

2023 Dementia Survey Report

What people have told us
about what is working well for people living with
Dementia in Sheffield
and what needs to improve

Sheffield Dementia Strategy

2019-24

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Context and Introduction

The [Sheffield Dementia Strategy \(2019-2024\)](#) was developed together by people living with dementia, their families, and the organisations working to support them.

The Strategy aimed to make sure that people living with dementia of all ages and their families are supported to live to their full potential.

It included **13 Commitments** which described how, together, we would do this in Sheffield:

1

Sheffield will become a dementia friendly city.

2

We will ensure prevention becomes an integral part of the dementia work.

3

We will improve access to the diagnosis of the diseases that cause dementia at the earliest possible stage for the people of Sheffield.

4

For people with dementia, support in Sheffield will be more personalised, local and accessible to help people to remain independent for as long as possible.

5

We will provide high quality support to families and carers of people with dementia in Sheffield to help people with dementia maintain their independence for as long as possible.

6

Sheffield will continue to provide out of hospital emergency assessments and short-term care when people need it and in the most appropriate setting.

7

Sheffield will continue to provide specialist inpatient assessment and treatment for people who are unable to receive care in their own homes.

8

We will make sure that more people get access to personalised, good quality palliative and end of life care when they need it.

9

We will improve care for people with dementia attending A&E and those admitted to Sheffield Teaching Hospitals.

10

Care and support services will take account of the needs of people with dementia.

11

We will support the clinical and non-clinical research community in Sheffield.

12

We will provide guidance to clinicians in relation to the best medicines for dementia, including when to initiate and review medication.

13

We will monitor the strategy and the implementation plan supporting it.

The organisations working on the Dementia Strategy – Sheffield City Council, Sheffield’s NHS organisations, and key voluntary and community sector partners, including Age UK Sheffield, People Keeping Well organisations, Alzheimer’s Society, and St Luke’s Hospice – have continued to progress activity towards the 13 Commitments since 2019. We have regularly reviewed our priorities and activity to ensure that we have been responsive to the needs of people in Sheffield.

Commitment 13 of the 2019-24 Dementia Strategy is that *We will monitor the strategy and the implementation plan supporting it* and as part of this ensure this that the voices of people living with dementia and caring for those living with dementia are heard and inform the work of the Strategy.

In summer 2023, we started the process of reviewing the current Strategy to enable us to update and then relaunch a refreshed Dementia Strategy to run from 2025-2030. As outlined in this report, engagement with people living with dementia, their families, and the organisations working to support them was a key part of this review. We talked to people to find out what is working well for people living with dementia in Sheffield, and what else needs to happen to build on this.

This report covers:

1. [How we will use the feedback from the engagement to shape the refreshed Strategy for 2025-2030](#)
2. Headlines from the engagement that we carried out about the Strategy:
 - a) [Our Dementia Survey](#)
 - b) [Sheffield Dementia Involvement Group \(SHINDIG\)](#)
 - c) [Additional feedback People Keeping Well Dementia Link Workers](#)
 - d) [Additional feedback from paid care workers](#)
 - e) [Engagement with Dementia Strategy Implementation Group \(key partner organisations\)](#)
3. [How we will feedback to people who contributed to the engagement](#)

1. How we will use the feedback to shape the refreshed Dementia Strategy for 2025-2030

Dementia Strategy Implementation Group partner organisations are working together to rewrite the Dementia Strategy for 2025-2030.

This will result in:

- A refreshed Dementia Strategy document, which summarises the difference the work of the strategy will make for each Commitment.
- More detailed workplans that will describe the steps that we will take to make the commitments in the Dementia Strategy – these will be updated annually and monitored regularly by Dementia Strategy Implementation Group.

Each Commitment has an identified lead organisation, and organisational leads are ensuring that the detailed feedback from the engagement is reflected in the “What will be different?” narrative in the new Strategy. We will continue to involve people with lived experience in the ongoing development of the strategy and its implementation plans.

