



HEALTH OVERVIEW AND SCRUTINY COMMITTEE

1 NOVEMBER 2023

OUTCOME OF CONSULTATION ON THE LEICESTER, LEICESTERSHIRE AND RUTLAND JOINT LIVING WELL WITH DEMENTIA STRATEGY 2024-28

JOINT REPORT OF THE DIRECTORS OF ADULTS AND COMMUNITIES AND PUBLIC HEALTH

Purpose of the report

1. The purpose of this report is to present the outcome of the consultation on the draft Leicester, Leicestershire and Rutland (LLR) Joint Living Well with Dementia Strategy 2024-28 following a formal consultation exercise. The draft Strategy is attached as Appendix A.
2. The Committee is invited to make comments prior to presenting the outcome of the consultation and seeking approval of the final LLR Joint Living Well with Dementia Strategy and delivery plan for Leicestershire to the Cabinet on 24 November 2023.

Policy Framework and Previous Decisions

3. The relevant policy framework includes:
 - a) National legislation and guidance:
 - The Care Act 2014;
 - The White Paper - People at the Heart of Care: adult social care reform - December 2021;
 - The Mental Capacity Act 2005;
 - The NHS Long Term Plan 2019;
 - The Challenge on Dementia 2020.
 - b) County Council policies/strategies:
 - Leicestershire County Council Strategic Plan 2022-2026: the Dementia Strategy has relevance to all five outcomes of the Strategic Plan, but contributes particularly to the 'Keeping People Safe' outcome.
 - Adults and Communities Department Ambitions and Strategy for 2020–2024: the Dementia Strategy demonstrates how the Council will promote wellbeing for people with dementia, and prevent, reduce, delay and meet need for formal adult social care.
 - Leicestershire Joint Health and Wellbeing Strategy 2022-2032, which states that the partners will provide joined up services that support people and carers to live independently for as long as possible, including those with dementia.

- Medium Term Financial Strategy (MTFS), which sets the financial context for delivery of the Dementia Strategy in Leicestershire.
4. The Adults and Communities Overview and Scrutiny Committee considered a report on the draft Strategy and proposed consultation at its meeting on 5 June 2023. Comments were received from members, including recommendations that accommodation for people living with dementia should be featured in the Strategy. This has now been added into the draft Strategy. Other comments received suggested that more focus should be given to dementia diagnosis rates and the disparity between City and County. It was confirmed that this issue would be picked up through the place-based strategy delivery plans.
 5. On 23 June 2023 the Cabinet approved a formal 10 week consultation exercise.

Background

6. The third LLR Living Well with Dementia Strategy which, following public consultation and approval will cover the period 2024-2028, is underpinned by the guiding principles from the NHS Well Pathway for Dementia.
7. The current Strategy running from 2019-2022 was approved by the Cabinet on 16 October 2018. Due to the unprecedented circumstances caused by the pandemic, the joint LLR Dementia Programme Board decided to extend the existing Strategy by an additional year to 2023.
8. The previous Strategy generated a number of LLR wide actions, most of which have progressed, and others which are proposed to continue into the next Strategy.
9. Achievements of the current Strategy include:
 - Continuation of a strong partnership approach through the LLR Dementia Programme Board with LLR councils, the ICB, Leicestershire Partnership NHS Trust (LPT), University Hospitals of Leicester (UHL), the voluntary sector and other allied professionals.
 - Dementia risk factors are part of primary care health checks.
 - Primary Care practices are using a tool to assist them develop dementia-friendly GP practices.
 - A Joint Strategic Needs Assessment (JSNA) chapter on dementia has been completed which informs the new Strategy.
 - Information and advice supporting people living with dementia has been promoted across the area, particularly through the Dementia Support Service (DSS) and the LLR Dementia Friendly Guide.
 - There has been successful procurement and operation of the advice and guidance Dementia Support Service in Leicester and Leicestershire provided by Age UK LeicesterShire and Rutland.
 - A small group of people with lived experience supported the procurement of the Dementia Support Service and the drafting of the new Strategy and have become members of the Dementia Programme Board.
 - The local dementia-friendly community network continues to support dementia awareness and is linked closely with the Dementia Programme Board.
 - Living well activity and awareness raising has been prioritised in most of the neighbourhood plans for LLR.

