

Appendix B

Summary Report of Rutland Responses to Public Consultation and Engagement:

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

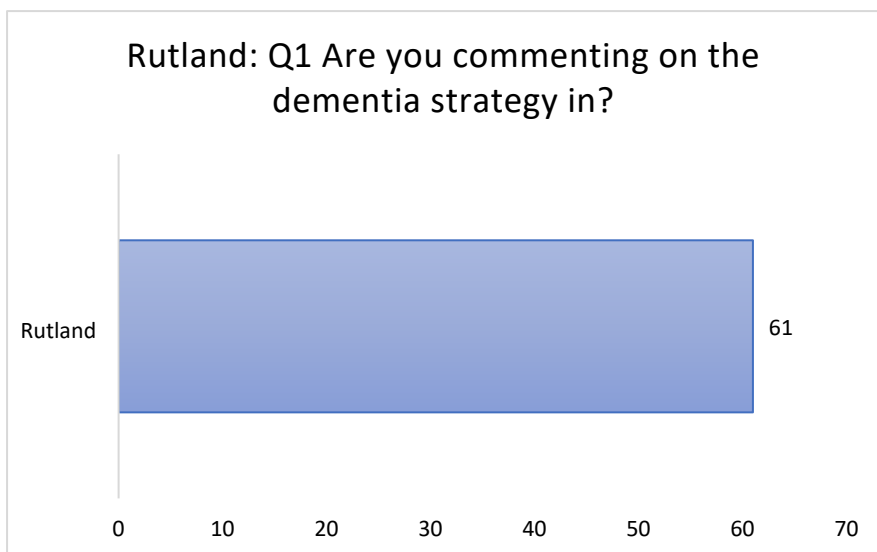
1. Purpose of the report

This document provides a summary of the findings from Rutland respondents of 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 was presented to the Dementia Programme Board on the 21st 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 Leicester, Leicestershire and Rutland was 358. 61 responded from Rutland, 206 responded from Leicestershire and 91 responded from Leicester City. This is a high number of responses when compared to previous Dementia in Strategy consultations and other similar consultations and demonstrates the effort from officers to consult as widely as possible.

Figure one - Response from Rutland



2. Key Themes Emerging for Rutland

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

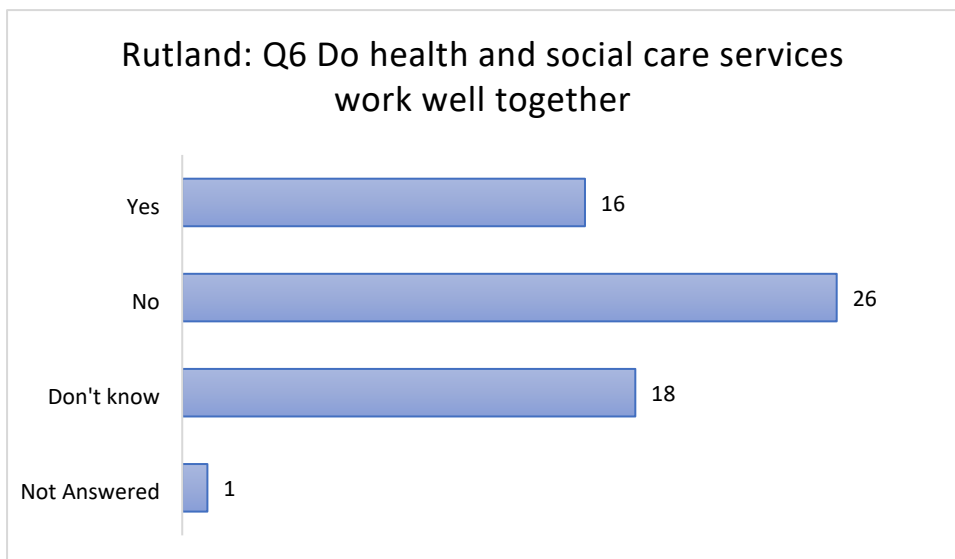
- The draft strategy was welcomed by many respondents and mostly respondents agreed that the aims of the draft strategy were the right ones.
- People noted that the process of having an assessment and diagnosis had changed and was improving. The process now involves a CT scan followed by face-to-face assessment.
- A consistent positive theme in the feedback was a request for 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.
- One responder stated, Admiral Nurses are invaluable and offer so much support, we are lucky in Rutland that there is a service that covers where my parents live but we are aware that they are not in all counties. They are a vital source of help, support and comfort and there should certainly be more of them!
- 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.
- 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.