2. Headlines from the engagement that we carried out about the Strategy

a) Our Dementia Survey

To help with the review, in the summer of 2023, the Dementia Strategy Implementation Group (DSIG) - a cross-organisational Group which oversees the Strategy - launched a short survey (running across July, August and September) to help us gain people’s views on what is working well and what else needs to happen.

We also updated people about the progress we had made on the Strategy so far via www.bit.ly/sheffielddementiayousaidwedid

An online survey was produced to support all partners to engage with the public in a consistent manner. This was distributed through various networks to reach a wider audience, including the Dementia Strategy partners (with a focus on supporting people living with dementia and their carers to complete the survey); GPA1 Primary Care Network dementia group, and SHINDIG (Sheffield Dementia Involvement Group).

The information distributed consisted of links to:

- An online survey to review the Sheffield Dementia Strategy 2019-24.
- Sheffield Dementia Strategy Commitments 20219-24.
- A summary of what’s changed since the Strategy began in 2019.
- A more detailed version of what’s changed (including how we responded to the last Dementia Survey in 2019)
- Practical information about living with dementia in Sheffield.

The information was also available as a paper copy in order to increase participation.

Survey Respondents

We had 183 responses in total. The breakdown of respondents is as follows.

About you

1. **Please tell us about yourself.** *If you are completing the survey on behalf of someone else, please fill this in based on their details.*

Are you: *

A person living with dementia

An unpaid carer or family member

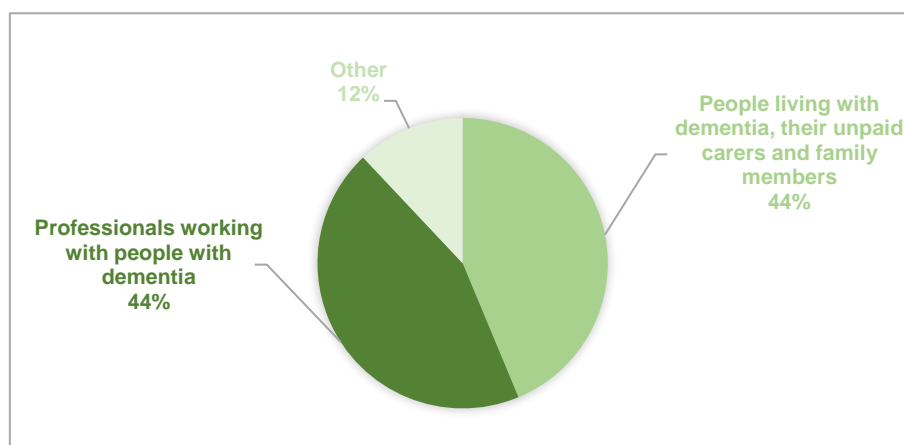
A professional or volunteer working with people with dementia

Other

How people described themselves	Number of survey respondents
A person living with dementia	26
An unpaid carer or family member	54
A professional or volunteer working with people with dementia	81
Other	22

