



**CABINET - 24 NOVEMBER 2023**

**LEICESTER, LEICESTERSHIRE AND RUTLAND  
JOINT LIVING WELL WITH DEMENTIA STRATEGY 2024-2028  
OUTCOME OF CONSULTATION**

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

**PART A**

**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 2024-2028 and to seek approval of the final Strategy and the County Council's Delivery Plan (attached as Appendices A and B respectively to this report).

**Recommendations**

- 2 It is recommended that:
  - a) The outcome of the consultation on the draft Leicester, Leicestershire and Rutland Joint Living Well with Dementia Strategy 2024-2028, including the comments of the Adults and Communities and Health Overview Scrutiny Committees, be noted;
  - b) The Leicester, Leicestershire and Rutland Joint Living Well with Dementia Strategy 2024-2028 be approved;
  - c) The Leicestershire County Council Delivery Plan be approved.

**Reasons for Recommendations**

- 3 The Strategy seeks to support people with dementia in the Leicester, Leicestershire and Rutland area and has been informed by the experiences of those living with dementia or as a carer, their families and the organisations supporting them.

**Timetable for Decisions (including Scrutiny)**

- 4 Subject to respective governance processes across LLR partners for final approval of the Strategy, the intention is to launch the Strategy in January 2024.

- 5 The Adults and Communities Overview and Scrutiny Committee considered a report on the draft Strategy at its meeting on 5 June 2023 and its comments were included in the report to the Cabinet on 23 June 2023.
- 6 The Health Overview and Scrutiny Committee considered a report on the draft Strategy at its meeting on 1 November 2023 and its comments are set out in Part B of this report.

### **Policy Framework and Previous Decisions**

- 7 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.
- 8 In October 2018, the Cabinet approved the LLR Living Well with Dementia Strategy 2019-2022 and associated delivery plan.
- 9 On 23 June 2023 the Cabinet approved a formal 10-week consultation exercise on the draft Strategy.

### **Resource Implications**

- 10 There is no additional investment attached to this Strategy. Each organisation will tailor their associated budgets in accordance with the priorities in the Strategy.
- 11 The Director of Corporate Resources and Director of Law and Governance have been consulted on the content of this report.

**Circulation under the Local Issues Alert Procedure**

12 This report will be circulated to all members of the County Council.

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## **PART B**

### **Background**

- 13 The third LLR Living Well with Dementia Strategy is underpinned by the guiding principles from the NHS Well Pathway for Dementia.
- 14 The current Strategy covered the period 2019-2022 but due to the unprecedented circumstances caused by the COVID pandemic, the joint LLR Dementia Programme Board decided to extend the existing Strategy by an additional year to 2023.
- 15 The previous joint Strategy generated a number of LLR-wide actions, most of which have been progressed, and others which have been incorporated in the next joint Strategy and will be included in each partner organisation's associated delivery plans, which will be monitored by the LLR Board.

### **Achievements**

- 16 Achievements and strengths of the current Strategy include:
  - Continuation of a strong partnership approach through the LLR Dementia Programme Board with LLR councils, the Integrated Care Board (ICB), Leicestershire Partnership NHS Trust (LPT), University Hospitals of Leicester (UHL), the voluntary sector and other allied professionals.
  - Ensuring that dementia risk factors are part of primary care health checks.
  - Encouraging and assisting Primary Care practices to develop dementia-friendly GP practices.
  - A Joint Strategic Needs Assessment (JSNA) chapter on dementia has been completed which informs the new Strategy.
  - Successful procurement and operation of the advice and guidance Dementia Support Service (DSS) in Leicester and Leicestershire provided by Age UK LeicesterShire and Rutland.
  - Information and advice supporting people living with dementia has been promoted across the area, particularly via the DSS and the LLR Dementia Friendly Guide.
  - 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 the LLR area.
  - 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.

Challenges

- 17 There are several areas of activity which have proven challenging. One of these is a substantial reduction in diagnosis rates as a result of the Memory Assessment Service closing due to the pandemic, as face-to-face clinical appointments and because the staff were deployed to work elsewhere.
- 18 There is also a disparity in the diagnosis rates in Leicestershire and Rutland compared to Leicester. Currently the diagnosis rates are: West Leicestershire 59.1%, East Leicestershire and Rutland 58.7% and Leicester 74.7%. The national target is 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 making it difficult for people living in less accessible or rural areas of the County to reach. County officers will continue to support LPT in making the case for running diagnosis clinics in County locations. The revised Strategy has a focus on “seldom heard” groups including rural communities.