- 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.
- Provide transport to local activities, as people lose 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:

Figure 2



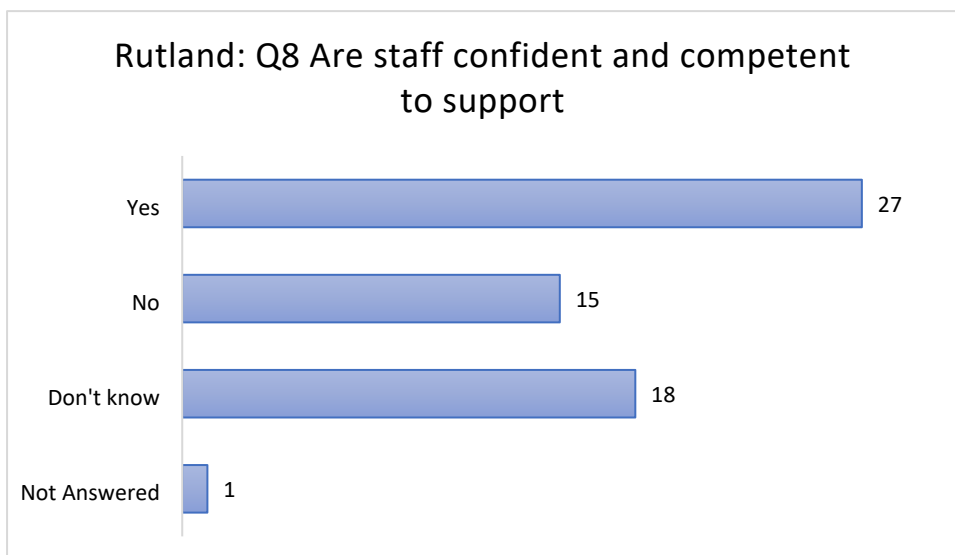
Where respondents said no to this question, they were asked to provide comments. Some of the key comment's responses were:

- Differing demands and priorities make it hard for a joined-up approach. There is little cross over in communication and often the representative from health is unknown.

- There is nothing in OAKHAM for older people like this only private groups.
- Referral to other care agencies did NOT happen after diagnosis. (Initial drug treatments failed and was therefore discharged from the care of the specialist)
- As a carer I was left totally bereft to try and find out IF there was any help and support locally. After two different trial contacts made by myself, failure ensued because of total unsuitability, Eventually discovered and self-referred to an Admiral Nurse who was excellent and liaised on my behalf with other 'agencies' I feel from what I have observed, that not all parties communicate between each other fully, and I as a carer, have had to chase for information to be shared, I feel it could be more joined up.
- People with dementia who live alone are bypassed unless they have family or friends who contact services
- Coordination of support is weak; funding is scare and only short term for Voluntary Sector in our rural area
- Lack of coordination between, carers, Drs and hospitals
- I had to go Private to get a CT scan (during COVID)
- Different social worker every couple of months

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

Figure 3.



Option	Total	Percent
Yes	27	44.26%
No	15	24.59%
Don't know	18	29.51%
Not Answered	1	1.64%

Once again, where people said no, they were asked to provide comments.

- After a brain scan my Dad's GP said my dad did not have dementia. I told him I believed he did based on my experience working as an OT and observing Dad's symptoms, it took another 12 months to get a referral to Memory clinic for a diagnosis.
- I said yes but want to add that we have a lot of resource on the Learning Hub which is targeted to supporting persons with dementia, which is valuable and should be highlighted to staff, thank you!
- I suspect that some are more experienced and confident than others. I have noticed that many hospital staff do not seem to understand the needs of someone with dementia very well.
- I don't think they know how. We had 2 assessments one for my husband and one for me as his carer. They got our names correct but not much else.
- Experience of practitioners varies – not sure that hospital staff fully understand the needs of someone with dementia.
- Poor experience with my GP

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

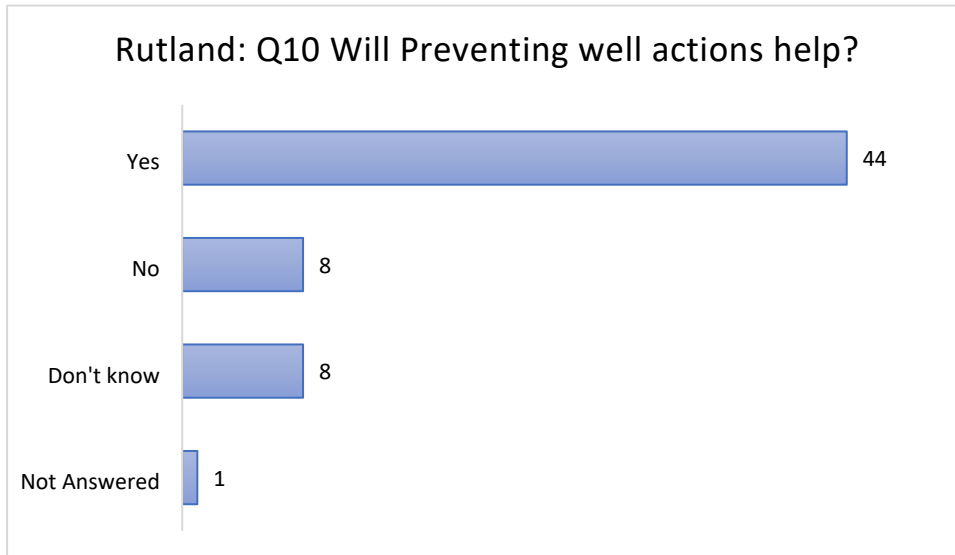
Key Actions Preventing Well - We Aim to

- 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

People were asked: Do you think these actions will help reduce or delay the onset of dementia?