- A small team of Admiral Nurses (specialist dementia nurses) worked within UHL to provide inpatient expertise to staff and patients living with dementia as well as a meaningful activities team.
- The County Council's Positive Behaviour Support team has begun a new approach to supporting care providers concentrating on managers and employers to develop best practice in supporting people who present challenges through developing policy, support tools, training and culture change.
- Additional expectations were added to the new Home Care for Leicestershire contracts to improve and monitor the quality of care for people with dementia.

10. Areas of activity which have proven challenging are:

- Diagnosis rates have reduced substantially as a result of services closing due to the pandemic. There is also a disparity in the diagnosis rates in the County compared to the City. Currently the diagnosis rates for the LLR area are; West Leicestershire 59.1%, East Leicestershire and Rutland 58.7% and Leicester 74.7% against a national target of 66.7%. This disparity is thought to be partly as a result of the diagnosis clinics being run exclusively at Glenfield Hospital in the Leicester conurbation, and therefore difficult for people living in less accessible or rural areas of the County to reach. In response, LPT has committed to running diagnosis clinics in County locations as opposed to solely at the Memory Assessment Service in Leicester. There is a focus on "seldom heard" groups in the revised Strategy and this will include rural communities in Leicestershire.
- Admissions avoidance, admissions and discharge pathways and post-discharge support for people with complex dementia remain a priority.
- Ensuring people and professionals have access to the tools they need to be confident and competent to live with or care for someone with dementia remains a priority.
- Activity that supports people to remain independent, requires further improvement with communities and in neighbourhoods.

The revised Strategy for 2024-2028

11. The revised draft Strategy, attached as Appendix A to this report, has been developed by a subgroup of the Dementia Programme Board which comprises the County Council, Leicester City Council, and Rutland County Council, the ICB and voluntary sector organisations.
12. From November 2022, the co-production group of the Dementia Support Service provided insight into the action points as well as offered advice on the content and layout of the Strategy from the perspective of having dementia or caring for someone with dementia.
13. Healthwatch LLR surveyed over 250 people living with dementia across LLR that attended social groups or completed a written survey. The feedback, which has informed the Strategy and which will shape the delivery plans of the partner organisations can be summarised as:
 - There are inconsistencies across LLR with variations in the speed and types of diagnostic pathways.
 - Despite multiple channels of information, there are inconsistencies in people's experiences of access to, and appropriateness of it.

- There is an inconsistent provision of, and access to support services with many different barriers to be addressed.
 - People living with dementia and their carers who had access to services provided by Admiral Nurses, Age UK, Voluntary Action South Leicestershire (VASL) and the Alzheimer's Society highly value the support and information they receive.
 - There is poor recognition of the needs of those with early onset dementia.
 - There were suggestions supporting the need for a single point of access, such as a hub, to improve information and access to services.
14. A younger onset dementia event in November 2022 included a facilitated focus group engagement activity with 19 people under the age of 65 living with dementia.
15. The Council's Engagement Panel was informed of the Strategy and officers will report back periodically to update through the consultation period.
16. In addition to this engagement, local and national intelligence was used including:
- The JSNA for Dementia 2018-2021.
 - Feedback from surveys and interviews with officers, providers and people using day services on the impact of the COVID-19 pandemic and carer needs.
 - Contract and commissioning meetings with the Dementia Support Service provided by Age UK on current needs and issues facing people receiving their service.
 - Feedback from members of the LLR Dementia Programme Board who either commission or provide dementia specific support.
 - Feedback from other voluntary organisations supporting people living with dementia particularly around access to support from diverse communities.
17. The revised Strategy is intended to be implemented from January 2024 (subject to the Cabinet's approval and similar governance processes in Leicester City and Rutland Councils). It is proposed that this Strategy is set for a period of five years. There is scope through the Dementia Programme Board to measure the Strategy's actions against any new and emerging health and social care national policy and amend local delivery plans if required. Any substantive changes to the Strategy would be subject to Cabinet approval.
18. The Strategy will be presented as pages on each of the three Councils' websites or as a link from each of the three Councils' websites to one host website, and therefore design and formatting are minimal at this stage.

