



Long Term Conditions across the Lifecourse

JSNA

2015

CONTENTS PAGE

Executive Summary	3
1. Introduction	18
1.1. Context – what is the background to this JSNA?	
1.2. Scope – what is the focus of this JSNA and why?	
1.3. Process – how has this JSNA been produced?	
1.4. Structure – how is this JSNA report organised?	
2. LTCs across the lifecourse	23
2.1. What are LTCs?	
2.2. A lifecourse approach to LTCs	
2.3. Lifecourse approaches and socioeconomic differences	
2.4. Lifecourse approaches to specific LTCs	
2.5. What is this telling us?	
3. LTCs in the population: characteristics of those at high risk of poor health outcomes	31
3.1. Describing the ‘high risk’ group	
3.2. Multiple Conditions	
3.3. Limitation, pain and mental health	
3.4. Specific conditions of interest	
3.5. What is this telling us?	
4. LTCs in Cambridgeshire: describing the population at high risk of poor health outcomes	53
4.1. Working with the data on LTCs for Cambridgeshire	
4.2. Estimates of numbers and proportions in adults and older people with multiple conditions in Cambridgeshire	
4.3. Estimates of numbers and proportions of people with LTCs with overlapping limitation and mental health	
4.4. Characteristics of groups at higher risk	
4.5. Which populations in Cambridgeshire are disproportionately at risk?	
4.6. What is this telling us?	
5. Living with LTCs : local views on improving care	67
5.1. Gathering local views	
5.2. Challenges facing people with LTC in Cambridgeshire	
5.3. Local solutions and opportunities proposed	
5.4. What is this telling us?	
6. Care management for the population with LTCs: the House of Care	73
6.1. Policy context for care management: the house of care model	
6.2. Person-centred care	
6.3. What is this telling us?	
7. Improving care management: targeting and intervening	82

7.1. Identifying high risk patients: diabetes case study	
7.2. Evidence-based approaches that prevent escalation of health and care needs	
7.3. Evidence for the inclusion of mental health interventions in the management of physical conditions	
7.4. Local examples of care management of the high risk population	
7.5. What is this telling us?	
8. Improving care management: supporting self-management	103
8.1. Self-management	
8.2. Evidence for interventions to support self-management	
8.3. Population groups requiring additional support with self-management and care planning	
8.4. Local and national assets for supporting self-management	
8.5. What is this telling us?	
9. Key Findings & Conclusions	120

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LOCAL VIEWS – THE VOICE OF LOCAL PEOPLE WITH LTCS

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EXECUTIVE SUMMARY

1. INTRODUCTION – CONTEXT AND SCOPE

The Cambridgeshire Health and Wellbeing Board have requested a Joint Strategic Needs Assessment (JSNA) on Long Term Conditions (LTCs) across the lifecourse. 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. Nearly a third of people in Cambridgeshire (31.7%) reported having at least one LTC¹ in the GP survey, and the 2011 census found that 90,420 people (15.1% of household residents) reported a long term activity-limiting illness.²

The JSNA is focussed on adults and older people with LTCs who may be considered 'at-risk' of poor health outcomes (such as admission to hospital or increased need for care). These individuals may not be currently known to acute health or long term social care services, despite being at higher risk of admissions to such services. Improvements to the management of their care may offer significantly improved health outcomes for them as individuals, the community that support them, and to those providing services.

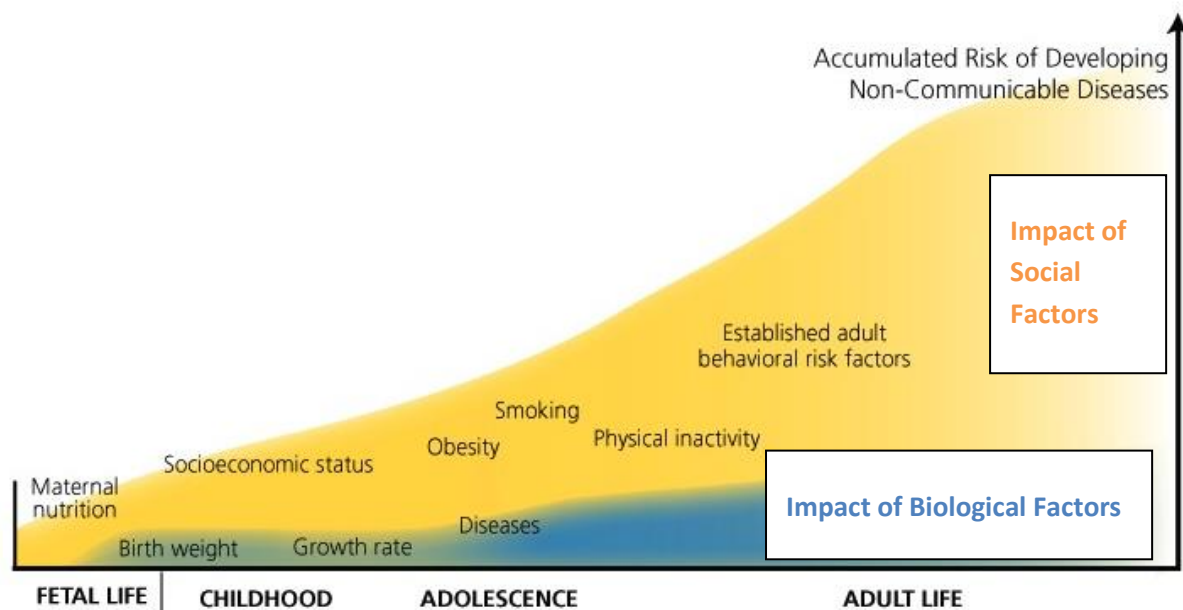
Therefore, evidence to inform understanding has been collected, synthesised and analysed from epidemiological population data, qualitative evidence on the views of local patients and carers, and reviews of the literature and policy related to care management. Initial findings were presented to stakeholders in May 2015 and the jointly identified key findings are described in this summary.

2. LTCS ACROSS THE LIFECOURSE

A lifecourse approach to LTCs explicitly recognises the importance of time and timing in understanding causal links between exposures and outcomes across the lifecourse at a population level. LTCs develop over a long period of time and similarly, many important adult risk factors for LTCs (poverty, smoking, diet, physical activity) also have their own natural histories. Thus by adopting a lifecourse approach to LTCs a range of potential interventions, which includes the wider determinants of health, that could reduce the risk of development of a condition or improve health outcomes is a useful and holistic population health approach. Adopting a lifecourse approach does not focus only on the recognition of early-life influences, as the majority of adult LTCs are longer-term consequences of the complex accumulation and interaction, of early and later-life exposures. A lifecourse perspective on LTCs relies on a multidisciplinary framework for understanding how early- and later-life biological, behavioural, social, and psychological exposures affect adult health.

¹ LTC dashboard NHS England | 2013/14 GP Survey data, response rate 34.3%

² Defined as an illness lasting at least 12 months, with any limitation. 2011 Census, ONS

Figure A: Cumulative risk factors for long term conditions

Source: Adapted from Darton-Hill et al, 2004

By maintaining a lifecourse approach we are also able to explore the impact of age, sex, ethnicity, socio-economic status and other wider determinants of health that clearly impact on LTCs. For example, a systematic review summarising five studies consistently showed an inverse association between socioeconomic status and the presence of more than one LTC. Studies have highlighted that young and middle aged adults living in the most deprived areas had rates of multimorbidity equivalent to those aged 10-15 years older in the most affluent areas. In addition, those in the most deprived areas were more than twice as likely to have a mental health disorder compared to those in an affluent area.

This JSNA aims to complement the work and findings of the Primary Prevention JSNA which together describe local need and identify opportunities for intervention in response to LTCs across the lifecourse.

3. LTCS IN THE POPULATION: CHARACTERISTICS OF THOSE AT HIGH RISK

This JSNA is thematically scoped to particularly focus on care management for high risk people with adult-onset LTCs representing 10-15% of the population with LTCs. In discussion with local stakeholders, the key characteristics that described people with LTCs with an increased risk of poor health outcomes were determined as:

- Multiple long term physical and mental health conditions.
- Important level of limitations, such as in activities of daily living (ADL).
- Living with a significant level of pain.
- Experiencing depression and/or anxiety.

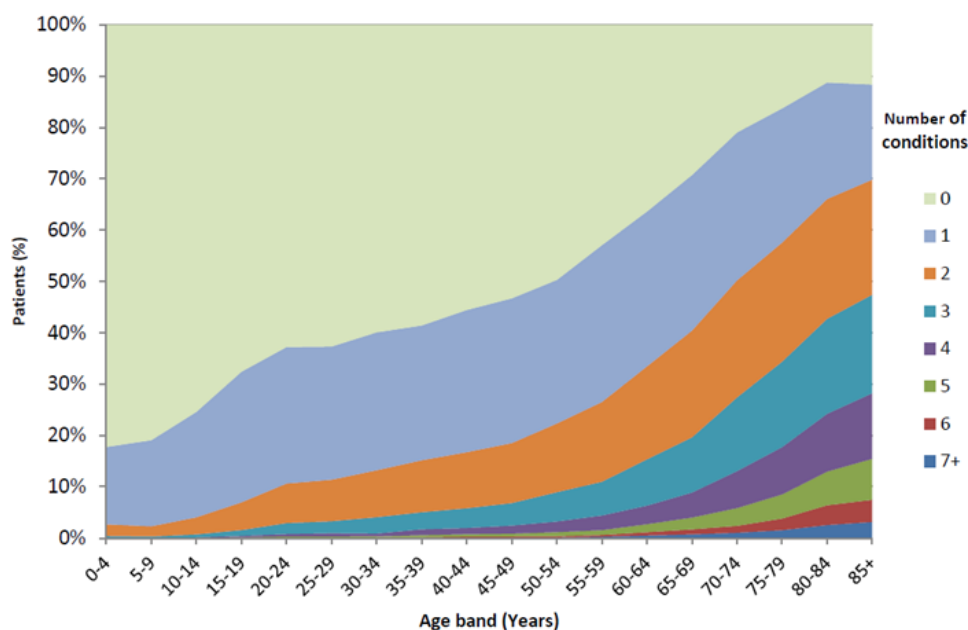
The Department of Health estimates that those with multiple LTCs are due to rise from 1.9 million in 2008 to 2.9 million in 2018. The definition of multimorbidity (usually as the co-existence of two or more LTCs) is not applied uniformly in studies which vary by:

- Which health conditions are included and how they are categorised.
- Whether mental health issues are included within multiple conditions or looked at separately.
- Whether two or more conditions, or three or more conditions, should be used as a cut off for multiple conditions.
- Whether acute conditions should be included as well as chronic conditions, and what is the definition of a chronic condition (eg three months or 12 months).
- Whether severity of disease should also be included.

A recent high quality systematic review of 39 prevalence studies found the prevalence of multimorbidity varied from 12.9% in participants 18 years and older, to 95.1% in a population aged 65 years and older; as studies were not comparable, no summary measure was provided.

The overall prevalence of multimorbidities consistently increases with age, especially after the age of 40. Two large, population-based studies show that the number of chronic conditions an individual has also increases with age, with many of those in the older age groups having 4 or more conditions, shown in figure B. The prevalence of multimorbidity tends to be higher in women.

Figure B: The number of chronic conditions by age group



Source: Kasterdis et al. 2014³

³ Kasterdis P, Street A, Dolman M et al (2014) The Importance of Multimorbidity in Explaining Utilisation and Costs Across Health and Social Care Settings: Evidence from South Somerset's Symphony Project

There are few consistent patterns from studies assessing which disease conditions cluster together, partly due to different study populations, different condition definitions and different methods used to cluster conditions. A systematic review in older adults found depression was the disease that was most commonly clustered with other conditions (along with hypertension and diabetes). A second systematic review similarly found a large number of disease patterns but grouped these into three main patterns:

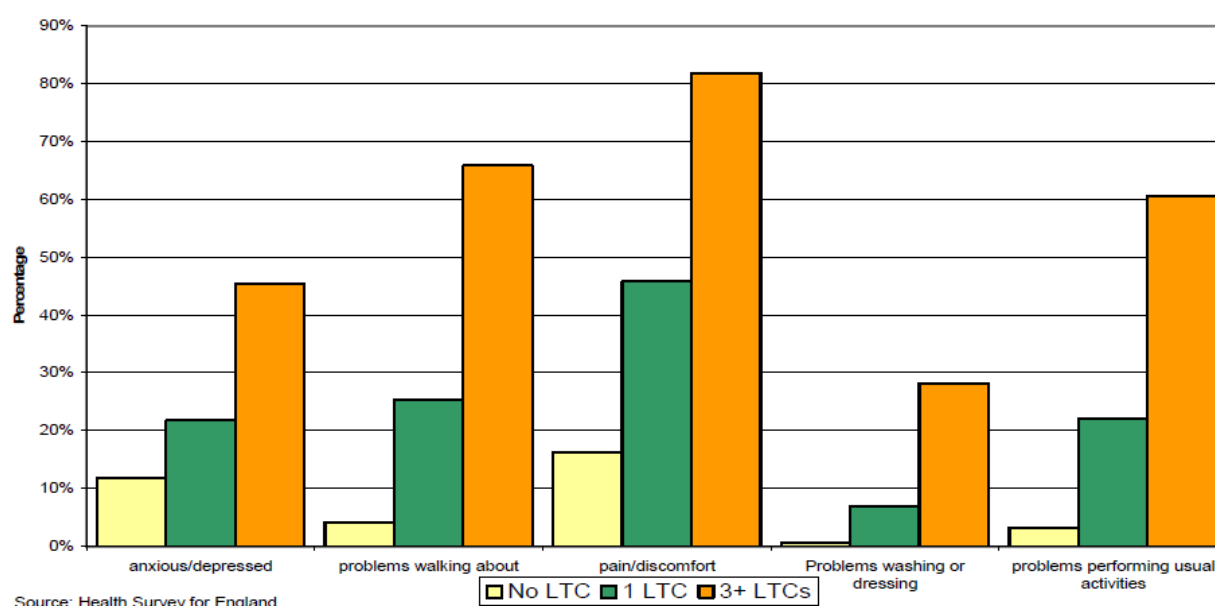
- Cardiovascular and metabolic disorders
- Conditions including at least one mental health disorder
- Conditions including at least one musculoskeletal disorder

South Somerset's Symphony Project found that some conditions are more likely than others to be diagnosed in combination with other diseases. For example, almost 50% of those with asthma have no other condition, whereas only 10% of those with a stroke or COPD have no other condition and more than 50% have more than three conditions.

An analysis by the Department of Health shows the increases in health and social care costs as the number of LTCs an individual has increased. A comprehensive analysis of individual level data including primary, community, acute, mental health and social care data in South Somerset identified that the average cost per patient increases considerably with every additional chronic condition. The marginal increase in average costs initially rises the more conditions are recorded. For example the average cost of those with two conditions is £860 more than for those with one condition, and this increases to a difference of £1,820 between those with 4 and those with 3 conditions. However beyond this point, the marginal cost increases become smaller.

The Department of Health analysis of limiting LTCs demonstrates that those with limiting LTCs are the most intensive users of expensive services and have an increased likelihood of not working.

Chronic pain is an important mediator of a reduced quality of life for people with LTCs. People with multiple conditions are particularly severely affected. An analysis of the EQ-5D (measure of health outcomes) in the Health Survey for England found that almost half of all people with a LTC report moderate or extreme pain, rising to 80% of people with three or more conditions (Figure C).

Figure C: Health Survey for England data on impact of 0, 1 or 2 LTCs

Source: Health Survey for England

Common mental disorders are highly prevalent with long term conditions.⁴ The Kings Fund 2012 evidence review found research evidence consistently demonstrates that people with LTCs are two to three times more likely to experience mental health problems than the general population, with much of the evidence relating to affective disorders such as anxiety and depression. Compared with the general population, people with diabetes, hypertension and coronary artery disease have double the rate of mental health problems, and those with COPD and cerebrovascular disease have triple the rate. There is also evidence for higher than usual levels of mental health problems among people with other conditions including asthma, arthritis, cancer and HIV/AIDS. Data from World Health Surveys indicates that people with two or more LTCs are seven times more likely to have depression.¹

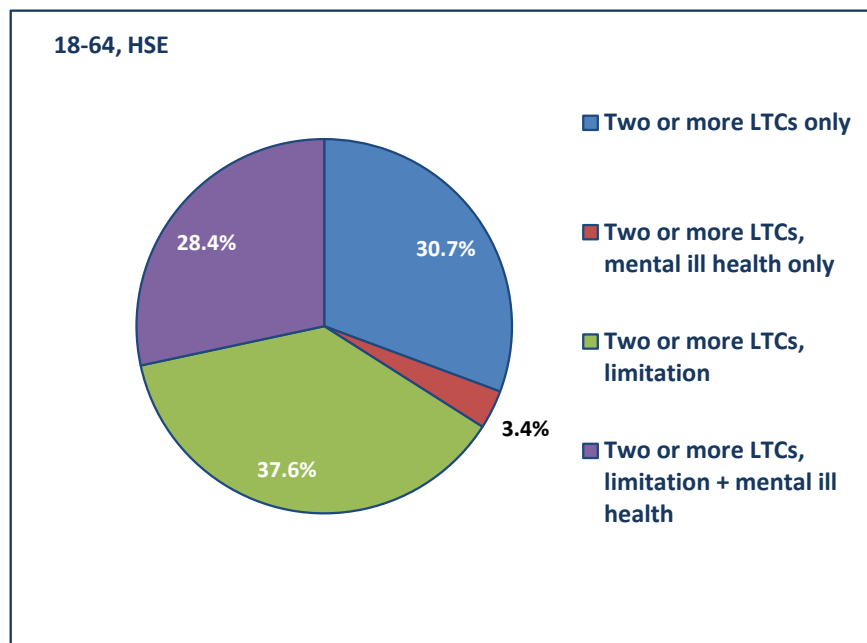
4. LTCS IN CAMBRIDGESHIRE

For the adult population aged 18 to 64 years, we have analysed individual level data from the Health Survey for England (HSE 2012) and applied those results to the local Cambridgeshire population. In terms of health conditions the survey is all inclusive – during the face to face interview, participants report any longstanding illnesses and specify up to six conditions. A longstanding illness is defined as any physical or mental health condition or illness lasting or expected to last 12 months or more. If a longstanding illness reduces participants' ability to carry out day-to-day activities, either a little or a lot, it is considered a limiting longstanding illness. Mental health status in the 2012 survey was measured by GHQ-12 score with a score of four or more representing probable mental ill health. Because mental health conditions were also included as a long standing illness (self-reported) the analysis adjusted this for the count of LTCs.

⁴ Department of Health (2013a) Annual Report of the Chief Medical Officer *Public Mental Health Priorities : Investing in the Evidence*

Results for the adult population show that 9.8% of people reported two or more longstanding illnesses. This equates to over 39,000 people in Cambridgeshire. The number of people aged 18 to 64 years estimated to have two or more LTCs and who report limitation is around 14,700 people. When mental ill health is considered as well (Figure D) around 11,000 people report two or more LTCs, with limitation and with mental ill health as defined by a GHQ-12 score of 4 or more.

Figure D: Proportion of people aged 18 – 64 years with multiple (two or more) long standing illnesses with and without limitation and/or mental ill health (based on GHQ-12 score of four or more)

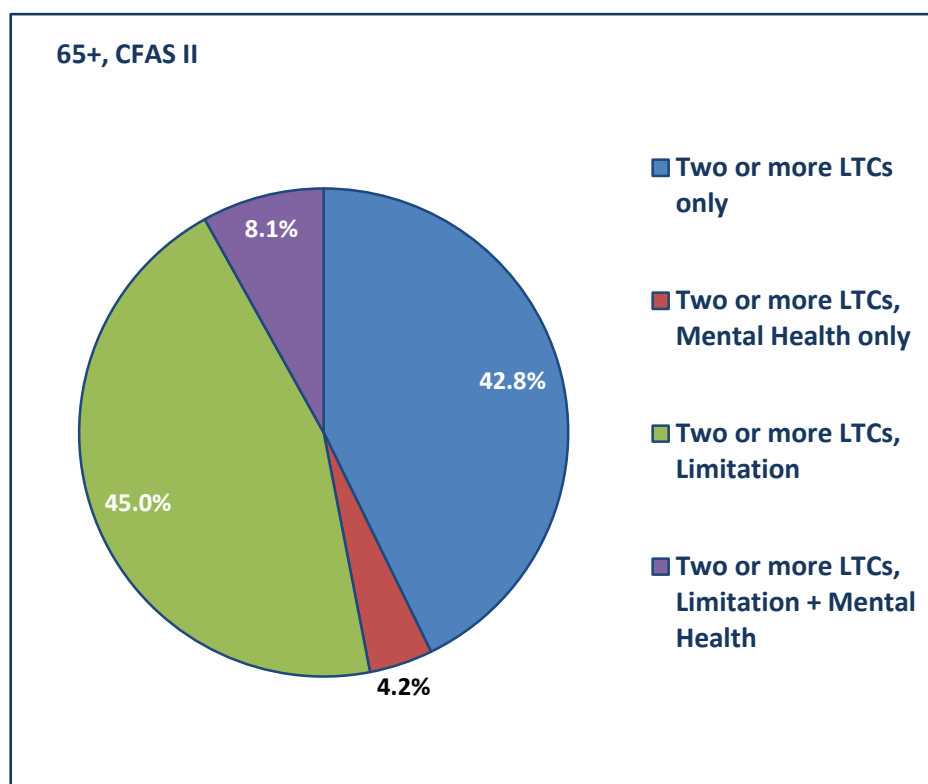


Source: Health Survey for England (2012) survey estimates. Note: count of illnesses excludes self-reported mental health conditions and probable mental ill health is based on GHQ-12 score of four or more.

For the older population aged 65 and above, we have had the opportunity to use local data from the MRC Cognitive Function and Ageing Study (CFAS II). We used the Cambridgeshire centre sample from CFAS II. For the purpose of this JSNA, we selected the following conditions as LTCs: Angina, Intermittent Claudication, Hypertension, Cancer, Diabetes, Parkinson's Disease, Stroke, Myocardial Infarction and Chronic Obstructive Pulmonary Disease (COPD), Asthma, Arthritis and Thyroid problems.

Figure E shows that 45% of people aged 65 and over with two or more LTCs experience limitation. Applied to the Cambridgeshire population, this suggests around 29,800 people aged 65 and over with two or more LTCs and limitation, an additional 2,800 people with mental ill health and an additional 5,400 with multiple LTC, limitation and mental ill health (dementia, anxiety and depression). In total, it is estimated that 66,200 people aged 65 and over in Cambridgeshire have two or more LTCs.

Figure E: Proportion of people aged 65 and over with multiple (two or more) LTCs with and without limitation and/or depression or anxiety (based on GMS AGECAT)

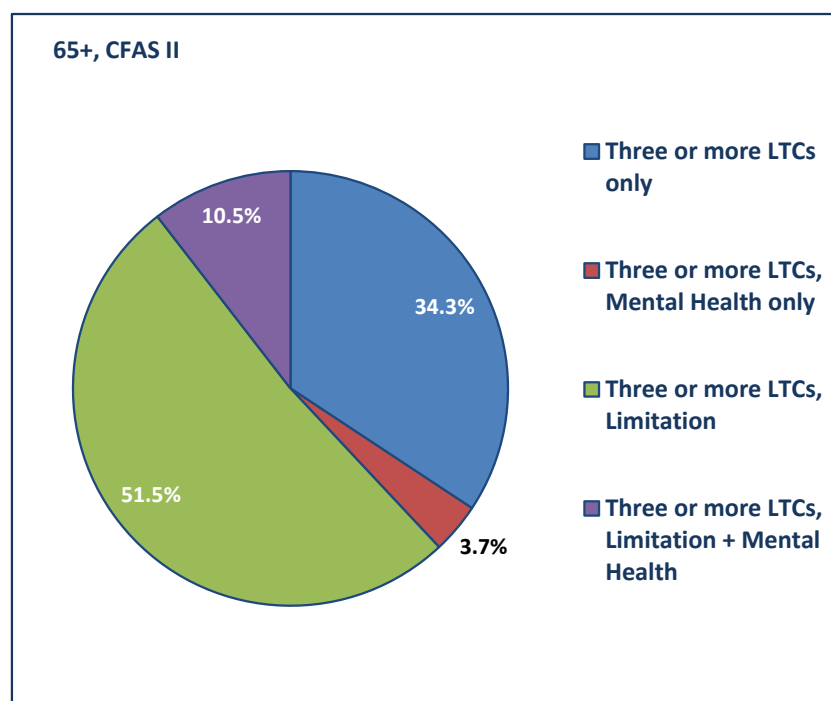


Source: MRC Cognitive Function and Ageing Study (CFAS II) (100% = people with 2+ LTC)

The analysis in older people was extended to those with three or more long term conditions in order to discriminate further.

Over 51% of those with multiple (three or more) LTCs experience limitation (Figure F). Applied to the Cambridgeshire population, this suggests around 17,700 people aged 65 and over with multiple LTC with limitation, an additional 1,300 people with mental ill health and an additional 3,700 with multiple LTC, limitation and mental ill health (primarily dementia, anxiety and depression). In total, it is estimated that 34,700 people aged 65 and over in Cambridgeshire have three or more LTCs.

Figure F: Proportion of people aged 65 and over with multiple (three or more) LTCs with and without limitation and/or depression or anxiety (based on GMS AGECAAT)



Source: MRC Cognitive Function and Ageing Study (CFAS II)

Further data are presented in the JSNA which describe the population with multiple conditions, limitation and mental health conditions in terms of their demographic characteristics (age, sex, socioeconomic status).

5. LIVING WITH LTCS: LOCAL VIEWS

As experts by experience, the voice of people in Cambridgeshire living with LTCs, and their carers, is absolutely essential to this JSNA. A range of workshops and partnership working was organised with the priority of ensuring that views were represented fairly, capturing in-depth qualitative information with a targeted range of groups. Through this careful engagement, views were heard from at least 30 individuals who are local patients and carers. Where details were collected, participants varied in age from 44 to 87 years, 71% were female. Their disease profiles included diagnoses asthma; COPD; type 2 diabetes; osteoarthritis; fibromyalgia; depression; arthritis; cancer and multiple sclerosis. The information collated was synthesised to identify emergent themes.

Contributors detailed challenges and difficulties that they faced including the sheer impact of the physical, emotional and mental health symptoms, including pain and fatigue. Many are also providing care for family and friends with even more complex needs, and experience the complexity of balancing caring responsibilities with their own health issues. Both patients and Carers stated that they have not often felt that their expertise is respected by healthcare professionals. Much of the discussion centred on the interactions with health and care services for people with multiple conditions; there were notable frustrations for a perceived lack of care co-ordination for multiple physical and mental health conditions, for example in managing multiple medications.

There are also wider impacts on quality of life associated with living with LTCs and stakeholders highlighted some of these concerns, including managing household tasks, getting out and about, financial and practical issues, and a lack of knowledge of what is available in the community for support or social opportunities. Local contributors were also able to give examples of good practice that they had experienced, and their wish list of step changes that would make a significant difference to their care. These included:

- Being listened to and expertise recognised.
- Having a single point of access to care when they need it.
- Experiencing timeliness and flexibility in terms of their health and care.
- Valuing high quality care and support from health staff.
- Being given more information about what support is available.
- Support with self-management and for managing emotional symptoms and pain.

When these perspectives are viewed in the round, the dominant theme for the health and care system that emerged is that there is a level of fragmentation, a lack of communication between different services and providers of care and a very broad web of care that people with LTCs interact with; this can mean that coordination is difficult and care is not optimal. The vast majority of the solutions proposed by local individuals, and similarly echoed by community organisations, fit an overarching approach of developing and extending flexible, coordinated, person-centred care for people with LTCs and their carers in Cambridgeshire.

6. CARE MANAGEMENT: THE HOUSE OF CARE

Simon Stevens' Five Year Forward View states that 'LTCs are now a central task of the NHS; caring for these needs requires a partnership with patients over the longer term rather than providing single, unconnected "episodes" of care'. There is a clear recognition that the NHS needs to adapt to meet the challenges of the future and that the management of LTCs is a key part of this. NHS England has identified a set of key areas for action to be taken forward in partnership with Clinical Commissioning Groups and other partners such as Local Government:

- Helping patients take charge of their care
- Enabling good primary care
- Ensuring continuity of care (better integration of care and information sharing across organisational boundaries)
- Ensuring a parity of esteem for mental health
- Reducing avoidable emergency admissions

NHS England recognises that care needs to be designed and implemented around the individual, and so has adopted the King's Fund 'House of Care' model as a framework to describe the components of personalised care (Figure G). The 'House of Care' is a co-ordinated service delivery model which is designed to deliver proactive, holistic, preventive and patient-centred care for people with long term conditions.

Figure G: The House of Care Model

The house of care metaphor is used to illustrate a whole-system approach, emphasising the interdependency of each part and the various components that need to be in place to hold it together. The house relies on four key interdependent components, all of which must be present for the goal, person-centred coordinated care, to be realised:

1. *Commissioning* – which is not simply procurement but a system improvement process, the outcomes of each cycle informing the next one.
2. *Engaged, informed individuals and carers* – enabling individuals to self-manage and know how to access the services they need when and where they need them.
3. *Organisational and clinical processes* – structured around the needs of patients and carers using the best evidence available, co-designed with service users where possible.
4. *Health and care professionals working in partnership* – listening, supporting, and collaborating for continuity of care.

The model is different from other approaches as it encompasses all people with long-term conditions, not just those with a single disease or in high-risk groups, and it assumes an active role for patients, with collaborative personalised care planning at its heart. Two other, more structural components of personalised care have also been identified by NHS England:

- Risk stratification and case finding – how to segment a population and provide person-centred care to those most in need recognising resource constraints.
- Multi-disciplinary team working – how health and care professionals work together to support people with complex care needs.

7. IMPROVING CARE MANAGEMENT: TARGETING AND INTERVENING

It appears clear that health and care services should take a population-level 'care management' approach that, whereby particular patients felt to be 'high risk' are identified for proactive care, however there are important considerations, which are discussed in this chapter. The chapter:

- Reviews methods that are available to identify 'high risk' patients
- Reviews the evidence on interventions that are effective in preventing adverse outcomes
- Considers the effectiveness of mental health strategies within specific LTC care pathways
- Provides examples of local care management assets.