Figure 4



Option	Total	Percent
Yes	44	72.13%
No	8	13.11%
Don't know	8	13.11%
Not Answered	1	1.64%

If no, give reasons why

- Health needs to be promoting the prevention model rather than getting involved at the point people are at crisis
- Early diagnosis, so that medications can be taken early and compliance is likely to be better
- Try to remove the stigma and fear associated with dementia
- Making it easier to access early diagnosis and have access to medical support

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, Maintenance Cognitive Stimulation Therapy (MCST), in community centres and villages.

- There needs to be a greater emphasis on promoting dementia prevention methods such as lifestyle behaviour changes.
- Being clearer about the 'screening' and communicating that with patients/the public
- Early screening at annual health checks
- Access to assessment and support earlier
- Widen referrals out so you do not just have to go through GP's – e.g. if communities were to support assessment of potential diagnosis – there needs to be a direct referral route for them rather than GP

Key Actions- Diagnosing Well - We will continue to:

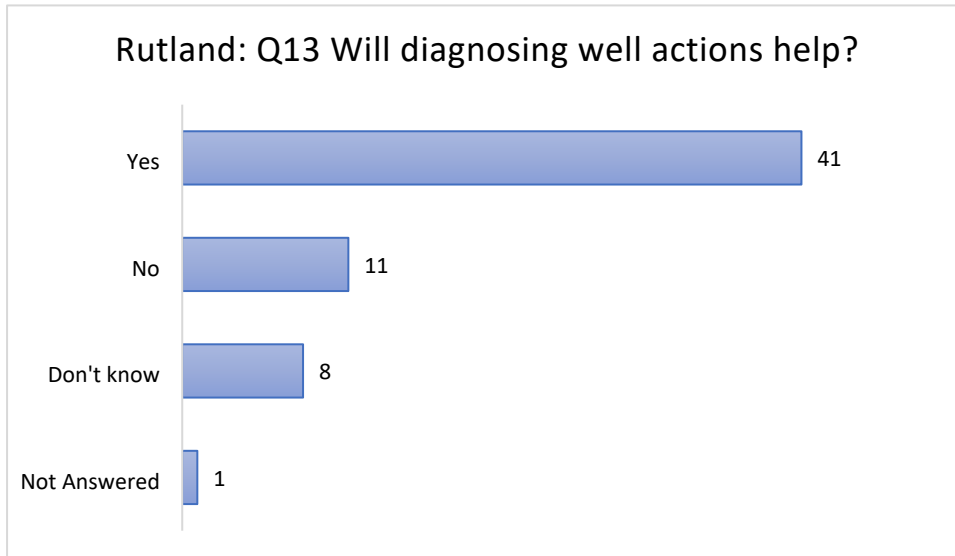
- Use pharmaceutical treatments and consider a range of treatment options that have proven benefits to people with dementia.

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.

People were asked: Do you think these actions will support reducing waiting times and ensure a timely diagnosis?

Figure 5



Option	Total	Percent
Yes	41	67.21%
No	11	18.03%
Don't know	8	13.11%
Not Answered	1	1.64%

If no, please give reasons why:

- 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.
- Educate public to destigmatise dementia so they are less scared to express their concerns about their memory, cognition or word finding issues.
- Educate GPs to refer to memory clinics for review, not just take a radiologist's assessment from a scan.
- Make clinics more accessible by running clinics also in rural areas not just city hospital. Attending a city hospital takes people with early dementia well outside their comfort zone.

- Rarer dementias not well served at Diagnosis and after care.

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.

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?

