APPENDIX C

Summary Report of Leicestershire Responses to Public Consultation and Engagement on the

Leicester, Leicestershire and Rutland's Living Well with Dementia Strategy 2024-2028

1. Purpose of the report

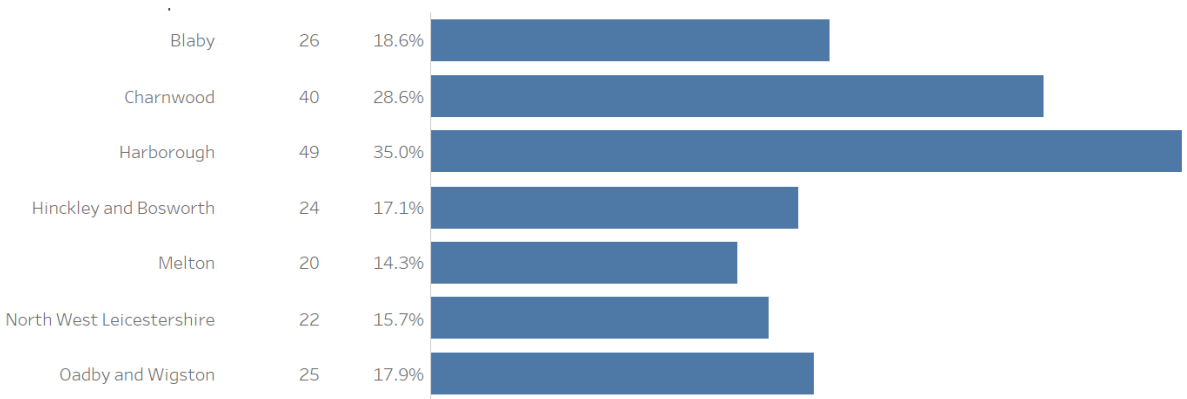
This document provides a summary of the findings from Leicestershire respondents on the public consultation undertaken between 17 July-22 September 2023 on the draft **Leicester, Leicestershire and Rutland's Living Well with Dementia Strategy 2024-2028.**

The overall LLR Consultation report will be presented to the Dementia Programme Board on the 21 November 2023. The information gathered during this consultation will be used to inform the way forward and the final version of the strategy and associated, place-based action plans.

The total responses relating to LLR was 358, 206 Leicestershire only, 91 who responded in regard to Leicester and 61 in regard to Rutland. This is a high number of responses when compared to previous Dementia Strategy consultations and other similar consultations and demonstrates the effort from officers to consult as widely as possible.

Areas people stated they were responding in relation to (more than one area could apply)

Figure one.



2. Key Themes Emerging for Leicestershire

The key positives identified in the analysis of this consultation are:

- The draft strategy was welcomed by the majority of respondents and overall respondents agreed that the aims of the draft strategy were the right ones.

- People noted that the process of having an assessment and diagnosis had changed and was improving. The process now involves a CT scan followed by face-to-face assessment
- A consistent positive theme in the feedback was the development of specific community activity groups for people living with dementia and their carers.
- Whilst there were concerns raised about some examples of poor care in health and social care services, there were also some very dedicated professionals and good services available in Leicestershire.

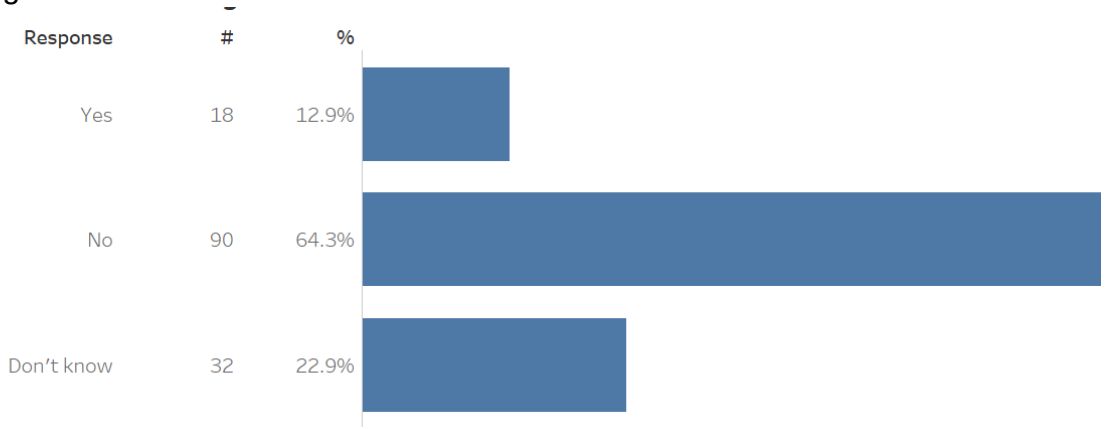
Key findings from the responses in terms of where things need to improve are:

- The developments listed in the strategy require a ring-fenced budget to achieve all this and the consultation and associated documentation indicates there is no budget attached to this.
- Too much jargon in Strategy and action plan
- The Action Plan only has “aims” and uses words like review and support. It does not provide a clear measurable Action Plan on how this is going to be achieved.
- Concerns were expressed over the communication and care planning between NHS Primary and Hospital Care and Local Authority Social Care Services
- Referral from the Memory Assessment Service to the local Dementia Support Service run by Age UK should be mandatory
- Staff in all areas need better and specialised dementia training and is to a clear and monitored agreed standard.
- Concerns were raised over the removal of funding for Admiral Nurses support and there were numerous comments praising the specialist knowledge and supportive nature of Admiral Nurses.
- Need Admiral Nurses across the County
- Comments were received that suggested screening and supporting people based on risk – those who live alone, have dementia in family history, are less likely to connect with services.
- Therapeutic activity and support after a diagnosis isn’t available for all in all areas.
- Don’t discharge to care homes or with home care that cannot support the person well or adequately
- All people should have access to meaningful activity whether in a care home or at home or going to activities locally
- Support informal carers better at all stages of the person’s dementia. Informal carers felt overwhelmed, alone and find it hard to get the support they need.
- Provide Transport to local activities, as people loose licence, income and rurality means no buses
- Have conversations early and support staff to sensitively to discuss Advanced Decisions and record the RESPECT form on shared records.

3. Overview of Responses and Themes Relating to Each Question

Respondents to the consultation were first asked, **"Do you think that the health and social care services that support people living with dementia work well together?"** The responses were as follows:

Q6 – Figure 2

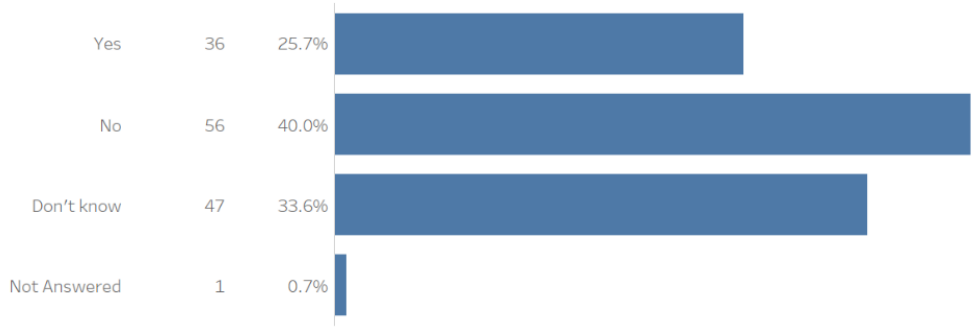


Where respondents said no to this question, they were asked to provide comments. Some of the key comments responses were:

- Not one professional coordinating so people don't know who is doing what
- Very confusing trying to find out what is available and who does what
- Hospital care and discharge poor regarding communication and quality
- Support from General Practice inconsistent needs to be face to face for someone with dementia and also include their main carer
- Admiral Nurses were the only ones supporting and coordinating care but they have been stopped
- People are at risk of falling through the net especially those living alone
- Hospital discharge and treatment in hospital poor
- Reliance on online information not helpful for someone with dementia
- Dementia patients in the main are not properly supported in hospital and in care home due to lack of understanding, poor training and monitoring.
- People with dementia who live alone are bypassed unless they have family or friends who contact services

Next, people were asked, "**Do you think staff are confident and competent to support people with dementia?**". The responses said that:

Figure 3.



Once again, where people said no, they were asked to provide comments. Key themes emerging from this were:

- Staff seem overwhelmed
- Staff in all areas need better and specialised dementia training
- Admiral support removed and they did have specialist knowledge
- Is there an agreed LLR approach to the standard of training for dementia and how is this monitored?
- Informal carers having to training paid carer on how to communicate and look after person
- Agency staff less well trained on wards
- Stressful sourcing care and finding care that is competent to care for people with dementia
- No help or support for carer or patient
- Better when nurses and medics have specialised role in dementia
- Training doesn't cover values as much as needed- ie people with dementia are not treated as people with a past and feeling
- Loss of mental capacity used when person has capacity to delivery care

The consultation survey then went through the key areas of the strategy, focused around preventing, diagnosing, supporting, living and dying well with dementia.

Key Actions Preventing Well - We Will Continue to

- Screen for risk factors for dementia at health checks and raise awareness of the risk factors for dementia
- Raise awareness of dementia and its symptoms