Several methods can be used to identify patients that are high risk and might theoretically benefit from an intervention or care management approach:

- **Clinical Experience:** Clinicians and other healthcare professionals are able to draw from the full richness of information obtained through a person-to-person encounter, particular if they have ongoing contact with an individual patient over a period of time. A key problem, however, is that effectiveness at a population level relies on patients having contact with a health service at an appropriate stage, which in itself indicates a level of active involvement in care management that may reduce future risk.
- **Thresholds:** This approach uses previously defined criteria that define or describe high risk patients. This approach is conceptually straightforward and can help to ensure costly interventions are reserved for those most in need. However, this approach essentially waits for individuals to become more unwell before intervening, which means an opportunity to prevent disease progression may have been missed.
- **Predictive Modelling:** This is a data-driven approach, which seeks to establish statistical relationships between sets of variables in order to predict future outcomes. The tools tend to be run periodically on a large cohort of patients, with the tool 'flagging' those emerging above a certain pre-defined level of risk and who can be considered for referral to an intervention. These tools are commonly used in conjunction with case management programmes or 'virtual wards' for the highest risk patients. Predictive modelling remains part of the national policy approach to managing LTCs and some evidence suggests predictive models are superior to both threshold approaches and clinician experience in identifying patients at risk of future hospital admissions.
- **Patient Activation:** Patient activation' is a concept that describes the knowledge, skills and confidence a person has in managing their own health and health care. Patient activation is changeable and can be increased through interventions, which generally focus on the development of skills and on building confidence. Effective interventions tend to be tailored to an individual's level of activation. For instance, tailored coaching attempts to meet patients where they are and tailor support to their activation level. Patient Activation Measures (PAM) could be used together with clinical information to identify individuals who are not currently high risk but who are likely to need greater or lesser levels of support to remain that way:

PAM level	Disease burden	
	Low	High
High	Electronic resources	Electronic resources and peer support
	Usual team members	Usual care team
	Focus on prevention	Focus on managing illness
Low	High-skilled team members	High-skilled team members
	Focus on prevention	More outreach
		Focus on developing skills to manage illness

Although “managing demand” and reducing unplanned as well as elective hospital admissions and admission to care is a clear priority, we have yet to achieve much success in attaining these reductions and avoiding admissions. The problem is complex and there are many causes, with issues around population demographics, acute and community care, and the wider environment contributing to the challenge of reducing admissions and preventing escalation of needs. In view of these factors this section aims to provide an overview of the current evidence exploring interventions to prevent hospital admissions and admissions to care settings. In the final section of this Chapter, the evidence will be brought together in a proposed model. Wherever possible, we refer to evidence from systematic reviews and robust national guidance documents rather than individual studies. This section will not include interventions focused on the clinical management of diseases – for example, pharmacological agents.

Understanding which admissions are avoidable also aids in targeting interventions and resources. Ambulatory or primary care sensitive conditions (ACSCs) are those for which hospital admission could be prevented by interventions in primary care. A recent report by the King’s Fund identified interventions where there is evidence of an impact on hospital admissions:

- Continuity of care with a GP
- Hospital at home as an alternative to admission
- Assertive case management in mental health
- Self-management
- Early senior review in A&E
- Multidisciplinary interventions and tele-monitoring in heart failure
- Integration of primary and social care
- Integration of primary and secondary care

Avoiding re-admissions is also a critical component to consider when aiming to prevent escalation of health and care need. The current health care system attempts to discharge elderly patients quicker from acute care facilities. Consequently, hospital re-admission is common; however, re-admission may be only one aspect of important adverse outcomes, particularly when considering the impact on social care. There is strong evidence that an individualised discharge plan for hospital inpatients is more effective than routine discharge care that is not tailored to the individual.

Complementing the evidence base, National Expert Panels have recommended the following key approaches to reducing and preventing unplanned hospital admissions:

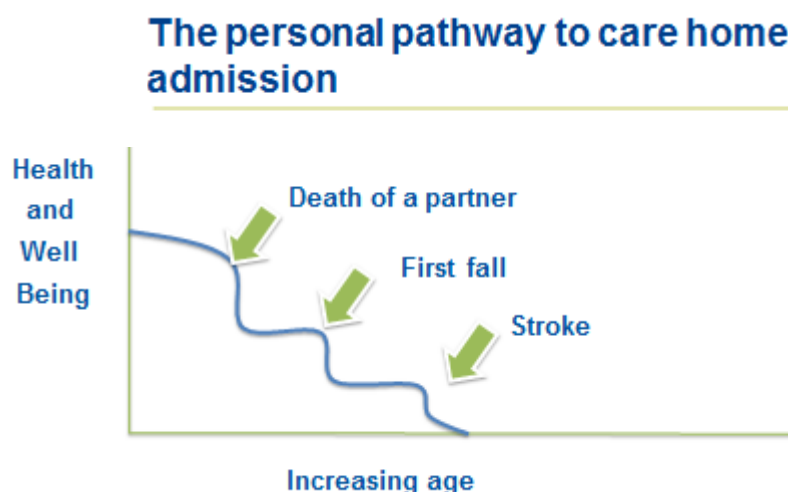
- Direct delivery of rapid access care in the community
- Access to rapid response nursing and social care at home
- Intermediate care and acute nursing home beds
- Mental health crisis teams
- Rapid access specialist clinics
- Increased nursing home capacity for acute illness.

There is a clear link between hospital admissions and subsequent admission to care home with more than 30% of older people previously living at home in the community being discharged to a care setting after a hospital admission. This figure doubles for people living with dementia. Most of the literature exploring admissions to care homes focusses more on identifying the risk factors that are associated with increased risk of admission to care homes settings, thereby providing options for targeted intervention. Critical characteristics, circumstances and events which lead to a care home admission include (in order of highest prevalence):

- Urinary incontinence
- Dementia
- Bowel incontinence
- Depression
- Visual impairment
- Stroke
- Diabetes
- COPD
- Learning disability

In addition factors including age, sex, ethnicity, deprivation, health service use and drugs prescribed, patterns of social care needs and usage, activities of daily living (ADL) restriction, number of family members, use of day services and people living alone (in particular, older men without partners) impacted on admission to care home. Although certain conditions are particularly prevalent, individual situations are often varied and complex. Therefore, delivering services at a population-level is challenging. Most people going into care homes do have high levels of need, however, lengthy periods of deterioration often coupled with a service interface with social care and health suggests that there are likely to be opportunities earlier along the pathway to support people to remain independent longer.

Evidence suggests that the focus in terms of reducing escalation should be on preventing specific events occurring (or managing the impacts of those specific events if they are unpreventable) exemplified in figure H.

Figure H: Patterns in care home admissions

A three-tiered model of approaching the organisation of services across the health and social care spectrum to ensure health and care needs do not escalate and to ensure a focus on reducing demand rather than meeting it include:

- Services that seek to support a person's lifestyle and engagement with their community.
- Integrated services that seek to maintain a person within the community
- Targeted interventions that aim to restore a person back to a preceding state of health and well-being.

8. IMPROVING CARE MANAGEMENT: SUPPORTING SELF-MANAGEMENT

The role of patients and carers in the day to day management of LTCs is essential, and engaged, informed patients and carers is a pillar of the house of care model. It is estimated that during each year for a person with LTCs, only a few hours are spent in the presence of health care professionals. The vast majority is 'self-care' or 'self-management' of conditions within the normal context of peoples' lives. Not all patients experience the same levels of motivation or confidence towards self-management. However the research on patient activation suggests that with effective support and education, these skills can be developed and strengthened, even among those who are initially less confident, less motivated or have low levels of health literacy.⁵

Two major evidence reviews by the NHS National Institute for Health Research on self-management support interventions⁶ include findings that:

⁵ Hibbard J, Gilbert H (2014) Supporting people to manage their health: An introduction to patient activation. The King's Fund, May 2014, London.

⁶ Taylor SJC, Pinnock H, Epiphaniou E et al. (2014) A rapid synthesis of the evidence on interventions supporting self-management for people with long-term conditions: PRISMS – Practical systematic Review of Self-Management Support for long-term. Health services and delivery research. December 2014, 2:3. Panagioti M, Richardson G, Murray E et al. (2014) Reducing Care Utilisation through Self-management Interventions (RECURSIVE): a systematic review and meta-analysis. Health Services and Delivery Research, December 2014; 2:54.

- Supporting self-management is inseparable from high-quality care for people with LTCs.
- Supported self-management must be tailored to the individual, their culture and beliefs, and the time point in the condition.
- Organisational support is crucial. Promotion of effective self-management support requires a health-care setting in which everyone believes that care should be based on shared decision-making.
- Self-management support was associated with small but significant improvements in Quality of Life, with the best evidence for diabetes, respiratory disorders, cardiovascular disorders and mental health.
- Only a minority of self-management support studies reported reductions in health-care utilisation in association with decrements in health.
- Evidence for significant reductions in utilisation following self-management support interventions was strongest for respiratory disorders and cardiovascular disorders.

Overall, there is a lack of evidence available on the impact of self-management support interventions in the context of multiple conditions. One systematic review⁷ explored the perspectives of patient with multiple chronic conditions, finding a mismatch; patients reported difficulties in dealing with physical and emotional symptoms, in particular depression, pain and fatigue, yet medical task management remained the focus of medical interventions. Nonetheless, many researchers hold the view that people with multimorbidity may gain more from self-management/ patient education programmes than those with single conditions.

Extrapolating the research findings from the available studies to multimorbidity or the population at risk of poor health outcomes may suggest that:

- Self-management support should be considered within the context of a collaborative patient and health care professional relationship.
- Self-management support may have a small effect size on health and social care utilisation and costs, and a larger effect size on patient quality of life outcomes.
- Self-management support for people with multiple conditions may be particularly applied to common functional challenges, and the difficulties in managing physical, and especially emotional, symptoms.

There are a range of population groups of people with LTCs or caring for people with LTCs who may benefit from alternative or additional support in self-management for their conditions, particularly in supporting behaviour changes, increased skills, and maintaining motivation including people with learning disabilities, cognitive impairment, sensory impairment or low levels of patient activation.

The resources available for supporting patient activation and self-management in Cambridgeshire include local support groups and a strong and active community sector. There are also valuable national assets including many websites and organisations for people with specific conditions which provide a range of forms of information, advice and peer support.

⁷ Liddy, C., Blazkho, V., Mill, K. Challenges of self-management when living with multiple chronic conditions. Systematic review of the qualitative literature. *Can Fam Physician* 2014; 60:1123-33.

1. INTRODUCTION

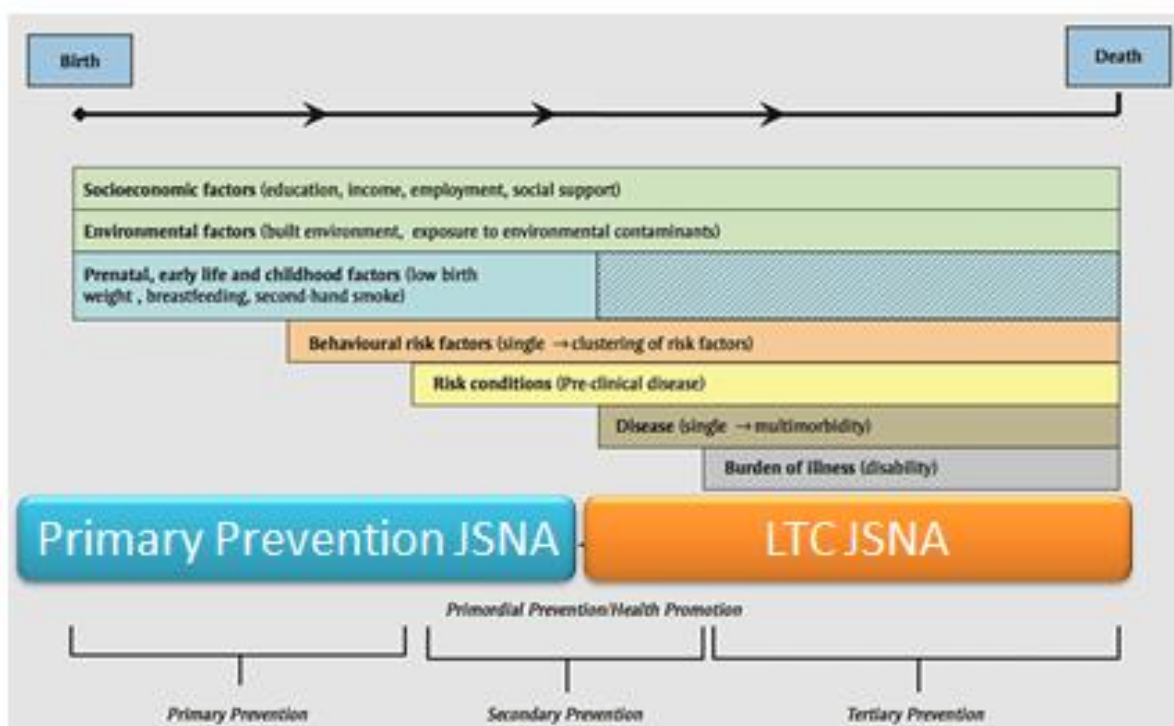
1.1. CONTEXT – WHAT IS THE BACKGROUND TO THIS JSNA?

The Department of Health estimates that around 15 million people in England have one or more long term condition(s) (LTC).⁸ A LTC has been defined as ‘a health problem that can’t be cured but can be controlled by medication or other therapies’. LTC includes 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. Nearly a third of people in Cambridgeshire (31.7%) reported having at least one LTC⁹ in the GP survey, and the 2011 census found that 90,420 people (15.1% of household residents) reported a long term activity-limiting illness in Cambridgeshire.¹⁰

The Cambridgeshire Health and Wellbeing Board have requested a Joint Strategic Needs Assessment (JSNA) on LTC across the lifecourse. The JSNA will include work to estimate current and future numbers of people with LTC in Cambridgeshire given population growth and ageing. A clear and accurate description of the current needs of people with LTC will provide a foundation for the development of integrated approaches to enhance the health and wellbeing for people with LTC while promoting independent and inclusive living.

This JSNA aims to complement the work and findings of the Primary Prevention JSNA which together describe local need and identify opportunities for intervention in response to Long Term Conditions across the lifecourse (figure 1.1).

Figure 1.1: A lifecourse approach



⁸ Department of Health LTC compendium 3rd Edition

⁹ LTC dashboard NHS England | 2013/14 GP Survey data, response rate 34.3%

¹⁰ Defined as an illness lasting at least 12 months, with any limitation. 2011 Census, ONS

1.2. SCOPE – WHAT IS THE FOCUS OF THIS JSNA AND WHY?

This JSNA is focussed on the management of care for adults and older people with LTC who may be considered 'at-risk' of poor health outcomes (such as admission to hospital or increased need for care). These individuals may not be currently known to acute health or long term social care services, despite being at higher risk of admissions to such services. Improvements to the management of their care may offer significantly improved health outcomes for them as individuals, the community that support them, and to those providing services.

Stakeholders and experts involved in the scoping process identified the characteristics that contribute to increasing health needs of principal interest as:

- Multiple LTC at the same time
- Substantial limitations due to LTC
- People with LTC experiencing significant pain
- Depression and anxiety

The work will explore evidence-informed approaches to keep people independent, safe and well. Emphasis will be placed on how to ensure care is person-centred and collaborative, recognising that people with LTC are experts in their health. The vital importance of self-care principles will be highlighted, alongside the opportunities for prevention of ill health across the lifecourse.

1.3. PROCESS – HOW HAS THIS JSNA BEEN PRODUCED?

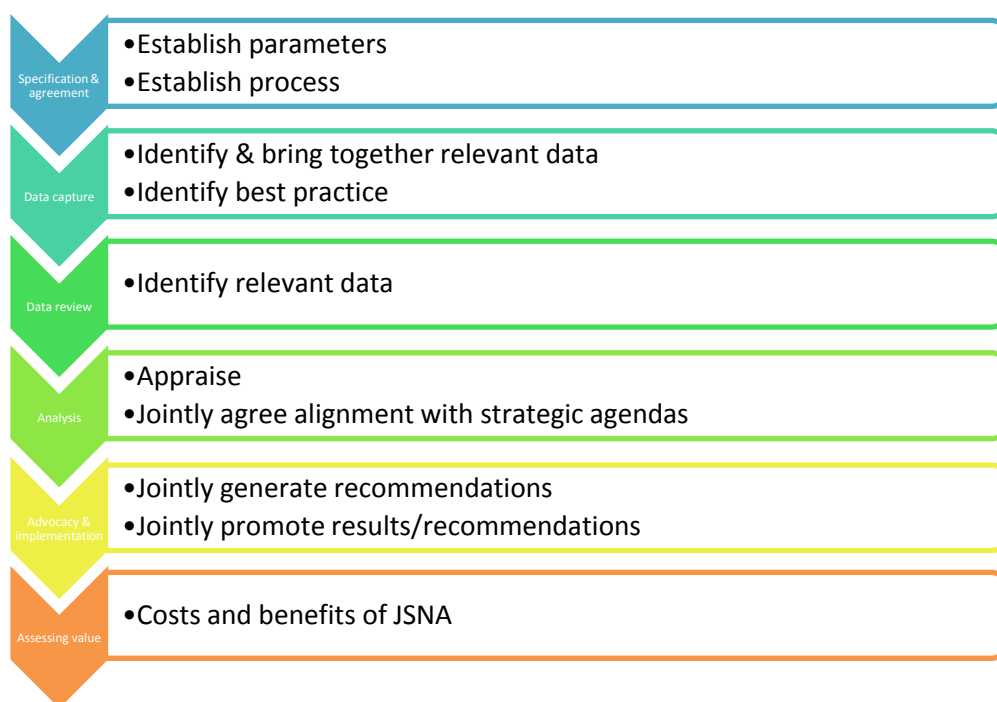
There have been several stages in the development of this JSNA (illustrated by figure 1.2).

Due to the scale of the topic of LTCs across the Lifecourse, a thorough scoping process was undertaken. A stakeholder event was held in 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. Participants considered local data on mortality, admissions and prevalence; multimorbidity and limiting conditions were explored through group discussions. 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 scoping paper was approved by the Health and Wellbeing Board in January 2015, detailing a thematic focus on people with adult-onset LTCs at high risk of poor health outcomes. In light of the agreed scope, a JSNA working group with colleagues from across Cambridgeshire County Council and Cambridgeshire & Peterborough Clinical Commissioning Group (CCG) considered evidence and input including key epidemiological data, high-quality evidence and national guidance, patient and citizen views, complemented by ongoing consultation with stakeholders to produce this work. A local views

workshop was also held in April to ensure the views of people with LTCs and their carers remained at the centre of the JSNA.

Figure 1.2: Flow chart to describe the Cambridgeshire JSNA process

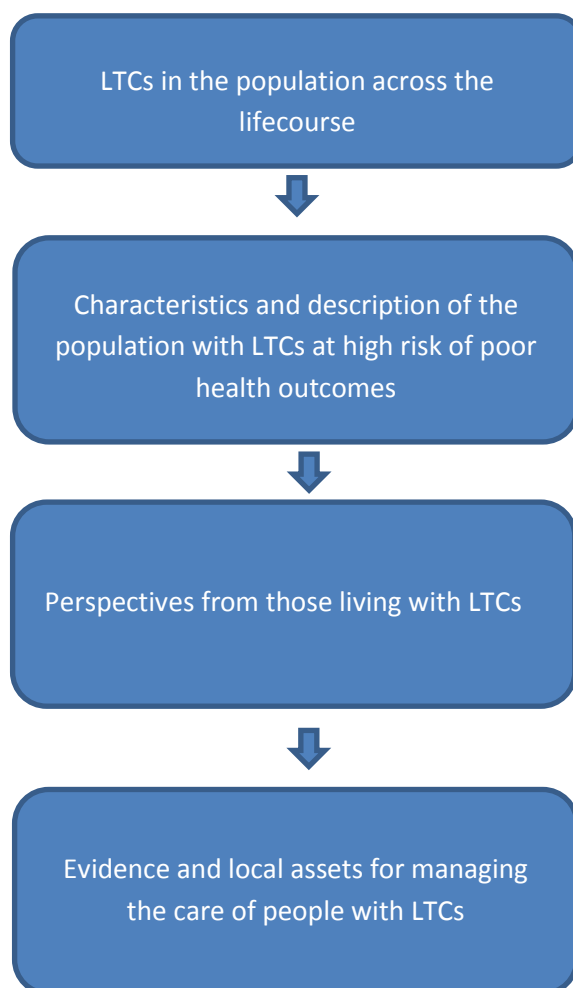


The preliminary data and evidence was presented to 40 stakeholders at an event in May 2015 to jointly elucidate key findings. The event concluded with Panel discussion, driven by key Stakeholder Panel members from Cambridgeshire County Council, Cambridgeshire & Peterborough CCG, Uniting Care Partnership and Hunts Forum (representing local third sector organisations) to explore the application and alignment of this work with current local workstreams across agencies.

This JSNA provides important evidence and information to support the commissioning of services across health and social care and to encourage awareness and signposting of available public health improvement programmes and services available across Cambridgeshire. The process and production of the JSNA is timely as new structures and service design models are currently in effect across the county and for which this piece of work will provide a base and foundation for further work across several local priority areas.

1.4. STRUCTURE – HOW IS THIS JSNA REPORT ORGANISED?

This JSNA report has been prepared from data and evidence gathered by the working group, and is organised to provide this intelligence in a logical order as:



Blue text boxes like this are used to highlight key pieces of information ...

... Blue pins are used to draw attention to local examples, and findings for Cambridgeshire

At the end of each chapter, the data and evidence is examined to consider ‘what is this telling us?’ about needs in the local population.

The content of this report is complemented by data supplements on key conditions that are prevalent in Cambridgeshire & Peterborough, specifically:

- **Cardiovascular Disease (CVD)**
 - **CHD; stroke; peripheral arterial disease; atrial fibrillation; heart failure**
- **Hypertension**
- **Diabetes**
- **Chronic Kidney Disease (CKD)**
- **Chronic Obstructive Pulmonary Disease (COPD)**

Where possible these conditions have been used as exemplar or case studies in the main body of this report.

2. LTCS ACROSS THE LIFECOURSE

2.1. WHAT ARE LTCS?

As long term conditions (LTCs) have evolved and our understanding of features and issues associated with LTCs developed, so too have definitions attempted to represent the complexity linked to these conditions. LTCs have previously been defined as health problems that can't be cured but can be controlled by medication or other therapies. This definition has expanded to take into consideration the permanent changes that LTCs may imply and impose on an individual's life. Other definitions can include references to duration, quality of life, impact of disease and alternative terms such as chronic disease or long-standing illness.

However, the House of Commons Health Committee (2014) identified several issues with the above definition:

- Represents a single disease model.
- Confusing and uncoordinated care for those with multiple conditions.
- Cancer not specifically included.
- Does not cover conditions which significantly impact quality of life.

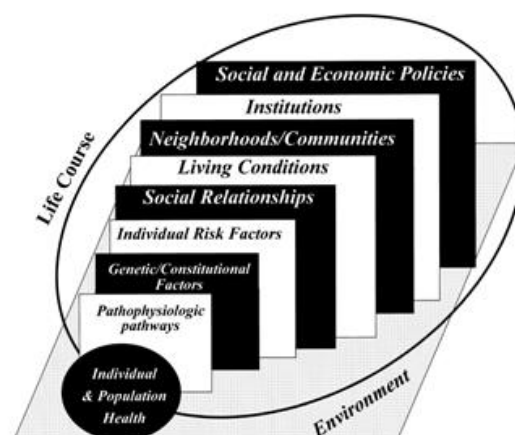
In response to the above issues, recommendations to revise definitions to emphasise person-centred approaches (treating the person, not the condition) and approaches that take more than one LTC into account (treating the person with multiple conditions as a whole) have been made.

For purposes of this JSNA, 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.

2.2 A LIFECOURSE APPROACH TO LTCS

A lifecourse approach to long term conditions explicitly recognises the importance of time and timing in understanding causal links between exposures and outcomes across the lifecourse at a population level.

Figure 2.1: Determinants of population health



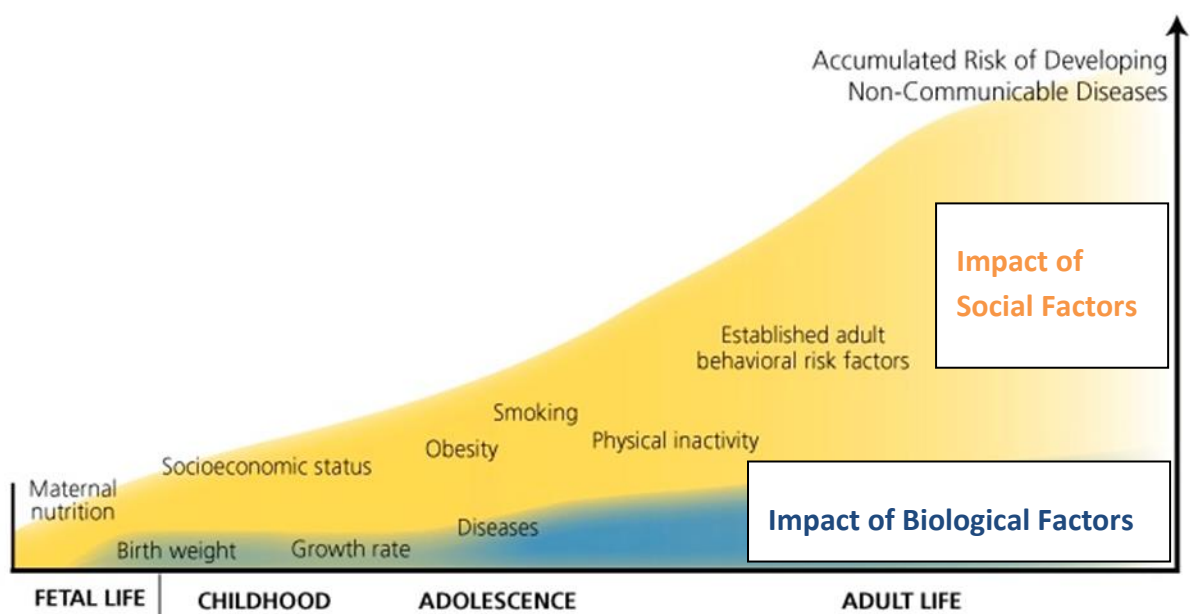
By maintaining a lifecourse approach we are also able to explore the impact of age, sex, ethnicity, socio-economic status and other wider determinants of health that clearly impact on LTCs.

Source: Adapted from *Promoting Health: Intervention Strategies from Social and Behavioural Research* by the National Academy of Science.

Long term conditions develop over a long period of time and similarly, many important adult risk factors for LTCs (poverty, smoking, diet, physical activity) also have their own natural histories. Thus by adopting a lifecourse approach to LTCs a range of potential interventions, which includes the wider determinants of health, that could reduce the risk of development of a condition or improve health outcomes is a useful and holistic population health approach.

Adopting a lifecourse approach does not focus only on the recognition of early-life influences, as the majority of adult LTCs are longer-term consequences of the complex accumulation and interaction, of early and later-life exposures. A lifecourse perspective on LTCs relies on a multidisciplinary framework for understanding how early- and later-life biological, behavioural, social, and psychological exposures affect adult health.

Figure 2.2: Cumulative lifecourse risk factors for long term conditions



Adapted from Darton-Hill et al., 2004

Source: Adapted from Darton-Hill et al, 2004

By maintaining a lifecourse approach, we are also able to explore the impact of age, sex, ethnicity, socio-economic status and other wider determinants of health that clearly impact on LTCs. For example, a systematic review summarising five studies consistently showed an inverse association between socioeconomic status and the presence of more than one LTC. Studies have highlighted that young and middle aged adults living in the most deprived areas had rates of multimorbidity equivalent to those aged 10-15 years older in the most affluent areas. In addition, those in the most deprived areas were more than twice as likely to have a mental health disorder compared to those in an affluent area.

This JSNA aims to complement the work and findings of the Primary Prevention JSNA which together describe local need and identifies opportunities for intervention in response to Long Term Conditions across the lifecourse.

2.3 LIFECOURSE APPROACHES AND SOCIOECONOMIC DIFFERENCES

Differences in life expectancy between social groups have clearly been demonstrated and a strong case can be made for the contribution of socioeconomic conditions to LTCs at different stages of the lifecourse.¹¹ The specific weightings of the contributions of early and later life socioeconomic conditions may differ according to outcomes. They will also vary according to how risk factors for a particular LTC are linked to socioeconomic conditions over the lifecourse and may differ across place, time and population groups.

Socioeconomic differentials in LTCs are best understood through consideration of how a variety of exposures that increase risk of developing a particular LTC are influenced by social circumstances across the lifecourse.

A number of studies have examined the influences of child and adulthood socioeconomic conditions on a range of LTCs and health-related outcomes in later adulthood. A large proportion of studies have focussed on the role of childhood socioeconomic conditions (indicated by occupation/education of parents) in relation to specific biological risk factors relevant to the development of LTCs:

- Blood pressure, lipid levels, body mass index (BMI).^{12,13}
- Health behaviours such as smoking, physical activity, alcohol consumption.¹⁴
- Psychosocial determinants such as loneliness, hostility, hopelessness.
- Mental health outcomes.¹⁵
- Perceptions of health.

Studies conclude that compared with those from high socioeconomic status backgrounds, children who grew up in low socioeconomic status families have significantly poorer health outcomes in relation to LTCs as adults. Similar patterns are observed for adults.¹⁶

2.4 LIFECOURSE APPROACHES TO SPECIFIC LTCS

Lifecourse approaches in relation to particular LTCs are outlined below.

2.4.1 LIFECOURSE APPROACH TO HEART DISEASE

Evidence indicates that cardiovascular disease (CVD) processes begin early in life and are influenced over the lifecourse by both non-modifiable and potentially modifiable behaviours, risk factors, and environmental exposures. Given that there are many risk factors that influence CVD, and the recent evidence to suggest that the risk associated with birth characteristics is modified by subsequent growth and development, it is unreasonable to expect decreases in CVD rates simply by improving

¹¹ 'Fair Society Healthy Lives' (2010). The Marmot Review.

¹² Davey Smith G, Hart C (2002). Lifecourse socioeconomic and behavioural influences on cardiovascular disease mortality: the Collaborative Study. *Am J Pub Health*; **92**:1295-8.

¹³ Lawlor DA, Ebrahim S, Davey Smith G (2002). Socioeconomic position in childhood and adulthood and insulin resistance: cross sectional survey using data from British women's heart and health study. *Br Med J*; **325**: 805-9.

¹⁴ Harper S, Lynch J, Hsu W-L et al (2002). Lifecourse socioeconomic conditions and adult psychosocial functioning. *Int J Epidemiol*; **31**: 395-403.

¹⁵ Ritsher JE, Warner V, Johnson JG et al (2001). Inter-generational longitudinal study of social class and depression. *Br J Psychiat*; **40**: S84-90.

