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PUBLIC REPORT

RUTLAND HEALTH AND WELLBEING BOARD

11 October 2022

JOINT STRATEGIC NEEDS ASSESSMENT – END OF LIFE

Report of the Director of Public Health

Strategic Aim:		Healthy and well
Exempt Information:		No
Cabinet Member(s) responsible:		Councillor S Harvey, Portfolio Holder for Health, Wellbeing and Adult Care
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Ward Councillors	N/A	

DECISION RECOMMENDATIONS

That the Committee:

1. Endorses the recommendations arising from the JSNA End of Life chapter, which seek to address the unmet needs and gaps identified therein.
2. Notes that the JSNA End of Life chapter will be used to inform the refresh of the LLR End of Life Strategy which will be undertaken by the Integrated Care Board.

1. PURPOSE OF THE REPORT

1.1 The purpose of this report is to provide the Health and Wellbeing Board with a summary of the recommendations that have arisen from the recently completed Joint Strategic Needs Assessment (JSNA) End of Life chapter.

2. BACKGROUND AND MAIN CONSIDERATIONS

2.1 The local authority and Integrated Care System (ICS - previously clinical commissioning groups) have an equal and joint statutory responsibility to prepare a JSNA for Rutland, 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.

2.2 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.

2.3 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.

2.4 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.

2.5 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.

3. SUMMARY OF JSNA END OF LIFE CHAPTER FINDINGS

3.1 The JSNA End of Life chapter provides 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 5. 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.

3.2 Findings from the chapter include:

- Everybody is affected by death, but most occur in older age groups with 48.2% of deaths in Rutland in 2020 attributed to people aged 85+ years. Rutland 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 Rutland 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.

4. SUMMARY OF JSNA END OF LIFE CHAPTER RECOMMENDATIONS

4.1 As a result of the JSNA findings, a set of recommendations have been developed with the aim of improving the help and support available for, and quality of life of, people approaching death and affected by it in Rutland.

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.

- Explore how accurately advance care plans are being followed and enacted, particularly for patients attending hospitals outside of LLR which may have different systems to those used locally.

- **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.

- Work to introduce beds specifically for end of life care provision locally in Rutland, to ease travel burdens and facilitate respite care.

- Consider how to introduce a form of routine follow up with those who have undergone a recent bereavement.

- **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.

5. CONSULTATION

5.1 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 51 people responded, 13 of whom had been recently bereaved, 7 had experience of being an informal carer to someone nearing the end of life, and 36 were paid staff working in end of life and palliative care services.

5.2 The results from this survey are presented in the JSNA End of Life chapter and were used to help shape the final recommendations.

6. ALTERNATIVE OPTIONS

6.1 The production of a JSNA is a statutory requirement. In July, the Health and Wellbeing Board noted the suggested approach to JSNA Development that identified End of Life as a key topic for consideration.

7. FINANCIAL IMPLICATIONS

7.1 The JSNA End of Life chapter has been completed within the existing capacity and resources of the Public Health Department and Leicestershire Business Intelligence team.

8. LEGAL AND GOVERNANCE CONSIDERATIONS

8.1 The JSNA is a statutory document and must meet the requirements for production of such documents. The End of Life chapter was produced with the support and input of a steering group consisting of local government partners, individuals who work in services that deliver end of life or palliative care, and members of related third sector organisations.

9. DATA PROTECTION IMPLICATIONS

9.1 A Data Protection Impact Assessments (DPIA) has not been completed for this JSNA chapter. The data collected through the consultation (Section 5) was processed in line with corporate requirements, following discussions with the Leicestershire County Council Information Governance team. All other data sources contributing to this chapter were secondary sources, with information anonymised if it was not presented in an aggregate format.

10. EQUALITY IMPACT ASSESSMENT

10.1 The JSNA chapter 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.

11. COMMUNITY SAFETY IMPLICATIONS

11.1 There are no direct community safety implications arising from the JSNA End of Life chapter.

12. HEALTH AND WELLBEING

12.1 The purpose of the JSNA End of Life chapter is to assess the related health and wellbeing needs across Rutland. Its findings will also inform the LLR End of Life strategy which is due to be produced by the Integrated Care Board, service plans, and commissioning.

13. CONCLUSION AND SUMMARY OF REASONS FOR THE RECOMMENDATIONS

13.1 The JSNA End of Life chapter has been produced using a combination of local and national sources. Unmet needs of the local population have been identified, and recommendations to address these have been formulated. This chapter will be used to inform the refresh of the LLR End of Life Strategy being undertaken by the Integrated Care Board.

13.2 The Health and Wellbeing Board is recommended to:

1. Endorse the recommendations arising from the JSNA End of Life chapter, which seek to address the unmet needs and gaps identified therein.

2. Note that the JSNA End of Life chapter will be used to inform the refresh of the LLR End of Life Strategy which will be undertaken by the Integrated Care Board.

14. BACKGROUND PAPERS

14.1 Published JSNA chapters to date can be accessed at https://www.rutland.gov.uk/my-services/health-and-family/health-and-nhs/joint-strategic-needs-assessment/. The JSNA End of Life chapter will be uploaded alongside these shortly, once it has undergone final approval by the steering group.

15. APPENDICES

15.1 There are no appendices to the report.

A Large Print or Braille Version of this Report is available upon request – Contact 01572 722577