

ADULT SOCIAL CARE SCRUTINY COMMISSION

Leicester, Leicestershire, and Rutland Living Well with Dementia Strategy Refresh – Consultation Results

Cllr Sarah Russell – Deputy Mayor, Social Care, Health and
Community Safety

Kate Galoppi – Director of Care Services and
Commissioning – Social Care & Education

Date 30th November 2023

Wards Affected: All

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1. Purpose

- 1.1 To provide an update on the refresh of the LLR Living Well with Dementia 2024-2028 strategy, particularly the results of the consultation on the draft strategy.

2. Summary

- 2.1 The present LLR Joint Living Well with Dementia Strategy concludes this year and the LLR Dementia Programme Board has been working on its review with a view to launching a refreshed strategy in January 2024.
- 2.2 As part of the review, a 10 week consultation on the refreshed priorities took place and this report sets out the results of the consultation and how these will impact upon the refreshed strategy. Findings in the city indicate that the strategy itself was generally well received. The free text responses highlighted some issues in the support that is currently offered:
 - There is a sense of lack of communication between systems and lack of sign posting to services.
 - There is a lack of awareness of what help is available amongst carers.
 - Awareness raising in BAME communities could be improved through making links with communities and working in partnership with community centres and places of worship.
 - It is important to consider language needs and cultural context when raising dementia awareness and diagnosis with BAME groups.
 - Community centres and opportunities for socialising and exercise are desired
 - Clear information and support from the diagnosis onwards are needed, a pathway map would be helpful.
- 2.3 The strategy will now be amended to reflect the findings and proceed to the Dementia Programme Board for agreement.
- 2.4 Of the 12,000 posts mentioned above, 11,500 are within the independent sector.

3. Recommendations

- 3.1 The Commission is recommended to note the content of the report.

4. Report

4.1 The proposed strategy was developed by the Dementia Programme Board, a body that consists of the three local authorities, the ICB, LPT, Primary Care, VCSE organisations, Healthwatch. As before, the strategy follows the [NHS Well Pathway for Dementia](#) which has 5 strands – Preventing Well – Diagnosing Well – Supporting Well -Living Well – and Dying Well.

4.1 The refreshed strategy is to be implemented from January 2024. It is proposed that this strategy is set to be live for a period of 5 years, until late 2028. Due to this extended life of the strategy, it is planned that the progress of the strategy action plan is monitored continuously by the LLR Dementia Programme Board (DPB).

4.2 A formal consultation has been undertaken to engage the public as well as professionals working in the dementia field on our strategy proposal.

4.3 Partners promoted the strategy amongst their networks such as care support provider networks, Dementia Programme Board, social media avenues, Your Leicester publication and available resources beyond what was initially planned such as AV display screens at GP surgeries. See appendix 2 for our consultation engagement plan, this provides detail of what avenues were taken to promote the engagement. People were able to call a listed phone number or email with any queries. Paper copies of the consultation were also made available upon request.

4.4 In addition to what is outlined in the plan, the County communications team undertook a Press release which featured the consultation in Leicester Mercury.

4.5 Direct engagement was also undertaken with community groups across LLR, this featured focus groups with 'Jamila's Legacy', Age UK Leicester Shire and Rutland, Alzheimer's Society and the Carers Centre. Commissioners proactively reached out to our VCS sector organisations offering to attend their sessions to talk about the strategy consultation.

4.6 In the city specific focus was drawn on to our diverse communities by commissioners reaching out to VCS organisations directly and offering support with consultation promotion and offering support with interpreter services where appropriate. Organisations were comfortable with promoting the consultation independently, some paper copies of the consultation were requested.

4.7 City commissioner also attended the Managers Forum in ASC and promoted the strategy consultation across Social Care practitioners.

Results

4.8 In total there were 358 responses across Leicester, Leicestershire and Rutland. Of these, 206 were specific to Leicestershire, 91 specific to Leicester and 61 specific to Rutland.

4.9 There was some engagement from our BAME communities (38 people in the city out of 91 respondents or 41%). This may highlight the wider challenge around dementia awareness and coming forward for a diagnosis in underrepresented communities. Details of respondent ethnic background can be found below:

Option	Total	Percent
Asian or Asian British: Any other Asian background	2	2.20%
Asian or Asian British: Bangladeshi	2	2.20%

Asian or Asian British: Indian	13	14.29%
Asian or Asian British: Pakistani	2	2.20%
Black or Black British: African	3	3.30%
Black or Black British: Caribbean	3	3.30%
Black or Black British: Somali	1	1.10%
Dual/Multiple Heritage: White & Asian	1	1.10%
Dual/Multiple Heritage: White & Black Caribbean	1	1.10%
Not Answered	2	2.20%
Other ethnic group: Any other ethnic group	2	2.20%
Prefer not to say	2	2.20%
White: Any other White background	1	1.10%
White: British	49	53.85%
White: European	3	3.30%
White: Irish	4	4.40%

2 responses have picked “Any other ethnic group”, which are stated as below:

1. Mixed from three generations.
2. Arab

4.10 The majority of the respondents were carers (47), followed by members of the public (14) interested in the consultation.

Option	Total	Percent
I am a family member / carer of a person with dementia	47	51.65%
I am an interested member of the public	14	15.38%
I work for a council	8	8.79%
I work for a dementia service provider	12	13.19%
I am a representative of a voluntary sector organisation, charity, or local community group	8	8.79%
I work for the NHS in secondary care	10	10.99%
I work for the NHS in the primary care network	1	1.10%
Other (please specify)	6	6.59%

Responses to the Well Pathway themes

4.11 The comments below have been extracted from the responses around the Well Pathway points used as a foundation of our strategy. It was interesting to note the very large degree of commonality of the responses, with the expected

feedback about cultural specificity of the City's needs and the rurality related issues of the two county authorities being the main differences.

Preventing Well

- Consider awareness raising in BAME communities through awareness raising campaigns and partnership with community centres and places of worship
- Improve diagnosis rates to help people earlier
- Improve the availability of community support

Diagnosing Well

- Diagnosis challenges for seldom heard groups e.g. language challenges and lack of awareness
- Family and carer involvement needed from the beginning
- The development of a structured diagnosis process is required
- More awareness around dementia
- Consider allowing virtual appointment options for those who would prefer this
- To ensure better diagnosis for BAME groups it is important to: consider language needs, consider cultural context and work with community groups to raise awareness

Supporting Well

- More admiral nurses
- Better training and education for family members and professional carers
- Better support for carers and improve carer awareness for what support is available

Living Well

- Clear information around support
- Social group support

Dying Well

- Early planning and information
- Family involvement
- Difficult conversation, need a cultural change

4.12 For a full analysis see Appendix 2.

4.13 LLR and ICB commissioners are now in the process of negotiating changes that are to be made to the strategy as a result of the consultation. Early discussions with partners indicate that required changes to the strategy are very minor and in the main connected to focusing on and strengthening certain aspects such as cultural appropriateness of all services throughout the pathway, the information and advice offer, the timeliness of the diagnosis pathway. None of these come as a surprise and are already actively being worked on.

4.14 The ongoing objective is to publish the strategy in January 2024 once all partners are in agreement with the final draft.

4.15 The Dementia Programme Board will be accountable for the delivery of the strategy. Organisations within the Board will have their own action plans and it is planned that place based groups will take a lead role in the delivery of a local response to the very particular issues that exist.

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5. Scrutiny Overview

6 Financial Implications There are no direct financial implications arising from this report. Matt Cooper, Business Manager (Finance), Ext. 37 2145
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7 Legal Implications There are no commercial legal implications. Tracey Wakelam Principal Lawyer Commercial, property and Planning

8 Equalities Implications When making decisions, the Council must comply with the Public Sector Equality Duty (PSED) (Equality Act 2010) by paying due regard, when carrying out their functions, to the need to eliminate discrimination, advance equality of opportunity and foster good relations between people who share a ‘protected characteristic’ and those who do not. Decision makers need to be clear about any equalities implications of the proposed changes. In order to consider the likely impact on those likely to be affected by the recommendation and their protected characteristics. Protected groups under the Equality Act are age, disability, gender re-assignment, pregnancy/maternity, race, religion or belief, sex and sexual orientation. The Leicester, Leicestershire and Rutland’s (LLR) Living Well with Dementia Strategy 2024-2028 sets the priorities across LLR for ways Social Care and Health services can support people living with dementia and their families and carers. The aim is to create a health and social care system that works together so that every person with dementia, their carers and families have access to and receive compassionate care and support not only prior to diagnosis but post diagnosis and through to end of life. The report shares the city results of the Living Well with Dementia 2024-2028 strategy consultation. Certain priorities noted target specific demographics to ensure that appropriate support is offered across the board. An equalities impact assessment is being conducted and iterations of this should continue to be active throughout the process; this explores the equality impacts of the proposal in more detail. Consultation that has taken place should be used to help to inform the impact assessment. The Equality Impact Assessment process should continue to be used as a tool to aid consideration around whether we are meeting the aims of the Public Sector Equality. Equalities Officer, Surinder Singh, ext. 37 4148
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9 Climate Change and Carbon Reduction Implications

There are no significant climate emergency implications directly associated with this report.

Aidan Davis, Sustainability Officer, Ext 37 2284

10. Background information and other papers:

The current dementia strategy can be accessed on our website through the link below.

[living-well-with-dementia-strategy-2019-2022-accessible-version.pdf \(leicester.gov.uk\)](https://www.leicester.gov.uk/media/2022/03/23/living-well-with-dementia-strategy-2019-2022-accessible-version.pdf)

11. Appendices

Appendix 1: Latest Draft (6) of the LLR Joint Living Well with Dementia Strategy

Appendix 2: Full Dementia Strategy Consultation Result: City

DRAFT version 6:

**Leicester, Leicestershire and Rutland Joint Living Well with Dementia Strategy
2023-2028**

Section 1: Introduction

Section 2: What is dementia?

Section 3: Our approach for the strategy

Section 4: National Picture

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Section 7: Local context and background

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- How dementia support currently looks
- Local policies that influence our work
 - Section 8: What people have told us
 - Section 9: What we are planning to do 2023-2028
- Overarching themes
- Preventing Well
- Diagnosing Well
- Supporting Well
- Living Well
- Dying Well
 - Section 10: Useful links

Section 1: Introduction

Supporting and helping those living with dementia and their carers remains a priority for Leicester, Leicestershire and Rutland's (LLR) health and social care organisations. Our strategy sets out Leicester, Leicestershire and Rutland's ambition to support people to live well with dementia. It continues to reflect the national strategic direction outlined in the latest Prime Minister's Challenge on Dementia which details ambitious reforms to be achieved by 2020. The strategy is written for people affected by dementia either directly or as a carer and for the professionals who work to support them.