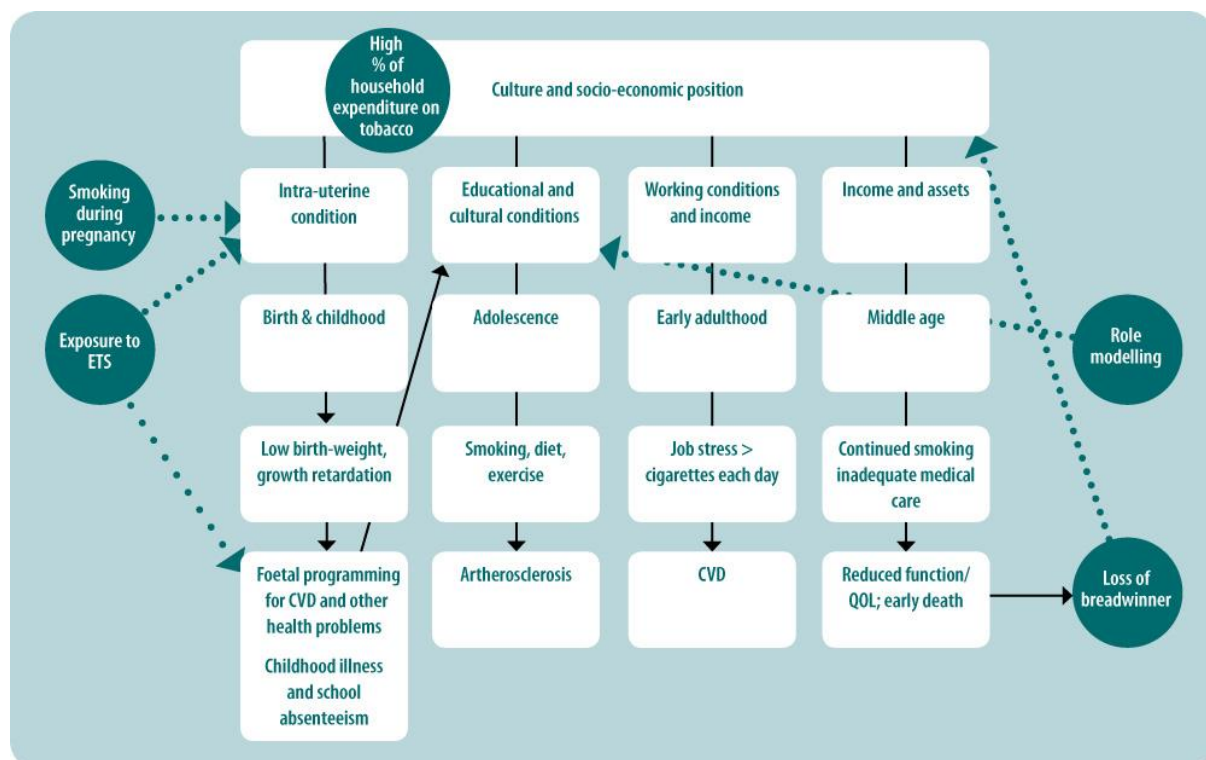
¹⁶ Poulton R, Caspi A, Milne B et al (2002). Association between children's experience of socioeconomic disadvantage and adult health: a life-course study. *Lancet* **360(9346)**: 1640-5.

birth weight and child nutrition. It is important to consider the impact of multiple risk factors across the lifecourse as a continuum for which targeted intervention at each level is necessary, with a focus on mid-life risk factors and health behaviours.¹⁷

Recent systematic reviews have concluded that those who experienced worse socioeconomic conditions in their childhood, independently of their circumstances during adult life, generally were at greater risk for developing and dying of CVD. The majority (80%) of prospective studies and all cross-sectional studies found an association between poor childhood circumstances and greater risk for coronary heart disease (CHD), angina, stroke and atherosclerosis in adulthood.¹⁸

Although CHD was associated inversely with socioeconomic conditions experienced during childhood, adult circumstances were also significant. Social processes associated with the continuity of socioeconomic conditions across the lifecourse had an impact on the development of major CHD risk factors such as dyslipidemia, hypertension, and smoking (Fig 2.3).¹⁹ This association extended to different indices of CHD, including CHD mortality, self-reported and medically diagnosed CHD and self-reported symptoms.

Figure 2.3: Socioeconomic contribution to CVD from a lifecourse perspective



Source: Adapted from M Scollo and the National Public Health Partnership

¹⁷ Hayman L, Helden L, Chyun D et al (2015). A Life Course Approach to Cardiovascular Disease Prevention. *J Card Nurs* 26(4): 22-34.

¹⁸ Galobardes B, Davey Smith G, Lynch JW (2006). Systematic Review of the Influence of Childhood Socioeconomic Circumstances on Risk for Cardiovascular Disease in Adulthood. *Ann Epidemiol*;16: 91-104.

¹⁹ Preventing chronic disease: a strategic framework background paper National Public Health Partnership. Melbourne, Australia: NPHP, 2001.

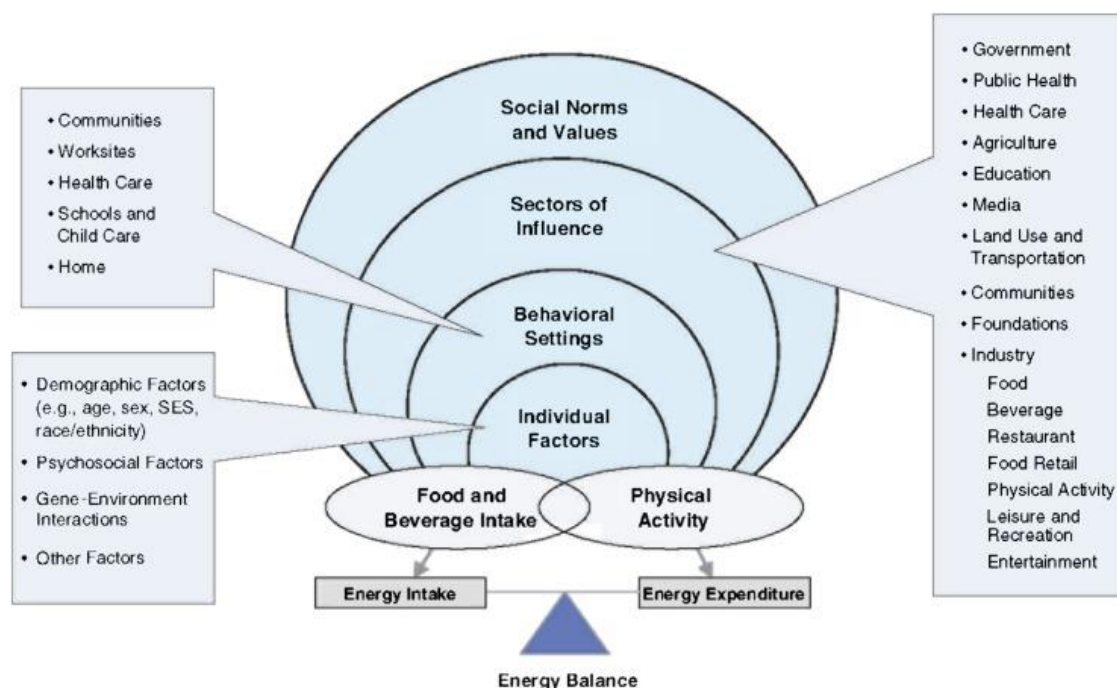
2.4.2 LIFECOURSE APPROACH TO DIABETES

Evidence indicates that the risk of Type 2 Diabetes Mellitus (T2DM) in adult life may be modified by risk factors operating across the lifecourse of an individual. An inverse association between birth weight and the prevalence of glucose intolerance (resulting in T2DM), in later life, has been demonstrated in several populations. Environmental and genetic factors are both likely to be important in determining the association between birth size and adult diabetes, with within-population diabetes risk determined more by environmental factors and between-population risk (eg ethnic differences) determined more by genetic elements.²⁰

However, emerging research suggests that insulin resistance in childhood is associated more strongly with obesity than with low birth weight. Cross-sectional surveys over the last few decades show that the prevalence of obesity has increased in all age groups (including children) which may explain the emergence of T2DM in children.²¹

Social gradients in risk for both obesity and T2DM have also been established. Both childhood and adulthood socioeconomic status are inversely associated with higher prevalence of both obesity and T2DM.²² Pathways underlying the associations between socioeconomic factors, birth weight, obesity and T2DM are complex and operate at different times across the lifecourse – a major challenge is to ameliorate socioeconomic differences in obesity that underpin these associations.

Figure 2.4: Levels and sectors of influence on obesity and diabetes risk, a lifecourse approach to preventive interventions



Source: Adapted from Hill et al. 2013

²⁰ Hu FB (2011). Globalization of diabetes: the role of diet, lifestyle, and genes. *Diabetes Care*; **34**(6): 1249-57.

²¹ Steinberger J, Daniels SR (2003). Obesity, insulin resistance, diabetes and cardiovascular risk in children. *Circulation*. **107**: 1448-53.

²² Hill JO, Galloway JM, Goley A et al (2013). Scientific statement: Socioecological determinants of prediabetes and type 2 diabetes. *Diabetes Care*; **36**(8): 2430-9.

2.4.3 LIFECOURSE APPROACH TO BLOOD PRESSURE

Blood pressure (BP) is a major risk factor for coronary heart disease (CHD), stroke and other LTCs. Though blood pressure in early adult life and in childhood may make small contributions to adult cardiovascular risk, BP during midlife and later life is the main influence on cardiovascular risk. The influence of potential determinants on BP in middle-age, therefore, provides the main indicator of their potential importance. The emergence of adult BP variation between individuals begins in early childhood and becomes stronger with age with adult differences between population groups emerging later during adolescence.²³

Several individual determinants of BP in middle-age appear to have similar effects on BP at younger ages:

- Body mass
- Alcohol intake
- Potassium and sodium intake
- Physical activity

Though the effects on BP are reversible, the conditioning of dietary and exercise behaviour from childhood and adolescence onwards is likely, in practice, to make these factors more difficult to reverse in middle-age, emphasising the importance of primary prevention at an early age. The evidence exploring the associations of dietary factors (during infancy and early childhood) and between birth weight and later BP is weak.

Considering socioeconomic contributions to BP levels, low socioeconomic status is associated with higher BP, and this association is particularly evident in the level of education.²⁴ The socioeconomic gradient in hypertension appears to emerge from childhood.²⁵ Furthermore, BP as a risk factor contributes to the development of health inequalities within LTCs. Evidence has demonstrated that increased levels of BP at the age of 50 are associated with large decreases in life expectancy and life expectancy free of CVD and increases in the number of years lived with CVD, myocardial infarct and stroke for men and women.

Early exposures are important either because they have direct long-term effects on health outcomes or because they make the continuation of exposure into adult life more likely.

Though a general pattern of BP progression from childhood has been demonstrated in the UK, adult influences, rather than early life influences, are the dominant influence on adult BP.²⁶

²³ Wills AK, Lawlor DA, Matthews FE et al (2011). Life Course Trajectories of Systolic Blood Pressure Using Longitudinal Data from Eight UK Cohorts. *PLoS Med* **8(6)**: e1000440. doi:10.1371/journal.pmed.1000440

²⁴ Leng B, Jin Y, Chen L et al (2015). Socioeconomic status and hypertension: a meta-analysis. *J Hypertens*; **33(2)**: 221-9.

²⁵ Van den Berg G, van Eijsden M, Galindo-Garre F et al (2013). Explaining socioeconomic inequalities in childhood blood pressure and prehypertension: the ABCD study. *Hypertension*; **61(1)**: 35-41.

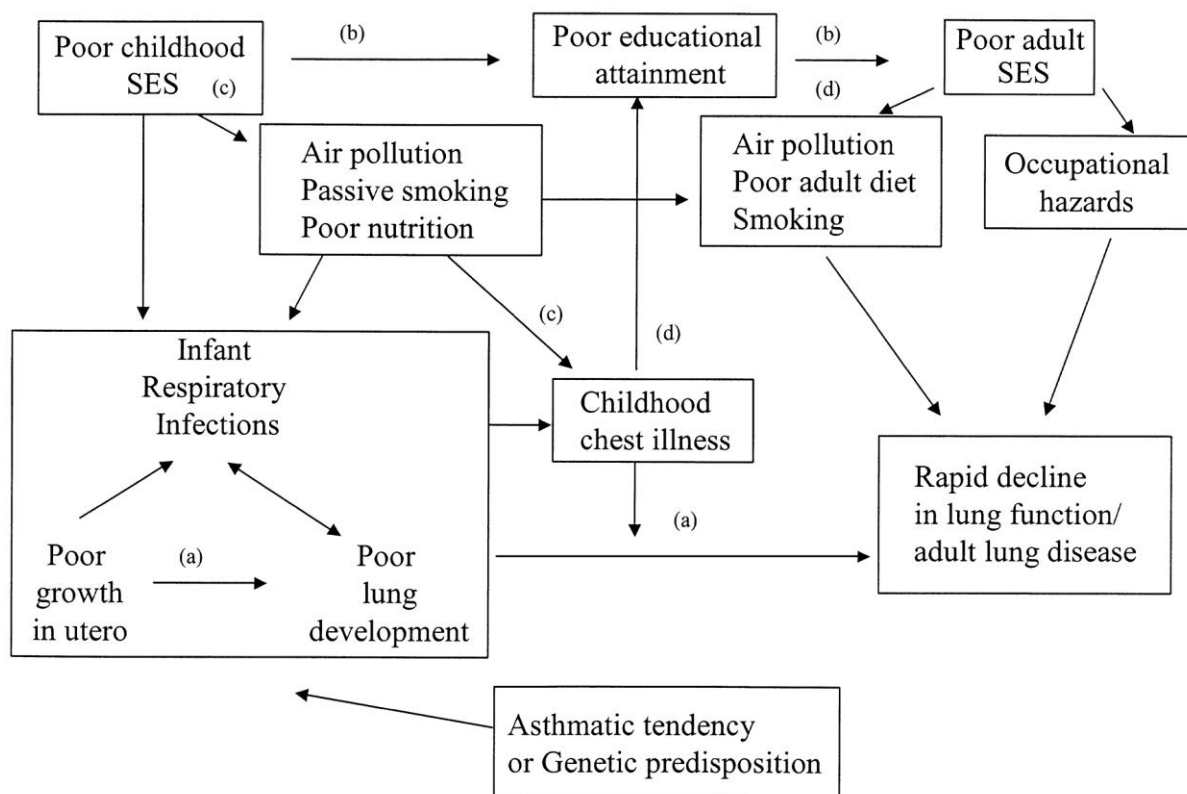
²⁶ Franco OF, Peeters A, Bonneux L et al (2005). Blood Pressure in Adulthood and Life Expectancy With Cardiovascular Disease in Men and Women: A lifecourse analysis. *Hypertens*; **46**: 280-6.

2.4.4 LIFECOURSE APPROACH TO RESPIRATORY DISEASE

Chronic obstructive lung diseases, like chronic obstructive pulmonary disease (COPD), have at least part of their origins in early life. Exposure to an adverse environment, during critical periods in early life, might lead to permanent developmental adaptations which results in impaired lung growth with smaller airways and lower lung volume, altered immunological responses and related inflammation, and subsequently to increased risks of chronic obstructive lung diseases throughout the lifecourse.²⁷

Exposures across the life course, that influence respiratory disease include biological, social, socio-biological and bio-social. An example of a conceptual model linking early exposures (such as socioeconomic conditions or poor in utero growth) with respect to the development of respiratory disease illustrates many possible pathways with potential mediating factors (Fig 2.5). Path (a) represent a predominantly biological pathway, whereby impaired foetal development impacts lung development. Path (b) represents a social pathway whereby adverse childhood socioeconomic status (SES) increases the risk of adverse childhood exposures as well as adult SES and smoking behaviour. Path (c) represents a sociobiological pathway whereby adverse childhood SES is associated with poor child and adult lung function. Path (d) represents a biosocial pathway where repeated childhood infections result in adverse educational attainment and lower adult SES. This model highlights the complexity of these inter-relationships.²⁸

Figure 2.5: Schematic representation of biological and psychosocial exposures acting across the lifecourse that may influence respiratory disease



Source: Adapted from Kuh and Ben-Shlomo 2008.

²⁷ Duijts L, Reiss IK, Brusselle G et al (2014). Early origins of chronic obstructive lung diseases across the life course. *Eur J Epidemiol*; **29**(12): 871-85.

²⁸ Kuh D, Ben-Shlomo Y (2004). A lifecourse approach to chronic disease epidemiology. Oxford University Press.

Events early in the development of the lung and immune system may influence susceptibility to later lung disease. However, while early intervention offers prospects for prevention there is also a clear need to modify risk at later stages. Control of smoking remains the highest priority.

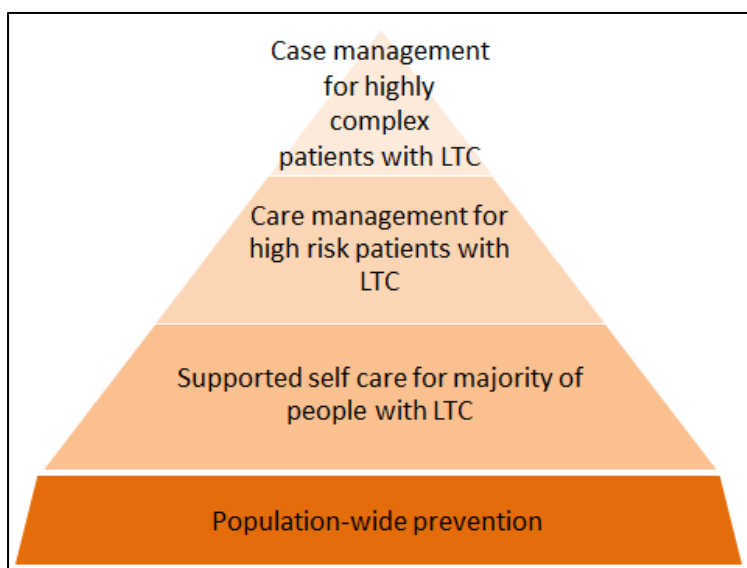
2.5 WHAT IS THIS TELLING US?

- A lifecourse approach to LTCs proposes that the combination, accumulation, and/or interaction of the social environments and biological insults experienced throughout the lifecourse impact current and future events, environments, and health conditions and thus ultimately impact adult health.
- LTCs have long induction times, with decades between exposure to risk factors and observed health outcomes.
- The burden of LTCs is not distributed equally in the population and the socioeconomic contributions across the lifecourse impact on health outcomes and LTCs.
- An exploration of influences at multiple levels can shed light, much more comprehensively, on the determinants of population health than a focus on single levels alone can, bringing together the impact of social and biological determinants.
- Lifecourse approaches demonstrate the complexity of population health, extending well beyond a deterministic approach that suggests that a particular health behaviour is the central factor responsible for health outcomes in populations.
- Lifecourse approaches provide organising principles that can guide analytic work and the production of more useful knowledge as well as service design and the organisation and implementation of both targeted and population-wide preventative interventions at all levels.
- There is a need for healthy public policy interventions that include government actions directed at entire populations, including health promotion and interventions to address the wider determinants of health, over and above curative interventions that are individual focussed.

3. LTCs IN THE POPULATION: CHARACTERISTICS OF THOSE AT HIGH RISK OF POOR HEALTH OUTCOMES

3.1. DESCRIBING THE 'HIGH RISK' GROUP

A population management approach to describe people with LTCs may use a framework or model to describe risk across the population. The model below is a hybrid of the model from Kaiser Permanente (a US chronic conditions' care provider)²⁹ and the model developed within the Cambridgeshire & Peterborough Clinical Commissioning Group Older People Adult Community Services outcomes framework.³⁰ This model divides the LTC population into those requiring 'case management'; 'care management' and 'supported self-care'.



There are many national programmes and interventions focussed on the 'most complex' patients ie those that comprise 1-2% of the population; they may be case managed by multi-disciplinary teams or within primary care, and provision commissioned separately.

This JSNA is thematically scoped to particularly focus on care management for high risk people with adult-onset LTCs – the second layer of the pyramid representing perhaps ~10-15% of the population with LTCs.

The JSNA therefore explores questions such as:

- What are the factors that might indicate a person has an increased risk?
- What are the triggers for escalation into the highly complex category?
- What are the principles of prevention for those at high risk? And that can be applied across the population with LTCs?

As a psychosocial interpretation the working group described the

This JSNA is thematically scoped to particularly focussing on care management for high risk people with adult-onset LTCs

²⁹ As presented in the University of Birmingham Health Services Management Centre Report (2006) 'Improving care for people with long term conditions – a review of UK and international frameworks' for the NHS Institute for Innovation and Improvement.

³⁰ Outcomes Framework Mark 3 available at: <http://www.cambridgeshireandpeterboroughccg.nhs.uk/pages/older-peoples-programme.htm>

high risk group as:

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.

In order to describe a 'high risk' population, the working group screened evidence and in discussion with local stakeholders defined a set characteristics key characteristics that described people with LTCs with an increased risk of poor health outcomes were determined as:

- **Multiple long term physical and mental health conditions.**
- **Important level of limitations, such as in activities of daily living (ADL).**
- **Living with a significant level of pain.**
- **Experiencing depression and/or anxiety.**

The high risk group has been described as: multiple conditions; limitation; pain and mental health conditions

These characteristics were examined and research evidence collected to describe in more detail the characteristics of a 'high risk' population. This is highlighted in the sections below within this chapter. Where possible in this JSNA work, a rounded description of 'high risk' has been applied considering all of these variables. However, this has not always proved possible, for example in formulating search questions for evidence reviews. Where necessary, multimorbidity has been used as a proxy grouping for the high risk category and has, therefore, developed as the predominant theme.

Multimorbidity has been used sometimes as a proxy descriptive for high risk

There is an increasing evidence base on the use of risk stratification tools to identify risk in the population, discussed further in section 7. Nonetheless there are limitations and often poor correlation between the methods. There is clear evidence that risk level is not a static measure, and people may move in and out of the 'high risk' level, even though the assumption is that the majority of patients continue to have similar health and care needs. For example, in a recent study in Kent, after a year, 80% of patients had moved out of the 'very complex' band, irrespective of the stratification tool used.³¹

3.2. MULTIPLE CONDITIONS

DEFINING MULTIMORBIDITY AND MULTIPLE CONDITIONS

There is no real consensus as to the precise definition of 'multimorbidity', or the similar term 'comorbidity'.³² Both terms require the co-existence of two or more diseases in the same patient. **Comorbidity** is sometimes used to indicate that the medical conditions are inter-dependent or associated with each other, perhaps with

³¹ NHS Improving Quality (2013) Population Level Commissioning for the Future: Kent Whole Population Dataset – Interim Report. Available at: www.nhs.uk/lcycoc

³² Jakovljević M, Ostojić L. (2013) Comorbidity and multimorbidity in medicine today: challenges and opportunities for bringing separated branches of medicine closer to each other. *Psychiatr Danub*. 2013 Jun;25 Suppl 1:18-28.

one predominant condition acting as an “index” condition. For example, diabetes can often cause chronic kidney disease. **Multimorbidity** is a relatively recent term, indicating the presence of multiple conditions where no particular condition is the “index” condition, such as an individual with diabetes and asthma.

Multiple conditions or multiple long term conditions can also be used as synonymous for multimorbidity, and is the terminology preferred by stakeholders.

However there is a lack of consistency in how any of these definitions are applied (Fortin 2012).³³ Key issues include:

- Which health conditions are included and which conditions count as separate conditions.
- Whether mental health issues are included within multiple conditions or looked at separately.
- Whether two or more conditions, or three or more conditions should be used as a cut off for multiple conditions.
- Whether acute conditions should be included as well as chronic conditions, and what is the definition of a chronic condition (eg three months or 12 months).
- Whether severity of disease should also be included.

A simple count of two or more conditions is often used as a definition for multiple conditions.

However, the list of health conditions included varies and can be from self-reported information or medical records

Multimorbidity:
the co-existence of
2 or more LTCs

NICE has created a broad definition of multimorbidity - “the combination of one chronic disease with at least one other disease (acute or chronic) or biopsychosocial (biological, psychological or social) factor (associated or not) or somatic (related to or affected by the body) risk factor. It is often defined more simply as the co-existence of two or more long term conditions”.³⁴

In this JSNA work, multimorbidity will be considered as the co-existence of two or more LTCs.

MEASURES OF MULTIMORBIDITY

Huntley (2012)³⁵ systematically reviewed the measures of multimorbidity used in 184 studies that assessed multimorbidity and the burden of disease in primary care and community settings.

The majority of studies (n=98 studies) used **disease counts**, where the number of conditions an individual has are simply counted up. However, the lists of conditions included in the counts varied from 9-35 different conditions or health problems. Disease counts may be based on self-rated information, clinician-rated information or extracted from medical records. This variability impacts prevalence estimates.

Adjusted Clinical Groups Systems (n=25 studies) uses medical records or insurance claims data and groups diagnoses into clinically appropriate groups. This approach has been used in South Somerset’s Symphony

³³ Fortin M, Lapointe L, Hudon C et al. (2004) Multimorbidity and quality of life in primary care: a systematic review. Health Qual Life Outcomes. 2004; 2: 51.

³⁴ National Institute for Health and Care Excellence (NICE) Guideline Scope (2014) Multimorbidity: the assessment, prioritisation and management of care for people with commonly occurring multimorbidity. Available at: <http://www.nice.org.uk/guidance/gid-cgwave0704/resources/multimorbidity-final-scope2>

³⁵ Huntley AL, Johnson R, Purdy S, Valderas JM, Salisbury C. (2012) Measures of multimorbidity and morbidity burden for use in primary care and community settings: a systematic review and guide. Ann Fam Med. 2012 Mar-Apr;10(2):134-41.

LONG TERM CONDITIONS JSNA

LTCS IN THE POPULATION: CHARACTERISTICS OF THOSE AT HIGH RISK OF POOR HEALTH OUTCOMES

Project where data has been combined from health and social care data source and uses episode treatment groups (ETGs) to describe chronic conditions.

Charlson Comorbidity Index (n=38 studies) is a score that evaluates prognosis based on age and weighting for specific comorbid conditions and is used in studies assessing the effect of multimorbidity on health outcomes such as mortality. Other illness scores are also used including the Cumulative Index Illness Rating Scale (CIRS) and the Duke Severity of Illness scale (DUSOI)

All measures are dependent on the range of conditions recorded, how accurately these have been recorded and whether there is any information on severity. Changes in medical practice over time in terms of recognition, earlier detection and diagnosis may well impact the prevalence of multimorbidity. For example, NICE hypertension guidelines changed diagnosis methods and hypertension levels (NICE CG127, 2011).³⁶

PREVALENCE OF MULTIMORBIDITY

OVERALL

Approximately 15 million adults with long term conditions live in the UK, and 6.75 million (45%) have more than one long term condition.³⁷ The Department of Health estimates that the number of people with three or more long term conditions long term conditions is set to rise from 1.9 million in 2008 to 2.9 million in 2018.³⁸

A high quality systematic review of 39 prevalence studies³⁹ found that the prevalence of multimorbidity varied from 12.9% in participants 18 years and older, to 95.1% in a population aged 65 years and older. In all but five studies, the prevalence estimates exceeded 20%. The definition of multimorbidity and populations studied varied between studies and therefore no summary measure was provided.

IMPACT OF AGE

The overall prevalence of multimorbidities consistently increases with age, especially after the age of 40 (figure 3.1).⁴⁰

Two large, population-based studies in Scotland⁴¹ and South Somerset⁴² show that the number of long term conditions an individual has also increases with age, with many of those in the older age groups having four or more conditions (Figure 3.2).

“We have hospitals that are designed to cure specific conditions and they are full of old people with multimorbidity on polypharmacy”

House of Commons Health Committee, July 2014

³⁶ NICE CG127, 2011: NICE Clinical Guideline 127: Hypertension: Clinical management of primary hypertension in adults. Available at <http://www.nice.org.uk/guidance/CG127>

³⁷ Department of Health (2012). Long term conditions compendium of information. Leeds, UK: DH.

³⁸ Department of Health (2012). Long term conditions compendium of information 3rd Edition. Available at <https://www.gov.uk/government/news/third-edition-of-long-term-conditions-compendium-published>

³⁹ Violan C, Foguet-Boreu Q, Flores-Mateo G, Salisbury C, Blom J, et al. (2014) Prevalence, Determinants and Patterns of Multimorbidity in Primary Care: A Systematic Review of Observational Studies. PLoS ONE 9(7): e102149.

⁴⁰ Violan C, Foguet-Boreu Q, Flores-Mateo G, Salisbury C, Blom J, et al. (2014) Prevalence, Determinants and Patterns of Multimorbidity in Primary Care: A Systematic Review of Observational Studies. PLoS ONE 9(7): e102149.

⁴¹ Barnett K, Mercer SW, Norbury M, Watt G, Wyke S, Guthrie B (2012). Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. Lancet. 2012 Jul 7;380(9836):37-43

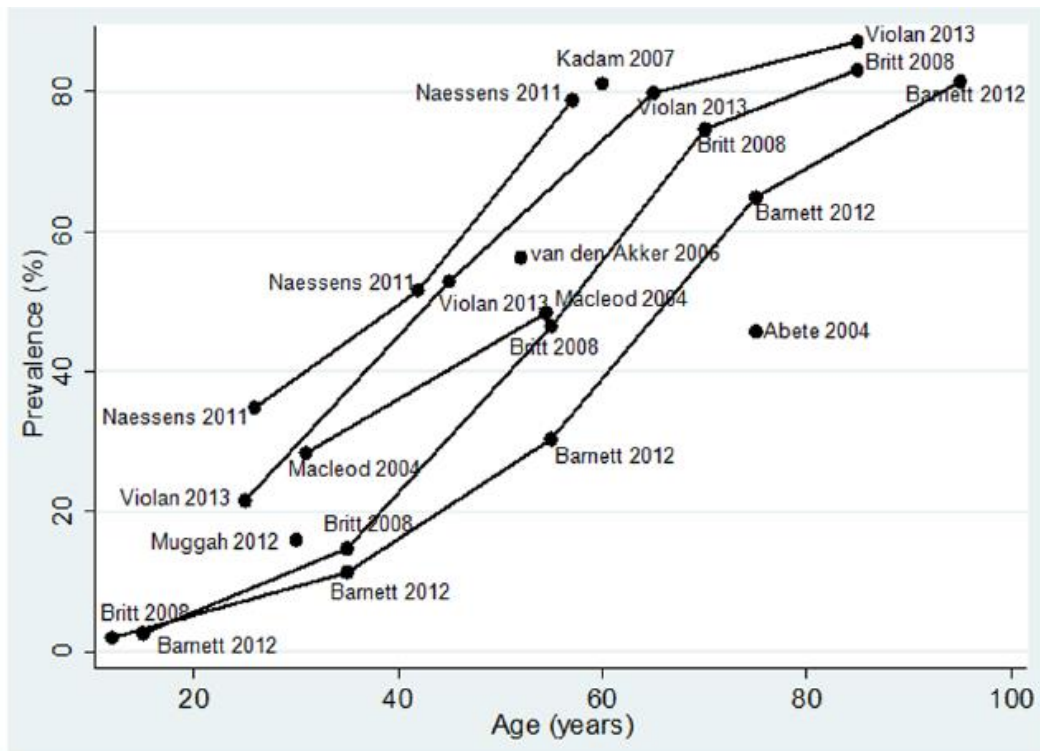
⁴² Kasteridis P, Street A, Dolman M et al (2014) The Importance of Multimorbidity in Explaining Utilisation and Costs Across Health and Social Care Settings: Evidence from South Somerset's Symphony Project

LONG TERM CONDITIONS JSNA

LTCS IN THE POPULATION: CHARACTERISTICS OF THOSE AT HIGH RISK OF POOR HEALTH OUTCOMES

This means that for older patients it is almost the norm to have many different conditions, yet the majority of clinical guidelines provided by organisations such as NICE are for individual conditions and often do not take account of multimorbidity.