- Publicise in a more inclusive way and in a variety of languages
- Not only about prevention and progression of the disease but what is available to help sufferers, carers and wider family members
- Provide training to include cultural competencies
- There should be no reason that different ethnic communities are treated differently as long as awareness of symptoms have been brought to everyone's attention

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
- Easy read formats
- Better educated GP's, educate public on symptoms and destigmatise.
- Memory clinics in rural locations
- Widen referrals out so you do not just have to go through GP's – e.g. if communities were to support assessment of potential diagnosis – there needs to be a direct referral route for them rather than GP
- Make access to medical services easier, rather than hidden behind answerphones, websites which are no intuitive and difficult for people with additional needs to navigate

Key Actions- Supporting Well - We will continue to:

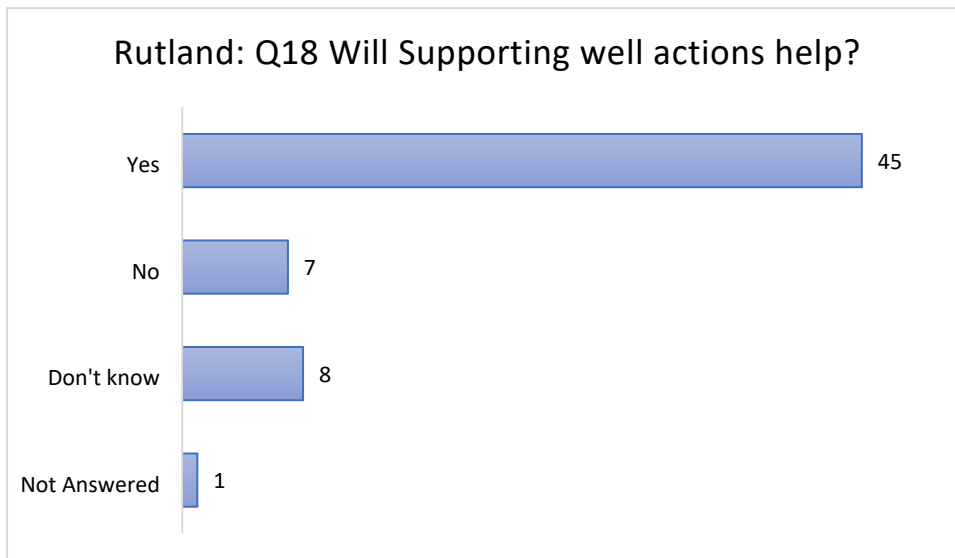
- Improve the hospital experience for people with dementia
- Apply the Leicester, Leicestershire and Rutland Carer Strategy actions to support people with dementia and their carers
- Raise awareness of support available for people with dementia and their carers

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

People were asked: 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



Option	Total	Percent
Yes	45	73.77%
No	7	11.48%
Don't know	8	13.11%
Not Answered	1	1.64%

If no, please give reasons why:

- More attention needs to be put in place for the carer, particularly if they are the only carer
- Financial cost is a problem to them in supporting someone with dementia, they often can't afford support services that are mentioned
- Families cannot afford transport to get to support groups or respite
- There was no support in Rutland when my mother left hospital

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.
- 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.
- 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
- 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.
- Regular reviews at least every 6 months by medical staff
- Mandatory referral from Memory Assessment service to local Dementia Support Service run by Age UK

Key Actions- Living well - We will continue to:

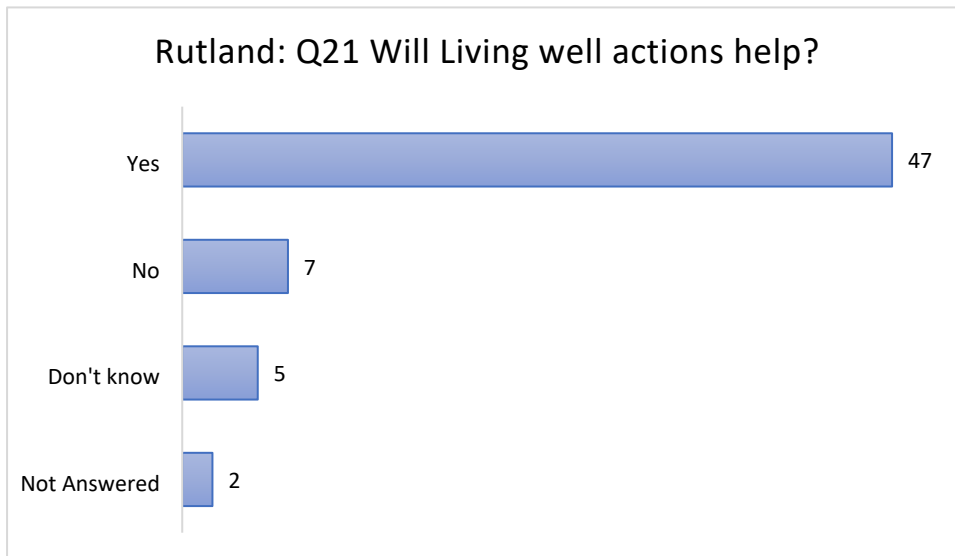
- Provide information and advice about living well with dementia that is accurate, timely, accessible, and joined up across Leicester, Leicestershire and Rutland
- Develop and promote dementia-friendly communities, dementia support services and other living well support
- Use funding opportunities when 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

People were asked: Do you think these actions will support people with dementia to continue living well for as long as possible?