Leicester, Leicestershire and Rutland's Living Well with Dementia Strategy was developed in 2019 and has since been refreshed to reflect our priorities for 2023-2028. The strategy has been developed in partnership between local health, social care and voluntary sector organisations and informed by people with lived experience of dementia.

An important focus of our strategy is to continue to deliver personalised and integrated care. We have used the NHS England Well Pathway for Dementia to give us a framework that puts the individual and their carer at the centre of service development and implementation across health and social care. We acknowledge that by collaborating in this way, efficiencies across the wider health and social care system will also be realised.

As a partnership, we are committed to minimising the impact of dementia whilst continually improving dementia care and support within the communities of Leicester, Leicestershire and Rutland, not only for the person with dementia but also for the individuals who care for someone with dementia. We will continue to actively encourage a person centred and strength-based approach. We also aim to improve access to diagnosis and support services for all patients and people drawing upon support especially those from seldom heard groups who currently do not access services.

Section 2: What is dementia?

[Prime Minister's Challenge on Dementia 2020](#): "Dementia describes a set of symptoms that include loss of concentration and memory problems, mood and behaviour changes and problems with communicating and reasoning. These symptoms occur when the brain is damaged by certain diseases, such as Alzheimer's Disease, a series of small strokes or other neurological conditions such as Parkinson's disease."

All types of dementia are progressive. The way that people experience dementia will depend on a variety of factors therefore the progression of the condition will be different.

People of any age can receive a dementia diagnosis, but it is more common in those 65 years old and over. Early onset dementia refers to younger people with dementia whose symptoms commence before the age of 65. Due to the life stage differences amongst younger people with dementia in comparison to the older population, different social issues are experienced.

No two people with dementia are the same and therefore the symptoms each person experiences

will also differ.

Section 3: Our approach

We aim to create a health and social care system that works together so that every person with dementia, their carers and families have access to and receive person centred compassionate care and support not only prior to diagnosis but post-diagnosis and through to end of life.

This strategy has been guided by principles developed by NHS England in their transformation framework. This 'Well Pathway for Dementia' is based on NICE guidelines, the Organisation for Economic Co-operation and Development framework for Dementia and the Dementia I-statements from The National Dementia Declaration.

Our vision is that Leicester, Leicestershire and Rutland are all places where people with dementia can live well through the following NHS England guiding principles:

- Preventing Well
- Diagnosing Well
- Supporting Well
- Living Well
- Dying Well

Furthermore, following the pathway as part of ongoing business we will focus on:

Leading, Integrating, Commissioning Training, and Monitoring Well

Section 4: National Picture

There are currently around 900,000 people with dementia in the UK. This is projected to reach 1.6 million people in the UK living with dementia by 2040 (Alzheimer's UK, 2019). The majority of people living with dementia are aged 65 and over, however there is a small portion of people under 65 living with dementia, approx. 40,000 (Alzheimer's Society, 2014).

Figures published by the Alzheimer's Society, Alzheimer's Research UK, Public Health England and WHO show that:

- there are over 25,000 people with dementia from black and minority ethnic groups in England and Wales, and this is estimated to rise to nearly 50,000 by 2026
- there are 209,600 new cases of dementia in the UK each year
- worldwide, around 50 million people are currently estimated to have dementia and there are 10 million new cases each year
- two thirds of people with dementia are women and over 600,000 women in the UK are now living with dementia. The condition is the leading cause of death in women in the UK.
- There are [over 700,000](#) unpaid carers of people with dementia in the UK. Women are more likely to take on unpaid caring roles for people with dementia and are two and a half times more likely than men to provide intensive, 24-hour care.

Section 5: Local Picture

There are currently over 9,000 diagnosed people living with dementia across Leicester, Leicestershire and Rutland. There was a total of over 14,000 people predicted to be living with dementia across Leicester, Leicestershire and Rutland in 2020 and data projections show that this number is estimated to increase to over 13,000 in County, 3,000, in City and 900 in Rutland by 2030 (POPPI).

1 in 14 of 65s and over in Leicester, Leicestershire and Rutland is thought to have a dementia, which is reflective of the national trend. It is estimated that there are 105,000 carers across Leicester, Leicestershire and Rutland, although specific data for how many people care for those with dementia is not available. For further information relating to carers, please see the Leicester, Leicestershire and Rutland's Joint Carers Strategy 2022-2025 'Recognising, Valuing and Supporting Carers in Leicester, Leicestershire and Rutland'.

Section 6: National Context and background

In February 2015, the Department of Health published the Prime Minister's Challenge on Dementia 2020, to support the National Dementia Strategy of 2009. This detailed why dementia remains a priority and outlined the challenges the United Kingdom continues to face in relation to dementia. The priorities identified within this are to improve health and care, promote awareness and understanding and research. The Challenge continues to promote the Well Pathway for Dementia and therefore this local strategy uses the same structure as a guide.

There are a number of other national drivers that shape and influence the way we can support people affected by dementia. Some are listed below:

- Care Act 2014: sets out a framework of how local authorities should protect and care for adults within their locality.
- Equality Act 2010: protects people from discrimination in the workplace and wider society.
- Health and Care Act: new legislative measures aim to make it easier for health and care organisations to deliver joined-up care for people who rely on multiple different services.
- People at the Heart of Care: adult social care reform White Paper: 10-year vision on how support and care will be transformed
- Living Well with Dementia: a national dementia strategy sets out a vision for transforming dementia services with the aim of achieving a better awareness of dementia, early diagnosis and high-quality treatment at whatever stage of the illness and in whatever setting.
- NHS Adult Social Care Outcomes Framework: measures how well services achieve the outcomes that mean the most to people.

Section 7: Local Context and Background

How dementia support currently looks

The Dementia Support Service is the commissioned post diagnostic service, it aids people's understanding of what and where support is available. Anyone affected by dementia can self-refer into the Dementia Support Service and there are also standard referral pathways for professionals. These services are commissioned by the Councils and NHS and are subject to competitive tender legislation so the provider may change over time. The commissioned service at point of publication of

the strategy is Age UK Leicester Shire and Rutland. Rutland County Council combine this support with their Admiral Nurse service.

There is a range of services and support available for people living with dementia across Leicester, Leicestershire and Rutland. Some of these services are provided by local community groups and the voluntary and independent sector and some is provided or commissioned by NHS and Local Councils. Some of this support is subject to an assessment of need. The main method of receiving health support for people with dementia is through their general practice and the two NHS Trusts, Leicestershire Partnership Trust and University Hospital Leicester. Different Councils have slightly different arrangements for accessing and delivering social care, but work to the same national eligibility criteria. More detailed information including contact details is contained within the online LLR Dementia Friendly Guide and the Dementia Support Service can also help with access. The NHS website also describes services and access to these.

Local policies that influence our work

Locally, a number of policies and approaches are informing our strategic thinking. This is important to consider as the support offered for people living with dementia and their carers often intersects with other parts of health and social care offers. We are mindful of collaborative working and wider considerations of where our strategy sits. Some areas of specific considerations are:

- [Leicester, Leicestershire and Rutland Joint Carers Strategy Refresh 2022-2025](#): establishes priorities in order to provide better support to carers locally.

- [Joint Health and Wellbeing Strategy](#) 2019-2024 sets out health priorities for Leicester and provides details of objectives for improved health outcomes.

City JSNA pending previous one out of date.

-[Leicestershire Dementia Joint Strategic Needs Assessment 2018-2021 : explains dementia through focusing on local concordance with other issues and demographics.](#)

Rutland main strategic plans

City strategic plan

City All Age Commissioning Strategy

[Leicestershire County Council Strategic Plan 2022-2026](#)

How the strategy is governed

The Leicester, Leicestershire and Rutland Living Well with Dementia Strategy is managed by the Leicester Leicestershire and Rutland Dementia Programme Board. This is part of the overall systems that are in place to improve health and wellbeing for the citizens of the area. The following shows how specific Statutory Partnership Boards connect.

Leicester, Leicestershire and Rutland Health and Wellbeing Partnership (LLR HWP).

This is a statutory committee bringing together an alliance of partners who are concerned with improving the care, health and wellbeing of the local population. Each local authority area has a Joint Health and Wellbeing Plan. These feed down to local area Health and Wellbeing Plans. The

Dementia Strategy enables these boards to consider activity that specifically addresses the local needs of people living with dementia.

Leicester, Leicestershire and Rutland Mental Health Collaborative Board

This board ensures a focus on Mental Health and Dementia at a high level particularly with services delivered by Leicestershire Partnership Trust in collaboration with all statutory partners.

Leicester, Leicestershire and Rutland Dementia Programme Board

Sitting under the Mental health Collaborative is the Dementia Programme Board which has specific responsibility to ensure the implementation and monitoring of the Dementia Strategy.

Membership

- Leicester City Council
- Leicestershire County Council
- Rutland County Council NHS Leicester, Leicestershire and Rutland Integrated Care Board
- University Hospitals of Leicester NHS Trust
- Leicestershire Partnership NHS Trust
- Leicester, Leicestershire and Rutland Dementia Friendly Community
- Age UK Leicester Shire and Rutland
- Alzheimer's Society
- Healthwatch
- National Institution of Health Care Research
- Local Universities
- Admiral nurses
- Dementia UK

Section 8: What people have told us

Healthwatch Leicester, Leicestershire and Rutland spoke to a range of people through focus groups, 1 to 1 interview and a large-scale survey to learn about the views of people living with dementia and their carers. This focused on people's experiences regarding the support that they have been in receipt of and their overall dementia journey from pre diagnosis. Overall, 523 people were engaged with through 36 focus groups, 34 through semi structured interviews and 126 through survey responses, these counts include people with dementia and carers. Some useful feedback was given and some suggestions for how support could be improved were made. This research is of great value to us and has informed our priorities.

People with younger onset dementia are often underrepresented and can have varying priorities to those 65 years old and over. DPB members arranged an event in November 2022 which focused specifically on the support for people with younger onset dementia and encouraged befriending and advice sharing between them and their carers. During the event 3 focus groups were held in which people with younger onset dementia and their carers were encouraged to share their experiences and advise on what support could be offered to improve their dementia journeys. This information is also of great value to the Dementia Programme Board and has been used to inform our priorities.

