

Agenda Item: 6**LONG TERM CONDITIONS ACROSS THE LIFECOURSE – SCOPING A JOINT STRATEGIC NEEDS ASSESSMENT FOR CAMBRIDGESHIRE HEALTH AND WELLBEING BOARD**

To: Health and Wellbeing Board

Date: 15 January 2015

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Purpose: This paper makes a proposal for the scope of the JSNA on the needs of adults with long term conditions living in Cambridgeshire, which will focus on a cohort of people who are living in the community, but whose needs are such that they are vulnerable to needing additional ongoing support from health or social care.

It explores the background to this JSNA, the scoping process and the different options for defining the group of interest. It provides recommendations from the working group about the areas the JSNA should focus on, taking into account the engagement of stakeholders with the scoping process.

1. INTRODUCTION AND CONTEXT

The management and care of people with long term conditions (LTC) has been described as one of the most fundamental health and social care challenges and has been a recognised focus area for Cambridgeshire, particularly relevant to Priority 2, focus area 1 of the HWB Strategy (2012-2017):

‘Support older people to be independent, safe and well: Promote preventative interventions which reduce unnecessary hospital admissions for people with LTCs, enable them to live independently at home or in a community setting where appropriate and improve their health and wellbeing outcomes, e.g. through falls prevention, stroke and cardiac rehabilitation, supporting voluntary agencies and informal carers.’

LTCs include any ongoing, long-term or recurring condition requiring constant care that can have a significant impact on people’s lives; limiting in quality of life. There is a range of terminology used to describe LTCs including long term illness, limiting illnesses, and chronic disease. However definitions which focus on a specific condition may not holistically describe the person living with the disease, especially for those who have multiple conditions. The Department of Health working definition of a LTC is: ‘A health problem that can’t be cured but can be controlled by medication or other therapies’¹. The House of Commons Health Committee has recently recommended that this definition is revised to emphasise the policy object of treating the person, not the condition(s).²

¹Department of Health (2013). Improving quality of life for people with long term conditions. Available at: <https://www.gov.uk/government/policies/improving-quality-of-life-for-people-with-long-term-conditions#background>

²House of Commons Health Committee. Managing the care of people with long-term conditions. Second report of session 2014-15. Published 3 July 2014, The Stationary Office, London.

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Reviewing, and ultimately reducing the impact of LTCs through ensuring appropriate community support and providing effective services where necessary, is important for a number of reasons:

- People with LTCs use a lot of health and social care resource; care of people with long term conditions accounts for 70% of budgets spent on health and social care in England. LTCs account for 50% of general practice (GP) appointments, 64% of outpatient appointments and 70% of inpatient bed days.³ People with LTCs are also twice as likely to be admitted to hospital and experience longer stays when they are admitted.
- The number of people with multiple LTCs increases with age and while the number of people with one LTC is projected to be relatively stable over next 10 years, those with multiple LTCs are set to rise to 2.9 million in 2018 from 1.9 million in 2008, as the population ages.²
- The prevalence of LTCs is unequally distributed across populations, and closely related to deprivation. LTCs often have a detrimental impact on quality of life and limit opportunities, for example those with a LTC have an increased likelihood of not working.⁴

This means that a clear and accurate description of the current numbers and needs of people with LTCs would provide the necessary foundation for developing integrated approaches to health and wellbeing for this group, while promoting independent living.

Two previous JSNAs touched on this area of work in Cambridgeshire. An 'Adults with a Physical or Sensory Impairment and or Long Term Condition' JSNA (2008) focussed on the main causes of disability. The JSNA provided data summaries for a range of LTCs derived from the Census 2001 and OPCS disability surveys (1988), both of which are now out of date. It also offered limited information on effective interventions. Similarly the 'Physical Disabilities and Learning Disabilities through the Life Course' JSNA (2013) focussed on physical and learning disabilities. It was acknowledged in that piece of work that a further strategic needs assessment could cover older people and people with LTCs more generally.

The Cambridgeshire Health and Wellbeing Board have requested a JSNA on LTC across the Lifecourse to be prepared for July 2015. The JSNA will include work to estimate current and future numbers of people with LTCs in Cambridgeshire given population growth and ageing, and the needs for preventive and treatment services. In addition to building on the intelligence around LTCs, the work will also draw from and complement the following recent JSNAs to ensure alignment of public health recommendations and approaches:

- Prevention of Ill Health in Older People (2013)
- Primary prevention of Ill Health in Older People (2014)
- Older People's Mental Health (2014)
- Carers (2014)

A thorough scoping process has been taken to explore the theme of LTCs across the Lifecourse to ensure that the JSNA produced is highly informative and useful to the Health and Wellbeing Board,

³NHS Long Term Conditions Compendium of Information (Third Edition). Published 30 May 2012

⁴NHS Long Term Conditions Compendium of Information (Third Edition). Published 30 May 2012

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and meets the needs of those working across the health and social care system in Cambridgeshire. This paper details the different approaches to describing the population with LTCs that have been considered by the JSNA working group, and presents the final proposed scope for the JSNA.