Other areas for improvement

- 19 Due to the complex nature of the needs of people living with dementia, people can be admitted to hospital and care homes where this could potentially be avoided. Similarly, complexity can delay discharge from hospital when people are clinically ready to leave. Therefore, admissions avoidance, discharge pathways and post-discharge support for people with complex dementia remain a priority.
- 20 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. To support the workforce and informal carers with the progressive and complex needs of people living with dementia, a range of support, tools and training must continue to be developed during the strategy period.
- 21 The JSNA for dementia set out that activity that supports people to remain independent requires further improvement with communities and in neighbourhoods to ensure that there is equal access across Leicestershire.

**The Revised Strategy for 2024-2028**

- 22 The revised draft Strategy (Appendix A) has been developed by a subgroup of the Dementia Programme Board which comprises the County Council, Leicester City Council, and Rutland Council, the ICB and voluntary sector organisations.
- 23 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.
- 24 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 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.

- 25 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.
- 26 The revised draft Strategy was also informed by the JSNA for Dementia, feedback from surveys/interviews with officers, providers and those using day services on the impact of the COVID pandemic and carer needs, meetings with the DSS, and feedback from the LLR Dementia Programme Board and voluntary organisations.

### **Consultation**

- 27 Consultation on the draft Strategy took place from 17 July 2023 to 22 September 2023. The consultation exercise was hosted by Leicester City Council on behalf of the partner authorities on its Citizens Space web portal, and was linked from the County Council's website.
- 28 The consultation was accessible online with printed copies available on request. Dementia focused community groups were also able to request attendance from LLR Council commissioners to present the draft Strategy and consultation questions to facilitate group responses from people living with dementia and their carers. As a result, direct engagement was undertaken with community groups across the LLR area, featuring focus groups with 'Jamila's Legacy', Age UK LeicesterShire and Rutland, Alzheimer's Society and the Carers Centre. Council commissioners proactively reached out to Voluntary Community and Social Enterprise (VCSE) sector organisations offering to attend their sessions to talk about the Strategy consultation.
- 29 The Councils' partners promoted the Strategy amongst their networks such as care support provider networks, the Dementia Programme Board, social media avenues, newsletters, the local press, and 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.
- 30 The Leicestershire Equalities Challenge Group was also consulted as part of the consultation.

Consultation feedback

- 31 In total there were 319 unique online responses across the LLR area. Of these, 206 were specific to Leicestershire, 91 specific to Leicester and 61 specific to Rutland, with some consultees providing responses relating to the whole area.
- 32 The responses relating to Leicestershire show an expected split between the districts, with Harborough, with a very active dementia support group, being the area with the most responses. The Melton area had the lowest.
- 33 An LLR-wide consultation report will be produced in the new year. Appendix C to this report focuses on the 206 responses that were specific to Leicestershire and a summary is given below.
- 34 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.
- 35 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 demonstrated a perception 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 referred to lack of consistency in staff supporting individuals living with dementia, leading to different approaches and lack of familiarity and confidence, removal of Admiral Nurse provision and uncoordinated discharge planning between health and social care.
- 36 Some of the key themes that have emerged from the responses are as follows:
- The cessation of Admiral Nurse provision in the County earlier in 2023, leaves a significant gap. (This was originally funded through Dementia UK and discontinued by Primary Care Networks when VCSE funding was removed).
  - The Memory Assessment Service (provided by LPT) should refer all people to the 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) has been requesting for the referral to be mandatory.
  - More community support and activities are required to fill the gaps between people being diagnosed and developing eligible adult social care needs.
  - There should be a recognised standard of training for staff working with people living with dementia.
  - There needs to be more training on helping people with dementia and co-morbidities (e.g. diabetes).

Leicestershire County Council Delivery Plan

- 37 The County Council has developed a headline Delivery Plan for its own activities which contribute to the priority areas within the Strategy. The Plan will be expanded

upon through co-production with people who have lived experience of dementia. All partners to the Strategy will develop a Delivery Plan for areas of focus within their remits, showing how they will use their organisation's resources in furtherance of the LLR Dementia Strategy.