Consultation on this draft strategy resulted in over 350 responses and people told us that they were broadly happy with our intended actions. In their feedback, people told us that we should pay attention to the following factors and these will be reflected in the final document:

- Lack of join up between health and social care and that some staff are not confident and/or competent to support people with dementia.
- Raising awareness about dementia in ethnic minority groups
- Provide culturally appropriate support and access across the Well pathway
- Loss of Admiral Nurse provision in the Leicestershire concerning and need more access throughout
- Improve diagnosis rates though improvement to pathway
- Memory Assessment Service should refer all people to the Dementia Support Service on diagnosis
- More support, information and advice is required to fill the gaps between people being diagnosed and developing personal care needs.
- Recognised standard of training for all professionals staff working with people living with dementia and more access to good quality training

The results of the engagement exercises are reflected in Section 9 of this strategy.

Section 9: What we are planning to do 2023-2028

We aim to provide and develop specific activity using the well pathway to meet our overall approach. Some areas will continue to be part of our usual day to day business and some we will aim to refocus and refresh and so have higher priority. This strategy identifies the high-level actions which will be specifically addressed by each organisation's delivery plan. Each organisation is responsible for drafting, following, and maintaining their delivery plan and reporting annually on its progress to the Dementia Programme Board. The expectation is that the delivery plans will be SMART (Specific, measurable, achievable, relevant, time bound) and organisations are accountable to the DPB governance to ensure high-level actions are being met.

This strategy does not have specific financial investment allocated in order to deliver the high-level priorities cross organisationally. Each organisation is responsible for ensuring that the activity and objectives are met using existing resources through allocated budgets by each organisation e.g. the Dementia Support Service is commissioned by Leicester City Council and Leicestershire County Council, these organisations had allocated a budget for the service, this ensures our 'Living Well' objective is met. Members of the Dementia Programme Board will continue to explore opportunities for funding through potential government allocated grants, however the priorities outlined are aimed to be achieved irrespective of extra funding being allocated.

Leading, Integrating, Commissioning Training, and Monitoring well

The overarching themes in the Well Pathway are important to address in this Strategy and relate to how we work as a health and social care system with our key partners.

The Dementia Programme Board (DPB) will continue to take responsibility for the following activities:

Leading, Integrating and Commissioning Well

- Promote practice that develops a strength-based approach to supporting families living with dementia
- Support and respond to the development of neighbourhood or place-based plans and other interdependent projects that impact on this Strategy
- Respond and adapt the strategic action plan as required to address any local or national policy change that impacts on people living with dementia
- Refresh the health and social care pathway for people living with dementia from Diagnosis to End of Life to ensure they are effective and efficient. We will aim to prioritise diagnosis and hospital discharge pathway.
- Use Public Health lead Joint Strategic Needs Assessments to support the commissioning of dementia friendly services for people with dementia. We will consider opportunities for joint commissioning and continue to jointly commission the Dementia Support Service.

Training well - Quality Improvements and workforce competency

- Ensure the quality aspects of personal care for people living with dementia are monitored within NHS and ASC contracts and work with providers to address any gaps.
- Promote and support access to good quality dementia training.

Monitoring well

- Report progress of the Strategy to the Mental Health Collaborative Board at least annually.
- Review the systems in place to implement, monitor and report on the Strategy adapting as required at least annually.
- Support local and organisational focused delivery plans, within which system wide actions will be agreed and implemented. System wide means across health, social care and housing responsibilities.

Well Pathway

Preventing Well

There is increasing awareness of the role of prevention in addressing dementia, particularly vascular dementia. Locally there are still gaps in understanding the connection between healthy living and dementia and opportunities with the public and patients to raise awareness. People have told us that there seems to be a grey area between a natural forgetfulness of ageing and the recognition of the onset of dementia and younger people have told us that dementia is also confused with depression. We have raised awareness of the risks of dementia through activity during Dementia Action Week such as through local publications, and a BBC Radio Leicester feature. Furthermore, Dementia Friendly Community Networks encourage dementia friendly work cross organisationally. Health promotion activity was reduced during the Covid pandemic due to the need to use available resources for public health infection control measures.

We will continue to

- Screen for risk factors for dementia within Primary Care Health Checks and raise awareness of the risk factors for dementia

We will aim to

- Promote dementia prevention methods such as lifestyle behaviour changes. We will share a message of “What is good for the heart is good for the brain” (Age UK).
- Promote involvement in research development and the value of early diagnosis.

Diagnosing Well

Research suggests that timely diagnosis of dementia is important to enable the start of appropriate treatment and support. From recent engagement from Healthwatch people indicated they waited on average 1-2 years before seeking help some as long as five years. We also know that people from South Asian communities are underrepresented in the figures we hold about diagnosis.

Government aspirations are that there is 6-week average wait between referral from GP to initial assessment and starting treatment. There is also a national target of 67% people with dementia having a diagnosis. Memory Assessment and Diagnosis services were severely disrupted during the Covid Pandemic both locally and nationally and referrals from GPs also declined. Locally, we were doing well before the pandemic and had reached the diagnosis targets across areas with Leicester reaching 85%. Unfortunately, the impact of the pandemic led to these falling by 13% across all areas. Annual NHS dementia care plans are also lower than the expected national average.

Local NHS Diagnosis Rates are recorded by clinical commissioning group areas and are:

- West Leicestershire 57.9%
- Leicester City 72.5%
- East Leicestershire and Rutland 56.5%

The percentages represent the proportion of people living with dementia that have a formal diagnosis as of January 2023.

We will continue to

- Use pharmaceutical treatments and consider alternative therapies that have proven benefits to people with dementia.

We will aim to

- Reduce Dementia 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 Dementia Diagnosis experience for people from South Asian communities. Explore culturally appropriate Dementia Diagnosis tool.

Supporting Well

National and local guidance reinforces the importance of having person centred support in place for individuals living with dementia and their carers. This is the ethos and working practice in this area and we continue to promote, influence and commission support aimed at both health and social care as well as within the voluntary sector. We aim to ensure this support is of good quality and meets the needs of individuals accessing these services. People have told us there are some barriers experienced by people accessing support.

We know that dementia is a progressive condition so people are likely to have increasing health and social care needs over time and most people will need personal care support in the later stages of dementia. They may also have other health conditions or frailty associated with old age. There are national criteria and assessment processes in place for Adult Social care and Continuing Health Care so some people will be required to self-fund their care.

The Covid pandemic had a substantial effect on families living with dementia, visiting care settings was restricted, people with dementia were particularly vulnerable to infection and informal carers, where possible, were providing an increased level of care and support. People living with dementia were also affected by changes in routines and increased isolation. Priority actions remain in place to discharge people safely from hospital as soon as they are medically fit for discharge and the stresses on informal carers and professional organisations who are providing care remain. Not all people with dementia have complex needs but where this is the case there are additional challenges to meeting their care, particularly where there are changes in behaviours that challenge the person and those caring for them.

We will continue to

- Improve the in-patient experience for people with dementia
- Promote the LLR Carer Strategy actions in relation to supporting people with dementia and their informal carers

We will aim to

- Refresh work that avoids hospital and care home admissions
- Refresh work relating to hospital discharge pathways and post discharge support that sustains people returning home or into care settings
- Support, refresh 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 sector
- Refresh pathways and person-centered support for seldom heard groups e.g., Younger Onset Dementia, diverse ethnicities, people with a Learning Disability, prison populations.
- Promote and develop good risk reduction methods that keep people safe and promote independence- including Care Technologies and practice in relation to the Mental Health Act, Capacity Act and Liberty Protection Safeguard including Positive Behaviour Support and Positive Risk-taking practice

Living Well

Living well with dementia relates to staying active healthy and connected to families and your community. It is also about a strengths-based approach (which focuses on strengths and not deficits, SCIE) to dementia both for individuals and communities. There is some research that both leisure activities and activities specifically for the brain can delay the progress of dementia. During the Covid Pandemic, we saw a surge of community spirit and neighbourliness as well as people feeling more isolated and for some this seems to have hastened the progression of their dementia. We also note that using video calling became a regular feature of communications. Since the end of lockdown, we have seen a resurgence of social groups in local communities able to meet the needs of people with dementia, both within dementia only and generic leisure and social groups.

Through the Dementia Support Service in Leicester and Leicestershire provided by AgeUK people are supported to live well with dementia pre and post diagnosis. The service has a dedicated team of staff, volunteers and a co-production group including people affected by dementia, who have all

contributed to shaping and developing its various elements. This includes specific post diagnosis information and advice sessions, 1-2-1 carer learning sessions and or group support. Many social groups developed have been launched with the view of offering a wide variety of activities to support people to live well with their dementia, including walking, music, gardening and woodwork groups as well as cognitive stimulation therapy. In Rutland the dementia support service is jointly provided by Admiral Nurses and a Dementia Support Worker providing a range of similar support as well as additional clinical support from the Admiral Nurses. There are also a range of other groups and activities run by a range of voluntary and public sector organisations aimed at supporting people with dementia, many can be found in the Dementia Friendly Guide. Furthermore, the LLR Living Well with Dementia Grant recently has helped local voluntary organisations to fund 29 community based projects aimed to support people living with dementia and their carers. An event for people with Younger Onset Dementia was put together by LLR commissioners in 2022 to offer people an opportunity to learn about support available to them and share their experiences.

People have told us that there is some variation in the availability and access to living well activities across Leicester, Leicestershire and Rutland. We know that people find it hard to access information about living well with dementia even though there are many good sources of information available. We also know that planning ahead can aid people to live well but also plan for potential changes in their abilities as their dementia progresses and manage crisis. Discussing “planning ahead” can be a difficult conversation and this is an area that needs more development.

We will continue to

- Promote the development of information and advice about living well with dementia that is accurate, timely, accessible, and joined up across LLR.
- Promote and develop the LLR Dementia Friendly Community and access to the Dementia Support Services and other living well support.
- Use funding opportunities, when they are available, to develop living well activity especially in areas which are less well served.

We will aim to

- Develop routine engagement processes with people living with dementia and carers to inform our work, including people with lived experience being involved in strategy development
- Promote and develop practice that supports people living with dementia plan and live well including crisis contingency planning, advanced care planning, and promote the benefits of Lasting Powers of Attorney.