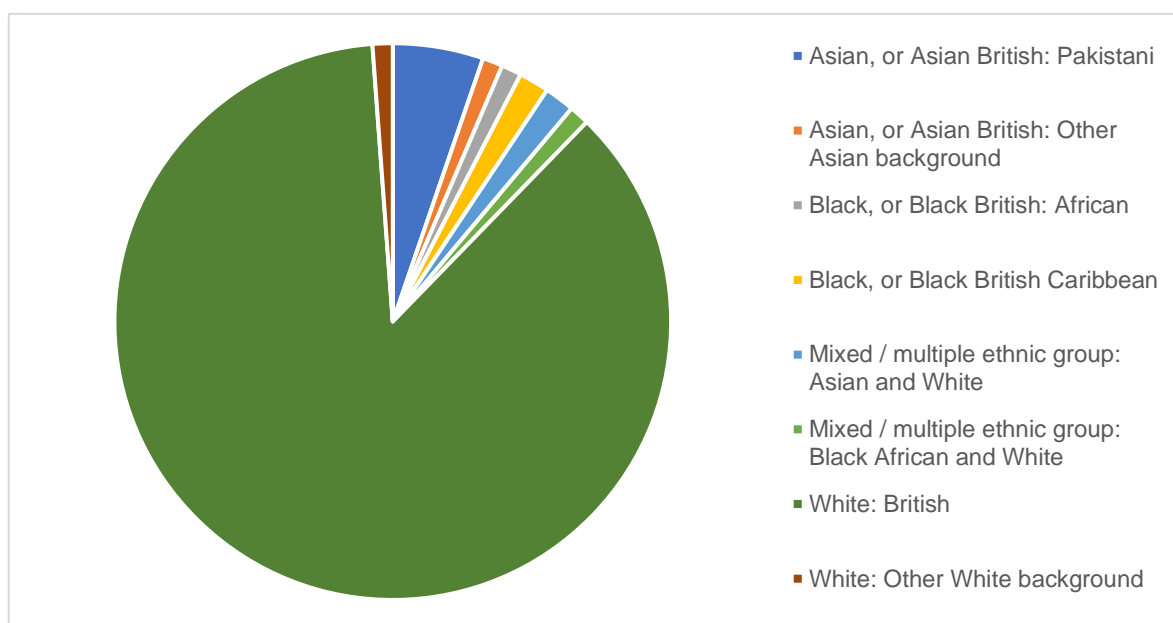
Those who used 'Other' described themselves in a range of ways including 'living with memory problems', 'young onset dementia', 'former carer' whose family member had passed away, 'helper', 'wife' and 'caring partner'. Some people fitted into more than one description, for example they were both an unpaid carer or family member, and their job or volunteer role involved working with people with dementia.

There was an equal split of responses from people directly affected by dementia (whether living with dementia themselves, or their family members and unpaid/informal carers) and the dementia professionals or volunteer workers supporting those families.



An optional equality monitoring form was included with every survey to monitor the demographics of respondents. A demographic analysis of respondents is shown below. The majority of respondents were White/British.

Ethnic background	Number of respondents of equality monitoring form
Asian, or Asian British: Chinese	0
Asian, or Asian British: Indian	0
Asian, or Asian British: Pakistani	9
Asian, or Asian British: Other Asian background	2
Black, or Black British: African	2
Black, or Black British Caribbean	3
Black, or Black British: Other Black background	0
Mixed / multiple ethnic group: Asian and White	3
Mixed / multiple ethnic group: Black African and White	2
Mixed / multiple ethnic group: Other Mixed / multiple background	0
White: British	148
White: Gypsy/Traveller	0
White: Other White background	2
Other: Arab	0
Other: Arab	0



Survey questions

The survey was deliberately kept short and simple, as we wanted to encourage as many people as possible to complete it.

Some people received support to answer the survey.

There were just three 'Tell us what you think' questions within the survey:

- **What is helping you (or the person you care for) to live as well as possible with dementia in Sheffield?** (This might include things like groups, services, people, places, attitudes, sources of information, or processes).
- **What is making it more difficult for you (or the person you care for) to live as well as possible with dementia in Sheffield?** (This might include things like groups, services, people, places, attitudes, sources of information, or processes).

The screenshot shows a survey interface with a teal header 'Sheffield Dementia Survey'. Below it, the section is titled 'Tell us what you think'. It contains three numbered questions, each with a text input field. Question 2 asks about factors helping with dementia in Sheffield. Question 3 asks about factors making it more difficult. Question 4 asks for anything else to say, with sub-points about unpaid carer experiences and ideas for services.

- **Is there anything else you'd like to say?** This might include about:
 - Your experiences as an unpaid carers or family member/person working with someone with dementia
 - Ideas for what services or organisations can do better, including to meet the needs of different ethnic groups/cultures?

Survey responses: helping people to live well with dementia



The following is a summary of the positive responses, which demonstrate what is helping people to live as well as possible with dementia in Sheffield.

- **Community dementia services**
 - Community and social activities provided by local dementia voluntary organisations are helping people to live well with dementia and maintain their independence while providing vital connection, stimulation and support while reducing loneliness.