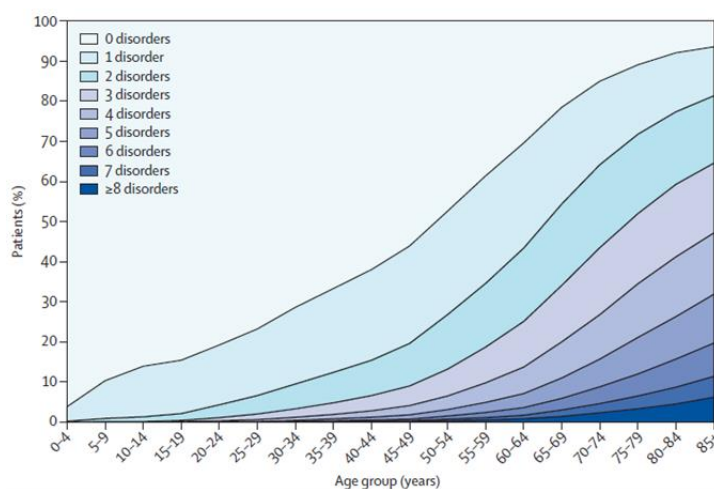
Figure 3.1: Systematic review summary showing the prevalence of multimorbidity by age group



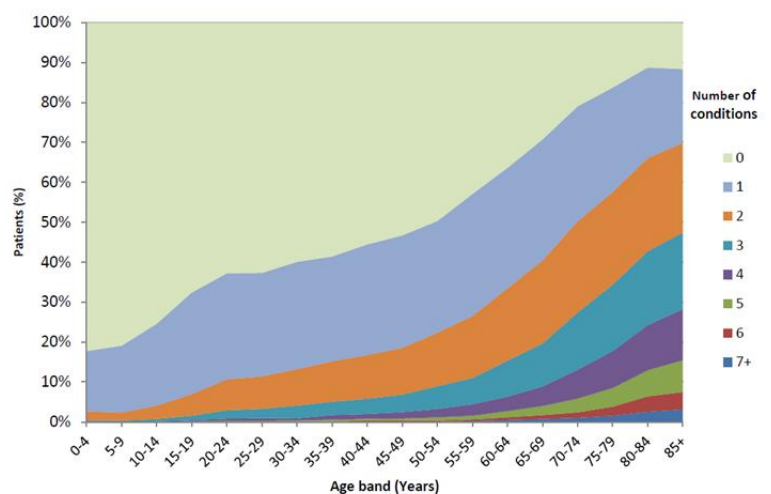
Source: Violan 2014

Figure 3.2: The number of chronic conditions by age group in two large, population-based UK studies

A) Barnett 2012



B) Kasterdis 2014

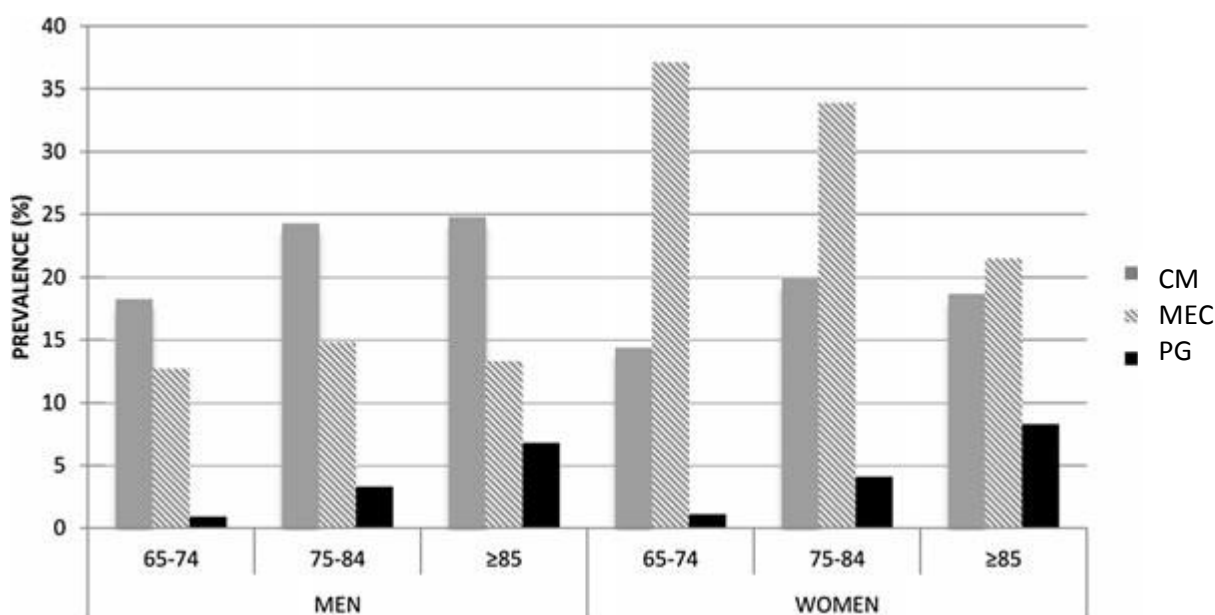


Source: Barnett 2012, Kasterdis 2014.

IMPACT OF GENDER

There are gender differences in the prevalence of multimorbidity. A recent systematic review reported a number of studies describing a greater prevalence of multimorbidity among females, relating this finding to a longer life expectancy and worse health status compared to males.⁴³ However, in studies that have explored specific disease patterns such as cardiometabolic (CM), psychogeriatric (PG) and mechanical (MEC), a higher prevalence of cardiometabolic diseases has been observed in men while higher prevalences in all other patterns observed among women (Figure 3.3).⁴⁴ This may be due to gender disparities in the diagnosis and treatment of cardiovascular diseases and have highlighted gender differences in the early detection, referral and treatment of cardiovascular diseases, leading to a higher probability of delayed treatment, and increased risk of emergency admissions and worse outcomes among the female population.⁴⁵

Figure 3.3 Prevalence of multimorbidity patterns by sex and age groups



Source: Abad-Díez 2014

IMPACT OF SOCIOECONOMIC STATUS AND OTHER FACTORS

A systematic review summarising five studies consistently showed an inverse association between socioeconomic status and multimorbidity, with most of these associations adjusting for age and gender. Multimorbidity is more common among deprived populations (figure 3.4) – particularly when mental health conditions are also present. There is evidence that the number of conditions can be a greater determinant of a patient's use of health service resources than the specific diseases.⁴⁶

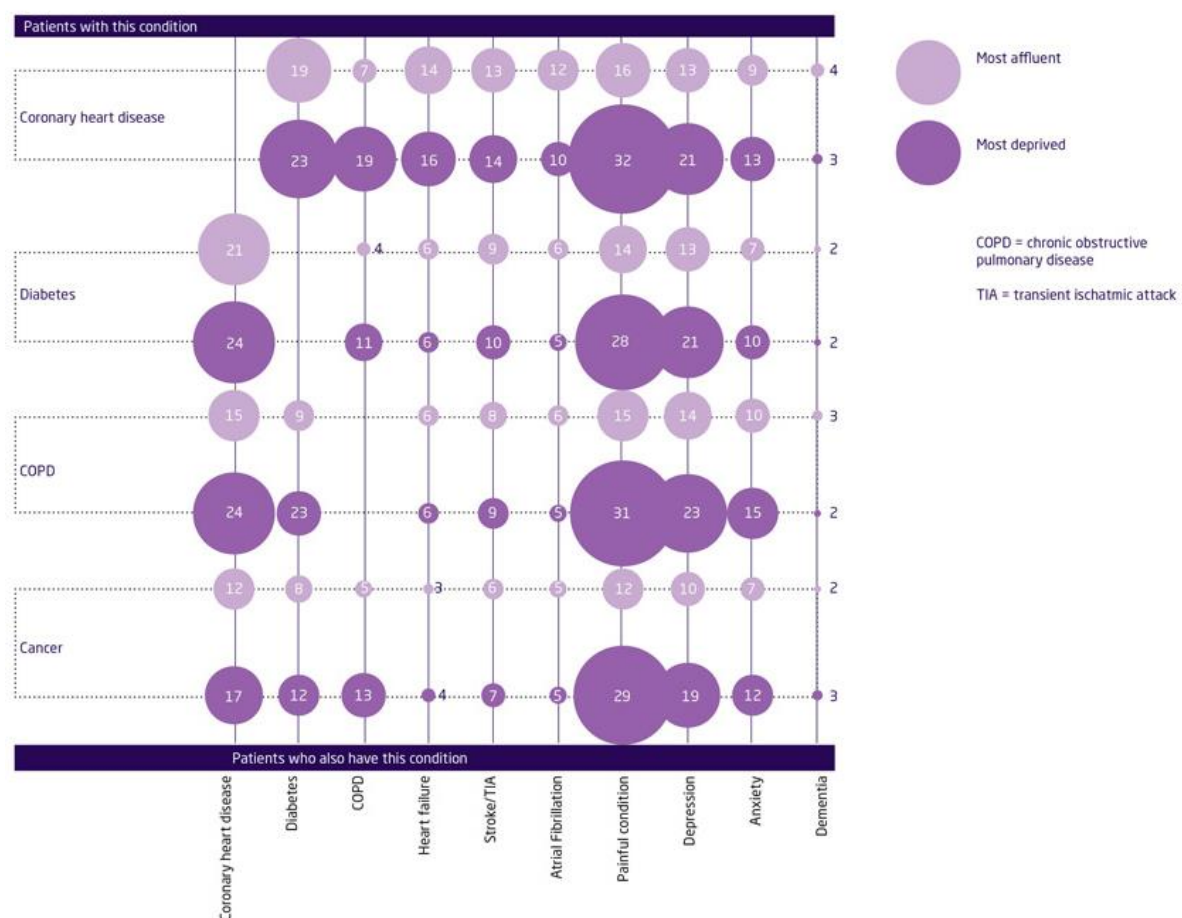
⁴³ Violan C, Foguet-Boreu Q, Flores-Mateo G, Salisbury C, Blom J, et al. (2014) Prevalence, Determinants and Patterns of Multimorbidity in Primary Care: A Systematic Review of Observational Studies. *PLoS ONE* 9(7): e102149.

⁴⁴ Abad-Díez J, Calderon-Larranaga A, Poncel-Falco A et al (2014). Age and gender differences in the prevalence and patterns of multimorbidity in the older population. *Geriatrics*; **14**: 75-81

⁴⁵ Bowling A, Bond M, McKee D et al (2001). Equity in access to exercise tolerance testing, coronary angiography, and coronary artery bypass grafting by age, sex and clinical indications. *Heart*; **85**: 680–686

⁴⁶ Barnett K, Mercer SW, Norbury M, Watt G, Wyke S, Guthrie B (2012). Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *Lancet*. 2012 Jul 7;380(9836):37-43

Figure 3.4 Patterns of selected co-morbidities between most affluent and most deprived deciles



Source: Kings Fund and Barnett 2012

Young and middle aged adults living in the most deprived areas have been shown to have rates of multimorbidity equivalent to those age 10-15 years older in the most affluent areas (Figure 3.5). In addition, those in the most deprived areas were more than twice as likely to have a mental health disorder compared to those in an affluent area (adjusted Odds Ratio 2.28, 95% CI 2.21-2.32) irrespective of the number of other conditions (Figure 3.5).

Some people in deprived areas will have multiple long term conditions 10-15 years earlier than those living in more affluent areas.

Figure 3.5: The impact of socioeconomic status on the prevalence of multimorbidity by age and the prevalence of mental health co-morbidities

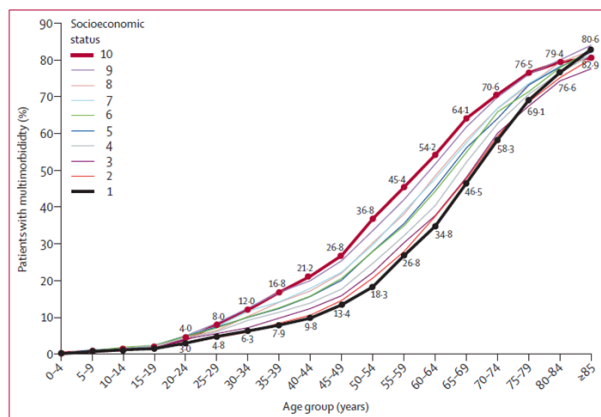


Figure 2: Prevalence of multimorbidity by age and socioeconomic status
On socioeconomic status scale, 1=most affluent and 10=most deprived.

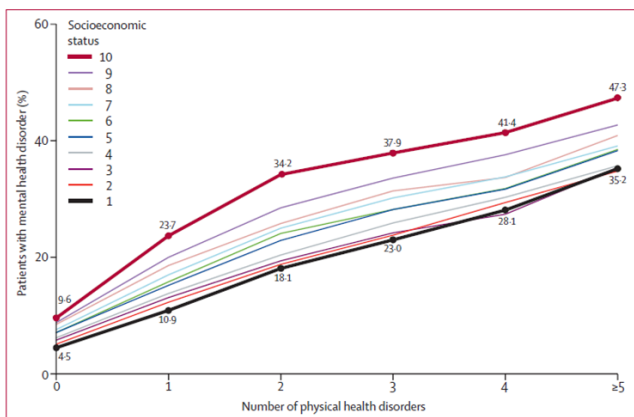


Figure 3: Physical and mental health comorbidity and the association with socioeconomic status
On socioeconomic status scale, 1=most affluent and 10=most deprived.

Source: Barnett 2012

CLUSTERING OF CONDITIONS

There are many studies that have assessed which disease conditions cluster together, however, there are few consistent patterns. This is partly due to different study populations, different condition definitions and different methods used to cluster conditions.

A systematic review⁴⁷ summarising 23 studies in older adults identified 165 combinations of two diseases with only 20 disease pairs being described in at least three studies. Depression was the disease that was most commonly clustered with other conditions (paired with eight different diseases), along with hypertension and diabetes (paired with six different disease). A second systematic review⁴⁸ similarly found a large number of disease patterns but grouped these into three main patterns:

- **Cardiovascular and metabolic disorders.**
- Conditions including **at least one mental health disorder.**
- Conditions including **at least one musculoskeletal disorder.**

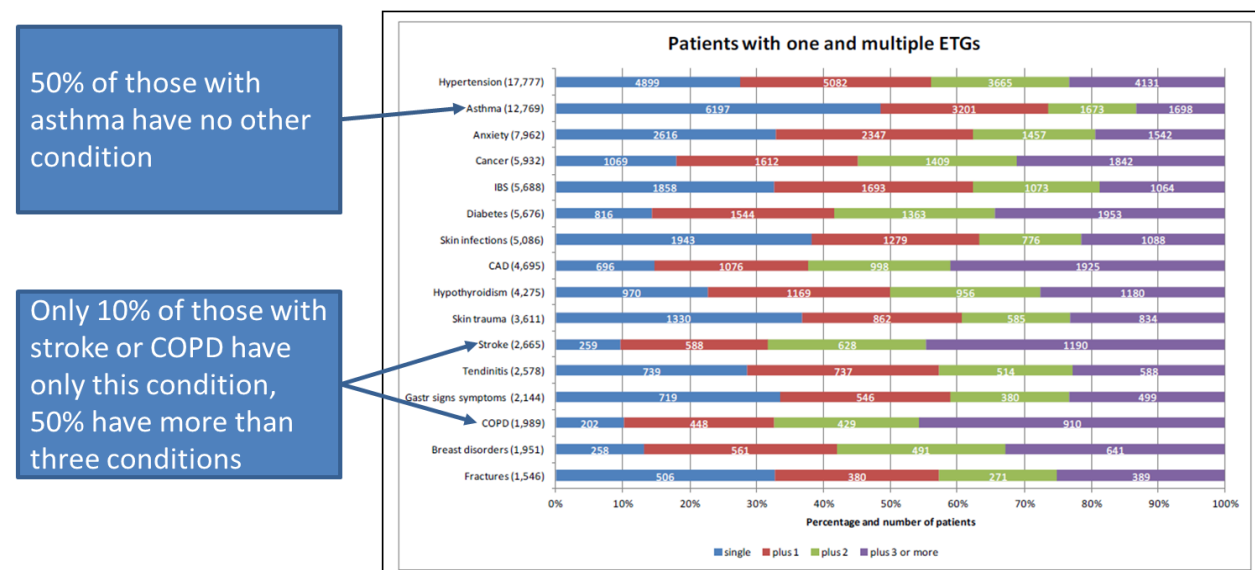
South Somerset's Symphony Project⁴⁹ did identify that some conditions are more likely than others to be in combination with other diseases. For example, almost 50% of those with asthma have no other condition, whereas only 10% of those with a stroke or COPD have no other condition and more than 50% have more than three conditions (Figure 3.6).

⁴⁷ Sinnige J, Braspenning J, Schellevis F, Stirbu-Wagner I, Westert G, et al. (2013) The Prevalence of Disease Clusters in Older Adults with Multiple Chronic Diseases – A Systematic Literature Review. PLoS ONE 8(11): e79641.

⁴⁸ Prados-Torres A, Calderón-Larrañaga A, Hanco-Saavedra J, Poblador-Plou B, van den Akker M. (2014) Multimorbidity patterns: a systematic review. J Clin Epidemiol. 2014 Mar;67(3):254-66.

⁴⁹ Kasteridis P, Street A, Dolman M et al (2014) The Importance of Multimorbidity in Explaining Utilisation and Costs Across Health and Social Care Settings: Evidence from South Somerset's Symphony Project

Figure 3.6: Patients with one and multiple chronic conditions

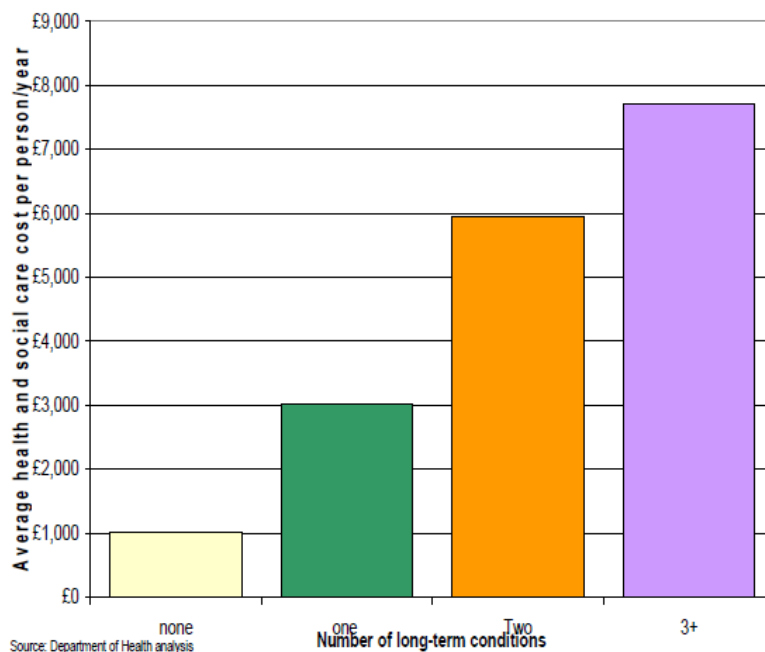


Source: South Somerset's Symphony Project. Kasteridis 2014

IMPACT OF MULTIPLE LTC ON UTILISATION

An analysis by the Department of Health shows the increases in health and social care costs as the number of long term conditions an individual has increases⁵⁰ (Figure 3.7)

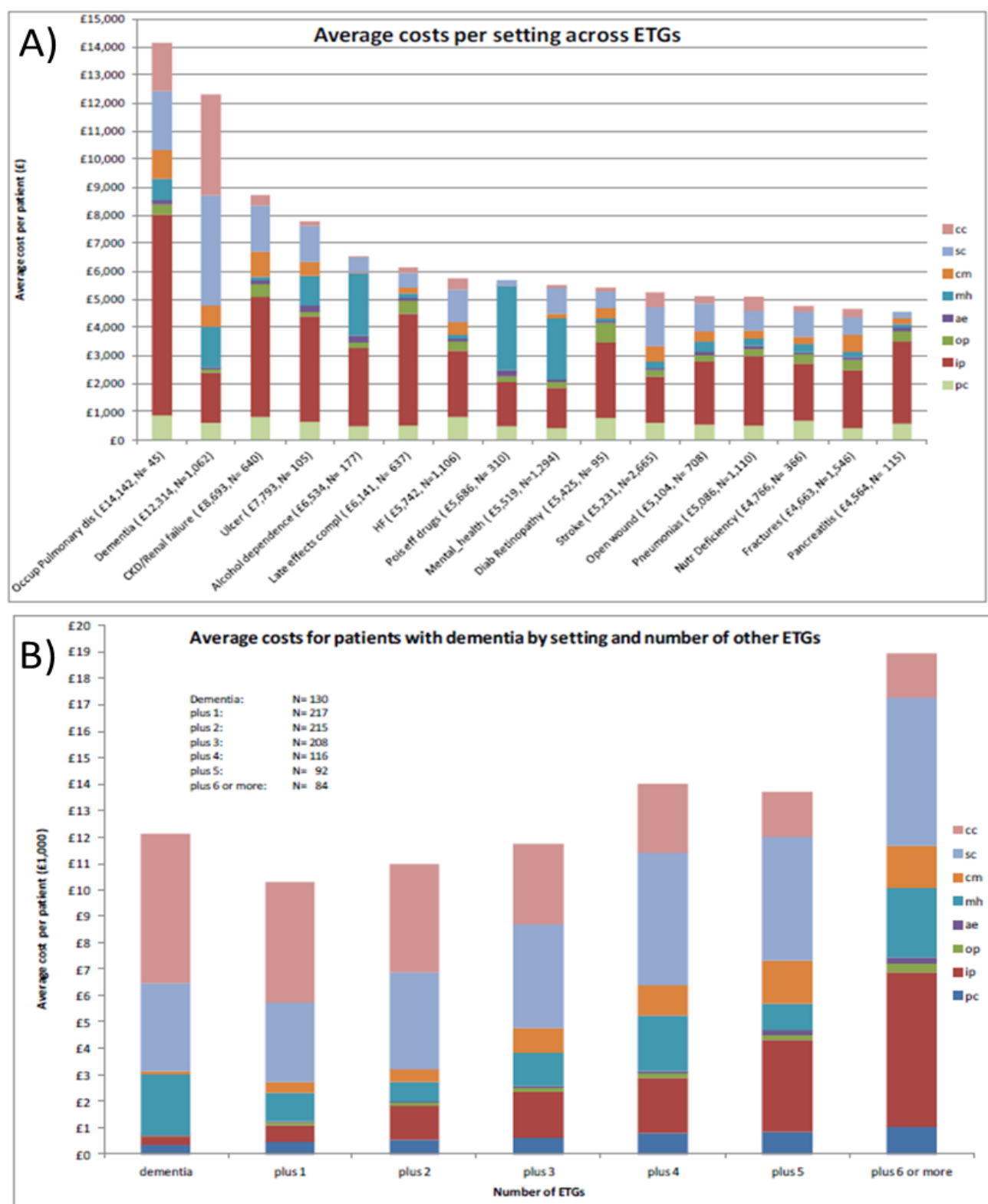
Figure 3.7: Average health and social care cost according to the number of long term conditions



Source: Long Term Conditions Compendium of Information, 3rd Edition

⁵⁰ Department of Health (2012). Long term conditions compendium of information 3rd Edition. Available at <https://www.gov.uk/government/news/third-edition-of-long-term-conditions-compendium-published>

Figure 3.8: The average cost per condition by setting for high cost diseases (A) and for dementia (B)



Source: Kasteridis 2014 Key: CC-continuing care, SC- social care, CM-community care, MH-mental health, AE- acute accident and emergency, OP – acute outpatient, IP- acute inpatient and day case, PC-primary care episodes and prescribing

A systematic review specifically looked at data from five prospective cohort studies of multimorbidity in primary care.⁵¹ One study suggested that certain combinations of chronic conditions (such as congestive heart failure, diabetes and chronic respiratory disease) presented a greater risk for physical decline and some combinations (chronic renal disease and osteoarthritis) had higher consultation rates.

The cost can vary according to setting and disease. For many of the conditions with the highest costs, inpatient costs account for much of the average costs per patient (eg occupational pulmonary disease, Figure 3.8 Graph A), however, for diseases such as dementia continuing care and social care are a much greater proportion of the average patient cost (Figure 3.8, Graph B).

A 2004 systematic review found an inverse relationship between the number of physical conditions and quality of life; though the impact on the social and psychological domains was less clear.⁵²

3.3. LIMITATION, PAIN AND MENTAL HEALTH

LIMITATION – BURDEN & IMPACT

Limitation associated with LTCs has an important impact on experience of living with health conditions, quality of life, and risk factors for an escalation in health and care needs.

LTCS, LIMITATION AND DISABILITY IN THE POPULATION

LTCs as chronic illnesses or diseases may contribute to the limitation of activity for a person; an activity limitation is a difficulty encountered by an individual in executing a task of action.

Whether considered by specific condition, or by a self-reported view, LTCs may be described as limiting or non-limiting. There is therefore some overlap in the definition of a 'limiting LTC' and a disability. The World Health Organisation describes 'disabilities' as *an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations.*⁵³

The level of activity limitation that a person experiences is usually assessed in terms of 'Activities of Daily Living' (ADL) or 'Instrumental activities of daily living' (IADL) – ADLs are activities relating to personal care and mobility about the home that are basic to daily living, IADLs are activities which, while not fundamental to functioning, are important aspects of living independently.⁵⁴

In the general population there is a correlation between age and ability to complete ADLs and IADLs with older, frailer people experiencing higher levels of limitation. The Health Survey for England annually applies the following list of activities in their questions for older people (aged 65 years and over) to assess limitation:

⁵¹ France EF, Wyke S, Gunn JM, Mair FS, McLean G, Mercer SW. (2012) Multimorbidity in primary care: a systematic review of prospective cohort studies. *Br J Gen Pract.* 2012 Apr;62(597):297-307

⁵² Fortin M, Lapointe L, Hudon C et al. (2004) Multimorbidity and quality of life in primary care: a systematic review. *Health Qual Life Outcomes.* 2004; 2: 51.

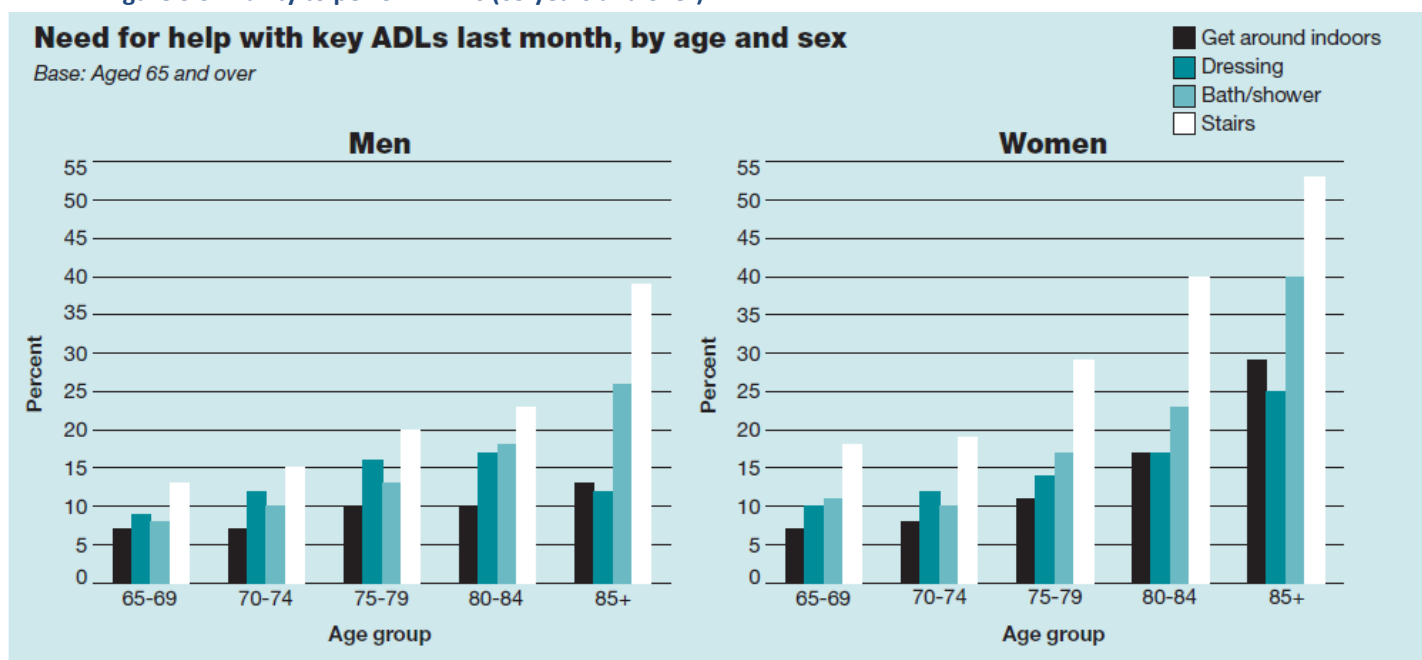
⁵³ World report on disability (2011) World Health Organisation. Available at: http://www.who.int/disabilities/world_report/2011/report/en/

⁵⁴ Health Survey for England 2013: Volume 1, Chapter 2: Social Care. Published December 2014. The Health and Social Care Information Centre: London.