Dying Well

We know that having early conversations with those affected by dementia, about advanced decisions and care planning can help both the person, their family and care providers at end of life. There are good practise models that look at dying well and the guidelines about RESPECT. According to the national census an estimated 65% of people with dementia die in care homes and 23% in hospital so these are the two care settings we aim to support good dying well practice in.

We will aim to

- Promote and develop good practice in relation to people with dementia including strengthening the link with End-of-Life pathways and RESPECT Procedures.

Section 10: Useful links (tbc)

¹ <https://www.nhs.uk/conditions/dementia/>

¹ <https://lightbulbservice.org/>

¹ <https://loros.co.uk/>

¹ <https://www.england.nhs.uk/mentalhealth/wp-content/uploads/sites/29/2016/03/dementia-well-pathway.pdf>

¹

¹ LLR Carer Strategy <https://www.healthandcareleicestershire.co.uk/refreshed-joint-carers-strategy-highlights-commitment-to-supporting-carers/>

¹ <https://www.england.nhs.uk/publication/dementia-friendly-health-and-social-care-environments-hbn-08-02-2/>

¹ <https://www.nice.org.uk/guidance/ng97>

¹ <https://www.resus.org.uk/respect/respect-patients-and-carers>

¹ <https://www.ons.gov.uk/peoplepopulationandcommunity/>

Appendix 2: Full Dementia Strategy Consultation Result: City

Dementia Strategy Consultation

Basic overview

The consultation was live for 10 weeks from the 17th of July until the 22nd of September. There were 91 respondents in the City. Majority of respondents were carers of a person living with dementia (47). 42 of the respondents were not from a White British background.

Key Emerging Themes for the City

- There is a sense of lack of communication between systems and lack of sign posting to services.
- There is a lack of awareness of what help is available amongst carers.
- Awareness raising in BAME communities could be improved through making links with communities and working in partnership with community centres and places of worship.
- It is important to consider language needs and cultural context when attempting to raise dementia awareness and diagnosis importance with BAME groups.
- Community centres and opportunities for socialising and exercise are important
- Clear information and support from the diagnosis onwards needed, a pathway map would be helpful

Preventing Well

- Consider awareness raising in BAME communities through awareness raising campaigns and partnership with community centres and places of worship.
- Improve diagnosis rates to help people earlier
- Improve the availability of community support

Diagnosing Well

- Diagnosis challenges for seldom heard groups e.g. language challenges and lack of awareness.
- Family and carer involvement needed from the beginning.
- The development of a structured diagnosis process is required.
- More awareness around dementia
- Consider allowing virtual appointment options for those who would prefer this.
- To ensure better diagnosis for BAME groups it is important to: consider language needs, consider cultural context and work with community groups to raise awareness

Supporting Well

- More Admiral Nurses
- Better training and education for family members and professional carers
- Better support for carers and improve carer awareness for what support is available

Living Well

- Clear information around support
- Social group support

Dying Well

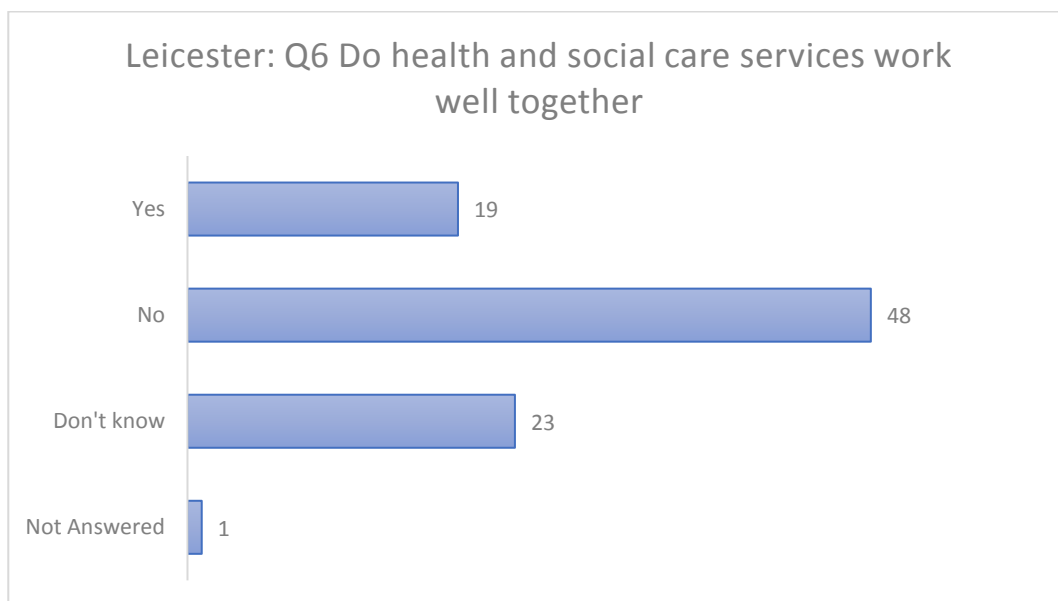
- Early planning and information
- Family involvement
- Difficult conversation, need a cultural change

Focus Group Key Points

- It is difficult to look after yourself when you are a carer. Difficult to think about your own needs and think about way of healthy living for yourself. Carer strain can affect lifestyle changes.
- Request for information/resources around Dementia to be available in different South Asian languages.
- Suggestions made to have regular Dementia awareness events within GP practices.
- Outreach Dementia support would benefit those who need home support.
- More opportunities for carers to talk about end-of-life care for their loved ones with Dementia.
- There were comments made on having more culturally sensitive support and awareness Dementia support interventions.
- Designated space for South Asian carers to talk about their experiences in caring for loved one with Dementia.
- To consider nutrition / physical health in Dementia care.
- Language support required at memory clinic and other Dementia support services.

City Consultation Response Analysis

Do you think that the health and social care services that support people living with dementia work well together?

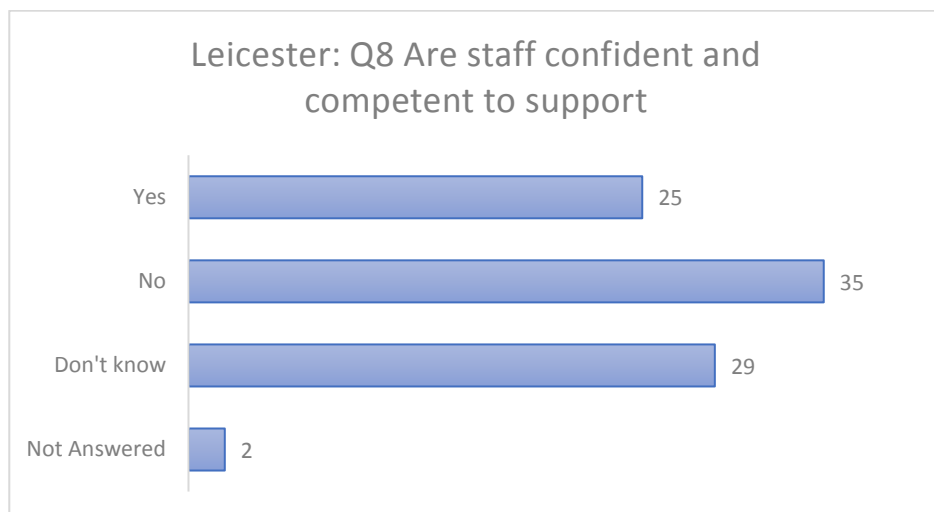


'No' response key themes:

- Lack of communication between systems and sign posting to services
 - o They don't communicate with the patient's doctor efficiently. Sending a letter addressed to the patient with dementia directly is not ideal and quite frankly lazy.
 - o No because health never sign posted my parents to support that was available to them. We had to find out everything ourselves.
 - o They never communicate. They fight over funding. And they do not work in an individual's best interests.
 - o There seems to be no communication between services and the family have to be the person passing on relevant information.
- Lack of awareness amongst carers

- Not all carers are aware of dementia, especially in Asian communities.
- Not enough is being done to support carers
- There is a lack of clear helpful information to support carers navigate the complex maze of available support, care and its funding

Do you think that staff are confident and competent to support people with dementia?



- There was a mixed response in regard to this question. Competency depended on area of care that is supported, and a lot of respondents noted that it can depend on the individual too. This could highlight the need for more consistent training.
 - Most are but some are not
 - Lack of information around early intervention approaches for people with dementia
 - More courses need to be offered. Staff need to be assessed regularly.

Preventing Well

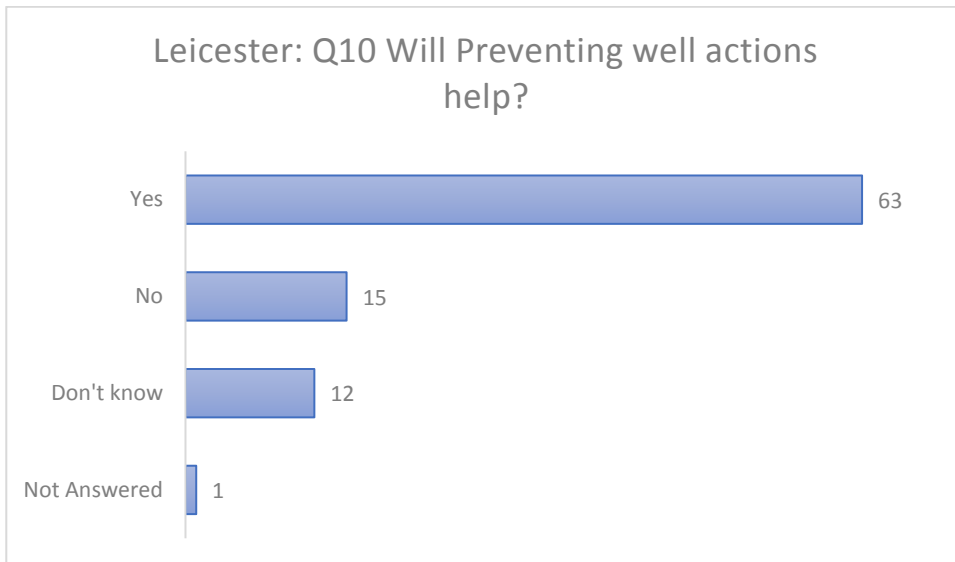
We will continue to

- Screen for risk factors for dementia within Primary Care Health Checks and raise awareness of the risk factors for dementia
- Raise awareness of dementia and its symptoms

We will aim to

- Promote dementia prevention methods such as lifestyle behaviour 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

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



- Concerns about carers being at greater risk of developing dementia noted
 - o I worry about the repercussions of isolation, capacity, mental ill health will have on family members that are caring for those with dementia. Sometimes, prioritising exercise and your own health is easier said than done. I wonder about the correlation this stressful and traumatic experiences will have on our own risks of later developing the disease.
 - o Our relative was a carer themselves which prevented them from living well. Stress, poor diet, social isolation due to caring responsibilities.
 - o They put their partners health/needs above their own.