Figure 7



Option	Total	Percent
Yes	47	77.05%
No	7	11.48%
Don't know	5	8.20%
Not Answered	2	3.28%

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
- Practical support needed 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
- Financial implications
- Drs appointments are usually by telephone

People were asked; 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, Age UK, range of Voluntary sector activities.
- Fund VSE permanently not just through short term grants

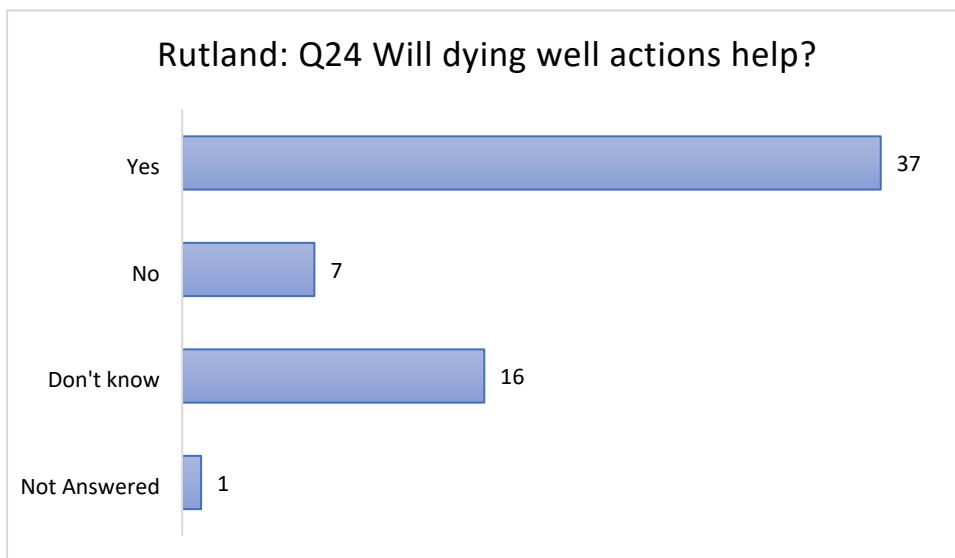
- Transport to access services as people lose their licences and no public transport
- Need all area to have access to activities and support.
- More day care and transport to these
- More supported housing instead of residential care homes

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)

People were asked: Do you think this action will support people with dementia to make decisions about their end of life plan?

Figure 8



Option	Total	Percent
Yes	37	60.66%
No	7	11.48%
Don't know	16	26.23%
Not Answered	1	1.64%

If no, please give reasons why:

- People with advanced dementia won't even be able to understand any questions let alone answer them. (By the way people do not die 'well' they die ill) Dying with dignity would be a far better use of words.
- As a carer, I am not aware of the ReSPECT process or what that means and if it has been applied to my family member.
- More emphasis on the early stages of dementia but TOTALLY ignoring those with the latter stages, which is very disheartening.

People were also asked: Is there anything else we could do to support people with dementia to make an informed choice around their end-of-life plan?

- Ensure information is in all available formats (i.e., easy read). Ensure that conversations are at the individual's pace - it is hard to discuss death, especially when it is your own. give them options, reserve your own judgement, give them time and support to make decisions on their own
- Ensure the end of life plan should always be with a carer present as they will know the dementia sufferer far better than anyone in the medical profession and will also know the life and personality traits of the person with dementia
- What about giving info about wills and power of attorney?
- Ensure RESPECT form in place before emergency and ensure it is shared with all medical professional
- 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 LCC 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, ASC sent an "all user" email internally and to care providers, local networks, housing and voluntary sector providers seeking their assistance with publishing the survey.