ADLs	IADLs
Getting up and down stairs	Shopping for food
Having a bath or a shower	Doing routine housework or laundry
Dressing or undressing	Getting out of the house
Getting in and out of bed	Doing paperwork or paying bills
Getting around indoors	
Taking medicine	
Using the toilet	
Eating, including cutting up food	
Washing face and hands	

In the population aged 65 years and over, the ability to perform ADLs varies by sex and by the activity involved (HSE 2013)⁵⁵ with mobility in using stairs the most problematic (figure 3.9).

Figure 3.9: Ability to perform ADLs (65 years and over)



Source: Health Survey for England 2013

However, different studies and surveys apply the definitions surrounding limitation differently. The term 'limiting long term illness' (LLTI) is used in the collection of national census data; the Office for National Statistics defines a LLTI as 'A long term health problem or disability that limits a person's day-to-day activities, and has lasted, or is expected to last, at least 12 months'.

Across the whole population,⁵⁶ the National Census collects data via the question "Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months? (include problems related to old age)".

In 2011, among all Cambridgeshire residents, 15.3% (95,027 residents) considered themselves to have a long term activity-limiting illness, below the average for England of 17.6%. The number of people affected by a long term



15.3% of Cambridgeshire residents have a long-term activity-limiting illness

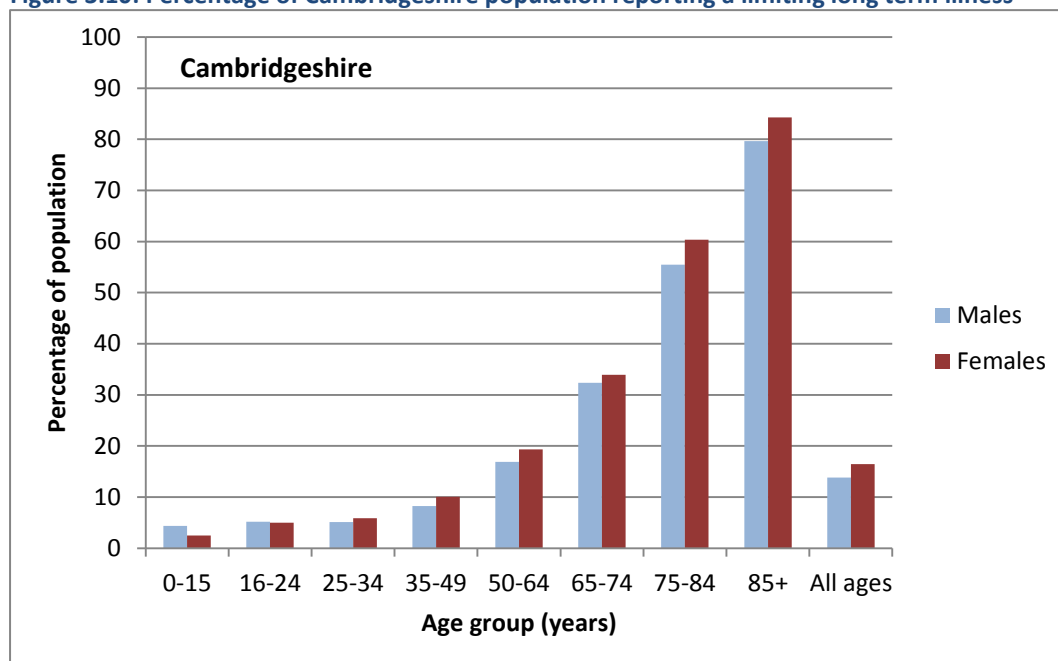
⁵⁵ Health Survey for England 2013: Volume 1, Chapter 2: Social Care. Published December 2014. The Health and Social Care Information Centre: London.

⁵⁶ Data from all usual residents *in households* (i.e. excluding residents in communal establishments such as hospitals, care homes and prisons)

activity-limiting illness in Cambridgeshire increased by 18% between 2001 and 2011, consistent with a growing and ageing population.⁵⁷

Among the working age population (aged 16-64 years), 10.3% of Cambridgeshire's population reported a long term activity-limiting illness, again below the England average of 12.7%.

Figure 3.10: Percentage of Cambridgeshire population reporting a limiting long term illness



Source: Census 2011 Health Summary for Cambridgeshire

In answering the question on long term activity-limiting illness, residents were asked to indicate the extent to which their day-to-day activities were limited: 'Limited a lot' or 'Limited a little'.

Among all residents with a long term activity-limiting illness, the percentage whose activities were limited a lot was lower in Cambridgeshire compared with the national average (41.6% v 47.1%).

Among the working age population in Cambridgeshire with long term activity-limiting illness, the percentage whose activities were limited a lot was smaller (38.8%). Comparisons with the national average and across the districts were very similar to those for all ages.⁵⁸

As self-reported data this gives an indication of the proportion of people experiencing limitation. However, it is harder to gain a measure of the level of limitation experienced by the population living with multiple LTCs, as neither the Census nor the Health Survey asks sufficiently detailed questions.



41.6% of people (all ages) reporting a long-term illness described it as limiting their day-to-day activities 'a lot'

38.8% of working age people reporting a long-term illness as limiting their day-to-day activities 'a lot'

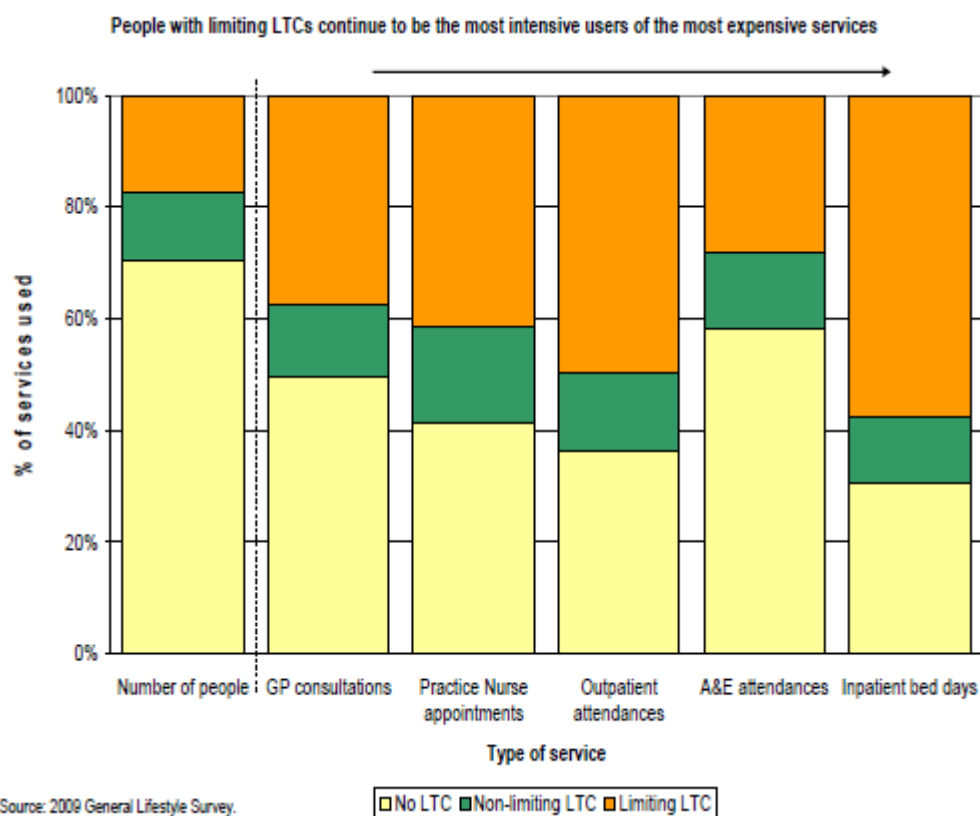
⁵⁷ Further age-standardised data from the 2011 Census are available in the report 'Census 2011 Health Summary for Cambridgeshire', available at: <http://www.cambridgeshireinsight.org.uk/health/2011census>

⁵⁸ Further age-standardised data from the 2011 Census are available in the report 'Census 2011 Health Summary for Cambridgeshire', available at: <http://www.cambridgeshireinsight.org.uk/health/2011census>

MEASURING THE IMPACT OF LIMITATION

Data from the UK General Lifestyle survey indicates that it is people with limiting LTCs that have higher use of both primary and secondary healthcare services compared to people with non-limiting LTCs (figure 3.11).⁵⁹

Figure 3.11: Healthcare services used by people with or without limiting LTCs.

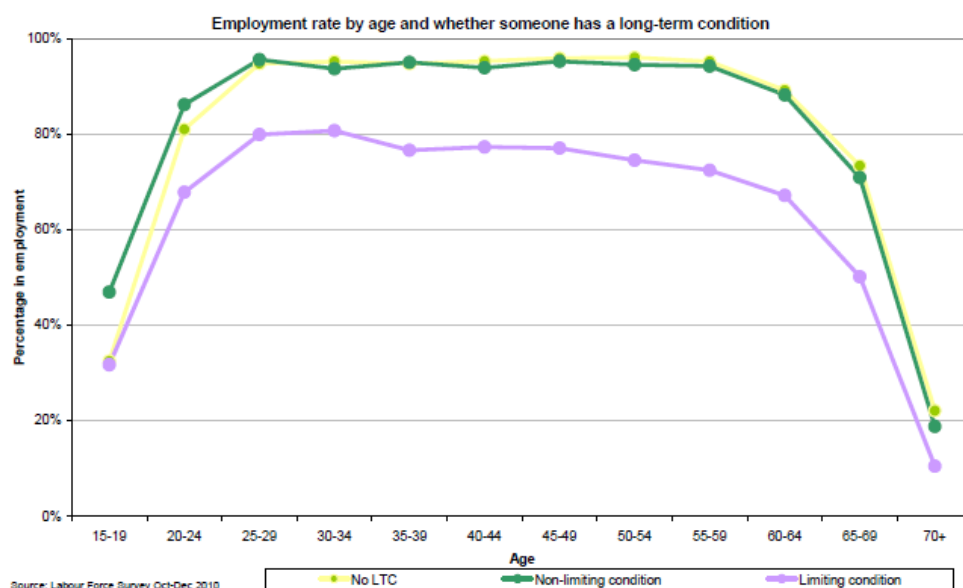


Source: Long Term Conditions Compendium of Information, 3rd Edition

Significant levels of limitation will contribute to increasing social care costs, as people with high levels of limitation are more likely to meet critical thresholds for services.

There are wider detrimental impacts of limitation on quality of life for people and their carers. For example, having a limiting LTC significantly reduces a person's chance of being in work. Being out of work is associated with poorer physical and mental health, and will have financial implications as well. Figure 3.12 shows the employment rate by age – the purple line for limiting condition(s) tracks well below those without a LTC or with a limiting LTC.

⁵⁹ Department of Health (2012). Long term conditions compendium of information 3rd Edition. Available at <https://www.gov.uk/government/news/third-edition-of-long-term-conditions-compedium-published>

Figure 3.12: UK Employment rate across age groups

Source: Labour Force Survey October 2010; Department of Health Long Term Conditions Compendium

PAIN - BURDEN AND IMPACT

Pain, especially chronic pain, has been identified as a particular risk factor for an increased level of vulnerability for those living with LTCs. This section explores the epidemiology and burden of chronic pain.

DEFINING PAIN

Pain is 'an unpleasant sensory and emotional experience associated with actual or potential tissue damage'. The definitions of chronic pain (pain persisting over a period of time) vary by duration in different studies, but the term is usually applied for pain enduring for at least three months.⁶⁰ Pain may be graded in terms of severity; there is a variety of scales and tools used to assess severity.

Pain may be a symptom of a long-standing illness such as arthritis or fibromyalgia. Many experts argue that chronic pain should be considered as an illness in its own right – a condition due to a fault or malfunction in the body's pain system.⁶¹ Chronic pain has not been consistently utilised nor applied in studies to investigate the prevalence of multimorbidity, for some of the reasons described in the section on multimorbidity above.

⁶⁰ Health Survey for England 2011: Volume 1, Chapter 9: Chronic Pain. December 2012. The Health and Social Care Information Centre: London.

⁶¹ Leadley RM, Armstrong N, Lee YC et al. (2012). *Chronic Diseases in the European Union: The Prevalence and Health Cost Implications of Chronic Pain*. Journal of Pain & Palliative Care Pharmacotherapy. 2012, 26; 310–325.

PREVALENCE OF CHRONIC PAIN

As a range of study methodologies have been used to estimate prevalence of chronic pain in the population, there is no single definitive percentage available; estimates typically range between 10% and 30%.⁶²

A large scale computer-assisted telephone survey by Breivik and colleagues across 15 European countries and Israel was completed with initial screening to identify respondents with chronic pain for in-depth interviews. They found a chronic pain prevalence of 19% of respondents who had suffered pain for ≥ 6 months (46,394 respondents, refusal rate 46%).⁶³

Prevalence estimates for chronic pain typically range between 10% and 30% of the adult population

A narrative review by Reid et al. 2011 on the epidemiology of chronic non-cancer pain in Europe derived a one-month prevalence of 19%; the point prevalence was 17.1%.⁶⁴ The authors believe this may be a conservative estimate of the prevalence as their review excluded studies focussing on specific conditions that have associated pain eg multiple sclerosis.

More recently Leadley and colleagues⁶⁵ considered data published between 2006-2011 on the prevalence of chronic pain as part of chronic diseases and the prevalence of chronic pain as a chronic condition in its own right. This review was inclusive of pain related to cancer. They noted again the plurality of criteria used in defining chronic pain in studies, and the difficulty in achieving a pooled estimate. The average prevalence of chronic pain found was 27% (range 7.4% to 46%). As a comorbidity with other conditions, chronic pain was most prevalent in Ehlers-Danlos syndrome (90% reported chronic pain). Other chronic conditions with highly prevalent reported chronic pain were diabetes (35%), cancer (9.9-56%) and kidney diseases (dialysis 57%; transplant 51%).⁶⁶

Similarly, to the prevalence in the whole-population, studies have used differing methodologies in regards to the co-existence of pain with long term illnesses and it is not, therefore, possible to provide a pooled estimate of the percentage of people living with LTCs with chronic pain.

Overall, there are several important demographic patterns of chronic pain in the population:

1. **Chronic pain increases with age.**⁶⁷
2. **Chronic pain is reported more prevalent in women.**⁶⁸
3. **Chronic pain is more commonly reported by those from socially or financially disadvantaged groups.**⁶⁹

⁶² Reid KJ, Harker J, Malgorzata MB et al. (2011). *Epidemiology of chronic non-cancer pain in Europe: narrative review of prevalence, pain treatments and pain impact*. Current Medical Research & Opinion, 2011, 27:2; 449–462.

⁶³ Breivik H, Collett B, Ventafridda V et al. (2006). Survey of chronic pain in Europe: Prevalence, impact on daily life, and treatment. European Journal of Pain, 2006, 10:4; 287.

⁶⁴ Reid KJ, Harker J, Malgorzata MB, Truyers C, Kellen E, Bekkering GE, Kleijnen J (2011). *Epidemiology of chronic non-cancer pain in Europe: narrative review of prevalence, pain treatments and pain impact*. Current Medical Research & Opinion, 2011, 27:2; 449–462.

⁶⁵ Leadley RM, Armstrong N, Lee YC et al. (2012). *Chronic Diseases in the European Union: The Prevalence and Health Cost Implications of Chronic Pain*. Journal of Pain & Palliative Care Pharmacotherapy. 2012, 26; 310–325.

⁶⁶ Leadley RM, Armstrong N, Lee YC et al. (2012). *Chronic Diseases in the European Union: The Prevalence and Health Cost Implications of Chronic Pain*. Journal of Pain & Palliative Care Pharmacotherapy. 2012, 26; 310–325

⁶⁷ Leadley RM, Armstrong N, Lee YC et al. (2012). *Chronic Diseases in the European Union: The Prevalence and Health Cost Implications of Chronic Pain*. Journal of Pain & Palliative Care Pharmacotherapy. 2012, 26; 310–325.

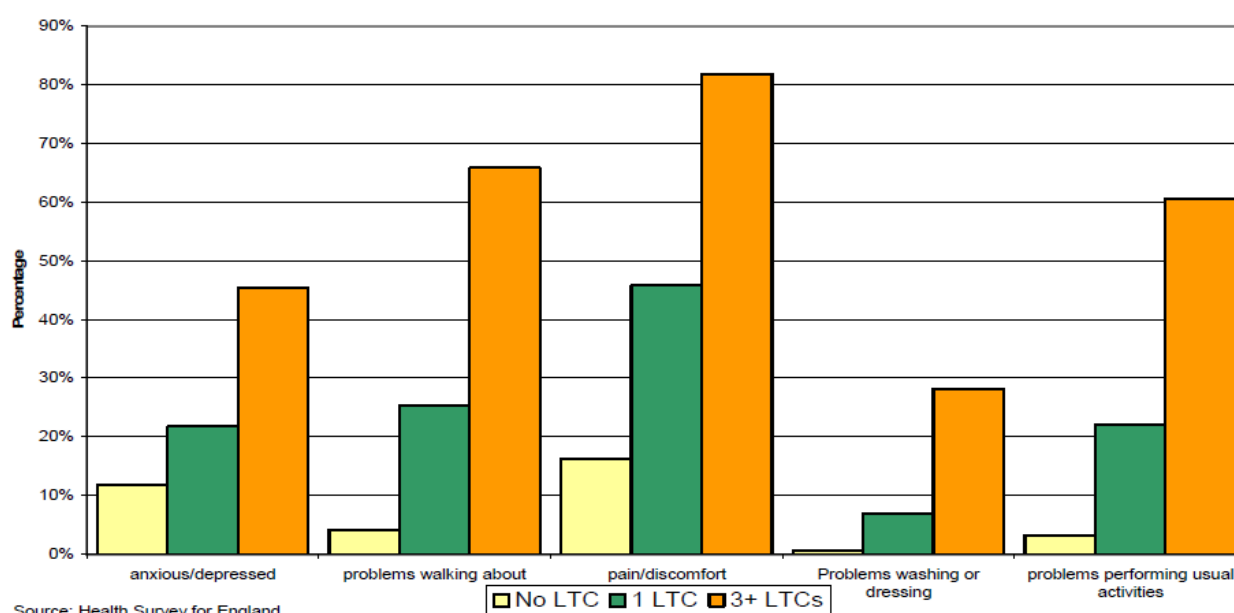
⁶⁸ Health Survey for England 2011: Volume 1, Chapter 9: Chronic Pain. Published December 2012. The Health and Social Care Information Centre: London.

4. Chronic pain is most prevalent in patients with other chronic diseases.⁷⁰
5. Chronic pain can be considered as a very common and costly chronic disease in its own right.⁷¹

IMPACT OF CHRONIC PAIN ON QUALITY OF LIFE

Chronic pain is an important mediator of a reduced quality of life for people with LTCs. People with multiple conditions are particularly severely affected (Figure 3.13). An analysis of the EQ-5D in the Health Survey for England found that almost half of all people with a LTC report moderate or extreme pain, rising to 80% of people with three or more conditions.

Figure 3.13 Impact of long term conditions and multiple long term conditions on quality of life (EQ-5D)



Source: Long Term Conditions Compendium of Information, 3rd Edition

The Health Survey for England in 2011 found that being in chronic pain was associated with poorer mental well-being, lower levels of happiness, and higher prevalence of anxiety/depression using a range of scales and metrics.⁷²

As highlighted in the EQ-5D measure, there are links between chronic pain and psychosocial and mental wellbeing. A narrative review of epidemiologic studies found that chronic pain should be understood in the context of psychosocial factors; psychological comorbidity may significantly change the

There may be interactions between pain and mood disorders in people with LTCs impairing their quality of life

⁶⁹ Health Survey for England 2011: Volume 1, Chapter 9: Chronic Pain. Published December 2012. The Health and Social Care Information Centre: London.

⁷⁰ Leadley RM, Armstrong N, Lee YC et al. (2012). *Chronic Diseases in the European Union: The Prevalence and Health Cost Implications of Chronic Pain*. Journal of Pain & Palliative Care Pharmacotherapy. 2012, 26; 310–325.

⁷¹ Leadley RM, Armstrong N, Lee YC et al. (2012). *Chronic Diseases in the European Union: The Prevalence and Health Cost Implications of Chronic Pain*. Journal of Pain & Palliative Care Pharmacotherapy. 2012, 26; 310–325.

⁷² Health Survey for England 2011: Volume 1, Chapter 9: Chronic Pain. Published December 2012. The Health and Social Care Information Centre: London.

LONG TERM CONDITIONS JSNA

LTCS IN THE POPULATION: CHARACTERISTICS OF THOSE AT HIGH RISK OF POOR HEALTH OUTCOMES

prognosis and course of chronic pain.⁷³ A cross-sectional population study of 21425 community-living adults in Belgium, France, Germany, Italy, the Netherlands, and Spain indicated the link between painful physical symptoms and major depressive episodes in patients.⁷⁴ Painful physical symptoms were reported by 50% of respondents with a mood disorder. Respondents with depressive episodes and pain had lower rates of help seeking for emotional reasons.

IMPACT OF CHRONIC PAIN ON THE HEALTH AND CARE SYSTEM

There are wider impacts to living with chronic pain – particularly in terms of limitation, employment and number of work days lost.

In the recent European study, the mean number of work days lost due to moderate to-severe chronic non-cancer pain in the last six months was 7.8 days and 22% had lost at least 10 work days. No study was identified that reported on the economic impact of chronic pain on healthcare systems in Europe.⁷⁵

There is evidence for higher utilisation of healthcare, for example a study using data from the Danish national health surveys found that individuals reporting long term pain averaged 12.8 contacts per year to the primary care sector compared with 7.3 for the control group; the pain population had higher hospital admission frequency.

However, there is limited UK data on utilisation of health services by people living with chronic pain. Similarly there is limited evidence available on the cost implications. The Chief Medical Officer report 2008 noted that estimates of back pain alone are around £12.3 billion a year – although back pain may have different aetiology to forms of chronic pain experienced by people with LTCs.

MENTAL ILL HEALTH – BURDEN AND IMPACT

Depression and anxiety are acknowledged as risk markers for poorer health outcomes in people with LTCs.

ANXIETY & DEPRESSION AND LTCS

Common mental disorders, which include depression and anxiety, are highly prevalent with long term conditions.⁷⁶ Data from the World Health Survey (2007) involving more than 245,000 people in 60 countries found an average of between 9.3% and 23% of participants with one or more chronic diseases had co-morbid depression.⁷⁷ Compared with the general population, people with diabetes, hypertension and coronary artery disease have double the rate of mental health problems, and those with chronic obstructive pulmonary

⁷³ Tunks ER, Crook J, Weir R (2008) Epidemiology of chronic pain with psychological comorbidity: prevalence, risk, course, and prognosis. *Canadian Journal of Psychiatry*. 2008, 53(4):224-234.

⁷⁴ Demyttenaere K, Bonnewyn A, Bruffaerts R, Brugha T, De Graaf R, Alonso J (2006) Comorbid painful physical symptoms and depression: Prevalence, work loss, and help seeking. *Journal of Affective Disorders*. 92: 2–3; 185–193.

⁷⁵ Reid KJ, Harker J, Malgorzata MB, Truyers C, Kellen E, Bekkering GE, Kleijnen J (2011). *Epidemiology of chronic non-cancer pain in Europe: narrative review of prevalence, pain treatments and pain impact*. *Current Medical Research & Opinion*, 2011, 27:2; 449–462.

⁷⁶ Department of Health (2013) Annual Report of the Chief Medical Officer *Public Mental Health Priorities: Investing in the Evidence*

⁷⁷ Moussavi S, Chatterji S, Verdes E, Tandon A, Patel V, Ustun B (2007) 'Depression, chronic diseases, and decrements in health: results from the World Health Surveys', *Lancet*, 370; 9590; 851–58.

LONG TERM CONDITIONS JSNA

LTCS IN THE POPULATION: CHARACTERISTICS OF THOSE AT HIGH RISK OF POOR HEALTH OUTCOMES

disease, cerebro-vascular disease and other chronic conditions have triple the rate. People with two or more long term conditions are seven times more likely to have depression.⁷⁸

In 2012 The Kings Fund published a review of evidence considering the link between mental health and long term conditions, focusing on people with a LTC and co-morbid mental health problems. The report summarises research evidence that consistently demonstrates that people with long term conditions are two to three times more likely to experience mental health problems than the general population, with much of the evidence relating to affective disorders such as anxiety and depression.

People with multiple conditions are 7 times more likely to have depression than the general population

There is particularly strong evidence for a close association with cardiovascular disease, diabetes, COPD and musculoskeletal disorders. There is also evidence for higher than usual levels of mental health problems among people with other conditions including asthma, arthritis, cancer and HIV/AIDS. Co-morbid mental health problems are particularly common among people with multiple long term conditions, with data from World Health Surveys indicating that people with two or more long term conditions are seven times more likely to have depression than people without a long term condition.⁷⁹

The mechanisms for the association between depression and morbidity in physical illness are not fully understood and may comprise diminished healthcare behaviour or physiological impairment, or a combination of the two.⁸⁰

IMPACT ON HEALTH AND COSTS

The implications of co-existing mental ill health and physical ill health are detrimental outcomes. People with mental health problems are known to have higher rates of respiratory, cardiovascular and infectious disease, and of risk factors including obesity, abnormal lipid levels and diabetes. For example, co-morbid depression doubles the risk of coronary heart disease in adults and increases the risk of mortality by 50%.⁸¹

In addition to poorer objective health outcomes, co-morbid health anxieties or mental health disorders are associated with poorer self-reported health outcomes and wider costs to an individual and family, for example through lack of employment, sickness absence, informal family care and support. The higher use of healthcare resources (and resultant costs) include: unnecessary investigation; increased presentations in primary care, emergency departments and outpatient clinics; increased use of medication; increased admissions with longer lengths of stay; and, in older people, increased risk of institutionalisation.⁸²

People with comorbid physical and mental health conditions may use more healthcare resources than others with LTCs, equivalent to an estimated £8-£13 billion of NHS spending in England

⁷⁸ Department of Health (2013) Annual Report of the Chief Medical Officer *Public Mental Health Priorities: Investing in the Evidence*

⁷⁹ The King's Fund and Centre for Mental Health (2012) Long Term conditions and mental health. The cost of co-morbidities

⁸⁰ Investing in emotional and psychological wellbeing for patients with long-term conditions, (2012) The NHS Confederation: London.

⁸¹ Investing in emotional and psychological wellbeing for patients with long-term conditions, (2012) The NHS Confederation: London.

⁸² Investing in emotional and psychological wellbeing for patients with long-term conditions, (2012) The NHS Confederation: London.

LONG TERM CONDITIONS JSNA

LTCS IN THE POPULATION: CHARACTERISTICS OF THOSE AT HIGH RISK OF POOR HEALTH OUTCOMES

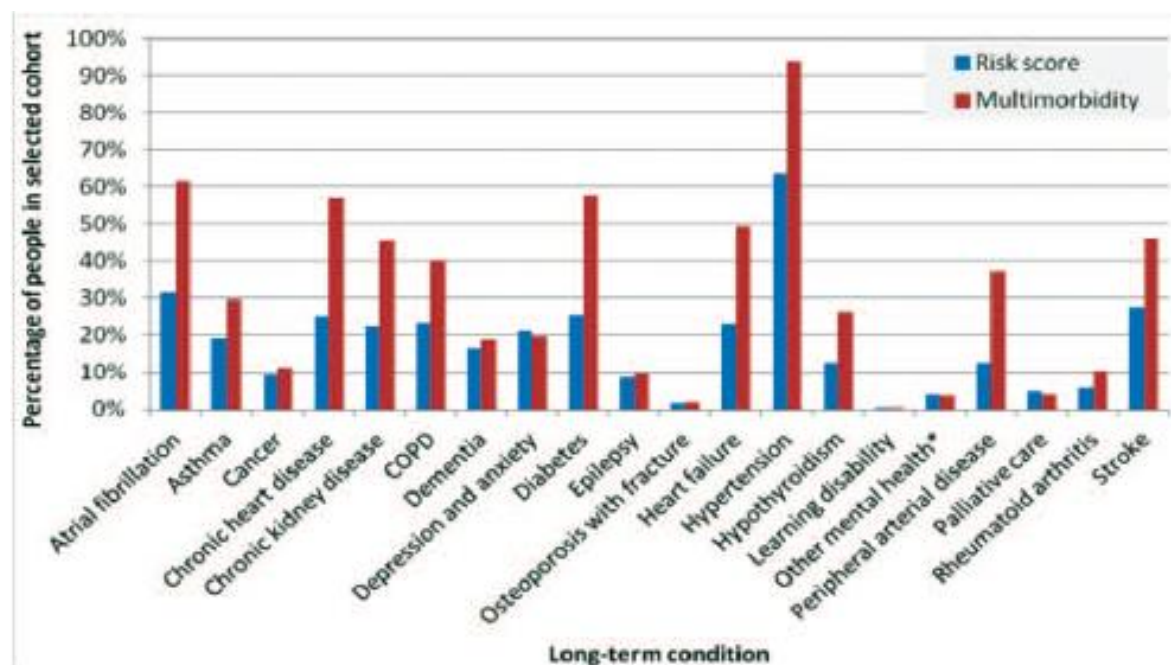
Naylor and colleagues, for the King's Fund, investigated the cost of co-morbidities and estimated that co-morbid mental health problems are typically associated with a 45–75 per cent increase in service costs.⁸³ They calculate that at least £1 in every £8 spent on long term conditions is linked to poor mental health and wellbeing, meaning that between £8 billion and £13 billion of NHS spending in England is attributable to the consequences of co-morbid mental health problems among people with long term conditions. It is further suggested that the majority of these costs will be associated with the most complex patients whose long term conditions are most severe or who have multiple co-morbidities.

3.4. SPECIFIC CONDITIONS OF INTEREST

To complement the thematic approach in this JSNA, several conditions have been analysed for the local population to provide detailed intelligence and updates for JSNA stakeholders, presented for both the resident population for Cambridgeshire, and the registered population for Cambridgeshire & Peterborough Clinical Commissioning Group.

The selection of these conditions was aligned with the particular interest in conditions that contribute to the burden of LTCs and particularly multimorbidity. In the population analysis for Kent and Medway⁸⁴ as part of the NHS England Year of Care programme for LTCs, one of the risk stratification methods was a count of conditions. This programme was focussed on the 'very complex' level of the population so they selected patients with five or more LTCs, equivalent to 0.3% of the total Kent population. They also explored the use of risk scores and other stratification methods. The disease profile for this 'multimorbidity' group is shown in Figure 3.14, in comparison with a risk score stratification method.

