

HEALTH AND WELLBEING BOARD: 1 DECEMBER 2022**REPORT OF THE DIRECTOR OF PUBLIC HEALTH****JOINT STRATEGIC NEEDS ASSESSMENT – END OF LIFE****Purpose of report**

1. The purpose of this report is to provide the Health and Wellbeing Board with an update on ongoing development of the Leicestershire Joint Strategic Needs Assessment (JSNA), and to provide a summary of the recommendations that have arisen from the recently completed JSNA End of Life chapter. The report also details the ongoing work to progress the other JSNA chapters.

Recommendation

2. It is recommended that the Health and Wellbeing Board:
 - a) Supports the recommendations of the Joint Strategic Needs Assessment (JSNA) End of Life chapter noting that the place priority actions will be delivered through the Joint Health and Wellbeing Strategy delivery plan and system actions via the Leicester, Leicestershire and Rutland End of Life Strategy which will be refreshed and take into account the findings of the JSNA.
 - b) Notes the timetable for the development of the remaining chapters identified in the current JSNA cycle and comments of the list of proposed future chapters, identifying any additional chapters required or particular priorities amongst the current list.

Policy Framework and Previous Decisions

3. The Health and Wellbeing Board considered a report in January 2018 which proposed that the JSNA would be published in subject-specific chapters throughout a three-year time period on an iterative basis, in line with Integrated Care System (ICS) and local authority commissioning cycles. This approach was supported with the JSNA outputs agreed as:
 - Subject-specific focused chapters/narrative of an assessment of current and future health and social care needs with recommendations
 - Infographic summary of each chapter
 - A Tableau self-serve data dashboard that is updated on a regular basis to allow users to self-serve high level data requests
4. Using effective online dashboard approaches also allows for some resources to be devoted to more targeted report-based needs assessment work, whether as a statutory requirement such as the PNA or deep dives into areas of priority defined by Joint Health and Wellbeing Strategies, such as end of life care, mental health or obesity.

Background

5. The local authority and ICS (previously clinical commissioning groups) have an equal and joint statutory responsibility to prepare a JSNA for Leicestershire, through the Health and Wellbeing Board. The Health and Social Care Act 2012 amended the Local Government and Public Involvement in Health Act 2007 to introduce duties and powers for Health and Wellbeing Boards in relation to JSNAs.
6. JSNAs are a continuous process and are an integral part of ICS and local authority commissioning cycles. Health and Wellbeing Boards have a responsibility to decide when to update or refresh JSNAs or undertake a fresh process to ensure that they are able to inform local commissioning plans over time.
7. The purpose of the JSNA is to improve the health and wellbeing of the local community and reduce inequalities for all ages. It should be viewed as a continuous process of strategic assessment and planning with the aim to develop local evidence-based priorities for commissioning which will improve the public's health and reduce inequalities.
8. The JSNA will be used to help to determine what actions the local authority, the local NHS and other partners need to take to meet health and social care needs, and to address the wider determinants that impact on health and wellbeing. The local authority, ICS and NHS England's plans for commissioning services will be expected to be informed by the JSNA.
9. The JSNA is a process which assesses the current and future health and wellbeing needs of the population and underpins local planning for health and care services, in particular the development of the Joint Health and Wellbeing Strategy. It will also contribute towards the ICS strategy development and involves working with local partners to ensure a broad approach to issues affecting health, including key social and economic determinants of health, where appropriate.
10. Analytical resources have been prioritised towards the Covid-19 emergency response effort during 2020/21 and 2021/22 and hence it has not been possible to maintain all of the JSNA refresh process during that time. However, it is now possible, following the pandemic, to begin to assess the data, including Covid-19 impact, across a range of topics. The national 2021 Census detailed data should also start to be released from Autumn 2022 and allow for refresh of a number of underpinning elements of the JSNA.

JSNA End of Life Chapter

Public Engagement

11. To help ensure the JSNA End of Life chapter captured the views of local people, a survey was created to ensure that lived experiences were incorporated. This was targeted at those who have been bereaved in the past three years, those who are or have been informal carers for a loved one approaching the end of life, and staff working in end of life and palliative care services. A total of 37 residents responded, and 36 staff working with people in health or social care.

