APPENDIX B

Summary Report of Leicestershire Responses to Public Consultation and Engagement:

Leicester, Leicestershire and Rutland's Living Well with Dementia Strategy 2019-2022

1. Purpose of the report

This document provides a summary of the findings from Leicestershire respondents of the public consultation undertaken between 19 April - 22 June 2018 on the draft **Leicester, Leicestershire and Rutland's Living Well with Dementia Strategy 2019-2022.**

The overall LLR Consultation report will be presented to the Dementia Programme Board on the 25th September. The information gathered during this consultation will be used to inform the way forward.

The total responses relating to Leicestershire was 155, 96 Leicestershire only and 59 who responded in regard to Leicestershire and Leicester and/or Rutland.

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

Blaby	70
Charnwood	62
Harborough	52
Hinckley and Bosworth	53
Melton	37
North West Leicestershire	50
Oadby and Wigston	50

In what capacity are you responding? (More than one category could apply)

I have a diagnosis of dementia	5%
I am a family member / carer of a person with dementia	43%
I am an interested member of the public	23%
I work for a council	25%
I work for a dementia service provider	10%
I am a representative of a voluntary sector organisation or charity	10%
I work as a GP / pharmacist or other healthcare professional	10%
I am a stakeholder (like an elected member, representative of statutory body)	1%
Other (please specify)	17%

2. Key Themes Emerging for Leicestershire

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

- The draft strategy was welcomed by the majority of respondents.
- There is a clear call for the delivery plans to be more specific about how actions will be delivered.
- A consistent concern about how the actions can be achieved without additional funding.
- A concern that the current financial situation is impacting on the quality and availability of care particularly to support people remain at home longer, care whilst in hospital and care services in the advanced stages of dementia.
- More awareness raising in local communities about the risks of developing dementia but more significantly more awareness and information about how to spot the early signs of dementia.
- More awareness raising in schools
- More support for families when the person appears to be in the early stages but for various reason will not visit their GP.
- More consistent post diagnosis support, key workers and specialist nurses like Admiral Nurses.
- More and improved dementia care training for staff caring for people affected by dementia - at all levels, to the skills level need for their role, including care training for family carers.
- Awareness training for allied staff who come into contact with people affected by dementia.
- More awareness raising about the fact younger people can have dementia and more age appropriate services and support.
- More information, awareness raising and specific diagnostic tools for people from BME communities.
- Improved information advice and support for people and families who are self-funding their care.
- Do more to support people make advance decisions.

3. Overview of Responses and Themes Relating to Each Question

Key Actions Preventing Well - We Plan to

- Help GP practices to be more aware of and give support to people with dementia by
- Use a standard professional guide
- Promote health checks in primary care
- Increase involvement of Public Health in the Board’s work.

Q1. Do you think these actions will raise awareness of risk factors associated with developing dementia?

Yes	77%
No	12%

Don't Know	12%

Q2. If no, give reasons why

This answer includes common comments including from people who answered yes

- GP’s should already be doing this but are under pressure.
- More Public Health awareness is needed so that people look after themselves
- Not everyone goes to the GP
- How do we encourage those who are reluctant to go to see their GP or are in denial and support their families with this?
- You need to distinguish between the risk factors like unhealthy lifestyles and early warning signs of dementia.
- Raising awareness needs to go right across all communities and organisations.
- More information about dementia and its causes needs to be available to the public. Particularly families with ageing partners and relations.

Q3. Is there anything else we could do to raise awareness of risk factors associated with developing dementia?

- More information and public campaigns coordinated between Public Health, district and borough councils and the voluntary sector
- Early health checks at GP’s
- Raise awareness of the professionals so it is picked up by any health contact, e.g. clinics like for heart and diabetes.
- Educate in schools
- More staff have dementia awareness training
- Use a full range of ways to get messages across, like posters, leaflets and social media, community centres, GP surgeries
- Tailor information and awareness raising to BME communities
- Provide information to families who have relatives with dementia. Are they at more risk of developing dementia?
- Reductions in social care services is considered by some as creating problems
- Some respondents suggested specialist nurses, like Admiral nurses would be helpful

Key Actions- Diagnosing Well - We Plan to:

- Promote information on what people should do if they are worried about their memory or have a diagnosis of dementia
- Speed up process of diagnosis
- Review memory assessment and referral processes
- Introduce diagnosis toolkit to care homes
- Promote post diagnostic information and support for people who have a diagnosis of dementia.