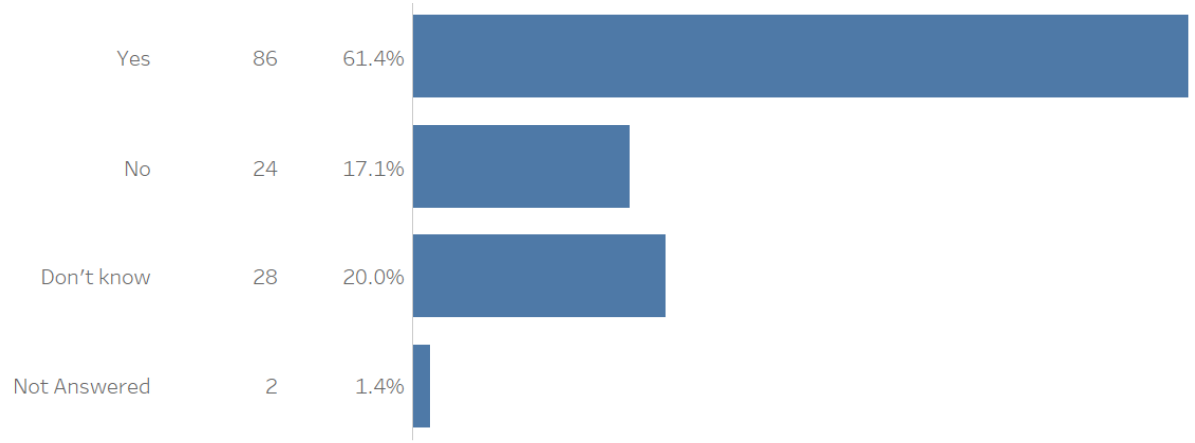
Key Actions Preventing Well - We Aim to

- Promote dementia prevention methods such as lifestyle behavior changes
- Promote the Global Council on Brain Health's message: 'What is good for the heart is good for the brain', meaning a healthy diet, exercise and lifestyle are good for both body and brain

- Encourage people to get involved in research and promote the advantage of early diagnosis

Figure 4

Q8. Do you think these actions will help reduce or delay the onset of dementia?



Q8a. If no, give reasons why

This answer includes common comments including from people who answered yes

- People do have healthy diets etc but still get dementia, People also make poor lifestyle choices at an early age
- Told its hereditary so lifestyle change won't help
- Only some dementias could be prevented by lifestyle change, could lead to blaming the victim

Q8b. Is there anything else we could do to reduce or delay the onset of dementia?

- More therapeutic activities for the brain and wellbeing that are cognitively stimulating and in in all areas- Brain gym, Cognitive Stimulation Therapy (CST), Singing for brain, in community centres and village
- Early screening at health checks
- Access to assessment and support earlier
- Change processed food laws
- Promote awareness of "game changing drugs" currently coming to end of successful trails
- Promote people getting involved in research

<u>Key Actions- Diagnosing Well - We will continue to:</u>

- Use pharmaceutical treatments and consider a range of treatment options that have proven benefits to people with dementia

Key Actions- Diagnosing Well - We aim to:

- Reduce diagnosis wait times
- Refine the dementia assessment pathway to ensure that people are diagnosed in a timely manner
- Improve patient access to the pre- and post-dementia support service
- Improve the diagnosis experience for people from underrepresented communities
- Explore culturally appropriate dementia diagnosis tools

Q9. Do you think these actions will support reducing waiting times and ensure a timely diagnosis?

Figure 5

Q9a. If no, please give reasons why:

This answer includes common comments including from people who answered yes

- Waiting times are a big concern, as they delay the use of drugs and other therapeutic activity that can delay progress of Alzheimer's Disease
- New process for CT scanning noted though some concern about getting these results and the wait for the follow up assessment, but have noticed improvements
- Admiral Nurse services lost
- Referral from the Memory Assessment Service to the local Dementia Support Service run by Age UK should be mandatory
- Rarer dementias not well served at Diagnosis and after care

Q9b. Is there anything else we could do to diagnose dementia better?

- Refine diagnosis pathway to make it as efficient as possible
- Ensure access to all people in all areas to pre and post diagnostic interventions – medication, advice, emotional support and therapeutic activities that delay progress of dementia.
- Continue to raise awareness of dementia across both public and professionals

- Screen earlier all people at risk- Consider prioritising people who live alone, who have dementia in family and those communities where stigma may be higher to come forward for a diagnosis
- GPs have face to face consultations to screen for dementia and time to listen to person and family, also do the Annual Health Care plan.

Q9c. Is there anything else we could do to improve diagnosis and raise dementia awareness amongst Black, Asian, Minority Ethnic (BME) and hard to reach groups?

- Work closely with community leaders and promote in places of worship and community centres
- Translate information into different languages.

Q9d. Is there anything else we could do to improve the diagnosis experience for people with learning disabilities, prison populations, rural and farming communities, younger onset dementia, armed forces and other seldom heard communities?

- Provide information in different formats, not just on-line,
- Train and link with specialist services for these groups so they understand symptoms, how to support and how to access a diagnosis and support
- Target training and support to those doing Health checks in primary care for over 50s

Key Actions- Supporting Well - We will continue to:

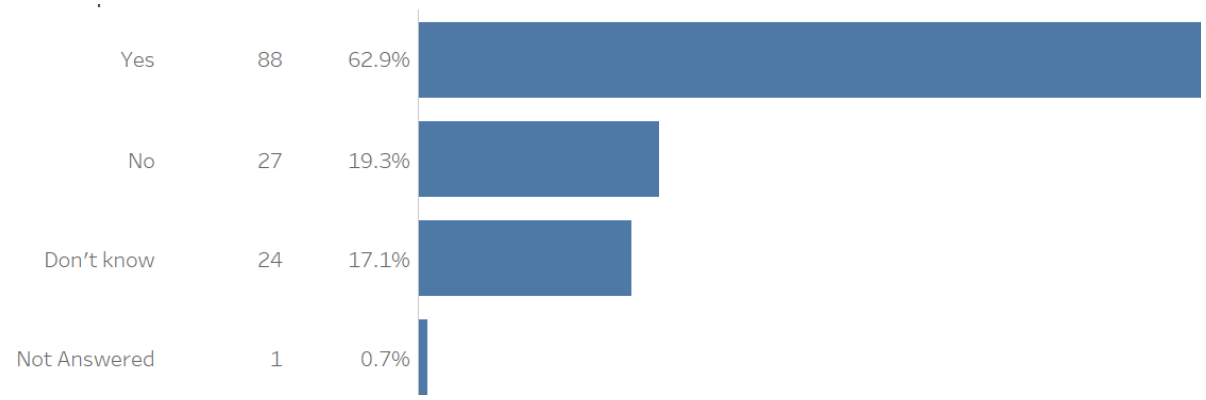
- Improve the hospital experience for people with dementia
- Apply the Leicester, Leicestershire and Rutland Carer Strategy actions to support people with dementia and their carers
- Raise awareness of support available for people with dementia and their carers

Key Actions- Supporting Well - We aim to:

- Review how we can avoid unnecessary hospital and care home admissions
- Review hospital discharge pathways and post discharge support that assist people returning home or into their residential care home
- Support, review and manage pathways for people who have complex needs including where there are behaviours that challenge
- Promote the development of 'dementia friendly' accommodation including in the community and residential care sectors
- Review pathways and person-centred support for seldom heard groups such as younger onset dementia, diverse ethnicities, people with a learning disability, prison populations, rural and farming communities and armed forces
- Promote and develop good risk reduction methods that keep people safe and promote independence

Q10. Do you think these actions will support people with dementia and their family and carers to have safe, high-quality health and social care?

Figure 6



Q10a - If no, please give reasons why:

This answer includes common comments including from people who answered yes

- Don't discharge to care homes or with home care that cannot support the person well or adequately
- Work with families about end stage care rather than seeing care homes as something to be feared, if that is what is needed
- Avoid care home admissions when people can be supported at home
- Value paid carers more, train and pay them more
- More ongoing training across board including hospital staff
- Social services ask about money first and if this is above limit don't give you any help
- Clearer pathway and support for more challenging conditions needed
- You need Admiral Nurses
- Carers left to try and find support alone
- Day care is desperately needed
- People who live alone could be overlooked
- What are the dementia training standards, how is this enforced?
- Things in the Enhanced Care in Care Himes introduced like nutrition so why are people avoidably admitted- who enforces?
- No detail of what will be done or how this will be achieved
- Monitor Care homes better and more regularly
- More support for younger people with dementia

Q10b- Is there anything else we could do to support people with dementia and their family and carers?

- Ensure Dementia specialist training is done to a clear standard for dementia care
- Honest open discussions with person and family about what can be done and what is advised and why.

- Have access to support, information and activities for person and family in all areas of County.
- Real practical support not just someone to listen
- Support informal carers better as this would help avoid crisis and admissions
- Help increase voluntary drivers and transport options who have training in dementia
- More support to fill gaps between diagnosis and when people have social care needs
- More respite for carers, more funded day care.
- Help informal carers and people with dementia not to feel so alone dealing with this
- Boards must have people with dementia on them “Nothing about us without us”
- Training in co morbid conditions like diabetes needed
- Fund more specialist care
- Reinstate Admiral Nurses across Leicestershire
- Create Dementia Specialist Centres for day services/Carer support / advice and information and therapeutic activity all under one roof. Too much time is spent by carers trying to access information and help from too many agencies.
- Explain what happens after sectioning and DOLS
- Regular reviews at least every 6 months by medical staff
- Stop carers having to wait hours for telephone calls or in telephone queues
- Level of profit for private business should be set nationally
- We were able to make massive change quickly during Covid why does it take many years to see improvement here?
- Mandatory referral from Memory Assessment service to local Dementia Support Service run by Age UK

Key Actions- Living well - We will continue to:

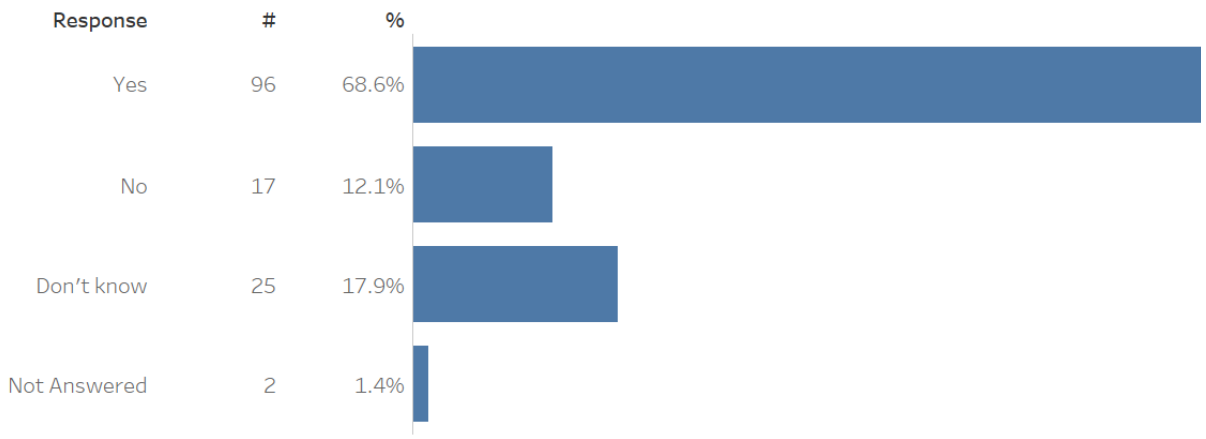
- Provide information and advice about living well with dementia that is accurate, timely, accessible, and joined up across Leicester, Leicestershire and Rutland
- Develop and promote dementia-friendly communities, dementia support services and other living well support
- Use funding opportunities when they are available, to develop living well activities especially in areas that are less well-served

Key Actions- Living well - We aim to:

- Engage with people living with dementia and their carers including people with lived experience, to be involved in strategy development and to inform our work
- Support people with dementia to plan and live well by promoting crisis contingency planning, advanced care planning and the benefits of appointing lasting power of attorney

Q11. Do you think these actions will support people with dementia to continue living well for as long as possible?

Figure 7



Q11a. If no, please give reasons why:

- All people should have access to meaningful activity whether in a care home or at home or going to activities locally
- On line survey and poster inaccessible
- Action not more leaflets
- Professionals are not consulting with LPA holder and especially in GPs.
- More information and activity at early stages noted, so is better than previous years

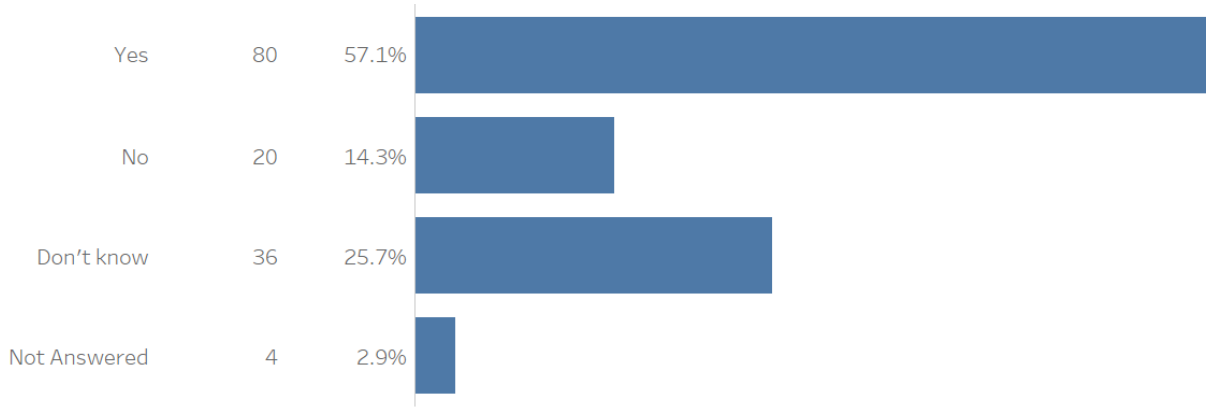
Q11b. Is there anything else we could do to support people with dementia to live well?

- Support informal carers better at any stage of the person's dementia
- Improve the quality of care especially in care homes
- Provide as much information as possible to families
- Use resources together and in a coordinated way- ie Social Prescribers, LAC, Age UK, range of Voluntary sector activities.
- Fund VSE permanently not just through short term grants
- Memory Hubs/ Meeting centres in all areas
- Transport to access services as people lose their licences and no public transport
- Some of the services in community mentioned as great example of early help – like Musical Memory Box, ADRE in Lutterworth. Brain Gym, Falls prevent for dementia, Informal learner training, memory cafes - Build on these
- Need all area to have access to activities and support.
- Have Admiral Nurses across Leicestershire
- More day care and transport to these
- More supported housing instead of residential care homes

Key Actions - Dying Well - We Aim to:

- Promote and develop good practice including strengthening the link with end of life pathways and the ReSPECT process (the ReSPECT process creates personalised recommendations for a person's clinical care and treatment in a future emergency in which they are unable to make or express choices)

Q14. Do you think this action will support people with dementia to make decisions about their end of life plan?
Figure 8



Q15. If no, please give reasons why:

This answer includes common comments including from people who answered yes

- Not the resources to do this work in Statutory services
- Needs to have clear processes to support advanced decisions early with person and their family, when person has lost mental capacity, it is too late.
- People don't know what RESPECT is
- Some asked about this at each medical appointment others never.
- Too much jargon in this point for people to respond to question
- Compassionate care at end of life does need improving
- These are difficult conversations to have so need training and support to do this

Q15a. Is there anything else we could do to support people with dementia to make an informed choice around their end-of-life plan?