2. THE SCOPING PROCESS

Stakeholders have been involved from the outset in shaping the scope of this JSNA, demonstrating a new way of working on a JSNA with earlier engagement than in the past. A stakeholder event was held on 5 November 2014 to understand the views from key stakeholders across health and social care, and explore opportunities to align this JSNA with priority workstreams and local commissioning decisions to ensure the JSNA is responsive to stakeholder needs.

Attendees included representatives from Cambridgeshire & Peterborough Clinical Commissioning Group (C&P CCG), Cambridgeshire County Council; Cambridgeshire Community Services, University of Cambridge Institute of Public Health; Healthwatch; Better Health Network; Public Health England; local Councillors and members of the Health and Wellbeing Board.

Participants at the scoping event discussed the preliminary analysis of local data including mortality, admissions and prevalence data presented by the working group. Multimorbidity and limiting conditions were explored through group discussions, considering the national evidence for associations with age, with socioeconomic status, and the impact on health and social care services.

There was undisputed recognition among stakeholders of the scale of topics within LTCs, and a desire for the JSNA to be useful and be translatable for decision making within the local health and social care system. Recurring themes were the factors that impinge on the quality of life for individuals, particularly chronic pain, and poor mental health including depression and anxiety. Stakeholders were interested in care principles that might be extended across a range of disease conditions where there were some commonalities, such as information on approaches where individuals could be supported and empowered to make changes to live well, and where strategic changes could be made at system-level to improve health outcomes, improve quality, and reduce costs.

The engagement of strategic stakeholders to date provides a powerful platform for ongoing partnership work. Additional consultation to gather local views from individuals living with LTCs, third sector organisations, and special interest groups is anticipated in February/March 2015. A joint process for identifying key findings from this work will provide further opportunities for joint working and co-production.

3. ISSUES AND OPTIONS

Through the scoping process, the JSNA working group has identified three important challenges to conducting a needs assessment on long term conditions with an appropriate scale and remit:

1. The vast scale of the range of conditions and diseases within the LTC umbrella
2. The variation of the population with LTC - there are multiple ways of describing this population including children, young people, adults of working age, and older people
3. The varying levels of impact of LTCs on health outcomes and limitations to daily living, and resultant interaction with health and care services

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In order to feasibly produce a JSNA for July 2015, the scope of this work needs to be further defined. Three alternative options in defining the focus of this work have been considered, and the issues and implications within each of these approaches are described below.

Option 1: Focus on specific disease conditions

To provide informative data to advise strategic decision making, conditions need to be distinguished due to the level of precision in health data e.g. the ICD-10 coding. For example cardiovascular disease on aggregate has the highest attributable mortality in Cambridgeshire but represents an array of clinical conditions, with their own protocols for care management. Evidence shows there is no consensus around disease clusters, and that it is not appropriate to group conditions in reviewing epidemiological data. So there is an inherent requirement to select specific conditions of interest.

There are a range of potential criteria that might be used in drawing up a shortlist of conditions to consider in detail, including:

- High prevalence or incidence in Cambridgeshire
- High impact on the individual (duration, severity, limitation)
- High impact on the care system (admissions, bed days, cost of services provided)
- High impact on society (including indirect costs)
- Conditions not covered elsewhere in JSNAs, existing strategies or priorities or national programmes
- Conditions where interventions would have significant cost savings to health and social care

By selecting several, perhaps five or six, prioritised conditions to review in detail (whichever rationale is used), there is an opportunity to draw key findings describing potential areas for important service improvements for certain patients. The limitation is that these detailed findings may not be generalisable to others in the population with LTCs. For example, the requirements for certain elements of care, such as pulmonary rehabilitation, pertain to one clinical diagnosis.

In line with an increasing emphasis on person-centred approaches as an integral part of a high quality care, local stakeholders have expressed a preference for information on managing care around the person rather than the condition(s) they have. While a level of detail on specific conditions could prove more informative for health care partners, it will be less useful for social care stakeholders, as bearing on the social care system is determined by functional limitations rather than diagnoses, nor so valuable for third sector and other local organisations supporting those living with LTCs as information to support a holistic care approach. Qualitative views from people with long term conditions and their carers strongly advocate a more personalised approach. This option of focussing on a few conditions is therefore not recommended.

Option 2: Focus on particular sub-population groups

(a) Children and young people with LTCs

Children and young people with long term conditions have very specific needs which are addressed by services and systems, as well as legal and ethical frameworks, that are distinct to adult services.