Q4. Do you think these actions will ensure that people receive a timely diagnosis?

Yes	72%
No	14%
Don't Know	14%
Not Answered	1%

Q5. If no, please give reasons why:

This answer includes common comments including from people who answered yes

- Resource pressures for NHS will have an impact on timely diagnosis
- Diagnosis in care homes are unnecessary and resource intensive if not likely to result in better care.
- People are fearful of going the GP so more education and awareness needed and more support for families to encourage them to get help.
- Post diagnostic support and services is just as important as a diagnosis important
- Raise awareness via Dementia Friends
- GP’s need more support/training to assess and review people.

Q6. Is there anything else we could do to diagnose dementia well?

- Listen and support families when person is unaware or in denial and will not go to GP’s or seek help
- All staff at GP surgery do a Dementia Friends session
- GP’s and practice nurses have specialist training in dementia
- Have someone available to speak to straight after diagnosis
- Speed up the time taken to diagnose, like access to scanning and memory clinic.
- Increase funding to dementia services
- Specific diagnosis tools i.e. culturally appropriate and for young onset dementia
- More public awareness of the early signs particularly for families
- Provider post diagnosis support
- Recognise that younger people get dementia too

Q7. 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?

- A better culturally appropriate diagnosis tool
- Raise awareness of health risks like diabetes and hypertension for vascular dementia
- Awareness raising in BME communities and with families by connecting with local community leaders, community centres, places of worship and religious events.
- Information to be clear and concise and relevant to all.

Key Actions- Supporting Well - We plan to:

- Monitor the dementia support services we buy to ensure they provide high quality
- Support, provide equal access for all and give good value
- Raise awareness of dementia with housing providers
- Develop high levels of expertise among staff delivering personal care
- Improve the experience of inpatient care and the hospital discharge process by ensuring staff involved are dementia aware.

Q8. Do you think these actions will give people with dementia (and their carers) access to safe, high quality health and social care?

Yes	69%
No	10%
Don't Know	19%
Not Answered	1%

Q9- If no, please give reasons why:

This answer includes common comments including from people who answered yes

- Resources and funding is an issue
- Training is not effective if staff do not have time to spend with the person
- People who self-fund need more support to access services
- Training needs to be provided to all care staff at a good standard and level

Q10- Is there anything else we could do to support people with dementia?

- Provide Admiral Nurses across Leicestershire
- Fund more care provision for people with dementia,
- Make financial assessments and access to funding easier.
- Better quality training that is refreshed and monitored
- More than the minimal 2 days training for care staff, more than Dementia Friends session
- More specific care homes for younger people
- Specific support for people from BME communities
- More support to family carers, information advice as well as services and training in care tasks.
- Support people who self-fund
- Better care on general hospital wards
- Listen more to people affected by dementia

Key Actions- Living well - We plan to:

- Make sure we talk with people with dementia and their carers to make our services relevant to their needs
- Support the Dementia Action Alliance to develop more dementia friendly communities

- Review the dementia information available to ensure it covers a range of topics
- Including accommodation options
- Promote dementia support services
- Agree a common set of care and support standards across Leicester, Leicestershire and Rutland
- Support work to improve residential services for people with complex dementia
- Develop training and support for care homes and other providers to manage crises.

Q11. Do you think these actions will enable people living with dementia to live well and safely within their communities?

Yes	76%
No	6%
Don't Know	17%
Not Answered	1%

Q12. If no, please give reasons why:

- Statements do not give clarity on what actions are going to be taken
- Need to support people to live at home not just look at care homes
- Without additional funding will this be possible?
- Needs to tailor to individual needs as well as have common standards

Q13. Is there anything else we could do to support people with dementia to live well?