- Have these conversations early and support staff to sensitively do this
- Ensure RESPECT form in place before emergency and ensure it is shared with all medical professional
- That all medical professionals using it consistently and are trained
- Promote LPA and ensure records note this is in place and contacts both NHS, ASC and Care Providers
- Be clear and share between professional and family when someone is now on an "End of Life Plan"

- Support people to die at home if this is theirs's and family's choice.

Additional Information

The Consultation was hosted by the City Council with links provided on the County Council and ICB websites to the online survey. The City Council also ensured that printed copies were available on request. Partners were encouraged to support people they work who were affected by dementia fill in the survey. In addition, the Adults and Communities Department sent an "all user" email internally and sent out over 600 emails to care providers, local networks, housing and voluntary sector providers seeking their assistance with publishing the survey.

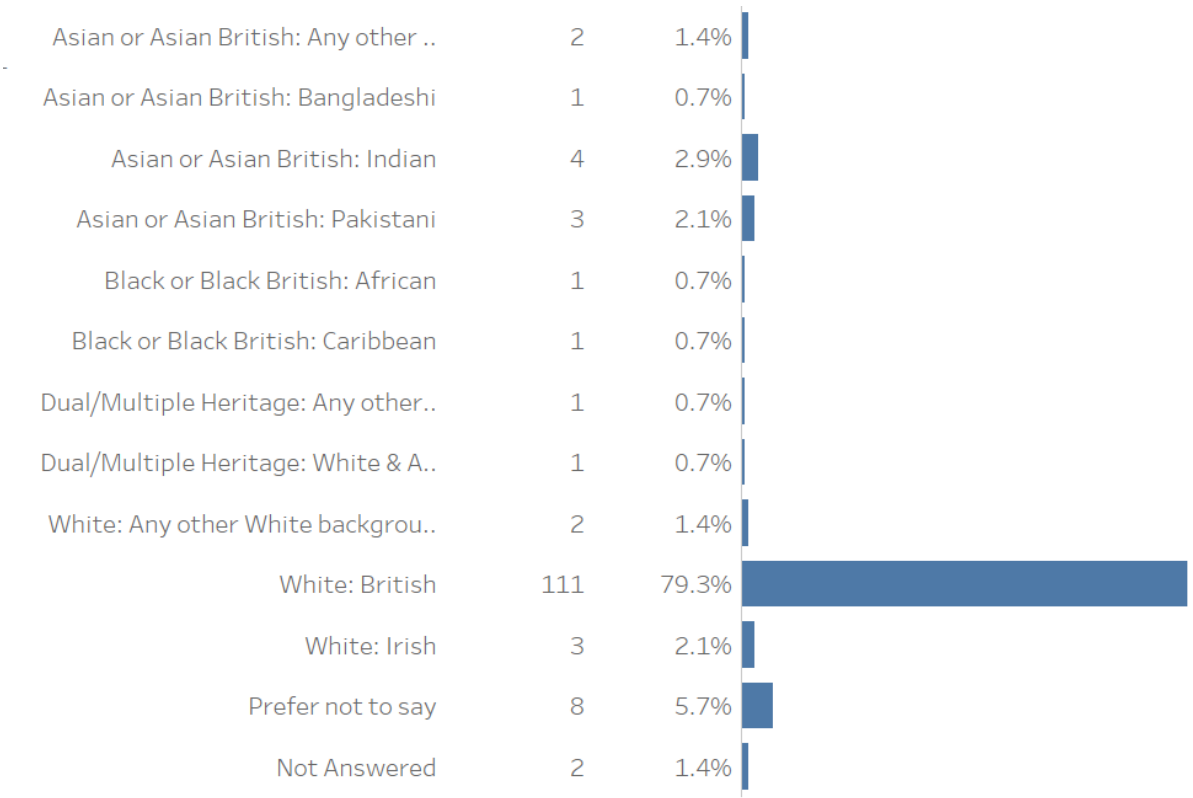
Additional consultation meetings were provided on request for people affected by dementia. Four meetings were attended by County Council Officers at which people were encouraged to fill in individual surveys.

Appendix 1 - Equality Monitoring Information

The tables below refer to demographic information from people who stated they were:

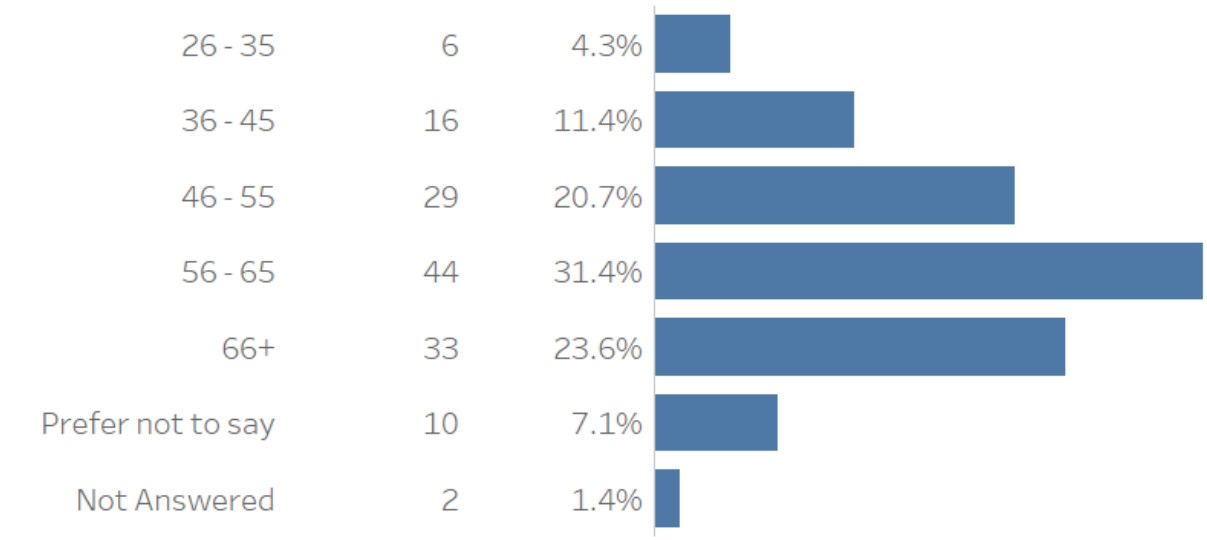
Ethnic Background

Figure 9



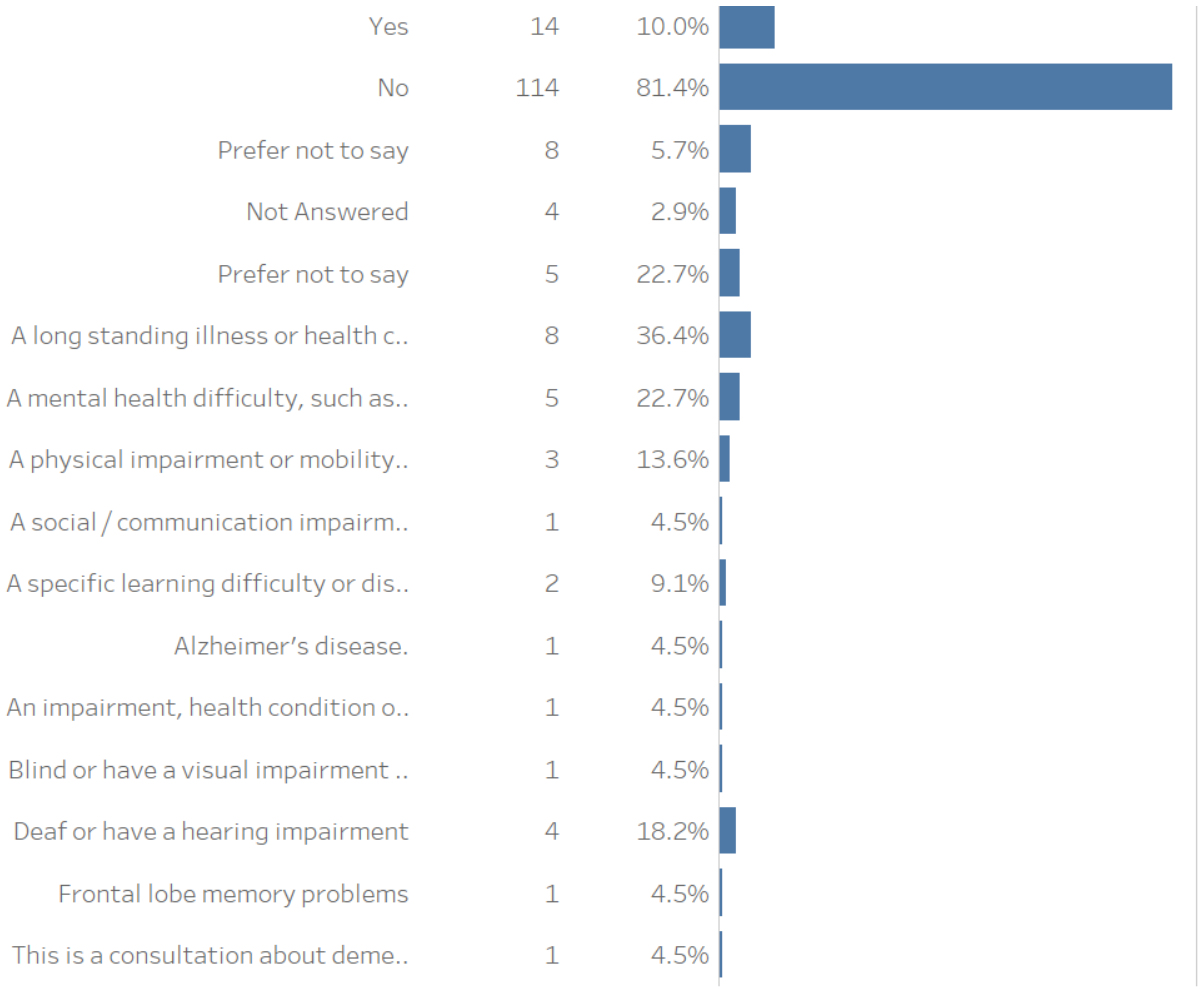
Age

Figure 10



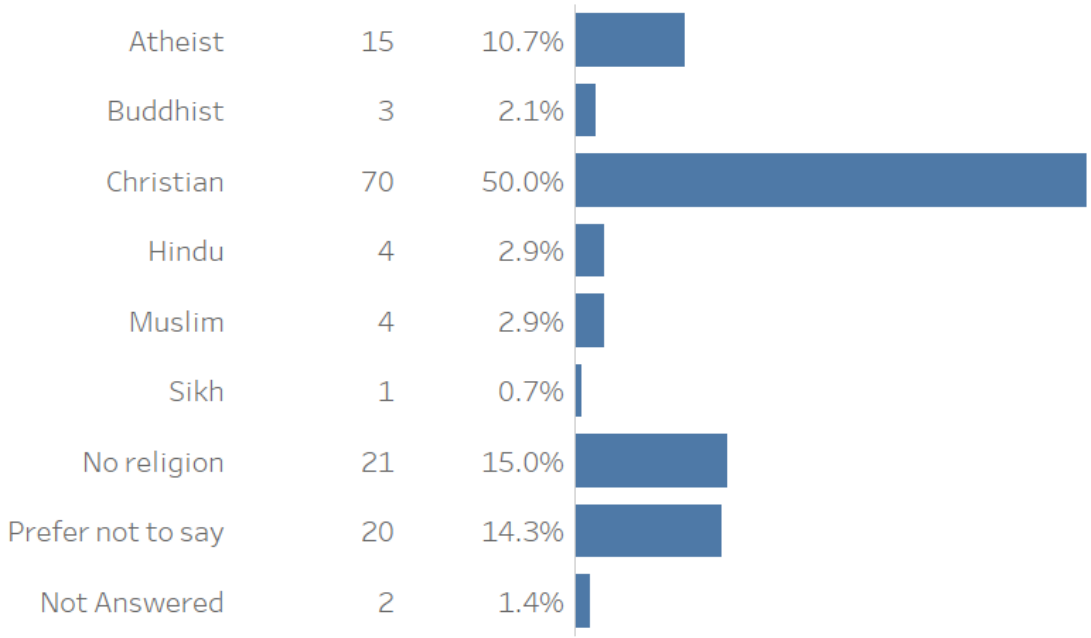