Figure 3.14: Disease profile of selected Kent patients with 'very complex' health and social care needs



Source: NHS Improving Quality, Kent whole population dataset

⁸³ The King's Fund and Centre for Mental Health (2012) Long Term conditions and mental health. The cost of co-morbidities.

⁸⁴ NHS Improving Quality (2013) Population Level Commissioning for the Future: Kent Whole Population Dataset – Interim Report. Available at: www.nhs.uk/nhsq/ltcyoc

The conditions that had a prevalence of 30% or greater in the multimorbidity cohort above equated well with the prevalent conditions in the population for Cambridgeshire, and matched the interest of our stakeholders; these were selected as specific conditions of interest. Specifically these are:

- **Cardiovascular Disease (CVD)**
 - **CHD; stroke; peripheral arterial disease; atrial fibrillation; heart failure**
- **Hypertension**
- **Diabetes**
- **Chronic Kidney Disease (CKD)**
- **Chronic Obstructive Pulmonary Disease (COPD)**

Further detail on these conditions can be found in the data supplements at the end of this report. Where possible, these specific conditions have been used as exemplar or case studies in the main body of this report.

3.5. WHAT IS THIS TELLING US?

- The content of this chapter presents a set of characteristics, as defined by local stakeholders and supported by research evidence, which describes a population at greater risk of poor health outcomes and admission to hospital or social care.
- There are no agreed characteristics for describing the 'high risk' population with LTCs who would benefit from the 'care management' even though they are identified conceptually within risk models. This JSNA used the professional knowledge of local stakeholders and practitioners supported by research evidence to describe a high risk group. Multimorbidity (multiple physical and mental health conditions) has been the predominant theme.
- Multimorbidity is the coexistence of two or more LTCs. The scale of multimorbidity, at national and international levels, is substantial and increases with age.
- There are significant gender differences in the presentation of multimorbidity patterns between men and women. A clear inverse association between socioeconomic status and multimorbidity exists and multimorbidity may present up to 15 years earlier in population groups living in deprived areas. This finding has implications for targeting of preventative interventions in Cambridgeshire.
- Data from research projects has not shown consistent patterns for which disease conditions cluster together due to differing methodologies. In older adults, depression may cluster most commonly with other conditions. Detail from the Symphony project in South Somerset does identify that some conditions including stroke or COPD are more likely to be in combination with other diseases.
- The average cost per patient may increase with every additional chronic condition which would support a focus on multiple conditions in Cambridgeshire.
- Activity limitation is particularly interesting in regards to the interaction with pain and mental health. Among the Cambridgeshire residents reporting a long term activity-limiting illness, 42.7% were limited 'a lot'; for the working age population this was 38.8% - representing a significant proportion of the LTC population, and may therefore have higher use of healthcare services, potential demand for social care, and poorer quality of life indicators.

LONG TERM CONDITIONS JSNA

LTCs IN THE POPULATION: CHARACTERISTICS OF THOSE AT HIGH RISK OF POOR HEALTH OUTCOMES

- Deriving from the study survey data available, chronic pain is likely to be prevalent in the LTCs population in Cambridgeshire and found to increase with age, and be more prevalent in women and lower SES groups. Interactions between pain and anxiety and depression may impair quality of life as well as moderate to severe pain contributing to absence from work.
- The co-existence of physical and mental health conditions is high; people with multiple conditions are seven times more likely to have depression than the general population. Co-morbid anxiety and depression may be useful indicators for people who may more healthcare resources.

4. LTCS IN CAMBRIDGESHIRE: DESCRIBING THE POPULATION AT HIGH RISK OF POOR HEALTH OUTCOMES

4.1. WORKING WITH THE DATA ON LTCS FOR CAMBRIDGESHIRE

The complexity of describing the population with multiple conditions has been considered in Chapter 3. Key issues include how to define; which conditions are included and count in the definition; whether or not mental health is considered as a long term condition; how many conditions count; and whether or not acute or chronic conditions or disease severity is taken into account. Prevalence estimates from research studies vary depending on which approach is taken. Due to the heterogeneity of findings, it was not considered useful to repeat this type of analysis using local data as it would only add one additional analysis to an already complex area. Without linkage of data between hospital admissions, social care and GP records, an analysis would be severely limited in its scope.

WORKING WITH THE DATA ON LTCS FOR THE ADULT POPULATION (18 TO 64 YEARS)

The approach for this JSNA has been pragmatic. For the adult population aged 18 to 64 years we have analysed individual level data from the Health Survey for England (HSE 2012) and applied the results to the Cambridgeshire population to estimate the numbers of people likely to be affected. In terms of health conditions, the HSE survey is all inclusive. During the face to face interview, participants report longstanding illnesses lasting or expected to last 12 months or more, and specify up to six conditions. Results from the survey are reported by ICD10 Chapter. If a longstanding illness reduces participants' ability to carry out day-to-day activities, either a little or a lot, it is considered a limiting longstanding illness. Mental health status in the 2012 survey was measured by GHQ-12 with a score of four or more representing probable mental ill health.⁸⁵ Since the approach for this JSNA was to consider mental health as a theme that cuts across all areas, the HSE data was adjusted accordingly and self-reported mental health was excluded as a long term condition in terms of disease counts.

WORKING WITH DATA ON LTCS FOR THE OLDER POPULATION (AGED 65 AND OVER)

For the older population (65+) we have had the opportunity to use local data from the MRC Cognitive Function and Ageing Study (CFAS II).^{86,87,88} We used the Cambridgeshire centre sample (consisting of the rural area of East Cambridgeshire and Fenland centred on Ely and surrounding villages, excluding Cambridge City). The sample is stratified based on the age groups 65-74 years and 75 years and over, with 50% of the sample in each age group. Nurse led interviews were completed between October 2008 September 2011. For mental health conditions (dementia, depression and anxiety) questions

⁸⁵ For a full report on GHQ -12 see <http://www.hscic.gov.uk/catalogue/PUB13218/HSE2012-Ch4-Gen-health.pdf>

⁸⁶ Matthews FE, Arthur A, LE Barnes et al, on behalf of the Medical Research Council Cognitive and Ageing Collaboration., A two-decade comparison of prevalence of dementia in individuals aged 65 years and over from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II. Lancet 2013; 13:61570-6. [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(13\)61570-6/abstract](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(13)61570-6/abstract)

⁸⁷ For further detail on method including sampling and AGE CAT see The Lancet: Supplementary Appendix <http://www.thelancet.com/cms/attachment/2011533974/2034048757/mmc1.pdf>

⁸⁸ For study protocols and further detail see website for Cognitive Function and Ageing Study www.cfas.ac.uk

provide the Automated Geriatric Examination for Computer Assisted Taxonomy (AGECAT) study diagnostics algorithm within a single interview, drawing on respondent and observer ratings.

In CFAS II, the following conditions are included as long term conditions: angina, intermittent claudication (equivalently peripheral vascular disease), hypertension, cancer, diabetes, Parkinson's Disease (PD), stroke, myocardial infarction (MI) and chronic obstructive pulmonary disease (COPD), asthma, arthritis and thyroid problems. We excluded two conditions only, pernicious anaemia and peptic ulcer. Since two conditions (hypertension and arthritis) tended to dominate in both CFAS II and HSE amongst the population aged 65 and over, this analysis initially used two or more long term conditions to describe multiple conditions in older people and was then extended to consider people with three or more conditions. For the purpose of this JSNA, limitation was defined as those who responded to this question "For at least the last six months, to what extent have you been limited because of a health problem in activities people usually do?" that they were "severely limited" and "limited but not severely."

We acknowledge that the definitions and methodology used in the local analysis for this JSNA differs to that used by CFAS. All interpretations presented are those of the JSNA working group. For both the HSE and CFAS II analysis we used weighted prevalence estimates using svy commands within Stata 12.1. More detailed information is available from both the HSE and CFAS analyses and can be requested from the Public Health Older People's Team.

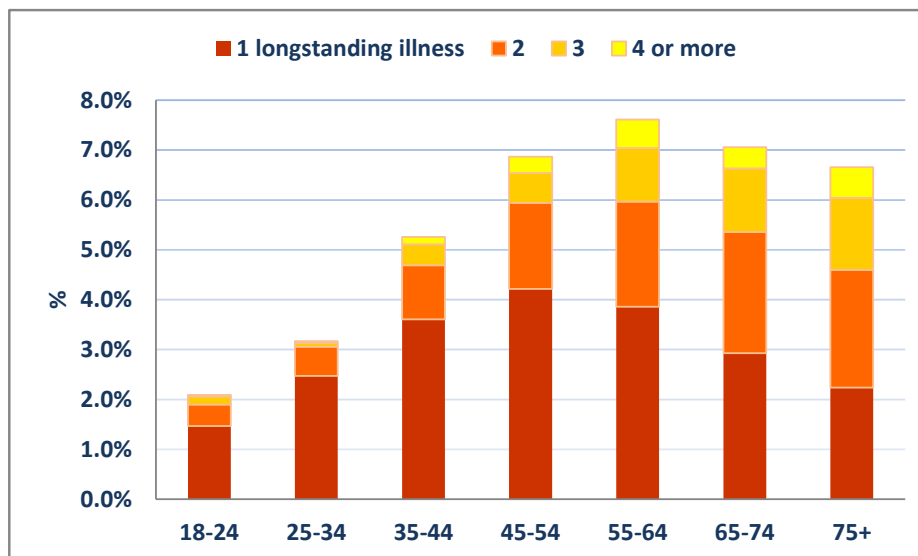
4.2. ESTIMATES OF NUMBERS AND PROPORTIONS OF ADULTS AND OLDER PEOPLE WITH MULTIPLE CONDITIONS IN CAMBRIDGESHIRE

DESCRIBING MULTIPLE CONDITIONS

As described in Chapter 2, the number of long term conditions a person is likely to have increases with age. Figure 4.1 shows the proportion of the population that reported one, two, three or four or more longstanding illnesses (lasting twelve months or more) in the Health Survey for England (HSE) 2012. Of those people who have long term conditions, 44% have more than one LTC which means that of the estimated adult population in Cambridgeshire aged 18 to 64 years in 2015 (512,500 people), approximately 225,600 people have more than one long term condition.



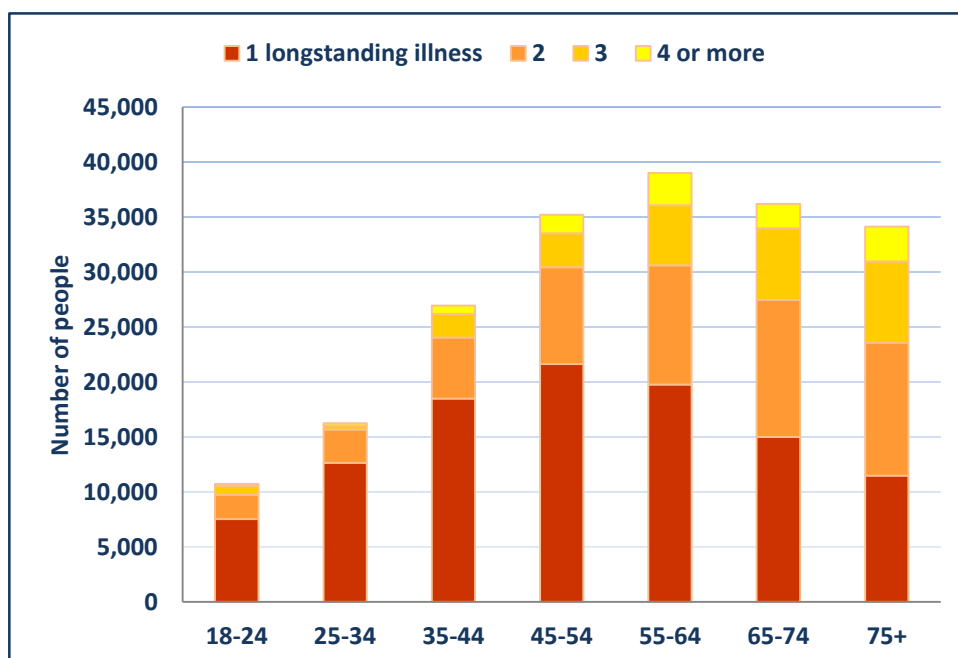
Figure 4.1: The proportion of people with one, two, three or four or more longstanding illnesses by age group, Health Survey for England (2012)



Source: Health Survey for England (2012)

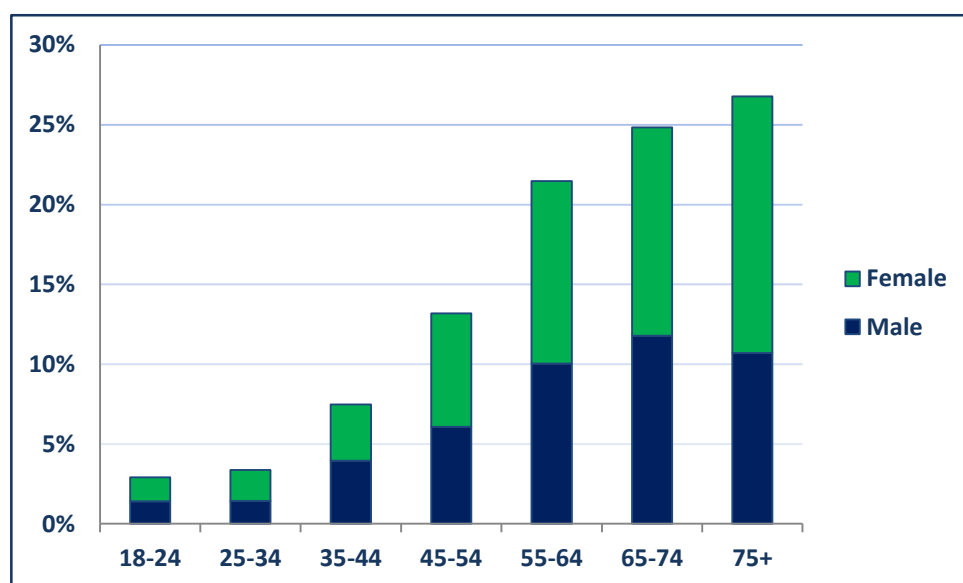
Figure 4.2 applies the estimates from HSE in people aged 18 and over to the Cambridgeshire population by age group.

Figure 4.2: The number of people with one, two, three or four or more longstanding illnesses by age group, Cambridgeshire, 2015



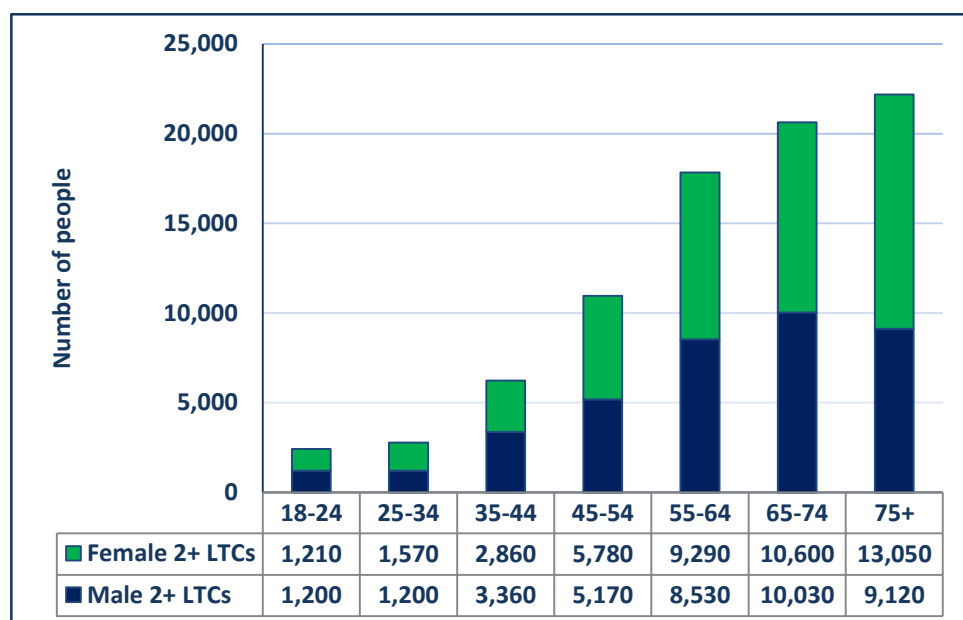
Source: Health Survey for England (2012) estimates applied to CCC RP&T 2012 based population forecast for 2015

Figure 4.3 shows the breakdown by gender for the population aged 18 and over.

Figure 4.3: Proportion of people with two or more (2+) long standing illnesses by age and gender

Source: Health Survey for England (2012). Note: count of illnesses excludes self-reported mental health conditions

In total, if the study estimates from HSE 2012 for people aged 18 and over are applied to the Cambridgeshire population, the estimated number of people with two or more longstanding illnesses is substantial. Over 83,000 people have two or more LTCs, of whom 53% are female, until by the age of 75 and over, 59% are female.

Figure 4.4: Number of people with two or more long standing illnesses by age and sex, Cambridgeshire 2015

Source: Health Survey for England (2012) survey estimates applied to CCC RP&T 2012 base population forecast for 2015. Note: count of illnesses excludes self-reported mental health conditions

ESTIMATES OF NUMBERS AND PROPORTIONS IN ADULTS (18-64 YEARS)

In the Health Survey for England (2012), 9.8% of adults aged 18-64 years reported two or more long standing illnesses (excluding mental health conditions). This equates to over 39,000 people in Cambridgeshire in 2015. The 95% confidence interval (95% CI) in Table 4.1 indicates the statistical certainty we can have around this estimate, and in this instance represents a range around this result – so from 36,000 to 42,000 people in Cambridgeshire aged 18 to 64 years are estimated to have two or more long term conditions.

Table 4.1: Number and proportion of people with long standing illness aged 18-64 years, 2015, Cambridgeshire

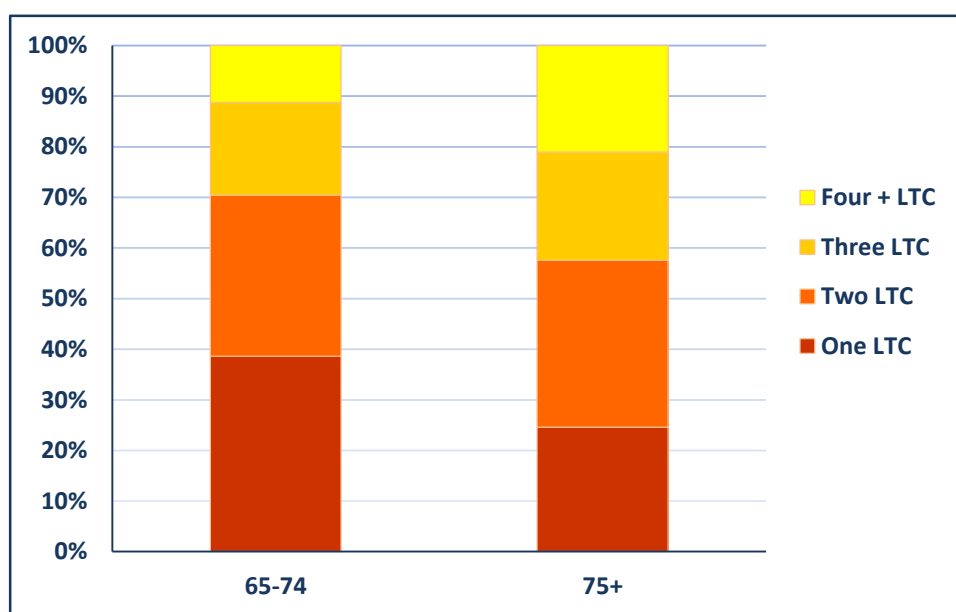
Number of illnesses	%	95% CI	Estimate of number of people in Cambridgeshire aged 18-64 years (2015) and range (95% CI)	
No longstanding illnesses	71.3	(70.1 - 72.5)	283,300	(278,500 - 288,100)
One longstanding illness	18.8	(17.8 - 19.9)	74,800	(70,800 - 79,000)
Two or more longstanding illnesses	9.8	(9.1 - 10.7)	39,100	(36,100 - 42,300)
Total	100			

Source: Health Survey for England (2012) estimates applied to CCC RP&T 2012 based population forecast for 2015

ESTIMATES IN OLDER PEOPLE (65+)

Figure 4.5 shows the proportion of older people with one or more long term condition by number of conditions and age group. As would be expected, there is more morbidity in the age group 75 years and over than in the age group 65 to 74 years.

Figure 4.5: Proportion of older people with long standing illness by age group and number of conditions



Source: MRC Cognitive Function and Ageing Study (CFAS II)

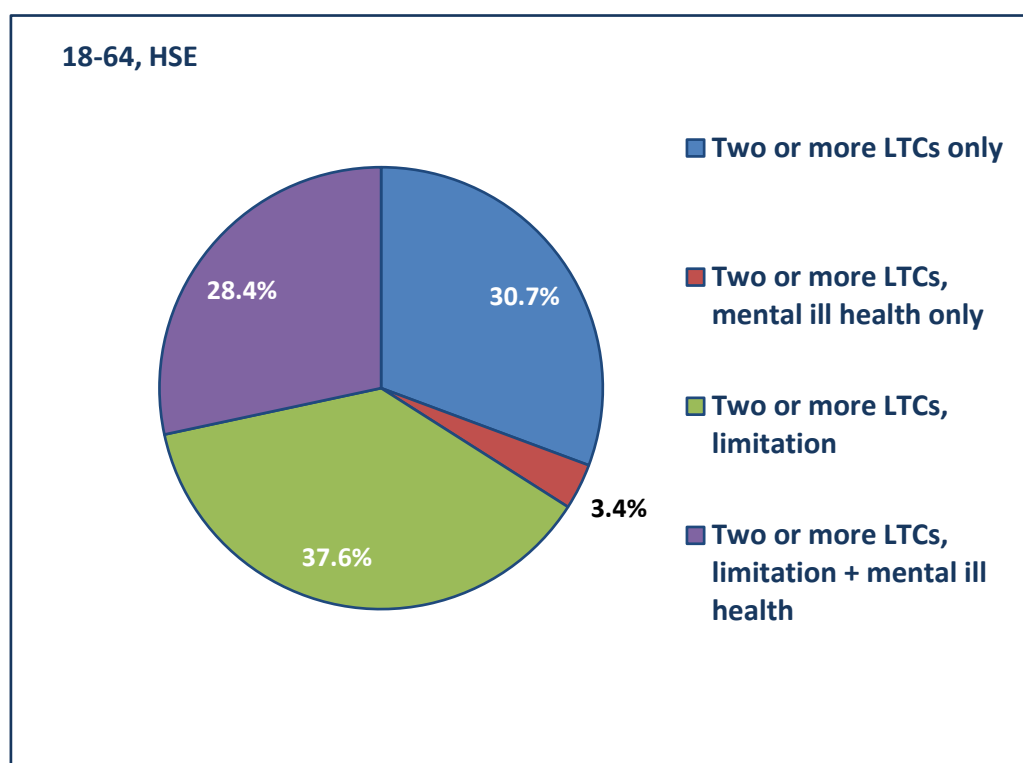
4.3 ESTIMATES OF NUMBERS AND PROPORTIONS OF PEOPLE WITH LTC WITH OVERLAPPING LIMITATION AND MENTAL HEALTH

From both surveys, HSE for adults and CFAS II for older people, the aim was to identify the numbers and proportions of people with multiple long term conditions and overlapping 'limitation' and mental ill health.

DESCRIBING MULTIPLE CONDITIONS WITH LIMITATION AND MENTAL ILL HEALTH IN ADULTS (18-64 YEARS)

Figure 4.6 shows the results from HSE 2012 for adults aged 18 to 64 years, with two or more long term conditions, and the impact of limitation and probable mental ill health. Amongst adults aged 18 to 64 years with two or more LTCs, nearly 31% have two or more LTCs only, an additional 3.4% have two or more LTCs with probable mental ill health, nearly 38% have two or more LTCs with limitation and over 28% have two or more LTCs, with limitation and with probable mental ill health.

Figure 4.6: Proportion of people aged 18 – 64 years with multiple (two or more) long standing illnesses with and without limitation and/or mental ill health (based on GHQ-12 score of 4 or more)



Source: Health Survey for England (2012) survey estimates. Note: count of illnesses excludes self-reported mental health conditions and probable mental ill health is based on GHQ-12 score of 4 or more

When these figures from HSE 2012 are applied to the Cambridgeshire population aged 18 to 64 years, the number of people estimated to have two or more LTCs and who report limitation is around 14,700 people. When mental ill health is considered as well (Table 4.2) around 11,000 people report two or more LTCs with limitation and with probable mental ill health as defined by a GHQ-12 score of 4 or more. The 95% confidence interval (95% CI) in Table 4.2 indicates the statistical certainty we can have around this estimate, and in this instance represents a range around this result – so from 9,600 to 12,700 people in Cambridgeshire aged 18 to 64 years are estimated to have two or more long term conditions with limitation and probable mental ill health.

Table 4.2: Proportion of people aged 18 – 64 years with multiple (two or more) long standing illnesses with and without limitation and/or mental ill health (based on GHQ-12 score of 4 or more)

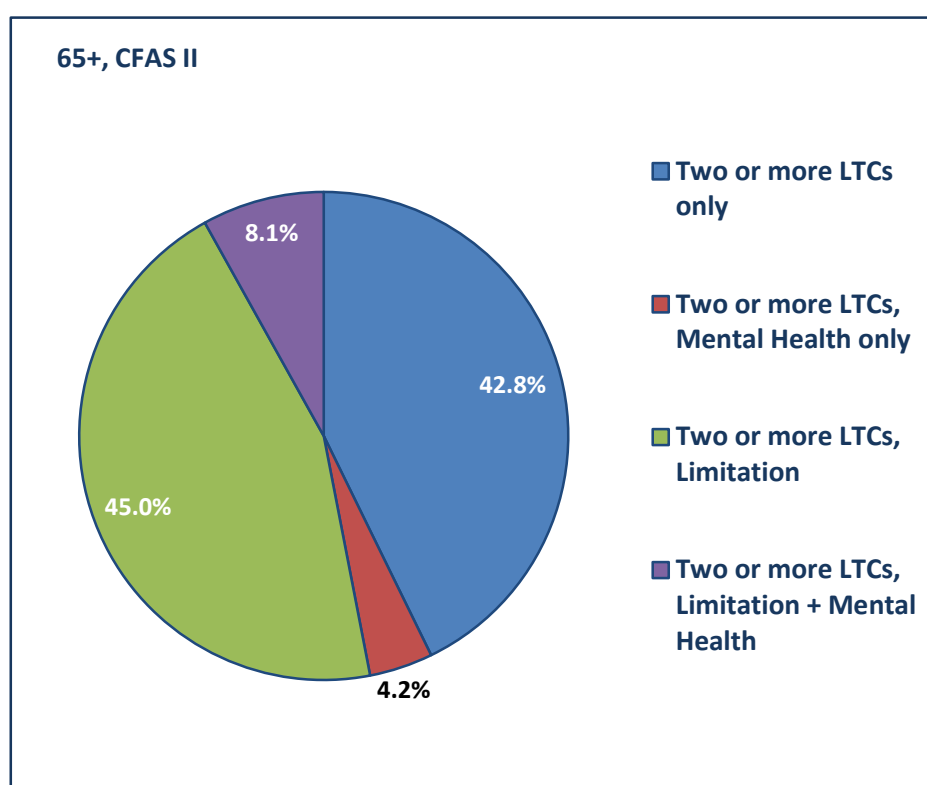
People aged 18-64 years with 2+ LTC	%	95% CI	Estimate of number of people in Cambridgeshire aged 18-64 years (2015) and range (95% CI)	
Two or more LTCs only	30.7	(26.7 - 34.9)	12,000	(10,400 - 13,600)
Two or more LTCs, mental ill health only	3.4	(2.1 - 5.3)	1,300	(800 - 2,100)
Two or more LTCs, limitation	37.6	(33.4 - 42.0)	14,700	(13,000 - 16,400)
Two or more LTCs, limitation + mental ill health	28.4	(24.6 - 32.5)	11,100	(9,600 - 12,700)
Total	100		39,100	

Source: Health Survey for England (2012) estimates applied to CCC RP&T 2012 based population forecast for 2015

DESCRIBING MULTIPLE CONDITIONS WITH LIMITATION AND MENTAL ILL HEALTH IN OLDER PEOPLE (65+)

Figure 4.7 shows the results from CFAS II for older people aged 65 years and over with two or more long term conditions and the impact of limitation and mental ill health. 45% of people aged 65 and over with two or more LTCs experience limitation (Figure 4.7). Applied to the Cambridgeshire population this suggests around 29,800 people aged 65 and over with two or more LTCs and limitation, an additional 2,800 people with mental ill health and an additional 5,400 with multiple LTC, limitation and mental ill health (dementia⁸⁹, anxiety and depression). In total, it is estimated that 66,200 people aged 65 and over in Cambridgeshire have two or more LTCs.

Figure 4.7: Proportion of people aged 65 and over with multiple (two or more) LTCs with and without limitation and/or depression or anxiety (based on GMS AGECAAT)



Source: MRC Cognitive Function and Ageing Study (CFAS II) (100% = people with 2+ LTC)

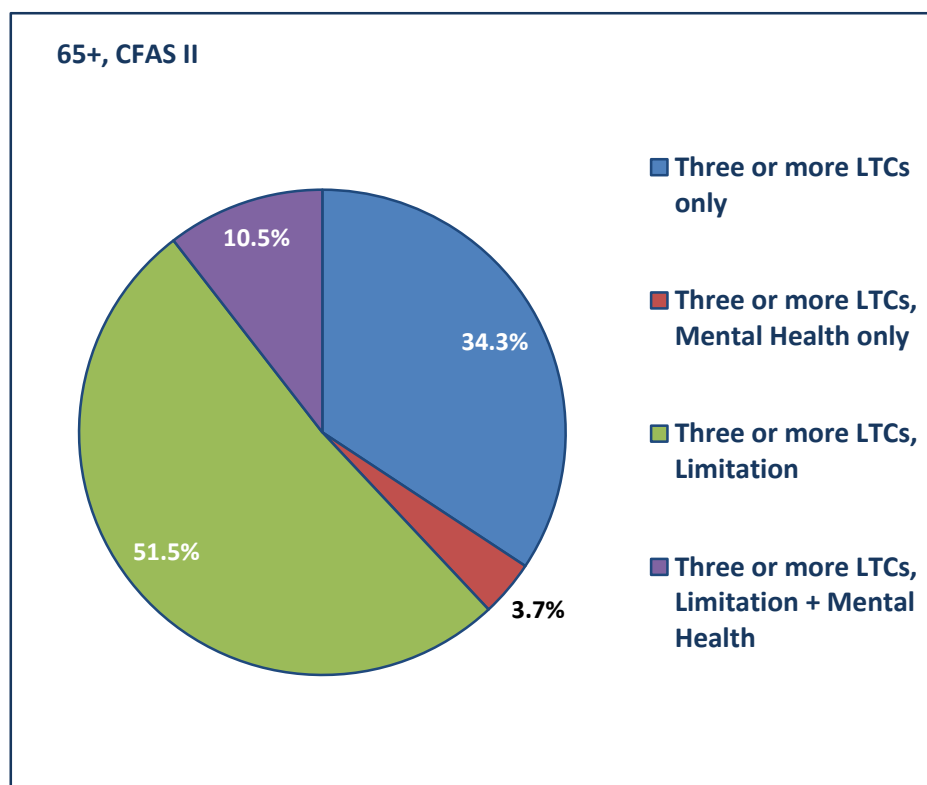
When looking at those people aged 65 and over with two LTCs only it was noticeable those over 52% do not report problems with limitation, nor are they identified within this dataset as having mental ill health. The analysis in older people was, therefore, extended to those with three or more long term conditions in order to discriminate further.

