nurses, carers and staff takes time and resources</li> <li>• Working age dementia patients would like other forms of activities such as golf etc.</li> </ul>

**Additional Comments: -**

The care plan proposal is interesting but as a person with a long-term condition, I am supposed to have a care plan but don't. How will this be different? Will it be enforceable?

**Feedback from Focus Groups**

**Focus Group 1:**

What do you feel are the key priorities for the	<ul style="list-style-type: none"> <li>• Understanding what was going to happen to the dementia patient with mental health (stages of dementia)</li> </ul>
---	--

<p>dementia pathway?</p>	<ul style="list-style-type: none"> <li>• Named Coordinator, key worker within the pathway – communicating bringing all information together, physical and mental support to dementia patient and families.</li> <li>• Consistent help and support</li> <li>• Training of all staff including carers, EOL and palliative care, continuing health, care planning, GPs and Hospital staff, care home staff.</li> <li>• Post Pandemic support patients feeling isolated, no access to day care, carers hubs and respite care. Carers course support during the pandemic is hard to hear people no talk fluently</li> <li>• No support from GP</li> <li>• Guidance around funding and pathway for relatives</li> <li>• Involving relatives Group for care home relatives</li> <li>• Carers need support deterioration during the pandemic meet face to face regularly</li> <li>• Digital access is offered but not always appropriate</li> <li>• Social prescribing promoting community provision</li> <li>• Delay in initial assessment going to GP (time stops for family) No cure for dementia</li> <li>• National Campaign for dementia awareness of Dementia for families, carers and patients</li> <li>• Ethnic minorities and health inequalities, creating awareness to what they have access to</li> <li>• Difficulty in finding information initially for patients and carers</li> <li>• 6-week carers course find this through luck – Council websites (only available during worktime)</li> <li>• Admiral nurses are ok but did not give any feedback to carer or patient.</li> <li>• Good GP who has experience in dementia.</li> </ul>
<p>In addressing these priorities what benefits would there be to you, your family and local communities?</p>	<ul style="list-style-type: none"> <li>• If information around stages was shared would help with understanding processes.</li> <li>• Informing relatives on pathways and discussing</li> <li>• Enhanced health and care framework</li> <li>• Advanced care planning - communicating around EOL pathway discussing anticipatory medicines (ReSpect Form)</li> <li>• Music for the brain</li> <li>• Offering face to face therapeutic activities</li> <li>• Annual review is too long</li> <li>• Hard to find help and support groups</li> <li>• Hospital to be dementia friendly</li> </ul>
<p>What are the challenges of addressing these priorities?</p>	<ul style="list-style-type: none"> <li>• No support with no key worker. Newark support was out of area</li> <li>• No continuity of key worker with no review.</li> <li>• Main contact was with GP did not understand the process</li> <li>• Carers did not understand dementia, do not have the time</li> <li>• Digital Access</li> <li>• Dental care for dementia patients</li> <li>• Social Care and what are provided in the NHS</li> </ul>



**Focus Group 2:**

<p>What do you feel are the key priorities for the dementia pathway?</p>	<ul style="list-style-type: none"> <li>• Admiral Nurses in Nottinghamshire and Bassetlaw</li> <li>• Dementia Friends Training</li> <li>• Model of dementia care and support palliative care integrated service involve carers and families.</li> <li>• Sensory, physical and cognitive.</li> <li>• Shared care plan</li> <li>• Improve Physical Ability</li> <li>• Training of Carers, staff and support - Carers training Online session? You tube on basic daily tasks? training of how to and providing guidance and support.</li> <li>• Children in school's awareness of dementia</li> <li>• Reaching the BAME groups</li> <li>• Communication Listen and hear to all parties everyone is different. Organisations, carers, individuals.</li> <li>• Named coordinator SPA to help carer and patient to liaise with primary care.</li> </ul>
<p>In addressing these priorities what benefits would there be to you, your family and local communities?</p>	<ul style="list-style-type: none"> <li>• Having a care plan integrated within the Patient knows best NHS digital application would help families understand what is happening.</li> <li>• Communication clearer would allow families, carers and relatives to be able to update everyone</li> <li>• Training of all health care providers at all stages to ensure more understanding and fluid experience</li> <li>• Lack of awareness from children within schools if they are educated to understand the needs of patients with dementia, they may be able to support their family members more.</li> <li>• Listening to the carers around the patient needs because they know them better.</li> <li>• Care assessments and referrals and to alleviate waiting times for assessments.</li> <li>• Engagement with BAME communities and ensuring they are given the links and ability to access services available.</li> <li>• Allowing more physical activity for dementia patients would help their mental health and physical health.</li> <li>• Possibly having a BAME contact within the City to engage with ethnic communities.</li> </ul>
<p>What are the challenges of addressing these priorities?</p>	<ul style="list-style-type: none"> <li>• Transport to get to groups who provide day services</li> <li>• Training of all staff</li> <li>• Contacting different groups including schools</li> </ul>

**Focus Group 3:**

<p>What do you feel are the key priorities for the</p>	<ul style="list-style-type: none"> <li>• Understanding what was going to happen to the dementia patient with mental health (stages of dementia)</li> </ul>
--	--

<p>dementia pathway?</p>	<ul style="list-style-type: none"> <li>• Named Coordinator, key worker within the pathway – communicating bringing all information together, physical and mental support to dementia patient and families.</li> <li>• Consistent help and support</li> <li>• Training of all staff including carers, EOL and palliative care, continuing health, care planning, GPs and Hospital staff, care home staff.</li> <li>• Post Pandemic support patients feeling isolated, no access to day care, carers hubs and respite care. Carers course support during the pandemic is hard to hear people no talk fluently</li> <li>• No support from GP</li> <li>• Guidance around funding and pathway for relatives</li> <li>• Involving relatives Group for care home relatives</li> <li>• Carers need support deterioration during the pandemic meet face to face regularly</li> <li>• Digital access is offered but not always appropriate</li> <li>• Social prescribing promoting community provision</li> <li>• Delay in initial assessment going to GP (time stops for family) No cure for dementia</li> <li>• National Campaign for dementia awareness of Dementia for families, carers and patients</li> <li>• Ethnic minorities and health inequalities, creating awareness to what they have access to</li> <li>• Difficulty in finding information initially for patients and carers</li> <li>• 6-week carers course find this through luck – Council websites (only available during worktime)</li> <li>• Admiral nurses are ok but did not give any feedback to carer or patient.</li> <li>• Good GP who has experience in dementia.</li> </ul>
<p>In addressing these priorities what benefits would there be to you, your family and local communities?</p>	<ul style="list-style-type: none"> <li>• If information around stages was shared would help with understanding processes.</li> <li>• Informing relatives on pathways and discussing</li> <li>• Enhanced health and care framework</li> <li>• Advanced care planning - communicating around EOL pathway discussing anticipatory medicines (ReSpect Form)</li> <li>• Music for the brain</li> <li>• Offering face to face therapeutic activities</li> <li>• Annual review is too long</li> <li>• Hard to find help and support groups</li> <li>• Hospital to be dementia friendly</li> </ul>
<p>What are the challenges of addressing these priorities?</p>	<ul style="list-style-type: none"> <li>• No support with no key worker. Newark support was out of area</li> <li>• No continuity of key worker with no review.</li> <li>• Main contact was with GP did not understand the process</li> <li>• Carers did not understand dementia, do not have the time</li> <li>• Dental care for dementia patients</li> <li>• Social Care and what are provided in the NHS</li> </ul>