Consultation

19. Consultation on the draft Strategy took place between 17 July 2023 to 22 September 2023 hosted by Leicester City Council, on behalf of LLR partners, on their Citizens Space web portal.
20. The consultation was accessible online with printed copies available on request. Dementia focused community groups were also able to request attendance from LLR commissioners to present the draft strategy and consultation questions to facilitate group responses from people living with dementia and their carers.

21. 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 display screens at GP surgeries. 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. The County Council's communications service designed a press release which was featured across print media, including the Leicester Mercury.
22. Direct engagement was undertaken with community groups across LLR, featuring focus groups with 'Jamila's Legacy', Age UK LeicesterShire and Rutland, Alzheimer's Society and the Carers Centre. Commissioners proactively reached out to Voluntary Community and Social Enterprise (VCSE) sector organisations offering to attend their sessions to talk about the Strategy consultation. The Leicestershire Equalities Challenge Group were also consulted as part of the consultation.
23. In total there were 319 unique online responses across LLR. Of these, 206 were specific to Leicestershire, 91 specific to Leicester and 61 specific to Rutland, with some consultees providing responses covering the whole of LLR. Leicestershire responses show an expected split between the district and boroughs of the County, with Harborough being the area with the most responses and Melton the lowest. Harborough has a very active dementia support group and is usually a district that provides consultation responses related to dementia matters. An LLR wide consultation report will be produced, but the attached report (Appendix B) focuses on the 206 responses that were specific to Leicestershire.
24. Overall, responses to the consultation indicated that there is broad agreement with the aims identified through the Well Pathway for Dementia (Preventing Well, Diagnosing Well, Supporting Well, Living Well and Dying Well) with the majority of respondents agreeing that the actions listed in the Strategy are beneficial.
25. Concerns were raised in relation to the first two questions asked in the consultation, namely, "Do you think that the health and social care services that support people living with dementia work well together?" and "Do you think staff are confident and competent to support people with dementia?" The responses for these questions demonstrate that respondents perceive that there is a lack of join up between health and social care (64.3%) and that staff are not confident and/or competent to support people with dementia (40%). Comments were made detailing lack of consistency in staff, removal of Admiral Nurse provision and uncoordinated discharge planning between health and social care.
26. Some of the key themes that have emerged from the responses are as follows:
 - Admiral Nurse provision in the county, which ceased earlier in 2023, leaves a significant gap (originally funded through Dementia UK and discontinued by Primary Care Networks when Voluntary, Community Social Enterprise (VCSE) funding was removed);
 - Memory Assessment Service (provided by LPT) should refer all people to the Dementia Support Service (DSS) on diagnosis. This could lead to increased referrals into the DSS although this referral pathway should already be in place and the DSS provider (Age UK) have been requesting for the referral to be mandatory;

- More support is required to fill the gaps between people being diagnosed and developing eligible adult social care needs;
- Recognised standard of training for staff working with people living with dementia;
- More training required on co-morbidities (e.g. diabetes).

Resource Implications

27. There is no additional investment attached to this Strategy with a view to each organisation tailoring their associated budgets in accordance with the priorities in the Strategy.
28. The Director of Corporate Resources and Director of Law and Governance have been consulted on the content of this report.

Timetable for Decisions

29. A report will be presented to the County Council's Cabinet on 24 November 2023 to seek approval of the draft Strategy and Leicestershire County Council action plan.
30. Subject to respective governance processes across LLR partners for final approval of the Strategy, the intention is to launch the Strategy in January 2024.