- 38 The County Council's Delivery Plan is attached as Appendix B to this report.
- 39 The LLR Dementia Programme Board will hold the partner organisations to account for delivery of their actions, and will ensure that there is a joined up approach across the partnership.

### **Comments from the Health Overview and Scrutiny Committee**

- 40 The Health Overview and Scrutiny Committee considered the outcome of the consultation on the draft Strategy at its meeting on 1 November 2023.
- 41 Members were disappointed that Admiral Nurse provision in the County had been discontinued by Primary Care Networks when VCSE funding was removed and supported the campaign by Healthwatch for reinstatement of this specialist support.
- 42 The Committee emphasised the barriers to improving diagnosis rates including a reluctance on the part of individuals to get tested, which needed to be overcome, and welcomed action to encourage people to seek a diagnosis. It was commented that friends and relatives were often the first to notice signs of illness and members questioned whether there was sufficient awareness in communities.
- 43 Concerns were raised in particular about those people who lived alone and might, for instance, be reluctant to attend activities by themselves. Moreover, there was a danger that social isolation and a lack of mental stimulation could affect the speed at which dementia developed.
- 44 The Committee commended the Strategy to the Cabinet.

### **Conclusions**

- 45 The priority actions described in the Strategy are high-level as they must cater to all three Councils. Each will therefore have a delivery plan addressing its specific priorities against the Strategy action plan.
- 46 The LLR Dementia Programme Board will monitor the progress against the Strategy's priorities, and the organisational Delivery Plans in development and will support organisations to set targets for each year, underpinned by their respective delivery plans. The Board expects organisations to work collaboratively and recognise co-dependencies with other workstreams.
- 47 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 the Council's Public Health and Adults and Communities Departments 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.



- 48 In order to ensure that the priorities for the Council are delivered, a refreshed Council Dementia Strategy Delivery Group incorporating operational, strategic, commissioning and contracting managers has commenced to develop the Council's Delivery Plan and collaborations required with NHS Trusts, ICB and the Health and Wellbeing Board.
- 49 Responses 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.
- 50 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.
- 51 Subject to approval, the revised Strategy will be implemented from January 2024. There is scope through the LLR Dementia Programme Board to measure the Strategy's actions against any new and emerging health and social care national policy and amend the local delivery plans if required. Any substantive changes to the Strategy itself would be subject to approval through the governance processes of the three partner Councils.

### **Equality Implications**

- 52 As this is an LLR Strategy the Equality Impact Assessment (EIA) has been developed jointly with key Council and ICB colleagues and led by Leicester City Council. To ensure alignment with County Council processes the information has also been transposed onto the Council's template and where required has been added to reflect Leicestershire's demographic information.
- 53 The EIA is attached to this report as Appendix D, and in summary:
- The Strategy has an overall positive impact on people with a disability, i.e. those with dementia.
  - However, there are differential positive impacts for some groups, including people from some diverse ethnic backgrounds, who may have lower diagnosis rates than those who are white British.
  - Additionally, it is imperative that the health and social care system continues to ensure good services for younger people who have a diagnosis of dementia.
- 54 Although not within the scope of an EIA, rurality is a consideration and should be considered as part of the future approach to ensuring equity of access to services.

### **Human Rights Implications**

- 55 There are no human rights implications arising from this report.

## **Appendices**

- Appendix A Draft Living Well with Dementia Strategy 2024-28
- Appendix B Leicestershire County Council Delivery Plan
- Appendix C - Summary report of Leicestershire Responses to the Consultation
- Appendix D Equality Impact Assessment for Leicestershire

## **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>

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>

Leicestershire Joint Health and Wellbeing Strategy 2022-2032

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

Report to Adults and Communities Overview and Scrutiny Committee: 5 June 2023 – Leicester, Leicestershire and Rutland Joint Living Well with Dementia Strategy 2024-2028 - <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 2024-2028 -

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

Report to the Health Overview and Scrutiny Committee: 1 November 2023 – Outcome of the LLR Joint Living Well with Dementia Strategy 2024-2028

<https://politics.leics.gov.uk/ieListDocuments.aspx?MId=7169> (Item 9)