Is there anything else we should consider to reduce or delay the onset of dementia?

- Awareness raising in BAME communities through awareness raising campaigns and partnership with community centres and places of worship.
 - o Raising awareness about dementia is very important for ethnic minority groups in Leicester.
 - o More visible campaign posters and leaflets. I think it's difficult to get a diagnosis or early screening if people don't know what to look out for especially in the Asian community. It is often just called "old age" and so isn't supported in the same way.
 - o Sikh Temples or Hindi temples or Churches or Mosques or any religious institutions - their leaders can educate the public on this subject.
- Improve diagnosis rates to help people earlier
 - o Better access to diagnosis from doctors or other professionals.
 - o Better health checks by GPs
 - o Introduce routine screening for dementia earlier, as more and more people are diagnosed later, and medication only slows down the process. Earlier detection would lead to more preventive measures and slow down or improve the quality of life longer.
- Community support
 - o The way people can access exercise that is affordable, costs for swimming etc are quite high for the public in my view. Encouraging exercise for the mind is also something important.
 - o Target publication suitable for over 65s not just social media, use local radio stations, doctor surgeries, promote easy/friendly sessions at libraries, places of worship

- Social interaction and learning new skills are thought to delay onset of dementia. More community groups and day centre places could help.

Diagnosing Well

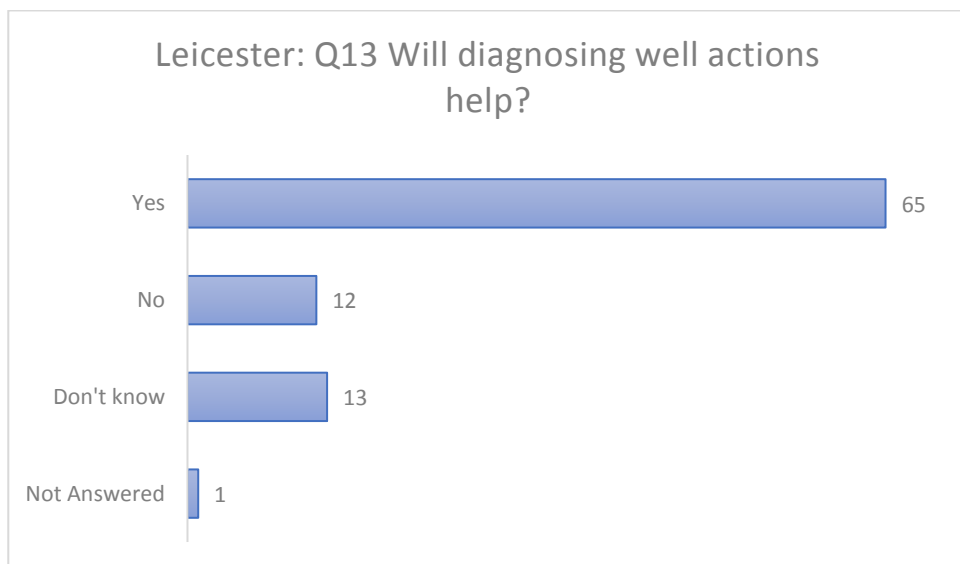
We will continue to

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

We will 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 diagnosis dementia support service.
- Improve the diagnosis experience for people from underrepresented communities.
- Explore culturally appropriate dementia diagnosis tools.

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



'No' response themes:

- Lack of awareness/ understanding of dementia
 - People wait to be diagnosed due to not understanding what will happen, fear, assume just part of getting older, not knowing the symptoms. There were signs at least a year or more before diagnosis but Covid and not knowing.
 - Have more cultural education such as in mosques or temples etc for communities in which there is higher stigma.
- Current diagnosis and referral process is poor.
 - You need to look at how the referral process is. It's awful!!
 - I feel the points above or too broad and general. I cannot see how they will be achieved. The diagnosis and care we received was appalling, we were told over the phone in a passing comment by the GP that my mother-in-law had Alzheimer's disease.

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

- Diagnosis challenges for seldom heard groups
 - o Some of the communities don't recognise the first signs of dementia, therefore, there is a risk of delaying getting support on time and to be diagnosed on time.
 - o Improve the diagnosis experience for all sections of the community
 - o A variety of assessment methods to consider, there is no 'one test fits all'. Especially if someone is illiterate and English is not their first language.
- Family and carer involvement from the beginning
 - o Involve other family members early on so that they can support and action plans going forward.
- Better develop a structured diagnosis process
 - o Provide written feedback from appointments so that is clear what has been discussed.
 - o At the point of diagnosis, provide a visual pathway of support document that has a list of contacts.
 - o Provide a personalised timeline of events so that we have a plan to loosely work towards.
 - o Improve referral system from secondary care - consider a secondary care referral pathway direct into memory clinic. Consider delirium follow up assessments - many of those with delirium progress to develop dementia.
- More awareness around dementia
 - o More education! To encourage people to go to GP with concerns about memory difficulties. There is still a stigma. People need to be aware of what treatment options are available. After diagnosis more follow up support. People feel like they have been abandoned after being given a diagnosis with little or no support offered.
- Virtual appointment options
 - o Consider more virtual first appointments - well received by family members especially for older and frailer groups of patients.

Is there anything else we could do to improve diagnosis and raise dementia awareness in Black, Asian and minority ethnic communities?

- Awareness raising
 - o These communities need more awareness raising in order to improve diagnosis. Many of them will seek support when it is too late.
 - o Establish better links with these communities. Provide funding to voluntary sector organisations working with those communities to support this strategy. Increase the number of staff from those communities who work in dementia services.
 - o Through advocates in the local communities raising awareness. Educating especially Asian and minority communities about living with dementia and myths about memory loss is not normally associated with old age.
- Ensuring that interventions cater to language needs
 - o Leaflets in different languages
 - o Account for language that is a barrier to understanding uncommon phrases like monarchy - marsupial etc. have an email address (this might be a radical step for you to take in) but it could make it easier for a family member to support someone with English as a second language though this process and EMAIL THE LINK or offer in person appointment - I've asked and begged for in person but this is viewed asking for something totally unacceptable and impossible to arrange
 - o Provide Information in a number of languages, target GP surgeries and local groups to highlight symptoms and support.
- Understand cultural needs
 - o Design diagnostic tools with them. Diagnostic clinics in communities with interpreters present

- Understanding of how different ethnic groups might "interpret" dementia ie it might not be in the same way that white British people might. Understand the differences in how cultures/religions/ethnicities perceive what "helps"-there are different ideas about what "support/care" is, we might feel it is around staying active, some cultures might feel its around resting.
- Groups within the community led by charity and health professionals together would be of benefit.
- Case studies where minority families talk about their experience of supporting a family member with dementia.

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?

- Community work to increase volunteer numbers and awareness
 - Targeted campaigns? Training for GPs, prison doctors etc?
 - Big yes through supporting non-profit organizations, churches and other religious organizations to create a cadre of volunteers who are well-educated on dementia issues and try to reach out to the deprived communities. In this way, you also saved and supported the young generation by having a mission in their lives to support and serve other with sincere love.
- Incorporate training around learning disabilities for teachers in schools and any institute that provide education to younger people.
- Ensure in person appointments are offered
 - OFFER IN PERSON APPOINTMENTS - ESPECIALLY FOR PEOPLE WITH SIGHT AND HEAIRNG LOSS - I cant emphasise enough how distressing it was for her to be unable to participated in this process - its scarred her and I am really worried about what conclusions will be made from her inability to see a rhino horn on a picture or hear the word monarchy

Supporting Well

We will continue to

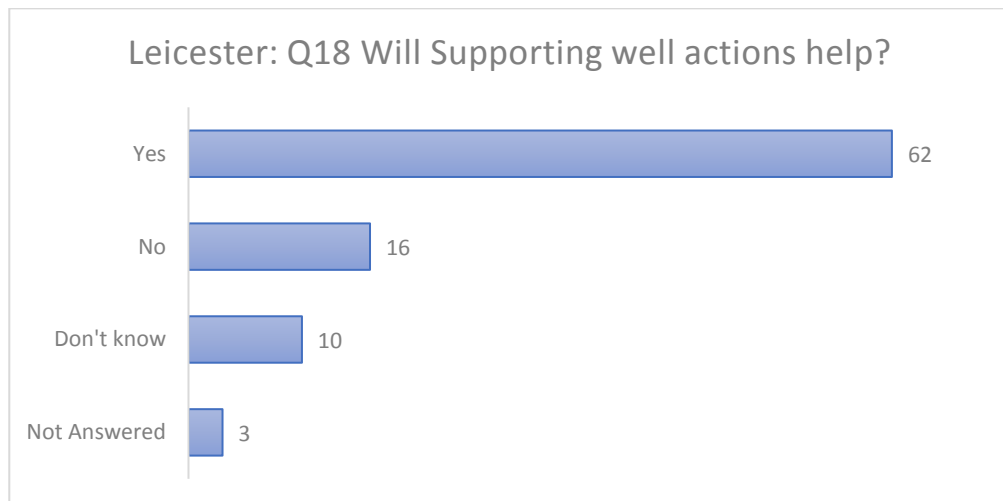
- Improve the hospital experience for people with dementia
- Apply the Leicester, Leicestershire and Rutland Carer Strategy actions to support people with dementia and their carers
- Raise awareness of support available for people with dementia and their carers

We will 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-centered 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.

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



'No' response results:

- A sense of being neglected after diagnosis was noted by some
 - o I do feel that people that have been diagnosed with Dementia are kind of written off by most Health professionals.
 - o You shouldn't lose sight of the person and only see the dementia. Many people with dementia want to feel useful and engaged in activity. Social dementia cafe's and places to go would be helpful.