12. Some of the themes emerging from this engagement include:

- Some recently bereaved people shared positive experiences of receiving support from their GP and from the hospice where their loved one passed, but the form of support most frequently spoken well of was that provided by family and friends.
- Many recently bereaved respondents told us that they had not received any bereavement support. This was not due to their feeling it was not needed, but rather its lack of availability.
- A common theme was that people didn't know where to look for information regarding available services and how to access them.
- The majority of carers told us that they received very little if any support whilst undertaking their caring role.
- Informal carers also felt that services aimed at supporting them and their loved ones are disjointed and would benefit from improved coordination.
- Many staff praised the teams they work with in providing support. This, combined with having access to the necessary equipment, being able to deliver person-centred care, and working closely with other services were cited as further strengths of existing services by staff.
- Many staff felt that they received adequate training to support them in caring for those near the end of life, but this wasn't universally accepted. Those whose primary role is in a specialty other than delivering palliative care in particular felt that they would benefit from additional training and support.

13. The results from this survey are presented in the JSNA End of Life chapter and were used to help shape the final recommendations. The full chapter can be found here <https://www.lsr-online.org/leicestershire-2022-2025-jsna.html> and it addresses need across all ages as well as identifying specific differences for children and adults as they occur.

Summary of JSNA End of Life Chapter Findings

14. The JSNA End of Life chapter has provided an overview of the data on End of Life care and support for those who are themselves at this stage of life, their loved ones, and for those who work in this area. Data was collected from multiple sources in addition to the public engagement described in section 11. These include data gathered by local organisations and services, locally commissioned reports, nationally collected data, and a literature search. The chapter also considers the relevant national and local policy and guidance context for this stage of life. The chapter reviews this range of national and local evidence under the guidance of a steering group and identifies any gaps or unmet need before making recommendations for future work or improvement.

15. Findings from the chapter include:

- Everybody is affected by death, but most occur in older age groups with 41.1% of deaths in Leicestershire in 2020 attributed to people aged 85+ years.

Leicestershire has a growing population, with the greatest cumulative change projected to occur in the 65+ age band. There is therefore a significant need for robust end of life pathways and services, which is likely to grow in the coming years.

- For many, conversations about end of life preferences currently occur too late to be able to have a meaningful impact, particular for groups such as those with dementia. Advance Care Planning (ACP) at a sufficiently early stage provides people with the opportunity to plan their future care and support whilst they have the capacity to do so. It has been shown to increase the chance that a person's wishes will be understood and followed, contributing to improved quality of care. Despite this, uptake is low, with as few as 9.7% shown to have an ACP in place prior to their final hospital admission. Contributing to this is a low level of understanding of terms relating to end of life care, and poor awareness of the support services available. These issues are exacerbated by a system which is often fragmented, with complex referral pathways and little formal coordination.
- The loss of a loved one is a traumatic life event, and as such, bereaved individuals have increased emotional, social, and practical needs. Whilst people in Leicestershire have told us they are often happy with the support received from services once they have accessed them, they have described a difficulty in identifying what help is available particularly at such a challenging time.
- Informal carers provide as much as 75-90% of homebased care for those nearing the end of life and are integral in supporting many people to remain at their place of choice. Despite significant financial, physical, and emotional costs to themselves in undertaking this important role, carers informed us that they feel unsupported and often overlooked by services. They are also often burdened with attempting to navigate and coordinate complex health and social care systems on behalf of their loved one.
- Staff working across the health and social care sector must be supported to feel confident in working with patients approaching the end of life. This is increasingly of import, given we are faced with an ageing and increasingly co-morbid population which interacts with multiple health services and specialties.

Summary of Recommendations JSNA End of Life Chapter

16. As a result of the JSNA findings, a set of recommendations have been developed with the aim of improving help, support, and quality of life for people approaching and affected by death in Leicestershire. Many of these recommendations are relevant across all ages with one that is specific to children and young people at end of life.