Disability

Figure 11



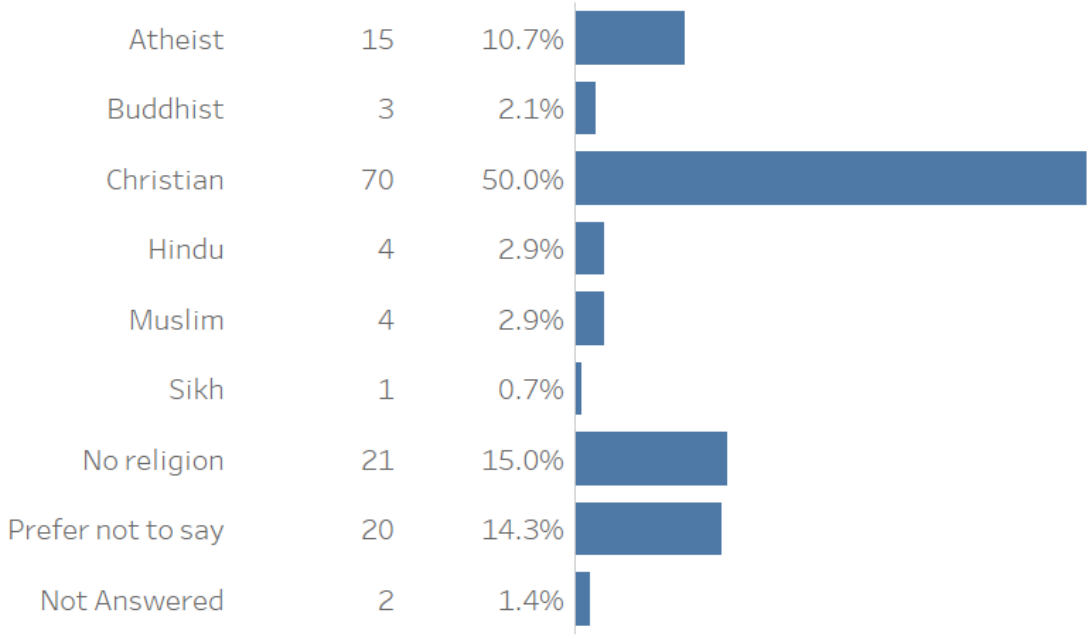
Religion

Figure 12



Sexual Orientation

Figure 13



Gender

Figure 14