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A young person will commonly have a single LTC which will require specialised attention responsive to the needs and in keeping with the development of the child. Therefore developing general approaches that will be applicable to adults with a range of LTCs and address multimorbidity, including promoting principles of self-care, will be inappropriate to managing a LTC in a young person. The trajectory of child-onset conditions is different to many adult-onset LTCs, for example asthma, with the highest incidence rates of asthma occurring in early childhood⁵, and three quarters of school-aged children with asthma outgrowing the condition by mid-adulthood⁶.

It is therefore not recommended that this JSNA aims to address both adult-onset and child-onset LTCs as these are distinct population groups with distinct prevalent disease as well as clinical and care needs. Combining them in a single JSNA would do neither the justice each group warrants.

It is recommended that this JSNA focuses on adult-onset LTCs and building on the work of the primary prevention JSNA⁷, presents population-wide opportunities for intervention and preventive strategies across the lifecourse. A lifecourse perspective on supporting the modification of risk factors, and instilling a person-centred approach within care provision, would nonetheless potentially offer some transferable learning to those working with children and young people and the approach set out for adults may be applicable to young people making the transition to adult services.

This approach focussing on adult-onset LTCs has been endorsed by our stakeholders. The current and future planned work in collaboration with C&P CCG on childhood LTCs will aim to address need in this population group at the level of detail it deserves.

(b) End of life care

Important and valuable work has been done recently within a C&P CCG workstream on end of life care, thus it is determined that this JSNA would not provide additional intelligence and end of life care is not recommended for inclusion here.

Option 3: Focus on risk, complexity and care management approaches

This option makes use of a framework for describing the population of people with LTCs. One framework is to represent the management approaches across the population. The model below is a hybrid of the model from Kaiser Permanente (a US chronic conditions care provider)⁸ and the model developed within the C&P CCG Older People Adult Community Services outcomes framework⁹. This model divides the LTC population into those requiring 'case management'; 'disease management' and 'supported self-care'.

⁵ Reed (2006) Journal of Allergy and Clinical Immunology 11(3): 543-548.

⁶ Bisgaard (2010) Journal of Allergy and Clinical Immunology 126(2): 187-97.

⁷ Available at: <http://www.cambridgeshireinsight.org.uk/primary-prevention-ill-health-older-people2014>

⁸ As presented in the 2006 University of Birmingham Health Services Management Centre Report: 'Improving care for people with long term conditions – a review of UK and international frameworks' for the NHS Institute for Innovation and Improvement.

⁹ Outcomes Framework Mark 3 document available at:

<http://www.cambridgeshireandpeterboroughccg.nhs.uk/pages/older-peoples-programme.htm>

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(a) The most complex patients with LTC

One option is to focus on the most complex patients.

It is estimated that about 5-10% of the population with long term conditions have the highest demands on the health and social care system, with more frequent consultations in primary care, admissions to hospital, and continuing health care. These individuals require complex (and often multidisciplinary) care management across community and acute sectors. Some of the reasons for this have been described in Older Services Financial Review (2012)¹⁰ and the chapter on admissions avoidance in PIHOP (2013)¹¹ and in ongoing analysis to inform demand management approaches.

There could be benefits in providing further intelligence on care management for the highest risk patients, particularly in light of the cost pressures on service provision, for example in considering the evidence to mitigate winter pressures. There may also be further opportunities to explore the provision of public health advice to inform workstreams on the management and care of frail older people and the development of integrated care pathways.

However, a focus on those already receiving the highest levels of support might prove less informative than alternatives. The main implication of a focus on the most complex patients is that the opportunities for early intervention and prevention to improve health outcomes may be limited recognising the severity and complexity of conditions. This focus would reduce the ability to draw conclusions for the wider population of those with LTC including self-management principles and the reduction of risk factors. It would not identify opportunities to invest resources earlier and prevent escalation in a situation and the support required, and thereby not meet the priorities and needs of commissioners. A detailed commentary to support the clinical management of complex disease is beyond the remit of JSNA work. This option is therefore not recommended.

¹⁰ Available at: <http://www.cambridgeshireinsight.org.uk/currentreports/jsna-older-peoples-services-and-financial-revie>

¹¹ Available at: <http://www.cambridgeshireinsight.org.uk/joint-strategic-needs-assessment/current-jsna-reports/prevention-ill-health-older-people-2013>

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(b) High risk patients with LTC

The option of focussing on those at high risk and requiring disease management has been identified as prospectively the most informative approach, with the highest potential impact on health and care outcomes, for example in reducing admissions. This option is therefore advocated by the working group and is discussed below in detail as the proposal for the scope of this JSNA.