Over 51% of those with three or more LTCs experience limitation (Figure 4.8). Applied to the Cambridgeshire population this suggests around 17,700 people aged 65 and over with multiple LTC with limitation, an additional 1,300 people with mental ill health and an additional 3,700 with multiple

⁸⁹ This analysis includes dementia from the respondent survey only. In CFAS II an additional number of people who were identified as likely to already have dementia were given informant interviews. These have not been included in this analysis. This is therefore an under-estimate of the total prevalence of mental health issues when dementia is included.

LTC, limitation and mental ill health (dementia, anxiety and depression). In total, it is estimated that 34,700 people aged 65 and over in Cambridgeshire have three or more LTCs.

Figure 4.8: Proportion of people aged 65 and over with multiple (three or more) LTCs with and without limitation and/or depression or anxiety (based on GMS AGECAAT)



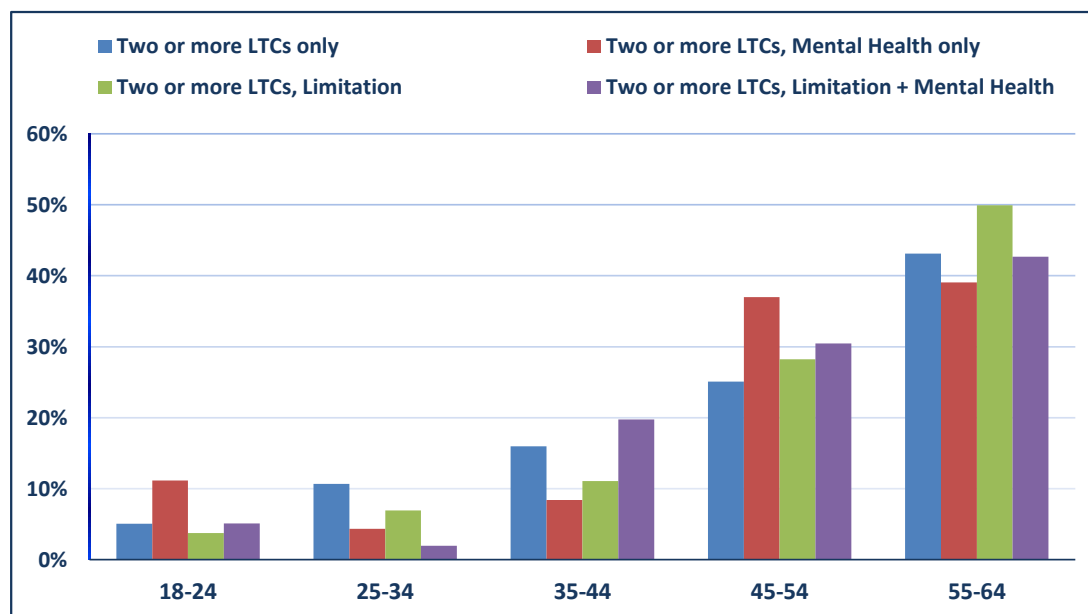
Source: MRC Cognitive Function and Ageing Study (CFAS II) (100% = people with 3+ LTC)

4.4. CHARACTERISTICS OF GROUPS AT HIGHER RISK

AGE, SEX, SOCIOECONOMIC STATUS IN ADULTS

Figure 4.9 shows the overlap of multiple conditions with and without limitation and/or probable mental ill health in adults aged 18 to 64 years using data from HSE 2012. Morbidity increases with age, however, there is a population with limitation and/or probable mental ill health present in each age group. In the ten year age bands from 35 to 64 years, 19.8%, 30.5% and 42.7% respectively are likely to experience two or more LTCs with limitation and with probable mental ill health. The impact of limitation in people aged 55 to 64 years is apparent.

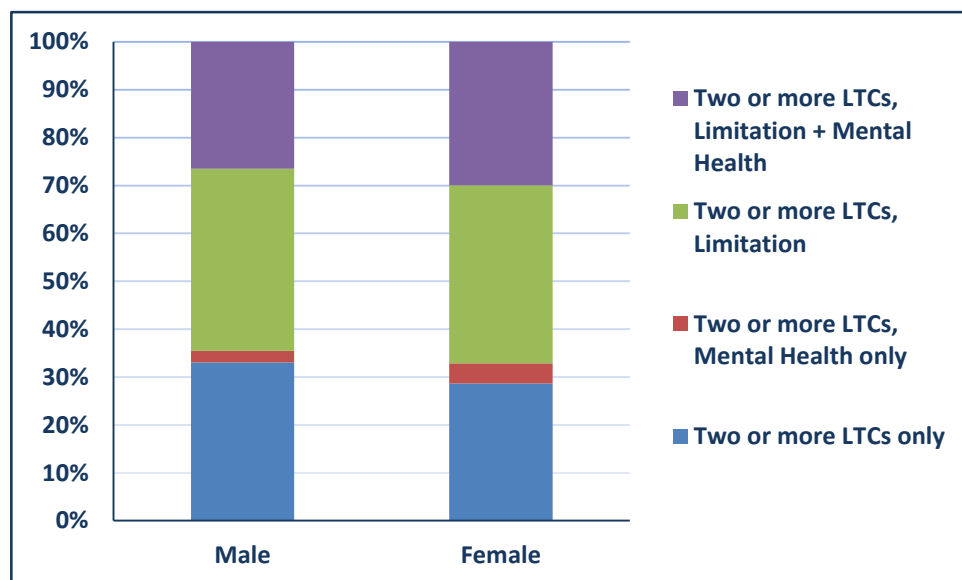
Figure 4.9: Proportion of people aged 18 – 64 years with multiple (two or more) long standing illnesses with and without limitation and/or mental ill health (based on GHQ-12 score of four or more) by age group



Source: Health Survey for England (2012) survey estimates. Note: count of illnesses excludes self-reported mental health conditions. Probable mental ill health is based on GHQ-12 score of four or more from HSE

As in other analyses, there is more morbidity amongst females than in males. Of those with two or more LTCs aged 18 to 64 years, 46% are male and 54% are female (Figure 4.10).

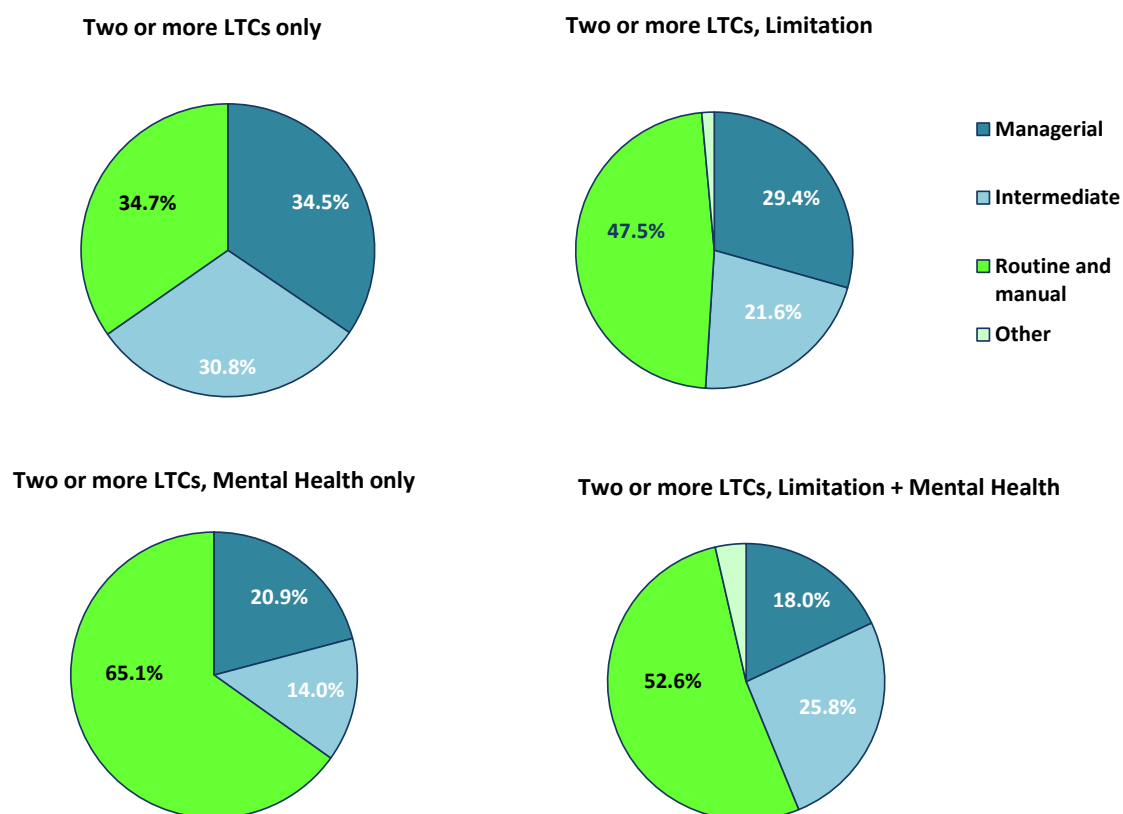
Figure 4.10: Proportion of people aged 18 – 64 years with multiple (two or more) long standing illnesses with and without limitation and/or mental ill health (based on GHQ-12 score of four or more) by gender



Source: Health Survey for England (2012) survey estimates. Note: count of illnesses excludes self-reported mental health conditions. Probable mental ill health based on GHQ score of four or more from HSE

Socioeconomic status is measured in HSE by NS-SEC based on occupation.⁹⁰ Figure 4.11 shows the breakdown for people aged 18 to 64 years with two or more long term conditions, with and without limitation, and/or mental ill health. The increasing impact of limitation as morbidity increases is apparent particularly for people in routine and manual occupations.

Figure 4.11: Proportion of people aged 18 – 64 years with multiple (two or more) long standing illnesses with and without limitation and/or mental ill health (based on GHQ score) by social class based on occupation (NS-SEC)



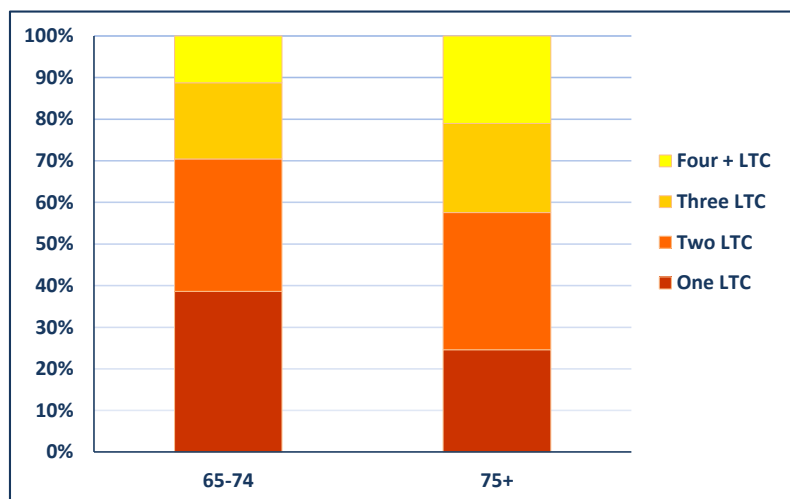
Source: Health Survey for England (2012) survey estimates. Note: count of illnesses excludes self-reported mental health conditions. Probable mental ill health based on GHQ-12 score of 4 or more from HSE

⁹⁰ NS-SEC is a social classification system that classifies groups on the basis of employment, based on characteristics such as career prospects, autonomy, mode of payment and period of notice. Participants are assigned to an NS-SEC category based on the current or former occupation of the household reference person. This is the 3 category NS-SEC – it is also available in five or eight categories. The population breakdown by NS-SEC is available from the 2011 Census.

AGE, SEX, SOCIOECONOMIC STATUS IN OLDER PEOPLE

The impact of age in the older age groups on the number of long term conditions is shown in Figure 4.12. People aged 75 years and over are more likely to have two, three or four or more conditions.

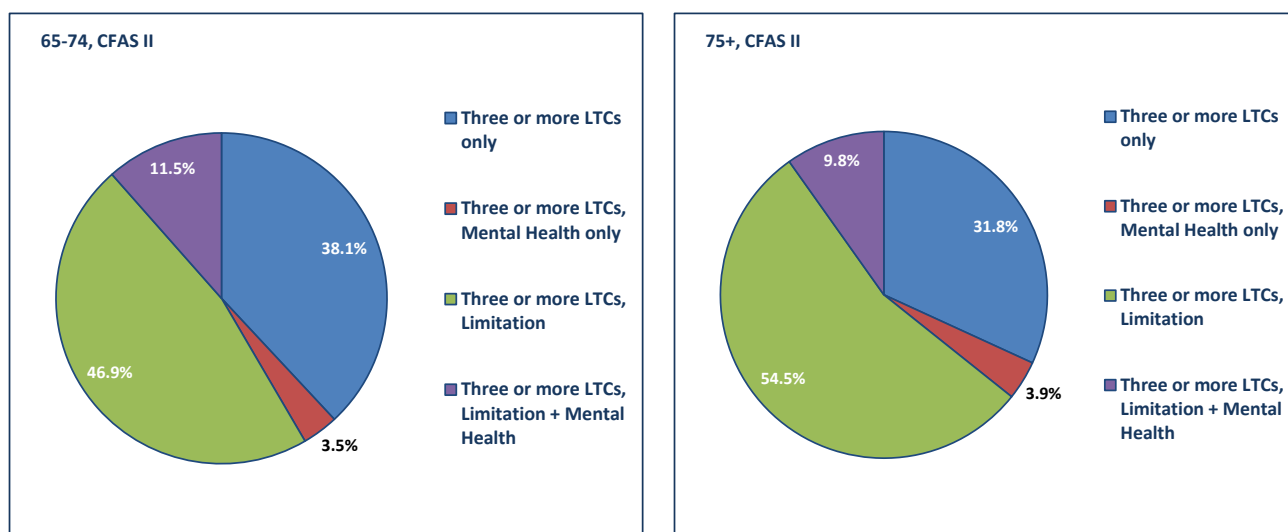
Figure 4.12: Proportion of people aged 65-74 years and 75 and over by number of LTCs in CFAS II



Source: MRC Cognitive Function and Ageing Study (CFAS II)

Figure 4.13 shows the impact of overlapping limitation and mental ill health in people aged 65 to 74 years and those aged 75 years and over in people with three or more long term conditions. The impact of limitation is higher in the older age group (75+) with 55% of people with three or more LTCs experiencing limitation.

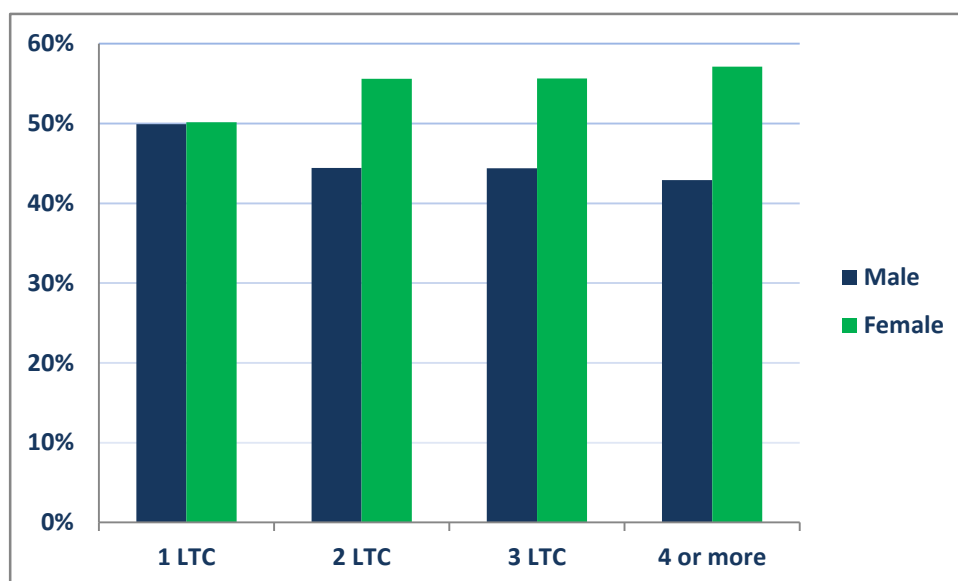
Figure 4.13: Proportion of people with multiple (three or more) LTCs with and without limitation and/or depression or anxiety (based on GMS AGE CAT) by age group



Source: MRC Cognitive Function and Ageing Study (CFAS II). (100% = people with three+ LTC)

Figure 4.13 shows the breakdown by gender and number of conditions. In the older population, 56% of those with two or more LTCs are female.

Figure 4.13: Proportion of people aged 65 and over by gender and number of conditions



Source: MRC Cognitive Function and Ageing Study (CFAS II)

4.5. WHICH POPULATIONS IN CAMBRIDGESHIRE ARE DISPROPORTIONATELY AT RISK?

Several potential areas of health inequality have been identified through this analysis:

- Amongst the older population, people with three or more LTCs experience higher levels of limitation and mental ill health.
- There is an important association between socioeconomic status and limitation in adults.
- Mental ill health is highly prevalent with multiple conditions throughout the adult and older population.
- There is some indication that males experience multiple LTCs at younger ages.



We have been unable to explore the patterns of LTCs among other specific vulnerable groups such as the homeless population, traveller communities, people with learning disabilities or sensory impairment, in the current analysis.

4.6. WHAT IS THIS TELLING US?

- The work for this JSNA has demonstrated that there are approaches to describing the population with multiple long term conditions that allow us to explore patterns and determine the number of people in the population likely to be affected.

- The number of people with multiple long term conditions is substantial. This analysis quantifies this for the population of Cambridgeshire and describes the overlap of multiple conditions with limitation and mental ill health.
- In both the adult and older population, there is a high prevalence of limitation amongst those with both two or more and three or more long term conditions.
- In both adult and older populations, it has been possible to identify the scale of the group at high risk of poorer health outcomes.
- There are patterns in terms of age, gender and socioeconomic status that may help to inform future service provision.

5. LIVING WITH LTCS: LOCAL VIEWS ON IMPROVING CARE

The views of people in Cambridgeshire living with long term conditions, and their carers, are absolutely essential to inform this JSNA, as experts by experience. This chapter provides detail on the views and perspectives that have been heard and gathered, identifying the dominant themes in describing the experiences of living with LTCs, and the perceived opportunities for solving some of the challenges that characterise the interactions with health and care services.

5.1. GATHERING LOCAL VIEWS

METHODOLOGY

As part of the stakeholder engagement plan for this JSNA, workshops and partnership working was planned in detail. The priority was to ensure that local views were fairly represented by gathering differing and varying perspectives through the process. The emphasis was on careful gathering of in-depth qualitative information with a targeted range of groups, rather than using a survey approach to gather summary information.

Workshops and partnership working was used to gather qualitative information

A range of questions was developed to explore these themes with local people, with a shortlist selected depending on the context it was used in, from a list including:

- What things (such as life circumstances, types of conditions) make you more likely to experience a decline in your health?
- What particular challenges do you think people with multiple conditions face because of having more than one condition?
- How far do you feel you are receiving support to self-manage your condition(s)? When is this support not effective?
- How many different people and services do you interact with for your care? Which aspects of your care and your life are negatively affected by this?
- In what ways could you be better supported in managing your conditions?
- How can care for people with long term conditions be more effective?
- What does collaborative care mean to you?
- What preventative steps would help to prevent a crisis?
- What further approaches would improve care locally particularly for those with multiple conditions including anxiety and depression? How can care for physical health conditions and mental health conditions be better joined up locally?
- What are your views on living with multiple conditions, limiting conditions, recurrent falls, pain and depression, and what are the main challenges in respect of these?
- What aspects of living with long term conditions, do you feel are not sufficiently recognised, particularly by local authorities and local health and social care commissioners?
- What do you believe are the local solutions for meeting some of these challenges?
- What resources and capacity do you have in helping to realise these solutions?

Following attendance at the national conference on LTCs, conversations were started with partners from the Coalition for Collaborative Care, and the East of England NHS Citizen Senate on hearing the Citizen voice.

An intensive workshop was planned with these partners with two focus groups who simultaneously considered challenges and solutions. The discussions were recorded and the majority of the content was fully transcribed, with some paraphrasing due to technical and capacity issues.

Links were also established with Healthwatch Cambridgeshire and Cambridgeshire Alliance for Independent Living, who raised the profile of this work and encouraged direct feedback, as well as conducting further consultation discussions with other groups including a local Breathe Easy group. Additionally, consultation work to inform the Public Mental Health Strategy raised relevant questions about wellbeing, such as through an interpreted focus group with deaf people organised by Cambridgeshire Deaf Association and this feedback was also fed in.

Due to the heterogeneity of information and sources, most of the data and information was paraphrased feedback rather than direct quotes, and some pertained to themes not considered here. The synthesis was to identify emergent themes, and is not a full thematic analysis.

LOCAL VIEWS' CONTRIBUTORS

Through the engagement work views were heard from at least 30 individuals who are local patients, carers, and further representatives who work with community and patient organisations providing support to people with LTCs.

Where details were collected participants varied in age from 44 to 87 years; 71% were female. Their disease profiles included of asthma; COPD; type 2 diabetes; osteoarthritis; fibromyalgia; depression; arthritis; cancer and multiple sclerosis. Some participants were both living with LTCs themselves and a carer for someone else with LTCs and limitations.

5.2. CHALLENGES FACING PEOPLE WITH LTC IN CAMBRIDGESHIRE

Contributors detailed significant challenges and difficulties that they faced as a result of having LTCs. The emerging themes are noted below alongside salient quotes that help to convey these points.

LIVING WITH MULTIPLE CONDITIONS

The physical, emotional and mental health symptoms associated with living with LTCs should not be underestimated:

- It is tiring and very hard work... *'it gets in the way of living your life'*
- There can be significant variability and fluctuation in health and function from day to day *'there is an element of variability of the condition. I find that people do not understand the variability – you can go from being reasonable to a few weeks later you need help...If I was on my own – not sure how I would cope'*



- Pain is difficult to live with and get help with *'pain is not recognised'; 'pain management is over on its own'*
- The emotional impact including stress and loneliness is significant *'no-one ever talks to you about your mindset'*
- Little things can have a big impact *'if I get poorly it takes me ages to get better again'*
- Medication – side effects of multiple medications and alterations in medication can have significant effects *'I have to have special prescriptions, and then on the grounds of the economy, it's actually [happened] twice, 'higher up' interferes and insists I go on the normal one... my own doctor she was very very cross that she wasn't contacted at all, but the result is that it made me so ill... I had the worst allergic reaction I've had for about ten years'*
- Not knowing where to get information to help yourself *'no one tells you – this is where you can go to get help'...*
- Not feeling expertise is respected by healthcare professionals *'the conditions may be the same, but we are all different and our experience of our condition may be unique to us'*

Both patients and carers reported frustration that their views weren't listened to by health care professionals as much as they'd have liked.

CARING RESPONSIBILITIES

The important perspective of carers was heard, recognising that many of those with LTCs are also providing care for family and friends with even more complex needs. The particular challenges that were highlighted include:



- Balancing caring responsibilities with own health issues *'who is taking my needs into account?'*
- Ongoing strain experienced by the carers *'the thing that keeps me awake at night is what if I get ill or can't look after him?'*
- Having to manage complex choices and decisions *'It is like having lots of balls in the air. Most of the time you can keep them up in the air but they are fragile. They are fragile because health and social care do not work well together'*
- Not feeling that their expertise is respected by healthcare professionals *'If the doctor comes in during that period of time [when cared for is doing ok] they assume that is the norm and they look at you as if you are making a fuss out of nothing. They go off and if you phone them the next day regarding issues – they may say she was alright yesterday. I say, well, she is not now.'*

USING THE HEALTH AND CARE SYSTEM

Much of the discussion centred on the interactions with health and care services for people with multiple conditions and there were notable frustrations such as:

- Lack of care-coordination for multiple conditions *'you may have multiple*



appointments, multiple tests (blood tests etc.) and even multiple medications and treatments – but no one appears to be coordinating the clinical care you receive'

- **Managing multiple medications** *'you can have wonderful medication but then to find out that one works against the other – but who is going to find that out for you? Because your GP doesn't want to know, the pharmacist doesn't, the specialist is busy – which one is going to solve that, that there might be something wrong?'*



- **Assistance isn't always timely** *'you just don't know from one day to the next just what you're going to wake up with'... 'it's also accessing those services, because there's a wait for that – if you need anything then you wait for that service – somebody's got to refer you, somebody's got to ring...'*
- **Inflexibility by health and care services if your circumstances change** *'if you suddenly find you need something to help you, say, wash, or get up from the toilet, ...how do you get that out in the community? I know people with MS who have needed equipment and have actually gone to hospital and been admitted to hospital because they then get the equipment'*
- **A lack of integrated and coordinated working between healthcare professionals** *'the core difficulty is communication'*

OTHER CHALLENGES AND IMPACTS

There are also wider impacts on quality of life and independence associated with LTCs. Stakeholders highlighted some of these concerns, including:



- **Independence at home and managing household tasks may be problematic** *'often those with declining health have to start rationing where there efforts go... housework, cooking, cleaning, socialising...'*
- **Getting out and about can prove really difficult** *'[for wheelchair users] Long term car parks, where you have to go back to the car to the [blue] badge in order to pay, some people struggle as they have to transfer into the car to get the badge, then transfer from the car to the chair, so that they can go back [and pay]. They didn't talk to users before they decided on the service'*



- Challenges related to maintaining employment after an employer has made ‘reasonable adjustments’ and the impact of part – or non-employment and reliance on grants on household finances and opportunities *‘depressing to give up a job you enjoyed’*
- A lack of information about what’s available *‘but you’ve got to know what’s there and you’ve got to go and get it’*

5.3. LOCAL SOLUTIONS AND OPPORTUNITIES

Local contributors were able to give examples of good practice that they had experienced, and their wish list of step changes that would make a significant difference to their care. These included:



- Being listened to and having their expertise recognised *‘you go along to the Consultant and it’s “what can I do for you” And then, it’s well, you are give some information, and “well you can do this, this or this, what do you want to do?”’*
- Having a single point of access to care when they need it *‘one number you call for help, available and weekends... to get some advice and some support to stop you going to hospital’*
- Having a care plan *‘a person-centred plan enables difficult discussions to happen...people to talk about practical things... who is important to you? their relationship? Those caring roles should be captured’*
- Experiencing timeliness and flexibility in terms of their health and care *‘you get around the appointment system if the need is urgent, because you have to get an urgent appointment’*
- Valuing high quality care and support from health staff
 - *‘my pharmacy are brilliant, I’ve used them for a long time’*
 - *‘some sort of nurse, would be really helpful, that could, sort of, take you across all the services’ ‘my GP is wonderful, my GP does most things’*
 - *‘I get regular physiotherapy and that’s a great help. It’s just an understanding of how to cope... and it’s managing your pain, knowing your limitations’*
- Being given more information about what support is available *‘help with jobs around the house and garden’*
- Support with self-management support *‘running your own care’*
- Support for managing emotional symptoms and pain such as coping techniques, mindfulness etc. *‘you learn skills that stay with you’*
- Support groups/family/neighbours etc. *‘Facebook groups and online media’*

Further examples of good practice demonstrate some of the significant local assets in Cambridgeshire:

- Members of a Breathe Easy group having an overwhelming sense of appreciation for the woman who organises the group for them – for her personal support, her knowledge and access to information.
- One woman highly valued the support she and her family got from her local Church community especially with practical things.
- Experiences of community nurses coordinating care effectively... *‘feeling that someone really cares for you.’*

- Highly appreciated End of Life care for a partner... *'she was put on the Addenbrooke's pathway... but it was people like the pharmacy, and the prescription clerks in the surgery – and they worked together. At that stage, time was precious, her prescription altered nearly every day, things were added, taken away, change, amounts decreased, increased, reformulations. And that side of things was totally handled for us... what would have been a time-consuming nightmare, because they got involved, totally changed. It didn't change the outcome, but it made it easier.'*

5.4. WHAT IS THIS TELLING US?

There are significant challenges intrinsic to day-to-day life with LTCs, which impacts on life at home and out and about. The difficulties and frustrations in accessing, using and receiving care from health, care and community services, where experienced, have added to the burden and strain of managing conditions and quality of life more generally. Nonetheless, local patients and carers have shared lived examples of good quality care they have received.

The dominant themes that have emerged from the discussions are:

1. In the health and care system there is a level of fragmentation, a lack of communication between different services and providers of care, and a very broad web of care that people with LTCs interact with – particularly those with multiple conditions; this can mean that coordination is difficult and care is not optimal.
2. People living with multiple conditions have particular concerns about the coordination of their care, the challenges of managing multiple medications, and a lack of flexibility in responding to changes in symptoms and needs.
3. There is a high value placed by local patients and carers on collaborative therapeutic relationships, where health care professionals listen, show respect, and recognise lived experience and plans are made collaboratively, and coordinated effectively between services.
4. Additional support would be valued around the emotional impact of living with the condition(s), recognising the additional triggers for increased stress, isolation or deterioration in health, and the role of carers should not be underestimated and the strain that they experience.