- Dementia cafes, dementia friendly-groups, dementia day activities, exercise programmes, friendship lunches, art & craft groups, and wellbeing centres were all mentioned by name.
- **Availability of information and advice**
 - Simplified referral routes, the ability to self-refer and gain information quickly has proved helpful in accessing much-needed services.
 - Having information resources such as helplines has enabled people to learn about dementia and the available services.
- **Support from family and friends**
 - People felt that support from family and friends was making invaluable to helping people to live as well as possible with their dementia.
 - Services that offer support for unpaid carers and have provided much-needed assistance and support.
- **Good support in some care homes**
 - People reported positively on dementia-friendly activities in some care homes and trips out.
 - Well-trained dementia-friendly and attentive staff were noted to make a big difference to the wellbeing of people with dementia, along with safe, homely and dementia-friendly environments, and personalised care plans.

Survey responses: making it more difficult for people to live well with dementia



The following is a summary of the negative responses, which demonstrate what is making it more difficult for people to live as well as possible with dementia in Sheffield.

- **Negative attitudes and lack of dementia understanding**
 - People described experiences of negative attitudes towards, and lack of understanding about, dementia across health and social care providers.
 - Lack of dementia knowledge and patience is also a problem for people when out and about in the wider community.
- **Lack of access to dementia information**
 - People reported that this has improved over recent years, but that some still don't have the dementia information they require, and don't know where to find it.
 - Many carers mentioned struggling for years before finding appropriate help, suggesting a need for more proactive outreach or easier access to information.
- **Inadequate support for unpaid/informal/family carers**
 - Many unpaid carers felt they don't receive enough support, both emotional and practical, for caring for those with dementia.

- Families often feel overwhelmed by the complexity of the care system, experiencing frustration with delayed or inaccessible help.
- **Some poor experiences of care provision**
 - People felt that that wasn't enough care provision, including one to one care and access to services for people in care homes.
 - Many services are understaffed, and staff aren't suitably trained in dementia care, which reduces the frequency and quality of care that people with dementia receive.
- **Diagnosis waiting times**
 - There are long waits for dementia diagnosis, particularly since the pandemic; this continues to be a real challenge to many families as it can lead to delays in receiving appropriate services, as well as difficulties in planning for the future.
 - People also reported feeling left on their own by medical professionals after a diagnosis, with information not available in a suitable format.
- **Transport barriers**
 - Accessing services is challenging without reliable and inexpensive transportation, further limiting the ability to participate in social activities, reduce loneliness and receive appropriate care.
 - People mentioned difficulties with the accessibility and lack of dementia-friendly public transport, community transport and private hire vehicles.
- **Cost of services/support**
 - Costs of services/support are a barrier for some people, for example some services are too expensive for people to access regularly.
 - Many people mentioned that groups cannot be run more frequently due to under-funding.

Examples of what people told us is helping them to live well with dementia



The following quotes from the 2023 Dementia Survey illustrate some of the key services and activities that are making a significant difference in helping people with dementia live well in Sheffield.

“The various community-based, dementia-friendly activities on offer definitely help our dad to live well and help us in providing opportunities to spend safe, quality time with him”.

“Groups really help, there doesn't seem to be any official support, so we rely on information and support from other group members”.

“The services provided by the voluntary sector such as day centres, memory cafes and befriending enable people with dementia to obtain

stimulation, meaningful activity and social contact while allowing their carers a break”.

“Family support only”.

“I am most grateful that in the last year and a quarter one of my sons lives with me in my home”.

"Being able to gain a source of information to self-refer and get help quickly has been very helpful".

"Wellbeing centres, Dementia Advice Sheffield helpline and local cafes have been a huge support".

"Dementia friendly groups, befriending services, and Alzheimer’s Society helpline have been invaluable".

"Interactions with others, stimulating activities (e.g., exercise, arts & crafts, armchair travel) have really helped".

“My friends are what helps me keep going and the occasional professional who understands...rare, but worth their weight in gold”.

“Attitudes and actions that help me...Properly listening to the person I care for. Taking time and not rushing her, while allowing me to explain and re-explain and re-explain without showing impatience means a lot”.