4. PROPOSED SCOPE

In consideration of the possible approaches described, and informed by ongoing consultation with our key stakeholders, **the working group propose that this JSNA is thematically scoped to particularly focus on care management for high risk people with adult-onset LTCs.**

These are adults of all ages with high risk of poor health outcomes and costs, but that may not be currently known to acute health or long-term social care services despite being at higher risk of (avoidable) admissions to such services, and where improvements to their management may offer significantly improved outcomes for them as individuals, the community that support them, and to those providing services.

These people are living in the community and this focus would explore evidence-based approaches to keep them independent, safe and well, and opportunities for early intervention to improve the management of their LTC. This population are described in the second layer of the pyramid model above within a 'disease management' approach.

The JSNA would take a lifecourse approach in highlighting the role of prevention across the lifespan as requested by our stakeholders, including the ongoing modification of lifestyle behaviours for health improvement, but particularly centering on secondary prevention (prevention aimed at preventing progression of disease e.g decreasing second heart attacks, congestive heart failure, or complications of diabetes) of adult-onset LTCs.

There would be an opportunity to consider the role of early intervention in responding to the triggers of social care need that have been identified in Cambridgeshire, and avoiding escalation of the needs of an individual. For example, older people with LTC may have numerous risks of injury from falls due to polypharmacy, impaired cognition, impaired mobility, and other falls-related risks. Therefore evidence-based information on prevention and early intervention would link into work to improve falls prevention and care pathways, and other workstreams to facilitate independent living.

The recurring theme of empowerment, recognising people as experts in their health and supporting co-production for improved management of their conditions and health would be considered. Findings on approaches to improve the support of self-management of LTCs may also be extrapolated to the majority LTC population, and beyond to the wider population in terms of reducing risk behaviours, where principles are identified that enable people to make health-informed lifestyle choices.

The proposed scope explains how this JSNA will focus on LTCs across the lifecourse. The JSNA will provide detail on the impact of LTCs in adults and older people. The JSNA will highlight opportunities for modification of risk factors and prevention of the escalation of needs.

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There would be opportunities to explore common care principles across those with multimorbidity and limitations to daily living, who have poorly managed conditions, through reviews of the literature, policy and guidance. Offering evidence-based approaches and local intelligence on providing the right care in the right place at the right time to those with LTCs would support the wider work of partner organisations. For example, this JSNA could provide timely and relevant intelligence to inform the design and implementation by a new provider of Older People and Adult Community Services.

With this approach, therefore the JSNA would be able to consider the following cross cutting themes:

- Multi-morbidity (people with LTCs more frequently have more than one LTC, therefore at higher risk of adverse outcomes and implications for approaches to care)
- Limitation (noting that those with limiting LTCs are the most intensive users of expensive services with increased levels of dependence)
- Pain and Mental health (including their impact on other LTCs)
- Inequalities (to ensure equality in access, health and wellbeing)
- Risk factors across the life course (to achieve health gains and reduction of the impact of LTCs)
- Models of care (and risk stratification or risk identification approaches to identify opportunities for integrated and person-centred approaches to care) – where appropriate these may include examples of a risk identification approach for a specific disease e.g. diabetes

In addition, detail on key epidemiological data, health and social care service availability and use for specific conditions would be included to complement this JSNA. This would provide intelligence to inform future health and social care planning and support broader workstreams, recognising the benefit of providing local up-to-date detail for our stakeholders. Data and commentary would be prepared for the conditions of highest local prevalence including cardiovascular disease, diabetes, COPD, neurological conditions, and infographics used to support their dissemination. There is the opportunity for flexibility in providing data analysis for other conditions and diseases as requested to meet the particular requirements of a range of stakeholder workstreams. However a detailed exploration of the quality standards, preventative opportunities, care packages and evidence-based recommendations for each of the specific conditions would fall beyond the scope of this JSNA.

There is a further need to analyse broader issues affecting people with LTCs including employment, income and financial wellbeing, housing, and transport. These themes would fall beyond the remit of this JSNA, but are acknowledged as enablers of independence, improved health and care outcomes and are addressed within other JSNA work; appropriate cross referencing will be used.

In conclusion the proposed scope is to focus the JSNA on LTC across the lifecourse on the improvement of integrated management and care for adults with long term conditions, highlighting the opportunities for prevention and avoiding escalation in health and care needs. The JSNA work will explore the principles of empowerment and self-care, and indicate findings on potential improvements to enable person-centred and high quality care. The overarching objective is for the JSNA to provide valuable information to the health and social care system, and to improve health outcomes of the population of people with LTCs across Cambridgeshire.

5. RECOMMENDATIONS

The Health and Wellbeing Board is asked to approve the proposed scope of the Long Term Conditions JSNA as outlined in Section 4.