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

- More admiral nurses
 - o More Admiral nurse across LLR will benefit in all aspects . It will also greatly support if more joined up working across the services so information can be passed onto to support families during there journey.
- Better education and training for professional and family carers
 - o I think nutrition and keeping people moving in hospital are vital. And that means training staff. They need to understand that a patient with dementia may say they don't want to eat when they do. The same with walking/moving. They need time and support to eat - not for food to be cleared away quickly. I think some staff 'get it', but there needs to be more education around these issues. From personal experience, I think they are vital. I do think it's good that family members are allowed to go and help people with dementia to eat etc, but not everyone has someone to support them in that way.
 - o Have more support to give respite to carers who look after family members with dementia in their homes.
- Better support for carers and an improved awareness of what support is available
 - o Better dementia training for health Care assistants in the community
 - o Make funding available to provide support that is clearly and easily accessible. More public awareness of what support is available before crisis point. General leaflets that has contact details, information on services to be widely distributed.
 - o When my father was admitted to hospital for a medical, non-dementia related condition, I was allowed to remain with him throughout the day from morning till bedtime. This was reassuring

for my father, 1 less patient for the nurses to fully cover. This made an enormous difference to my dad's experience because dementia makes him very confused and worried. I don't know if this is a formal policy, but I was grateful to have that allowance. If it is a formal policy to encourage 'carers' to support their family, then I would like to see it up in notice boards and on leaflets. It may be useful to use social media platforms to inform people too.

- More day centre places and community groups, and highly visible publicity about them.
- The carers support is useless the carers passport is absolutely nonsense and counts for nothing. I contacted the council and asked its purpose and no one was able to tell me how on earth it would be helpful. Carers need proper support. Caring for someone with dementia can impact psychologically, financially and effect your ability to keep a job. Knowing all the services to liaise with and what support you can get is time consuming. And most of it is hidden like continence assessments.

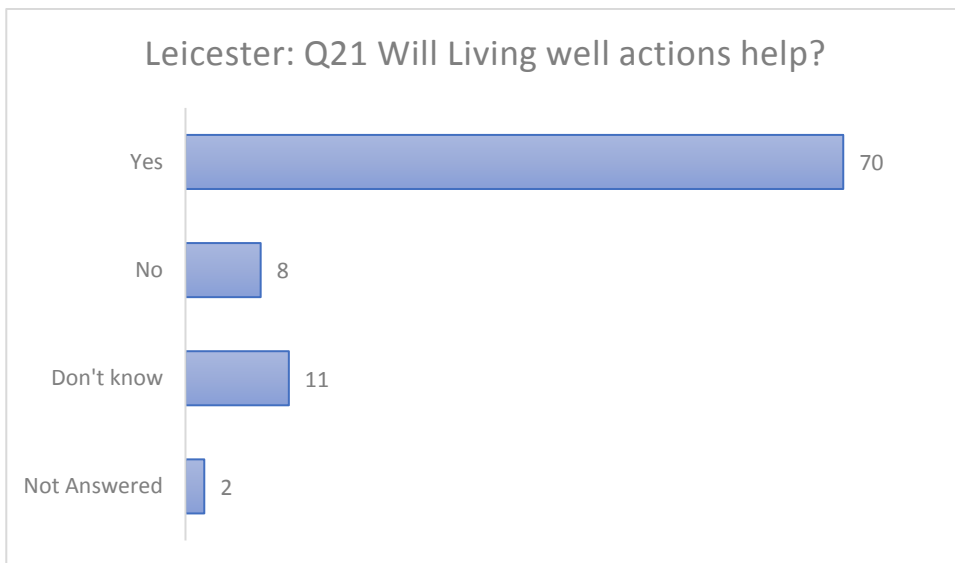
Living Well

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

We will 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



If no, please give reason why:

Few respondents commented and therefore themes around the 'no' responses cannot be extracted. A few people noted concerns about how this would actually be delivered without a funding commitment.

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

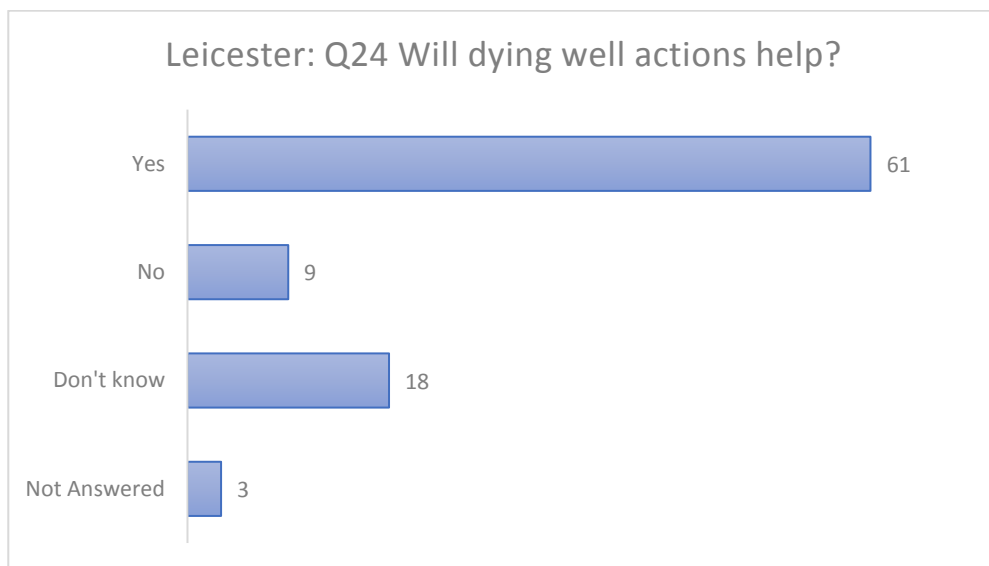
- Clear information around support
 - o Clarify exactly where one can go for help to get a diagnosis and ensure it is well advertised in the local newspaper, doctor's surgeries etc.
 - o Give as much information and advice up front... accessible to everyone in a variety of formats. Not purely digital as not everyone can access online services. In person help and printed literature should be readily available
- Social group support
 - o More day centre places.
 - o in addition you need to have meet up/ social / activity groups for the early on this journey
 - o Help with making sure there are specialist well trained people to work with people experiencing dementia, to live an "ordinary" life, do the things they would like to do as much as possible. Ensuring that these workers fulfil what they say they will and work in a strength based way.
 - o Provide environments and staff that are culturally in line with the ethnic group they are dealing with. This would reduce anxiety and increase individual understanding and awareness.

Dying Well

We will 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)

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



If 'no', please give reason why:

- There is currently a lack of discussion of end-of-life plans
 - o This has not been discussed with us as a family and certainly not directly with my mother-in-law- sadly, again I feel that these services perhaps become involved too late.

- Because my mum has had diagnosis for 4 plus years - at no point has a clinician asked about ResPECT , DNaCPR , advanced care plan= only because myself and my sisters are shouting and asking for support
- There is a lot of talk about end-of-life care and the respect process. However it is unclear where this information is to be stored on Systm1 to allow us to access this and put actions into place. I think this should be part of the core assessment and completed within this.

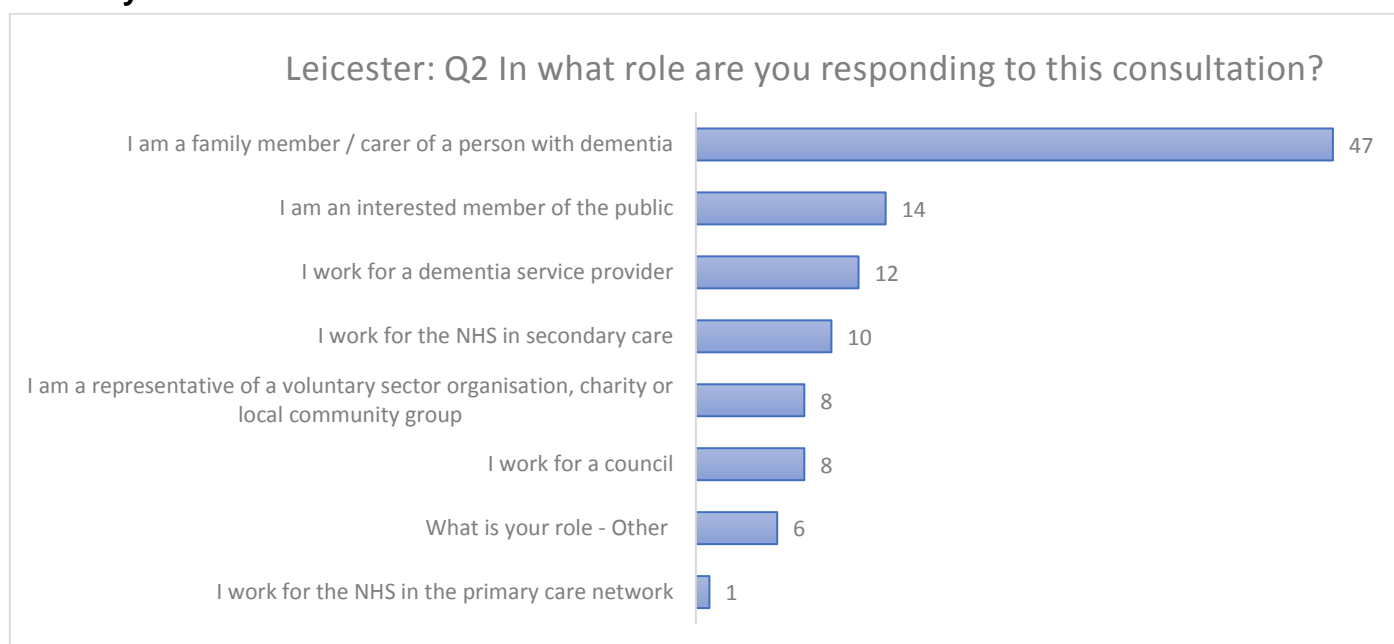
Is there anything else we could do to support people with dementia to make an informed choice around their end-of-life plan?

- Early planning and information
 - Provide opportunities for older people to express their wishes in relation to end of life while they are still mentally competent.
 - normalise advanced care planning at the earliest opportunity in adults. this may be through GPs
 - Encourage early discussion of advance care plans - feeding, medical treatment, preferred place of care etc.
- Family involvement
 - Involve their families. And understand that the person may not have capacity to make informed decisions, depending on when these choices are made.
 - If they have dementia, they will not be able to understand their end of life is happening so a plan may not be right for them. These conversations should take place with close kin.
 - This choice needs to be made with the family present if the person with dementia is at a stage where they don't fully understand.
- Difficult conversation, need a cultural change.
 - This is very difficult and needs cultural change to make it easier for people to talk about death and fear of death.
 -

Respondent background

In what role are you responding to this consultation?