Conclusions

31. The priority actions described in the document are high-level as they must cater to all of the organisations involved. Each statutory organisation will therefore have a delivery plan addressing its specific priorities against the Strategy action plan.
32. The Dementia Programme Board will monitor the progress of the action plans and will support organisations to set targets for each year, underpinned by their delivery plans. The Board expects organisations to work collaboratively to achieve the overarching Strategy actions. This includes working at a neighbourhood and place-based level and co-dependencies with other workstreams.
33. For adult social care the key actions are contained within the 'supporting well' section of the Strategy, and the 'living well' section is relevant to activity within Public Health and Adults and Communities more broadly. NHS commissioning and service provision, whilst also relevant to support, living with dementia and the end of life, has a responsibility for prevention and diagnosis.
34. In order to ensure that the priorities for the Council are delivered, a refreshed Dementia Strategy Delivery Group has commenced to develop the Council's Delivery Plan and collaborations required with NHS Trusts, ICB and the Health and Wellbeing Board.
35. Response rates to the consultation have demonstrated significant interest from a wide range of stakeholders and the comments received have provided valuable information for commissioners on areas of dementia support that can be improved.
36. Many of the comments received focus on issues within healthcare provision, namely the funding for Admiral Nurses and potential improvements to the Memory Assessment Service provided by LPT. There is also work to be undertaken on the

join up between health and social care provision and on the training provided to staff working with people with dementia and their carers.

Recommendation

37. The Committee is invited to comment on the draft Strategy and consultation findings prior to presenting the outcome of the consultation and seeking approval of the final LLR Joint Living Well with Dementia Strategy and delivery plan for Leicestershire to the Cabinet on 24 November 2023.

Background papers

LLR Living Well with Dementia Strategy 2019-2022

<https://resources.leicestershire.gov.uk/sites/resource/files/field/pdf/2018/12/24/LLR-Living-Well-with-Dementia-Strategy-2019-2022.pdf>

The Prime Minister's Challenge on Dementia 2020

<https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020>

NHS Well Pathway for Dementia <https://www.england.nhs.uk/mentalhealth/wp-content/uploads/sites/29/2016/03/dementia-well-pathway.pdf>

Joint Strategic Needs Assessment chapter for dementia <https://www.lsr-online.org/uploads/dementia.pdf?v=1649162842>

Leicestershire County Council Strategic Plan 2018-22 <https://bit.ly/3Pe6nh5>

Delivering Wellbeing and Opportunity in Leicestershire – Adults and Communities Department Ambitions and Strategy for 2020-24 <https://bit.ly/3swoTal>

People at the Heart of Care: Adult Social Care Reform White Paper <https://bit.ly/3w7FfsE>

NHS Long Term Plan <https://www.longtermplan.nhs.uk/>

Leicestershire Joint Health and Wellbeing Strategy 2022-2032

<https://politics.leics.gov.uk/documents/s166738/Appendix%20A%20JHWS.pdf>

Leicestershire County Council Medium Term Financial Strategy (MTFS)

Report to Adults and Communities Overview and Scrutiny Committee: 5 June 2023 – Leicester, Leicestershire and Rutland Joint Living Well with Dementia Strategy 2024-28 – <https://politics.leics.gov.uk/ieListDocuments.aspx?MId=7108>

Report to the Cabinet: 23 June 2023 - Leicester, Leicestershire and Rutland Joint Living Well with Dementia Strategy 2024-28 -

<https://politics.leics.gov.uk/ieListDocuments.aspx?MId=7077>

Circulation under the Local Issues Alert Procedure

38. A copy of this report will be circulated to all members of the County Council.

Equality Implications

39. As this is an LLR Strategy the Equality Impact Assessment for the whole draft Strategy has been developed jointly with key Council and ICB colleagues and led by Leicester City Council, and therefore used the City Council template. However, to ensure alignment with County Council processes the information has also been transposed onto the Council's template and where required to reflect Leicestershire's demographic information has been added, and attached to this report as Appendix C.

Human Rights Implications

40. There are no human rights implications arising from this report.

Appendices

- Appendix A Draft Living Well with Dementia Strategy 2024-28
Appendix B Summary report of Leicestershire Responses
Appendix C Equality Impact Assessment for Leicestershire

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