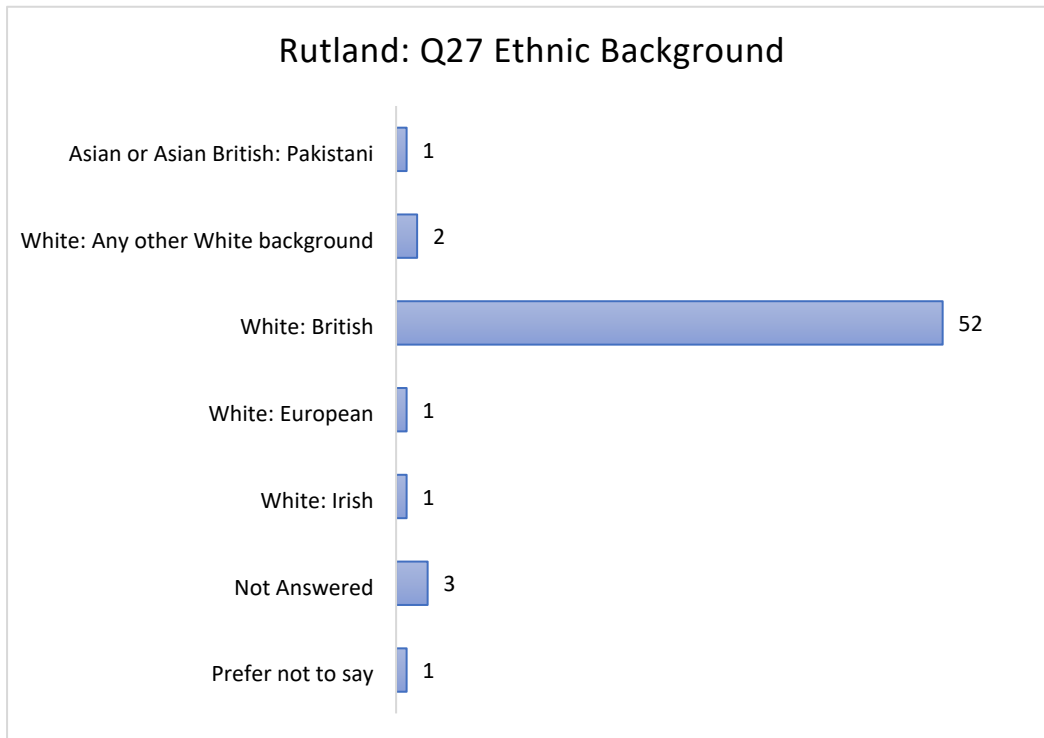
Additional consultation meetings were provided on request for people affected by dementia.

Equality Monitoring Information

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

Ethnic Background

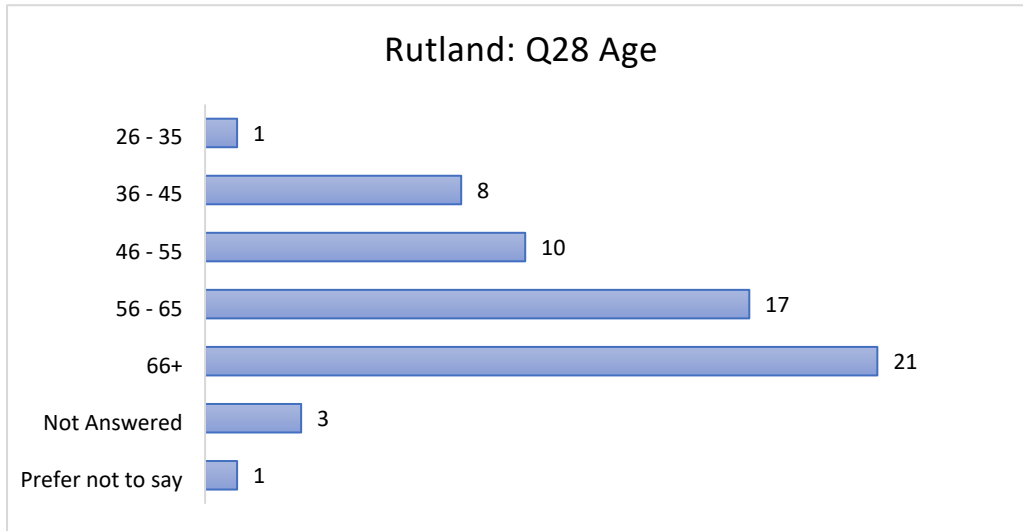
Figure 9



Option: Ethnic Background	Total	Percent
Asian or Asian British: Pakistani	1	1.64%
White: Any other White background	2	3.28%
White: British	52	85.25%
White: European	1	1.64%
White: Irish	1	1.64%
Not Answered	3	4.92%
Prefer not to say	1	1.64%