What is your role

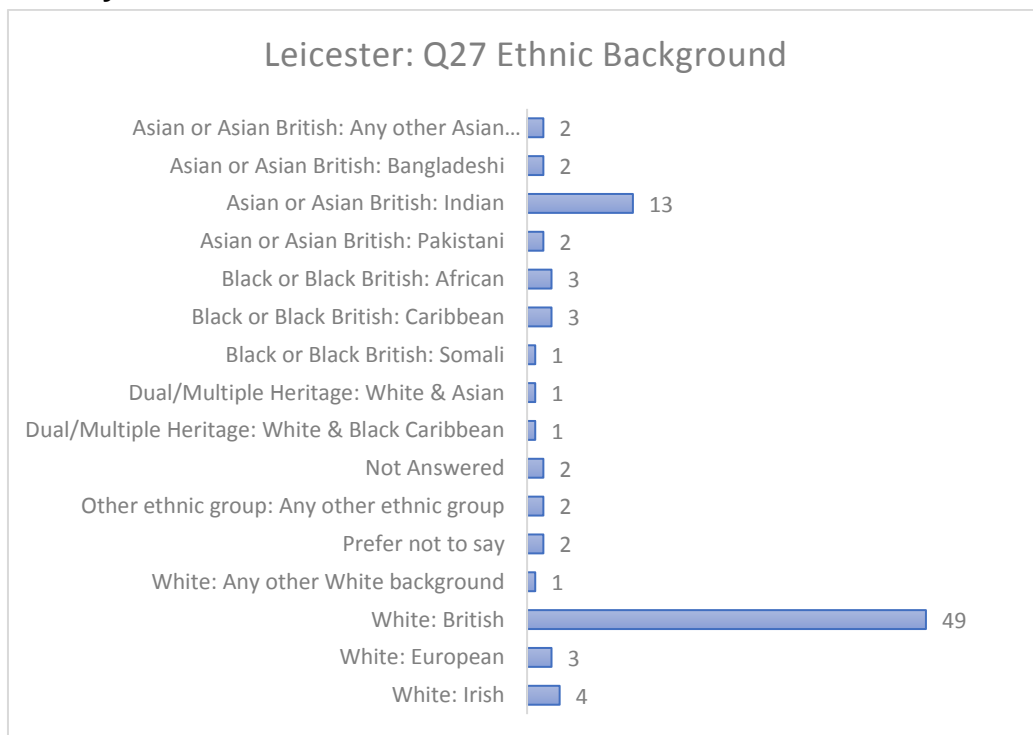


Option	Total	Percent
I am a family member / carer of a person with dementia	47	51.65%
I am an interested member of the public	14	15.38%
I work for a council	8	8.79%
I work for a dementia service provider	12	13.19%
I am a representative of a voluntary sector organisation, charity, or local community group	8	8.79%
I work for the NHS in secondary care	10	10.99%
I work for the NHS in the primary care network	1	1.10%
Other (please specify)	6	6.59%

Demographic details of respondents

Question 27: Ethnic background:

Ethnicity



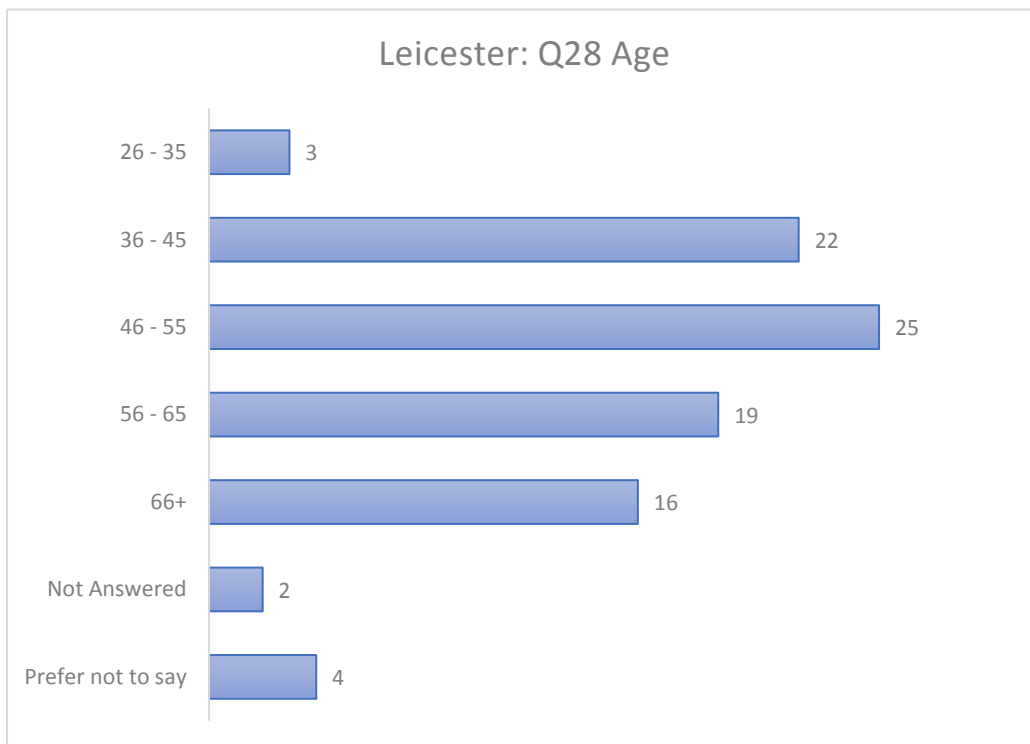
Option: Ethnic Background	Total	Percent
Asian or Asian British: Any other Asian background	2	2.20%
Asian or Asian British: Bangladeshi	2	2.20%

Asian or Asian British: Indian	13	14.29%
Asian or Asian British: Pakistani	2	2.20%
Black or Black British: African	3	3.30%
Black or Black British: Caribbean	3	3.30%
Black or Black British: Somali	1	1.10%
Dual/Multiple Heritage: White & Asian	1	1.10%
Dual/Multiple Heritage: White & Black Caribbean	1	1.10%
Not Answered	2	2.20%
Other ethnic group: Any other ethnic group	2	2.20%
Prefer not to say	2	2.20%
White: Any other White background	1	1.10%
White: British	49	53.85%
White: European	3	3.30%
White: Irish	4	4.40%

2 responses have picked “Any other ethnic group”, which are stated as below:

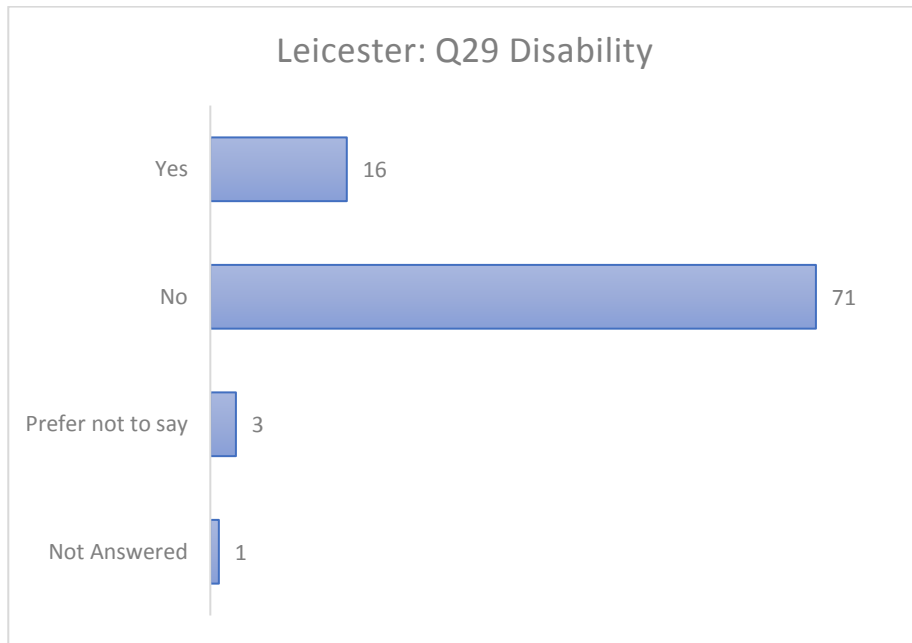
3. Mixed from three generations.
4. Arab

Question 28: Age:



Option: Age	Total	Percent
26 - 35	3	3.30%
36 - 45	22	24.18%
46 - 55	25	27.47%
56 - 65	19	20.88%
66+	16	17.58%
Not Answered	2	2.20%
Prefer not to say	4	4.40%

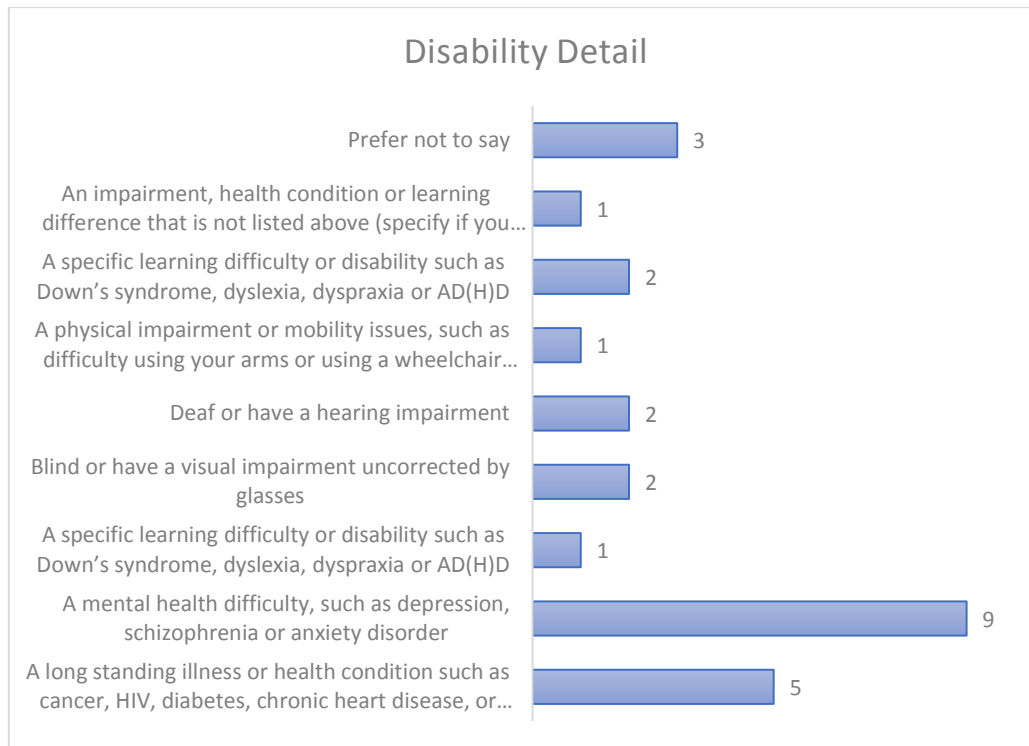
Question 29: Disability



Option: Disability	Total	Percent
Yes	16	17.58%
No	70	76.92%
Prefer not to say	3	3.30%
Not Answered	1	1.10%