The recommendations are:

- **Further exploration of the issue**
- Undertake a tailored piece of engagement to capture the views, preferences, and experiences of those who are themselves approaching the end of life.

- Produce a health equity audit to further explore inequalities in end of life care and how services can be tailored to better address the needs of disadvantaged groups.
- Further explore the reasons for deaths taking place at hospital / hospice / home / care home, to better understand if this is due to patient choice or factors such as a lack of community services meaning there is insufficient capacity to support people dying at home. To particularly consider those who live elsewhere but die in a care home.
- **Facilitating conversations**
- Seek to modify social norms by utilising behaviour change theory and social marketing, to improve the acceptability of discussing death and end of life preferences.
- Consider how conversations relating to end of life preferences and planning can be initiated at times surrounding major life events, by incorporating a Making Every Contact Count Plus (MECC+) approach.
- Seek to increase the number of people with an advance care plan.
- Encourage healthcare staff to initiate advance care planning discussions during early interactions, particularly for those with degenerative conditions such as dementia who will be less able to contribute meaningfully as their condition progresses.
- **Increasing public understanding**
- Undertake local campaigns aimed at enhancing the public's understanding of what is meant by end of life, the terms frequently used in relation to it, and the role of different services.
- Improve awareness of existing, locally available services.
- Build on work by Dying Matters to provide a central source of information and signposting advice to end of life and bereavement services.
- **Delivering services**
- Develop a more robust community out of hours offer so that support for those approaching the end of life and their carers is available throughout the week.
- Improve the coordination of services working together to deliver end of life care, to reduce the burden currently placed on patients and their loved ones.
- Promote continuity of care within services, particularly with primary and community services, to support the building of trusted relationships between patients and their health or social care provider.
- Consider how to introduce a form of routine follow up with those who have undergone a recent bereavement.

- Consider the need for a paediatric palliative care consultant and the need for community paediatric and nursing support that responds to the rising numbers of children and young people on end of life pathways with increasing complexity.
- **Supporting carers and staff**
- Improve the advice and support available to informal carers, so that they feel better equipped with the skills and knowledge to support their loved one.
- Consider how regular check-ins with informal carers can take place.
- Support informal carers in taking respite care, so as to ensure their own wellbeing.
- Ensure training is available and accessible for staff who do not regularly deliver end of life care as a core part of their role.

Current Topics for JSNA work

17. The current list of Leicestershire chapters for the JSNA that are being or due to be progressed are listed below. It is anticipated that this first list of planned chapters will be completed in 2022/23. Published chapters to date can be accessed at <https://www.lsr-online.org/jsna.html>

- *Supporting information: demographics, deprivation, economy – post release of Census data.*
- *Pharmaceutical Needs Assessment (elsewhere on agenda)*
- *End of Life Care (this item)*
- *Oral Health Needs Assessment (underway)*
- *Children and Young Peoples Mental Health*
- *Sexual Health HNA*
- *Carers JSNA*

18. Other theme areas for the future JSNA programming so far include:

- *Early Years*
- *Health Inequalities*
- *Adult Mental Health*
- *Covid Impact*
- *Access to health services*
- *Obesity*
- *Economy and workforce*

- *Housing*
- *Children and Young People's Physical Health*
- *Substance Misuse*
- *Multimorbidity and Frailty*

Background papers

<https://www.lsr-online.org/jsna.html>

Officer to Contact

Sally Vallance
Strategic Lead Healthcare Public Health
Leicestershire County Council
Email: sally.vallance@leics.gov.uk
Phone: 01163050705

Relevant Impact Assessments

Equality and Human Rights Implications

19. The JSNA chapters takes due regard to the equality and human rights of different population groups. The End of Life JSNA chapter will inform the future LLR End of Life strategy which will be subject to an EHRIA.

Partnership Working and associated issues

20. A range of partner organisations have roles to play in delivering care and support to those approaching the end of life, their loved ones, and those working in this area. This includes health and social care providers and the community and voluntary sector. Many partner organisations already meet through the LLR End of Life Care Taskforce and JSNA task and finish group, working together to define and plan the delivery of a longer term end of life care pathway across the health and social care system.

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