“Treating the person I care for as a real person with feelings that can be hurt and not treating her as a child”.

Examples of what people told us is making it more difficult for them to live well with dementia



The following quotes from the 2023 Dementia Survey illustrate some of the attitudes and actions that are making presenting significant challenges to helping people with dementia live well in Sheffield.

“Carers are isolated”.

“Recognition that dementia is a changing condition which can occur rapidly for some people. Carers identify how they struggle to undertake this role and are desperate for support which is meeting needs at the right time and are not left to struggle on alone”.

“It is tiring and emotionally hard work”.

“His denial”.

“The person I care for has refused to engage with any services, so I don't have any professional support”.

“The fact that if you are in a complex situation and apparently exhausted every organisation's criteria you are left to cope alone”.

“Lack of support, help from services – Don't abandon the carers of people with dementia who have money”.

“Lack of respite beds/ day support for when carers are struggling”.

“No easily accessible help, struggled for 8 years on our own until had to put mum in a care home, it's terrible the lack of help for willing carers”.

“More face-to-face workshops and training for family members and carers would be very helpful”.

“More support for carers please re: education and support groups with respite support provided so they can attend them/access support”.

“Not enough 1-1 support, not enough opportunity to link into DAS, health and social care staff not understanding dementia”.

“Memory clinic has very long waiting list and limited capacity to see patients (12 month wait for initial assessment)”.

“Lack of understanding/official training in local businesses (shops etc).”

“Attitudes and finances re travel costs”.

“Council, NHS, ignorance of Dementia, Barriers to Benefits, Council Tax Reduction, Bus Pass. I have an invisible Disability and am treated as if I am invisible, Adversarial systems and barriers. Lack of equality with other terminal conditions”.

“Biased GPs, don't care attitudes and the process of getting the correct care for variations of dementia”.

“All statutory services seem overstretched, doctor's, hospital, benefits, cost of carer at home is a lot. Lack of toilets”.

“Memory assessment waiting, GP's not understanding, lack of care in the community with trained workers”.

“Insufficient home care”.

b) Sheffield Dementia Involvement Group (SHINDIG)

The July 2023 meeting of SHINDIG consisted of 9 people living with a Dementia diagnosis and 8 carers/supporters, in a session entitled 'Influencing the Sheffield Dementia Strategy'. The discussion groups focused on the following two Commitments:

- Sheffield will become a Dementia friendly city.
- For people with Dementia, support in Sheffield will be more personalised, local and accessible to help people remain independent for as long as possible.

The following is a summary from the SHINDIG report of the main points drawn out by the discussion groups:

- Should we *have* to let people know about our diagnosis?
- A 'Dementia Friendly' approach would suit everyone.
- The attitude and body language of staff in public places is crucial to a person's experience of going out.
- Physical limitations often prevent engagement and remaining involved.
- There is not enough provision for carers, particularly those who are bereaved.
- Documents like an abbreviated 'This Is Me' document could be a useful tool for getting to know a person.
- People with dementia like to have a challenge and an opportunity to help others.
- It is important to have self-awareness and plan more complicated tasks in advance.
- 'Dementia Buddies' should be endorsed.
- Parking and access to certain places is a barrier to engagement.
- It is essential to see people '*living* with Dementia'.

The full report, and other SHINDIG reports, can be found here:

<https://www.shsc.nhs.uk/get-involved/service-user-groups/sheffield-dementia-involvement-group-shindig>

c) Additional feedback from Dementia Link Workers

Dementia Link Workers from the People Keeping Well dementia support organisations got together as a group in summer 2023 and discussed how differing demographics affect both type and level of need of the people with dementia we support regarding deprivation, ethnicity, and sexuality.