AGE

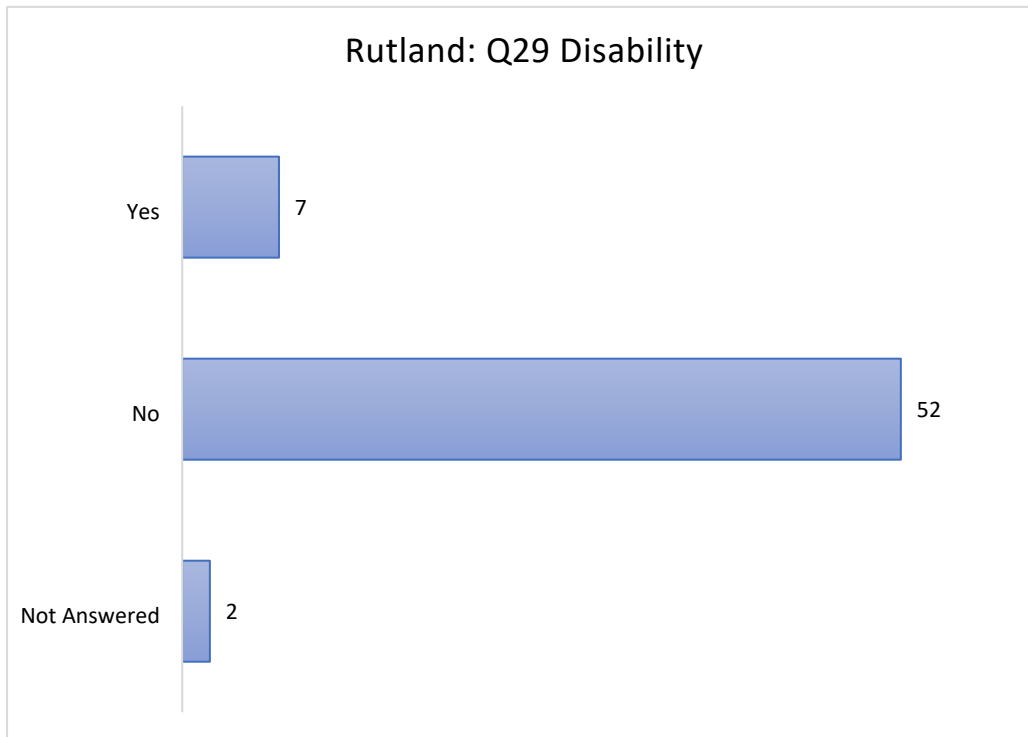
Figure 10



Option: Age	Total	Percent
26 - 35	1	1.64%
36 - 45	8	13.11%
46 - 55	10	16.39%
56 - 65	17	27.87%
66+	21	34.43%
Not Answered	3	4.92%
Prefer not to say	1	1.64%

Disability

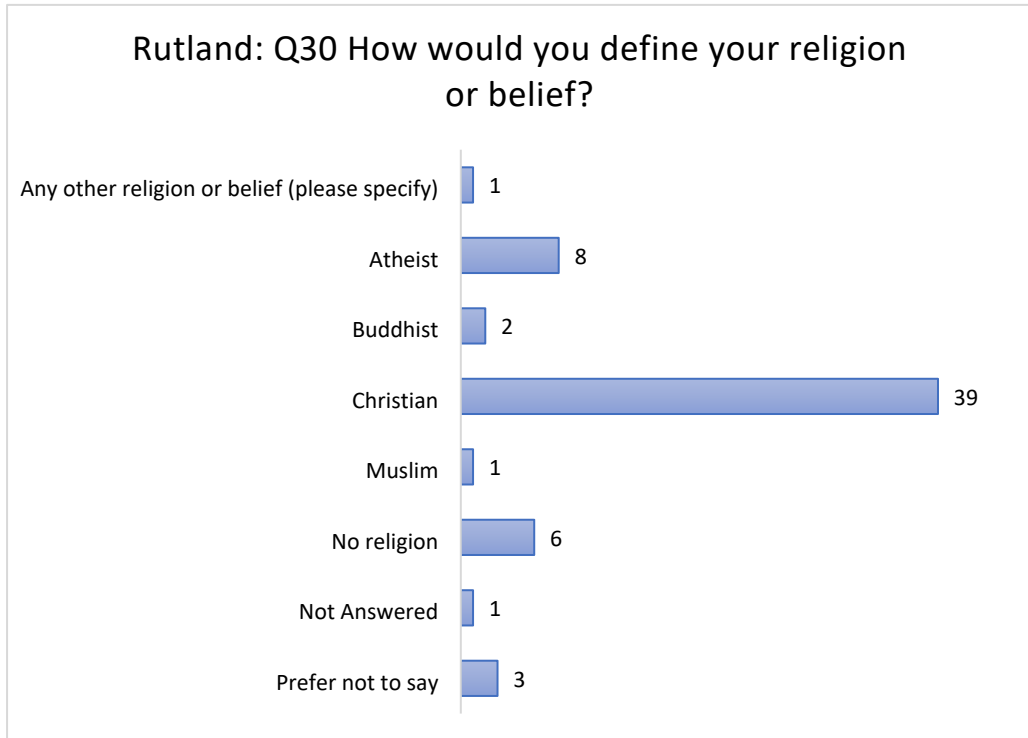
Figure 11



Option: Disability	Total	Percent
Yes	7	11.48%
No	52	85.25%
Prefer not to say	2	3.28%