Disability detail

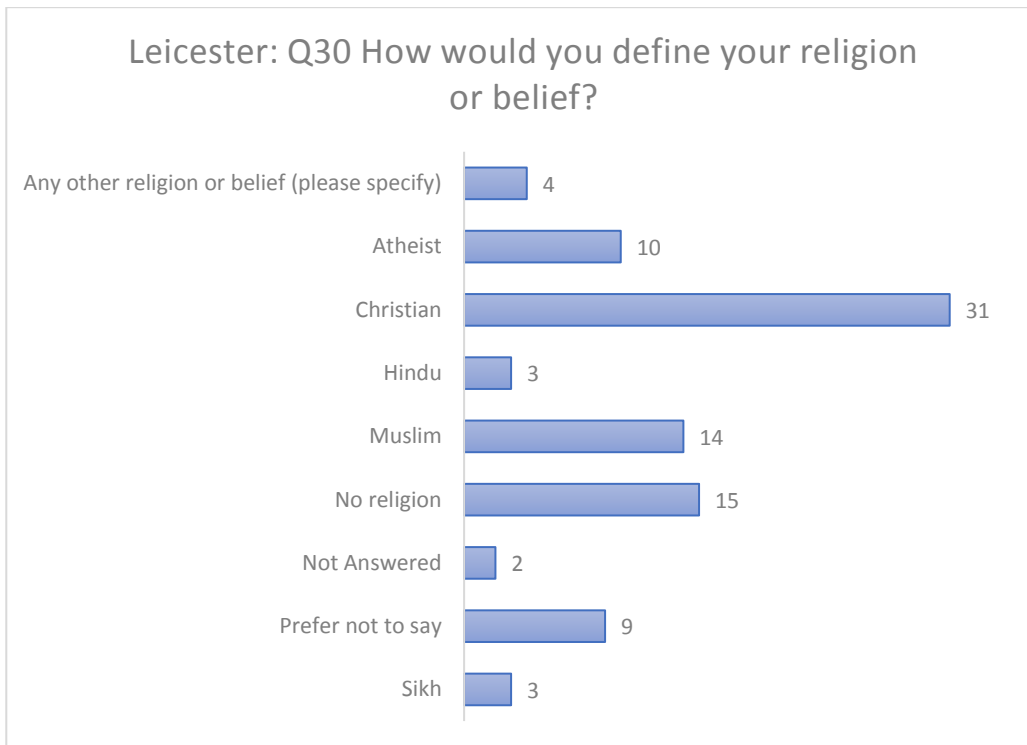
There were 26 responses to this question:



Option: Disability Detail	Total	Percent
A long-standing illness or health condition such as cancer, HIV, diabetes, chronic heart disease, or epilepsy	5	19.23%
A mental health difficulty, such as depression, schizophrenia or anxiety disorder	9	34.62%
A specific learning difficulty or disability such as Down's syndrome, dyslexia, dyspraxia or AD(H)D	1	3.85%
Blind or have a visual impairment uncorrected by glasses	2	7.69%
Deaf or have a hearing impairment	2	7.69%
A physical impairment or mobility issues, such as difficulty using your arms or using a wheelchair or crutches	1	3.85%
A specific learning difficulty or disability such as Down's syndrome, dyslexia, dyspraxia or AD(H)D	2	7.69%
An impairment, health condition or learning difference that is not listed above (specify if you wish)	1	3.85%
Prefer not to say	3	11.54%

Question 30: How would you define your religion or belief?

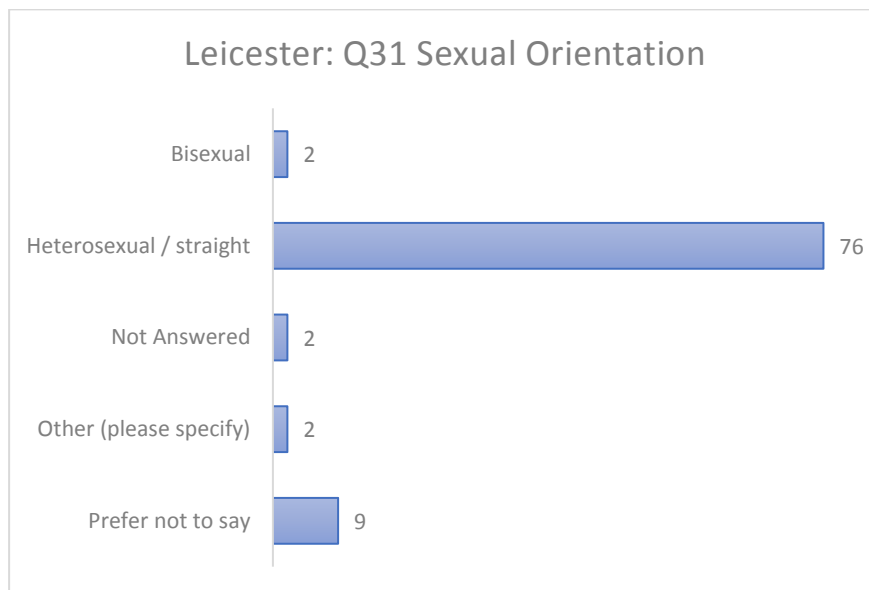
Religion



Option: Religion	Total	Percent
Sikh	3	3.30%
Prefer not to say	9	9.89%
Not Answered	2	2.20%
No religion	15	16.48%
Muslim	14	15.38%
Hindu	3	3.30%
Christian	31	34.07%
Atheist	10	10.99%
Any other religion or belief (please specify)	4	4.40%

Question 31: Sexual orientation. Do you consider yourself to be ...

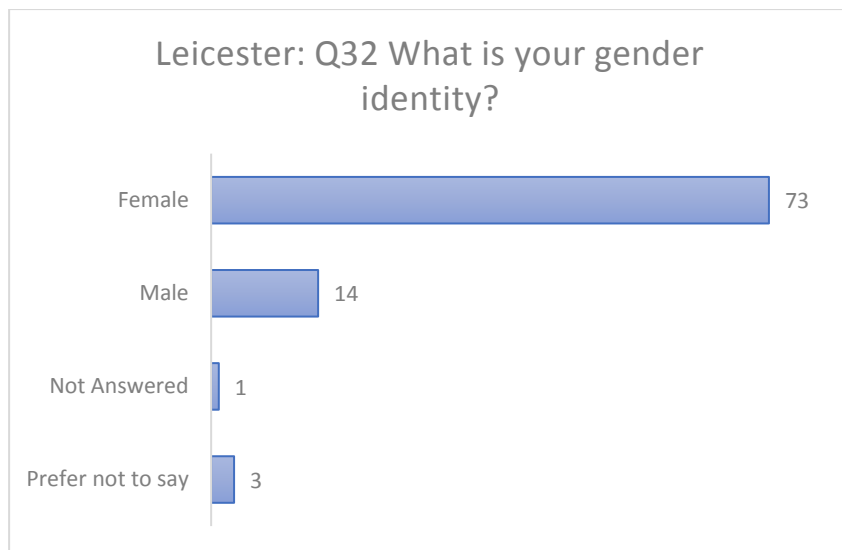
Sexuality



Option: Sexual Orientation	Total	Percent
Bisexual	2	2.20%
Heterosexual / straight	76	83.52%
Not Answered	2	2.20%
Other (please specify)	2	2.20%
Prefer not to say	9	9.89%

Question 32: What is your gender identity?

Gender



Option: Gender identity	Total	Percent
Female	73	80.22%
Male	14	15.38%
Not Answered	1	1.10%
Prefer not to say	3	3.30%

0

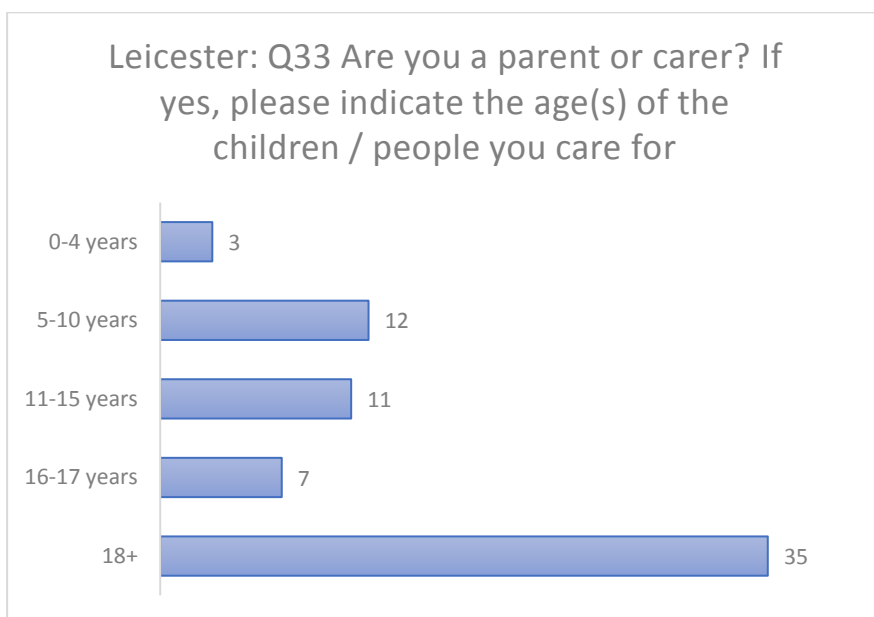
gender ID same as birth



Question 33: Are you a parent or carer? If yes, please indicate the age(s) of the children / people you care for

68 responses received for this question.

carer / parent ages



Option: Age of children/people caring for	Total	Percent
0-4 years	3	4.41%
5-10 years	12	17.65%
11-15 years	11	16.18%
16-17 years	7	10.29%
18+	35	51.47%