The key themes that they identified were that people within the demographics:

Dementia in areas of deprivation

- **Affluence and Engagement:** Those in deprived areas are generally less likely to engage with services and have higher levels of need and greater complexity. Many experience greater barriers such as debt and poverty. Those in affluent areas are more likely to engage with services and have navigated systems before accessing help.
- **Complexity and Care:** Dementia in deprived areas tends to present later and be more complex, with multiple issues (e.g., housing, family situations, and health) complicating care.
- **Separation and Perception:** People's perception of different areas affects their willingness to attend services, especially in deprived areas.
- **Carer Challenges:** Carers in deprived areas often face additional challenges like debt, mental health, and healthcare navigation, leading to quicker carer breakdowns.
- **Health Inequality:** Dementia seems to manifest earlier in deprived areas due to health inequalities, with healthcare responses varying by socioeconomic background.

Dementia in areas with pockets of deprivation

- **Support and Accessibility:** Deprived communities may better understand the benefits system, while affluent people may hesitate to seek help.
- **Family Dynamics:** Affluent families may live farther apart, complicating caregiving, while alcohol-related issues can be more normalised in wealthier areas.
- **Mental Health Services:** Support for mental health is short-term, and some affluent individuals don't recognise their need for help.
- **Barriers to Access:** Services often expect people to have resources (e.g., computers) or respond quickly, which can disadvantage those in chaotic life situations.
- **Complexity and Self-Advocacy:** People often don't know how to advocate for the right support, and services can seem patronising, worsening inequalities.
- **Pride and Stigma:** People may resist benefits or services due to pride, and socioeconomic status affects how they're treated by services.

Dementia and sexuality

- **LGBTQ+ Barriers:** LGBTQ+ individuals face additional challenges, such as homophobia, being outed in care settings, and not having children or family support. Misgendering, deadnaming, and lack of inclusive services are common concerns.
- **Fear of Discrimination:** Many LGBTQ+ individuals hesitate to disclose their sexuality due to fear of negative treatment by services. "People feel afraid to talk about their sexuality".
- **Lack of Data:** There is little data available on sexuality.

Dementia in ethnic communities

- **Cultural Barriers:** Dementia is often misunderstood or stigmatised in ethnic communities, with shame surrounding diagnosis. Families may not allow the term "dementia" to be used. Dementia is "not talked about" or "there is no [cultural] recognition of it".
- **Cultural Needs:** The cultural needs of people with dementia are not always met or understood.

- **Language and Engagement:** Language barriers, cultural misunderstandings, and reluctance to engage with formal healthcare services complicate dementia care. Some communities lack the vocabulary to describe dementia.
 - **Gender-Specific Services:** Certain ethnic communities require gender-segregated services due to cultural sensitivities.
 - **Role of Younger Generations:** Younger generations tend to be more accepting of dementia and mental health issues, helping bridge the gap in understanding.
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d) Additional feedback from paid care workers

Key themes from additional feedback from paid care workers were:

- The additional dementia training that they had received (e.g. Dementia Stars; ECHO training) was helping them to support people to live as well as possible with their dementia. More training and making people aware of how people with dementia react to certain things was still needed though.
 - Staff commented on the importance of being able to equip carers with the resources to provide quality and personalised care – but that there was often a lack of staffing/resources.
 - Staff commented on the importance of ‘Making people feel comfortable as much as possible’ and ‘Understanding the way [people with dementia] communicate and do things’ and the impact of ‘Not meeting people’s needs, as this will lead to frustration’.
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e) Engagement with Dementia Strategy Implementation Group (Key Partner Organisations)

The Dementia Strategy Implementation Group (DSIG) is a cross-organisational Group which oversees the Dementia Strategy. Between November 2023 and March 2024, the group had a number of detailed discussions about the Commitments in the current Strategy, covering what had been achieved to date and what needed to be continued (or added) to the workplan for the 2025-2030 Strategy.

The group felt that the majority of Commitments should be retained in the revised Strategy but that they needed to be reviewed and updated to reflect progress to date and that the next steps.