- More advice and support for younger people with dementia
- Make sure care homes can support people with behaviours that challenge and scrutinise those who are registered to provide dementia care who don’t manage.
- Support self-funders and provide better information and advice
- Provide more support for family carers at home
- Listen to people with dementia and ensure they are represented on the Dementia Programme Board.
- Have crisis plans with individuals in place e.g. if carer needs to go into hospital at short notice
- Provide more information about what Dementia Action Alliances are and do

Key Actions - Dying Well - We Plan to:

- Strengthen links with other working groups (such as palliative care teams), particularly around care for people with dementia who are approaching the end of their lives.

Q14. Do you think this action will ensure people with dementia can die with dignity in the place of their choosing?

Yes	65%
No	12%
Don't Know	23%

Q15. If no, please give reasons why:

This answer includes common comments including from people who answered yes

- Not on its own
- There needs to more emphasis on supporting people make advanced decisions whilst people have capacity
- People and families are not given a choice in reality to die at home and are moved to hospital or a care home
- Collaboration between experts in palliative care and experts in dementia care is needed
- More training for staff

Q16. Is there anything else we could do to ensure people living with dementia can die with dignity?

- Mores conversations early on about Advanced Decisions and care planning
- Value and support care staff and care homes and provide more training.
- Provide more discreet beds/side rooms for people who are dying
- Know when to stop providing invasive treatments
- Listen to families for end of life decisions and provide more information about what they might expect to happen as someone's dementia advances

Additional Information

The Consultation was hosted by the City Council with links provided on the LCC and CCG websites to the online survey, The City Council also ensured that an easy read version was made available as were printed copies on request. Partners were encourages to support people they work who were affected by dementia fill in the survey. In addition ASC sent an "all user" email internally and sent out over 600 emails to care providers, local networks, housing and voluntary sector providers seeking their assistance with publishing the survey. Local publicity was used during Dementia Action Week in May and via CCG and Council twitter feeds. The Health and Wellbeing Board was briefed on the 24th May and requested at a later point to have more information about what was happening in localities.

Additional consultation meetings were provided on request for people affected by dementia. Three meetings were attended by County Council Officers at which people were encourages to fill in individual surveys. A group of people with early on set dementia and their families invited both City and County Council Officer's to attend their meeting in May and gave detailed feedback relating to their needs and experiences. This largely echoes the findings of the survey and included, the need for information to keep active, healthy and live well, diagnosis being speeded up, the need for good financial advice at an early stage, advice for self funders, more flexibility with carer's and service user direct payments including being able to buy overnight respite at home and that people wanted to live at home and be supported there.

Appendix 1 - Equality Monitoring Information

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

Ethnic Background

Asian or Asian British: Any other Asian background	0.6%
Asian or Asian British: Indian	3%
Black or Black British: African	0.6%
Chinese	0.6%
Dual/Multiple Heritage: Any other heritage background	0.6%
Dual/Multiple Heritage: White & Black Caribbean	0.6%
White: Any other White background	0.6%
White: British	86%
White: European	1%
White: Irish	1%
Prefer not to say	3%
Not Answered	1%

Age

18 - 25	1%
26 - 35	5%
36 - 45	14%
46 - 55	32%
56 - 65	30%
66+	14%
Prefer not to say	4%
Not Answered	0.6%

Disability

Yes	14%
No	81%
Prefer not to say	5%
Not Answered	0.6%

Religion

Atheist	5%
Buddhist	1%
Christian	55%
Hindu	0.6%
Muslim	1%
Sikh	1%
No religion	24%
Any other religion or belief (please specify)	2%
Prefer not to say	9%
Not Answered	1%

Sexual Orientation

Bisexual	1%
Gay / lesbian	3%
Heterosexual / straight	83%
Other (please specify)	2%
Prefer not to say	8%
Not Answered	3%

Gender

Male	15%
Female	77%
Other (e.g. pangender, non-binary etc)	0.6%
Prefer not to say	5%
Not Answered	1%