Religion

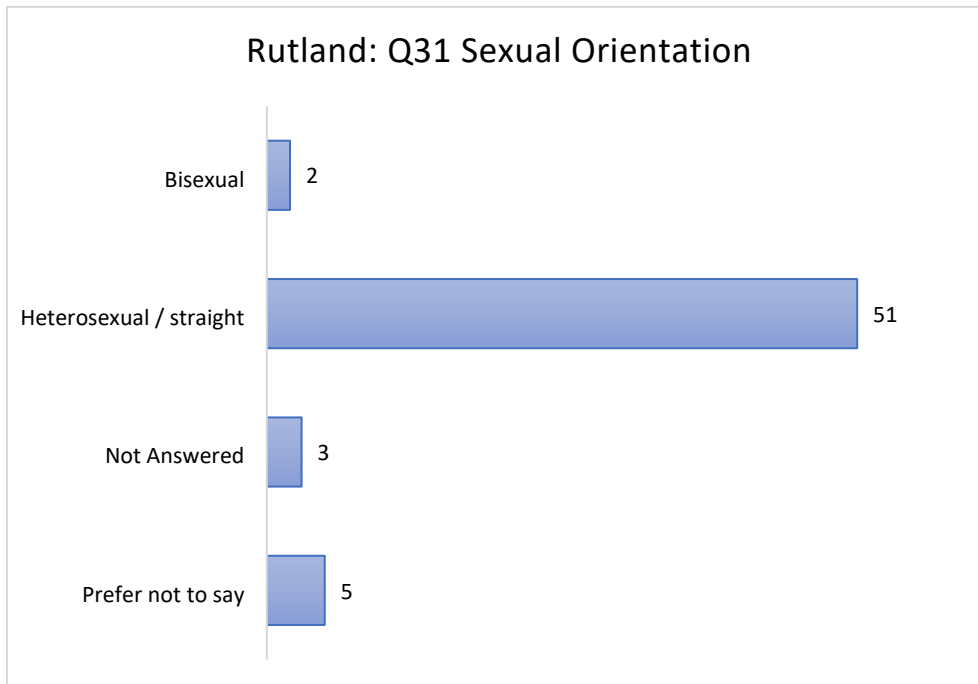
Figure 12



Option: Religion	Total	Percent
Any other religion or belief (please specify)	1	1.64%
Atheist	8	13.11%
Buddhist	2	3.28%
Christian	39	63.93%
Muslim	1	1.64%
No religion	6	9.84%
Not Answered	1	1.64%
Prefer not to say	3	4.92%

Sexual Orientation

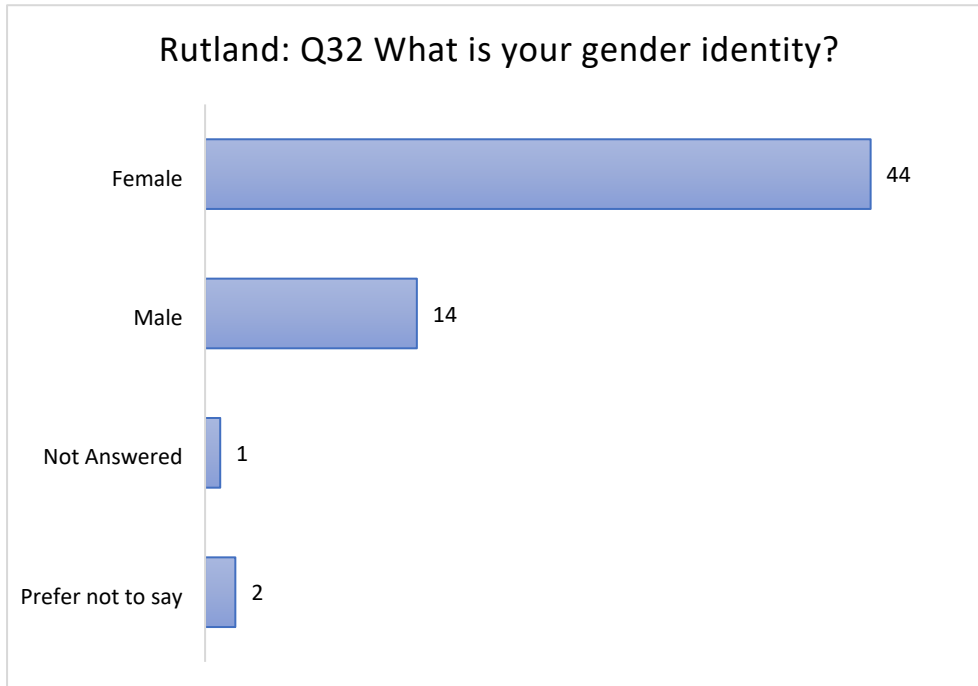
Figure 13



Option: Sexual Orientation	Total	Percent
Bisexual	2	3.28%
Heterosexual / straight	51	83.61%
Not Answered	3	4.92%
Prefer not to say	5	8.20%

Gender

Figure 14



Option: Gender identity	Total	Percent
Female	44	72.13%
Male	14	22.95%
Not Answered	1	1.64%
Prefer not to say	2	3.28%