The group agreed that some of the Commitments did not need to be continued as ‘stand-alone’ Commitments in the new Strategy but could instead be considered throughout the remaining Commitments and also as ‘business as usual’ activity, where this was relevant. These Commitments were:

- **Commitment 11**, *We will support the clinical and non-clinical research community in Sheffield.*
- **Commitment 12**, *We will provide guidance to clinicians in relation to the best medicines for dementia, including when to initiate and review medication.*

- **Commitment 13**, *We will monitor the strategy and the implementation plan supporting it.*

The group highlighted some key areas for consideration in the refresh of the 2019-24 Dementia Strategy:

- **Commitment 1**, *Sheffield will become a dementia friendly city:*
 - DSIG noted the progress made against the commitment but also the feedback from the survey which highlighted the work still needed to make Sheffield more dementia friendly (for example accessibility of transport).
 - DSIG noted areas we may want to increase/add a focus on included transport; and also looking at what dementia friendly means for diverse groups of people (ethnic minority groups; LGBTQ+ people; different faith groups; men and women etc).
- **Commitment 3**, *We will improve access to the diagnosis of the diseases that cause dementia at the earliest possible stage for the people of Sheffield:*
 - DSIG noted the progress that has been made against the commitment but also highlighted the significant challenges that are being faced with waiting times for diagnosis.
 - Reducing waiting times is a priority area of work for 2023/24 – it was agreed that this needs to continue to be a priority until waiting times are reduced.
 - It was also noted that the Learning Disability dementia pathway remains a specific area for improvement.
 - It was recognised that we needed to do more to support people with Mild Cognitive Impairment needed, to help reduce their risk of going on to develop dementia.
- **Commitment 4**, *For people with dementia, support in Sheffield will be more personalised, local and accessible to help people to remain independent for as long as possible:*
 - DSIG noted the progress that has been made against the commitment and the significant contribution of Voluntary/Community Sector organisations in Sheffield
 - Meeting the challenges around the growing demand for established community dementia services is a priority area of work for 2023/24 – it was agreed that this needs to continue to be a priority until additional resource has been identified.
- **Commitments 6** (*Sheffield will continue to provide out of hospital emergency assessments and short-term care when people need it and in the most appropriate setting*) **and 7** (*Sheffield will continue to provide specialist inpatient assessment and treatment for people who are unable to receive care in their own homes.*):
 - These commitments should be merged and revised to clearly focus on dementia crisis.
 - Key areas to consider include:
 - Waits for SHSC Older Adults Community Mental Health Team / Home Treatment Team
 - Waits for social care waits (especially for when someone 'not known to service' is in crisis)

- Feedback from Social Care survey shows that people don't always know where to go in crisis and aren't always able to connect people to services in time of crisis.
 - We need more nursing/enhanced capacity care home beds and more flexible/capacity to enable when people's needs change (as their dementia progresses), that they can still be met by their existing provider.
- **Commitment 9**, *We will improve care for people with dementia attending A&E and those admitted to Sheffield Teaching Hospitals:*
 - DSIG noted the progress that has been made against the commitment, particularly through the work of the STH dementia strategy and the STH Dementia Practitioners Team.
 - Reducing unnecessary hospital admissions and delayed discharge is a priority area of work for 2023/24 – it was agreed that this needs to continue to be a priority until these areas have improved.
 - Key areas to consider include:
 - Need to consider the role of the virtual ward and dementia champions
 - Need sign off this part of the strategy at STH Dementia Care Group to ensure alignment

DSIG noted that the role of Primary Care needs to feature more strongly within the revised Strategy.

3. How we will feedback to people who contributed to the engagement

The majority of engagement participants supplied feedback anonymously and therefore we cannot provide feedback to them directly. However, when we have carried out dementia surveys previously, we developed a short public “open letter” following the engagement that we circulated through the same channels as we circulated the invitations for people to take part in the engagement.

We will follow the same approach and share another “open letter” as part of the communications leading up to and launching the refreshed Dementia Strategy.

This will:

- Thank people who contributed to the survey and/or the wider engagement.
- Share examples of how the themes that came out of the engagement directly influenced what we included in the refreshed Strategy (“You said, We did”).
- Include examples of where partners have already started to work on these improvement areas.
- Include information about how people can access support in their community to live well with dementia or receive support as a carer (including if they are struggling).
- Also include information about access to training/non-clinical advice or signposting for people working in a paid role supporting people with dementia.

We are very grateful to everyone who took the time to contribute their views and experiences.