The vast majority of the solutions proposed by local individuals, and similarly echoed by community organisations, fit an overarching approach of **developing and extending flexible, coordinated, person-centred care for people with LTCs and their carers in Cambridgeshire.**

6. CARE MANAGEMENT FOR THE POPULATION WITH LTCS: THE HOUSE OF CARE

The effective management of patients with long term conditions and complex care needs has never been more relevant to health, care and local government than it is today. Relatively well-defined disease-specific pathways are in place for individuals with certain diagnoses – and, to a lesser extent, for those with multiple long term conditions. However, these approaches still rely on the patient seeking out treatment. Such approaches can result in reactive episodic care, where a patient only seeks help when in crisis. One means of addressing this is by taking a population-level ‘care management’ approach that seeks to reduce expensive and distressing emergency admissions and promotes high-quality proactive care for patients at risk of deterioration in the future, with the intention of preventing or slowing that deterioration.

It can seem obvious that health services should take this sort of approach, whereby particular patients felt to be ‘high risk’ are identified for proactive care, however, there are important considerations, which are discussed in this chapter. Section 6.1 presents an overview of the national policy context for the management of LTCS.

6.1 POLICY CONTEXT FOR CARE MANAGEMENT: THE HOUSE OF CARE MODEL

This section presents an overview of key concepts and principles in national policy that are relevant to care management and the management of LTCS.

6.1.1 PRINCIPLES AND POLICY CONTEXT

Simon Stevens’ Five Year Forward View⁹¹ states that ‘long term conditions are now a central task of the NHS; caring for these needs requires a partnership with patients over the longer term rather than providing single, unconnected “episodes” of care’. There is a clear recognition that the NHS needs to adapt to meet the challenges of the future and that the management of long term conditions is a key part of this. NHS England has identified a set of key areas for action to be taken forward in partnership with Clinical Commissioning Groups and other partners such as Local Government:

- Helping patients take charge of their care.
- Enabling good primary care.
- Ensuring continuity of care (better integration of care and information sharing across organisational boundaries).
- Ensuring a parity of esteem for mental health.
- Reducing avoidable emergency admissions

NHS England recognises that care needs to be designed and implemented around the individual, and so has adopted the King’s Fund ‘House of Care’ model as a framework to describe the components of personalised care.

⁹¹ NHS Five Year Forward View (2014). <http://www.england.nhs.uk/ourwork/futurenhs/>

6.1.2 HOUSE OF CARE – KING’S FUND

The King’s Fund describes a co-ordinated service delivery model – the ‘House of Care’ – which is designed to deliver proactive, holistic, preventive and patient-centred care for people with LTCs.⁹²



The house of care metaphor is used to illustrate a whole-system approach, emphasising the interdependency of each part and the various components that need to be in place to hold it together. The house relies on four key interdependent components, all of which must be present for the goal, person-centred coordinated care, to be realised:

5. *Commissioning* – which is not simply procurement but a system improvement process, the outcomes of each cycle informing the next one.
6. *Engaged, informed individuals and carers* – enabling individuals to self-manage and know how to access the services they need when and where they need them.
7. *Organisational and clinical processes* – structured around the needs of patients and carers using the best evidence available, co-designed with service users where possible.
8. *Health and care professionals working in partnership* – listening, supporting, and collaborating for continuity of care.

The house of care model is different from other approaches as it encompasses all people with LTCs, not just those with a single disease or in high-risk groups, and it assumes an active role for patients, with collaborative personalised care planning at its heart.

Collaborative personalised care and support planning is about:⁹³ helping patients and carers to develop the knowledge, skills and confidence to manage their own health; helping individuals and

⁹² The King’s Fund (2013). Delivering better services for people with long-term conditions: Building the house of care. London: The King’s Fund.

healthcare professionals to have more productive conversations about what matters most to that individual; a planned and continuous process of goal-setting, agreeing support needs and reviewing progress. Conversations rely on equal input from the individual and their carer alongside professionals and put the individual's needs in the wider context of their lives. Social and psychological needs, independence and community inclusion are seen as equally important as medicine or clinical treatments. The self-care aspect of personalised care and support planning is discussed in more detail in Section 8.

The move towards personalised care and the principles behind the 'house of care' model have been part of the development of social care services for many years, with the Government publication 'Putting People First' in 2007 making personalisation of social care services explicit national policy.⁹⁴ In Cambridgeshire, the 'Shaping our Future' strategy explains the approach to personalisation.⁹⁵ Development continues under the 'Transforming Lives' programme.⁹⁶

The current approach to support planning involves the consideration of the issues above through questions like those taken from guidance for professionals shown below.⁹⁷

Question	Things to consider
What is important to you?	<ul style="list-style-type: none"> • What are the things that must happen for you? • Who are the important people in your life? • Is there anything else that you want to include?
What do you want to achieve?	<ul style="list-style-type: none"> • What is working at the moment? • What needs to stay the same? • What isn't working well? • What part do you want to change?
How will you be supported?	<ul style="list-style-type: none"> • What help do you need? • When do you need it? • Who would you like to give you this help?
How will you keep safe, what risks are there?	<ul style="list-style-type: none"> • What do you think the risks are? • Who can help to manage them? • What can be done to keep you safe?
How do you want your personal budget to be managed?	<ul style="list-style-type: none"> • A direct payment? • An arranged service, or part direct payment and part arranged service?

⁹³ NHS England (2015). Personalised care and support planning handbook: The journey to person-centred care. <http://www.england.nhs.uk/wp-content/uploads/2015/01/pcsp-guid-exec-summ.pdf>

⁹⁴ HM Government (2007). Putting people first. http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_081119.pdf

⁹⁵ Cambridgeshire County Council (2009). Shaping our future. http://www.cambridgeshire.gov.uk/download/downloads/id/1062/shaping_our_future_strategy

⁹⁶ Cambridgeshire County Council (2014). Shaping our future: Transforming Lives. http://www.cambridgeshire.gov.uk/info/20166/working_together/579/delivering_the_care_act/3

⁹⁷ Cambridgeshire County Council (2012). Self directed support planning guide. Internal guidance for staff.

CARE MANAGEMENT FOR THE POPULATION WITH LTCS: THE HOUSE OF CARE LONG TERM CONDITIONS JSNA

How will you stay in control?	<ul style="list-style-type: none"> • Do you need help with making decisions? • If you do who helps you with this? • How do you make sure your wishes are taken into account?
What will make your plan happen?	<ul style="list-style-type: none"> • Who will help with this? • What will happen if things don't go according to plan?

By using these person-centred questions, social care staff have helped people develop good plans to improve their health and wellbeing and manage their long term conditions. The case study below is taken from Cambridgeshire County Council's Evidence Bank.

Although there is a strong body of knowledge and experience in person-centred planning in social care services in Cambridgeshire, person-centred planning in social care is not fully integrated with health services for people managing with long term conditions. Person-centred planning in social care is also supported by a Personal Budget and Direct Payments (although not everyone uses Direct Payments), which allows a very flexible approach to the provision of care and support. Two other, more structural components of personalised care have been identified by NHS England:

- Risk stratification and case finding⁹⁸ – how to segment a population and provide person-centred care to those most in need recognising resource constraints. This is discussed in more detail in Section 7.1.
- Multi-disciplinary team working⁹⁹ – how health and care professionals work together to support people with complex care needs. This is discussed below in the context of integrated care and also within Section 7.2 on evidence-based approaches that prevent escalation of health and care needs.

⁹⁸ NHS England (2015). Using case finding and risk stratification: A key service component for personalised care and support planning. <http://www.england.nhs.uk/wp-content/uploads/2015/01/2015-01-20-CFRS-v0.14-FINAL.pdf>

⁹⁹ NHS England (2015). MDT Development - Working toward an effective multidisciplinary/multiagency team. <http://www.england.nhs.uk/wp-content/uploads/2015/01/mdt-dev-guid-flat-fin.pdf>

“JB is an autistic lady with learning disabilities. She also has Scoliosis and therefore having a healthy weight and lifestyle are vital to ensure she has a good quality of life. She has been overweight for some time and her BMI had reached a dangerous level.

Following advice received from the GP with concerns that JB's weight could have increasing implications on her health, staff sought advice from a dietician and a healthy eating plan was devised for JB. Staff have been working hard to support JB to stick to this plan. This can be challenging at times. Due to JB's autism she often wants a large amount of food and becomes obsessed with certain food items. However with staff input the plan was able to include all of JB favourite foods, they were just prepared and cooked using healthy methods and portion sizes were reduced. JB has been involved in shopping, preparing and cooking her own meals with minimal support and prompts from staff. She also chooses her meals the day before and uses photographs to put her choices on a menu in the kitchen. JB has lost almost three stone and her physical health has improved dramatically.

JB's skills and independence have also improved. She is now able to shower, wash and dress herself. JB chooses her clothes for the day and can put on her own socks and shoes, something that staff had to do for her before she lost weight. JB appears to be very happy with this change and has enjoyed shopping for a new wardrobe to suit her new figure. JB's parents have been extremely pleased with the support she has received and are very happy that her independence and physical health have improved so dramatically.



Staff have respected and involved JB in this piece of work. She has been involved in each step and communication is kept clear and open to ensure JB is respected at all times. Her care and welfare have been met during each stage and the support was tailored to meet her individual needs. JB continues to follow this healthy eating plan and once her target weight is reached the staff team will liaise with the dietician to devise a maintenance plan that is both healthy and realistic for JB lifestyle."

6.1.3 INTEGRATION OF CARE

'Integration' is a commonly used term in the NHS, which reflects concern that patients describe experiencing fragmented care, particularly between primary, secondary and tertiary care, and between health services and social services. The Five Year Forward View reiterates a commitment towards integrating services around the patient, citing the following examples: a patient with cancer needs their mental health and social care coordinated around their physical health addressed at the same time as their me



Source: Kings Fund illness need their

Integration can take a variety of forms, involving providers, or providers and commissioners, working together to deliver better outcomes. Integration can occur at the macro, meso or micro level.¹⁰⁰

- Macro level - providers, either together or with commissioners, seek to deliver integrated care to the populations that they serve.
- Meso level - providers, either together or with commissioners, seek to deliver integrated care for a particular care group or populations with the same disease or conditions (eg older people or patients with multimorbidity), through the redesign of care pathways and other approaches.
- Micro level - providers, either together or with commissioners, seek to deliver integrated care for individual service users and their carers through a diverse range of approaches eg care co-ordination, care planning, use of technology and other approaches.

There is evidence to support the use of all these approaches. Interventions using multiple strategies to strengthen care co-ordination appear to be more successful than those using single strategies. In practice, these levels are often used in combination; this is in recognition of the fact that changes at the macro level, on their own, are limited in their ability to make a difference for service users and also to address the weaknesses of care fragmentation.

Common characteristics of Integrated Systems include:

- Multispecialty group practice
- Aligned incentives
- The use of information technology (IT) and guidelines
- Accountability for performance and defined populations,
- A physician–management partnership
- Effective leadership and a collaborative culture.

Evidence indicates that moves to achieve closer integration of care should continue. The Five Year Forward View sets out examples of how structural integration can be achieved, through Multispecialty Community Providers (MCPs) formed of groups of GP practices working together to provide a wider range of primary and secondary care services, or through Primary and Acute Care Systems (PACS) which achieve ‘vertical’ integration of primary and secondary care providers such that, ultimately, a single body could be accountable for all health needs of a registered list of patients.

To develop a more integrated system, conversations across public, third and community sectors in Cambridgeshire were used to build on the work of the Older



¹⁰⁰ The King's Fund (2010). Clinical and Service Integration, the route to improved outcomes. London: The King's Fund.

People's Strategy to identify key features of an integrated system. Several practical proposals have been outlined:¹⁰¹

- 1) A series of community-based programmes and support that help people to age healthily.
- 2) A recognised set of triggers of vulnerability to generate a planned system-wide response.
- 3) A universal network helping people to find high quality information and advice.
- 4) An aligned set of outcomes.
- 5) An integrated front door with an agreed principle of "no wrong door".
- 6) Shared assessment processes and information sharing.
- 7) A shared tool that describes vulnerability.
- 8) A locality-based multidisciplinary team approach.
- 9) Co-located staff.
- 10) Joint commissioning and aligned financial incentives.

These proposals will form a basis for planning future work together with local authority, district council, acute trust, CCG and UC stakeholders to implement a more integrated system across Cambridgeshire. Organisational integration alone is unlikely to deliver better outcomes and efforts must focus on clinical and service integration. Action is needed at the macro, meso and micro levels, and multiple strategies should be pursued at all three levels.

The development of new organisational systems and structures in Cambridgeshire offers a platform on which to develop integration and to commission and provide services in collaboration with health and care workers in community services, secondary care and local authority.

6.2 PERSON-CENTRED CARE



¹⁰¹ Black C, Smith M (2014). Developing and Integrated System for Cambridgeshire to Improve Outcomes for Older People. Cambridgeshire County Council.

Person-centred care aims to ensure a person is an equal partner in their healthcare and aims to move away from a focus on diseases and their management. The US Institute of Medicine (IOM) defined patient-centred care as healthcare that establishes a partnership among practitioners, patients and their families to ensure that providers and systems deliver care that is attentive to the needs, values and preferences of patients.¹⁰² In their view, this requires mutual, power-sharing relationships that are collaborative and include the “whole person” orientation. Different approaches to patient-centred care (PCC) have been defined across the literature and across organisations, however PCC maintains, at its core, an approach whereby the healthcare provider ‘tries to enter the patient’s world to see illness through the patient’s eyes’. This means that the provider is guided by the patient’s knowledge, experience, needs and preferences. In this way health and care providers come to understand the patient as a unique human being.¹⁰³ The importance of information-giving and shared decision-making is also fundamental to the PCC process. Mead has proposed a framework with the following dimensions for studying PCC:¹⁰⁴

Focus on people, their lives and their personal health issues.

- Biopsychosocial perspective.
- The ‘patient-as-person’ - understanding the personal meaning of the illness for each individual patient.
- Sharing power and responsibility.
- The therapeutic alliance.
- The ‘doctor-as-person’ – awareness of the influence of the personal qualities and emotion of the doctor on the doctor-patient relationship.

Shared decision making advocates focus on the need for clinicians to describe options, elicit patient preferences and agree on next steps in the decision making process.

A systematic review was conducted to identify PCC as an intervention in controlled trials (where patients had been involved as a partner) and to describe the outcomes of these studies. The 11 studies reviewed were carried out in a variety of contexts with diverse outcomes yet PCC as an intervention was shown to be successful in improving health outcomes and health behaviours in eight of the studies. The results suggest that person-centred care may lead to significant improvements, but the implementation and relevant effects needs further assessment.¹⁰⁵ Studies assessing the impact of PCC on specific conditions have also documented relative improvements across specific outcomes. A PCC approach after acute coronary syndrome improved general self-

¹⁰² IOM. Crossing the Quality Chasm. A New Health System for the 21st Century. Washington DC: National Academy Press, 2001.

¹⁰³ Winefield HR, Murrell TG, Clifford JV et al (1995). The usefulness of distinguishing different types of general practice consultation, or are needed skills always the same? *Family Practice*; **12(4)**: 402–7.

¹⁰⁴ Mead N, Bower P (2000). Patient-centredness: a conceptual framework and review of the empirical literature. *Social Science and Medicine* **51(7)**: 1087–110

¹⁰⁵ Olsson LE, Jakobsson Ung E, Swedberg K et al (2013). Efficacy of person-centred care as an intervention in controlled trials - a systematic review. *J Clin Nurs*; **22(3-4)**: 456–65.

efficacy without causing worsening clinical events¹⁰⁶ and PCC reduced agitation in people with dementia in residential care.¹⁰⁷



Interventions to promote PCC within clinical consultations have been found to be effective across studies in transferring patient-centred skills to providers.¹⁰⁸ However, despite the availability of evidence-based training manuals, there is a widespread use of person-centred intervention and training manuals that are not evidence-based. Clearer guidance is needed to ensure that commissioned training and interventions are based on robust evidence.¹⁰⁹

6.3 WHAT DOES THIS TELL US?

- At a national level, there is strong recognition of the importance of managing long term conditions, both in terms of improving outcomes and experiences for patients, and also in terms of ongoing financial sustainability.
- In national policy terms, there is a clear emphasis on developing models of care that are person-centred, personalised, coordinated and integrated around the needs of the patient.
- There is experience and established methodology in social care services of developing person-centered plans that follow very similar principles to the 'house of care' model, but there are still improvements that could be made, especially around integration with health services.
- Integration of services supports person-centred care. The foundations to build an integrated system for Cambridgeshire are in place and well-timed to link with the development of new health and care structures. However, strong efforts to achieve substantial change in system design and delivery are necessary to achieve successful and meaningful integration that translates into real improvements of outcomes for patients, their families and communities.

¹⁰⁶ Fors A, Ekman I, Taft C et al (2015). Person-centred care after acute coronary syndrome, from hospital to primary care - A randomised controlled trial. *Int J Cardiol* **6(187)**: 693-9.

¹⁰⁷ Chenoweth L, King MT, Jeon YH et al (2009). Caring for Aged Dementia Care Resident Study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster-randomised trial. *Lancet Neurol* **8(4)**: 317-25

¹⁰⁸ Dwamena F, Holmes-Rovner M, Gauden CM, et al (2012). Interventions for providers to promote a patient-centred approach in clinical consultations. *Cochrane Database of Systematic Reviews* **12**: CD003267. DOI: 10.1002/14651858.CD003267.pub2

¹⁰⁹ Fossey J, Masson S, Stafford J et al (2014). The disconnect between evidence and practice: a systematic review of person-centred interventions and training manuals for care home staff working with people with dementia. *Int J Geriatr Psychiatry*; **29(8)**: 797-807.

7. IMPROVING CARE MANAGEMENT: TARGETING AND INTERVENING

It may seem clear that health and care services should take a population-level 'care management' approach that, whereby particular patients felt to be 'high risk' are identified for proactive care, however there are important considerations, which are discussed in this chapter. Section 7.1 reviews the methods that are available to identify 'high risk' patients. Section 7.2 reviews the evidence on interventions that are effective in preventing adverse outcomes and 7.3 considers the effectiveness of mental health strategies within specific LTC care pathways. Section 7.4 gives examples of local care management assets. Overall, the ethics of identifying patients for a particular intervention or service are similar to the criteria set out for screening programmes (adapted from ¹³), in that:

- The adverse event to be prevented should be an important health problem;
- The natural history of the adverse event should be adequately understood by the organisation offering the preventative intervention;
- An accurate method should be available to identify high risk patients;
- There should be sufficient time for intervention between identification as high risk and the occurrence of the adverse event;
- The intervention offered to high risk patients should be accepted, acceptable and cost-effective; and
- Resources and systems should be available to identify and intervene appropriately.

The extent to which local care management approaches are in line with these criteria is discussed in the final section, Section 7.5: What is this telling us?

7.1. IDENTIFYING HIGH RISK PATIENTS: DIABETES CASE STUDY

This section briefly describes the different methods that can be used to identify patients that are high risk and might theoretically benefit from an intervention or care management approach. The section is written using diabetes as a case study for illustration.

7.1.1.1. DESCRIPTION OF DIABETES

Describing diabetes

Diabetes is a complex group of disorders with raised blood glucose as the most clear common feature. Type 1 diabetes develops if the body cannot produce any insulin. It cannot be prevented and it is not known why it develops. Type 1 diabetes is treated by daily insulin injections or via an insulin pump. Type 2 diabetes (T2DM) develops when the body can still make some insulin, but not enough, or when the insulin that is produced does not work properly (known as insulin resistance). T2DM is initially treated with a healthy diet and increased physical activity, but medication and/or insulin can be required. T2DM is progressive over a timescale of years, meaning that continued escalation of blood glucose lowering therapies is often required.

Symptoms

Symptoms of prolonged high glucose levels include increased urination, thirst, weight loss and fatigue. With further worsening, diabetic coma (ketoacidosis) may occur. The main complications of diabetes in the longer term are microvascular (eye, kidney, and nerve damage, potentially leading to blindness, dialysis or transplantation, amputation, painful symptoms and erectile dysfunction) and macrovascular (arterial disease affecting the heart, brain and feet). Many people with T2DM have the same risk of a cardiovascular event as someone without diabetes who has already had their first heart attack. Management of cardiovascular risk factors plays a large part in care of people with T2DM. Without careful management, a person with diabetes faces a reduced life expectancy of 6 to 20 years.

Complications

Many complications are preventable and there are multiple targets for the reduction of risk and improvement of health in people with diabetes. These include diet, obesity, activity levels, glucose control, blood pressure control, blood lipid control, blood thinning, laser therapy for eye damage, drug therapy to delay kidney damage, local foot care, and symptomatic treatments for various types of nerve damage. The necessary lifestyle changes, the complexities of management and the side effects of therapy make self-monitoring and education central parts of management.

Management

Individuals with diabetes may be managing other long term conditions, including those that are a consequence of diabetes as well as any number of other long term conditions, such as chronic obstructive pulmonary disease (COPD). In addition, diabetes doubles the odds of depression¹. A diagnosis of diabetes and dealing with the associated lifestyle changes can feel like an overwhelming task, which can have a negative impact on mood and motivation and contribute to depression. People with diabetes and depression tend to find it harder to stick to lifestyle and treatment regimens and have poorer metabolic and glucose control¹. This intensifies the symptoms of depression. Anti-depressants can affect glucose control, making it harder for individuals to self-manage. This vicious cycle demonstrates the importance of treating mental health aspects of long term conditions as well as physical aspects. Addressing depression can improve glucose control, mood and enhance quality of life.

7.1.2 IDENTIFYING HIGH RISK PATIENTS WITH DIABETES

The focus of this JSNA is on the management of existing LTCs, particularly the population considered at high risk. In the context of diabetes, this high risk population may include individuals with:

- Persistent poor glucose control
- Limiting complications
- At risk of an acute event related to their diabetes (eg ketoacidosis or severe hypoglycaemia)
- Diabetes that forms part of a complex set of diagnoses (which may include physical and mental health components).

A key point here is that this high risk designation is not static; individuals may move in and out of these states over time, in response to both changing physical factors and also changing psychological and social factors. It is important to identify patient with diabetes at higher risk because they may benefit from additional support, for example:

- To manage the tests and medicines associated with their treatment (this may range from basic education/counselling to structured programmes such as DAFNE or DESMOND or the Expert Patient Programme
- To implement or maintain lifestyle changes
- To manage the emotional and social consequences of living with a complex long term condition, potentially in the context of other health or social complications.

7.1.3 WAYS TO IDENTIFY HIGH RISK PATIENTS

CLINICAL EXPERIENCE

The default way to identify high risk patients is through clinical experience, instinct, knowledge and training. Clinicians are able to draw from the full richness of information obtained through a person-to-person encounter, particular if they have ongoing contact with an individual patient over a period of time. A key problem, however, is that effectiveness at a population level relies on patients having contact with a health service at an appropriate stage, which in itself indicates a level of active involvement in care management that may reduce future risk. Clinicians are however subject to a range of cognitive biases that may influence their perception of the risk/benefits of intervening. Evidence addressing this approach suggests:

- Clinicians may be able to identify patients who are currently high risk but are less able to identify those who are going to become high risk in the future.^{110,111}



¹¹⁰ Dudley RA, Medlin CA, Hammann LB, Cisternas MG, Brand R, Rennie DJ, and Luft HS. (2003) 'The best of both worlds? Potential of hybrid prospective/concurrent risk adjustment.' *Medical Care* 41[1], 56-69. 1996.

¹¹¹ Allaudeen, N. et al. (2011) 'Inability of providers to predict unplanned readmissions.' *J Gen Intern Med* (26)7: 771-776

USE OF THRESHOLDS

This approach uses previously defined criteria that define or describe high risk patients.

In the context of diabetes this could be a threshold HbA1c, above which a patient's glucose control is considered poor, or prior admission for ketoacidosis or hypoglycaemia.

This approach is conceptually straightforward and can help to ensure costly interventions are reserved for those most in need. There are two main disadvantages:

- Method essentially waits for individuals to become more unwell before intervening
- Interventions can potentially focus on those who have previously been high risk, rather than those who are likely to be high risk
- Thresholds are often binary, which does not reflect the underlying biological reality - There is no true figure below which everyone is low risk and above which everyone is high risk as risk is a continuum.

There is considerable natural variation in the progression of diseases and complications which often confounds the use of thresholds.

In diabetes, some people with apparently poor glucose management will develop complications later than some with apparently better glucose management.

PREDICTIVE MODELLING

Predictive modelling is a data-driven approach, which seeks to establish statistical relationships between sets of variables in order to predict future outcomes. Predictive modelling tools usually use regression modelling techniques and draw on data including: socio-demographics (age, sex and possibly a measure of socio-economic status), diagnoses, prior service usage (potentially both primary and secondary care) and pharmacy data which are run periodically on a large cohort of patients, with the tool 'flagging' those emerging above a certain pre-defined level of risk and who can be considered for referral to an intervention. Predictive modelling remains part of the national policy approach to managing LTCs.⁴

There is evidence to suggest predictive models are superior to both threshold approaches and clinician experience in identifying patients at risk of future hospital admissions,¹¹² however it is important to highlight:¹¹³

- Many tools have modest predictive accuracy, which carries the potentially adverse impact of false negative and false positive results
- 'Impactability models' focus on sub-groups of true positive patients seen as more likely to benefit from an intervention however these approaches have the potential to widen health

¹¹² King's Fund, NHS Modernisation Agency, New York University, Health Dialog (2005). Predictive Risk Project: Literature review [online]. Available at:

www.kingsfund.org.uk/current_projects/predicting_and_reducing_readmission_to_hospital/#context

¹¹³ NHS England (2015). Next Steps for risk stratification in the NHS.

inequalities by systematically excluding those who are expected to respond poorly or be harder to engage with (ie people with dementia, mental health problems or language barriers).

- There is little robust evidence that programmes being offered to patients identified as high risk through risk stratification actually improve outcomes while reducing costs
- Don't often capture wider social or contextual factors, which may be pivotal in understanding escalating need.

In the context of diabetes, disease-specific risk tools are not widely used in the UK, although examples exist from the US health system,¹¹⁴ including the Joslin Diabetes Center's Registry and Risk Stratification Tool.

PATIENT ACTIVATION

'Patient activation' is a concept that describes the knowledge, skills and confidence a person has in managing their own health and health care.¹¹⁵ A patient with lower levels of activation is less likely to play an active role in their health, less good at seeking appropriate health care, less good at following doctors' advice and less able to self-manage their health. Patient activation has been linked with health outcomes among healthy patients, as well as outcomes among patients who have many different types of physical health condition, including diabetes. For example:

- Higher activation scores are correlated with adherence to treatment and condition monitoring, across a range of different conditions and economic backgrounds, including disadvantaged and ethnically diverse groups and those who have less access to care.
- More-activated patients with diabetes are more likely to perform foot checks, obtain eye examinations and exercise regularly than less-activated patients and less likely to be hospitalised.
- More-activated patients are more likely to have clinical indicators in the normal range, including body mass index (BMI), blood sugar levels (A1c), blood pressure and cholesterol.
- More-activated patients have more positive experiences of care and report higher-quality interactions with doctors and report fewer care co-ordination problems.

Patient activation can be measured through the Patient Activation Measure (PAM). This consists of 13 statements about beliefs, confidence in the management of health-related tasks and self-assessed knowledge, scored in four groups or 'levels' shown in the table below.

¹¹⁴ Clark, CM *et al.* (2001). 'A systematic approach to risk stratification and intervention within a managed care environment improves diabetes outcomes and patient satisfaction.' *Diabetes Care*; 24(6): 1079-1086.

¹¹⁵ The King's Fund (2014). Supporting people to manage their health. An introduction to patient activation.

Figure 7.1: The four levels of patient activation

Level 1	Individuals tend to be passive and feel overwhelmed by managing their own health. They may not understand their role in the care process.
Level 2	Individuals may lack the knowledge and confidence to manage their health.
Level 3	Individuals appear to be taking action but may still lack the confidence and skill to support their behaviours.
Level 4	Individuals have adopted many of the behaviours needed to support their health but may not be able to maintain them in the face of life stressors.

Source: Kings Fund report

Patient activation is changeable and can be increased through interventions, which generally focus on the development of skills and on building confidence. Effective interventions tend to be tailored to an individual's level of activation. For instance, tailored coaching attempts to meet patients where they are and tailor support to their PAM level.^{116, 117}

PAM can be used in a range of ways from intervening to improve patient engagement and outcomes, to measuring the performance of health care systems or evaluating effectiveness of interventions. PAM can also be used to stratify populations to target interventions.

PAM could be used to stratify a population of diabetic patients to understand the types of support that might benefit particular patients. A newly-diagnosed patient with T2DM may currently have no complications and a reasonably-low HbA1c, and therefore not be obviously high risk. If they have low activation, however, they may not be in a position to take on lifestyle advice and progression of their condition may be rapid.

The PAM could therefore be used together with clinical information to identify individuals who are not currently high risk but who are likely to need greater or lesser levels of support to remain that way. The following table summarises this approach.

Table 7.1: Segmenting the population

PAM level	Disease burden	
	Low	High
High	Electronic resources	Electronic resources and peer support
	Usual team members	Usual care team
	Focus on prevention	Focus on managing illness
Low	High-skilled team members	High-skilled team members
	Focus on prevention	More outreach
		Focus on developing skills to manage illness

Source: From King's Fund, 2014, p28

¹¹⁷ Hibbard J, Gilbert H (2014) Supporting people to manage their health: An introduction to patient activation. The King's Fund, May 2014, London.

7.2. EVIDENCE-BASED APPROACHES THAT PREVENT ESCALATION OF HEALTH AND CARE NEEDS

7.2.1 PREVENTING ESCALATION

Preventing escalation of health and care need is a clear priority within health and care sectors. Although “managing demand” and reducing unplanned as well as elective hospital admissions and admission to care is such a priority, we have yet to achieve much success in attaining these reductions and avoiding admissions, despite considerable effort to deliver interventions across the service. The problem is complex and there are many causes, with issues around population demographics, acute and community care, and the wider environment contributing to the challenge of reducing admissions and preventing escalation of needs.¹¹⁸

There is also limited evidence on the effectiveness of interventions aimed at reducing admissions to health and social care settings. Interventions may be focused at different stages along the patient journey, focussed on individual patients developing skills in self-care to wider interventions population-level interventions such as care pathways and co-ordinated responses and interventions are often focussed on either admissions to health or admissions to care settings.

In view of these factors this section aims to provide an overview of the current evidence exploring interventions to prevent admissions in two parts: Part 1 (7.2.2) Preventing hospital admissions and Part 2 (7.2.3) – Preventing admissions to care settings. In the final section of this Chapter, the evidence will be brought together in a proposed model. Wherever possible, we refer to evidence from systematic reviews and robust national guidance documents rather than individual studies. This section will not include interventions focused on the clinical management of diseases – for example, pharmacological agents.

7.2.2 PREVENTING HOSPITAL ADMISSIONS

An admission to hospital, particularly an un-planned admission, is a disruptive and unsettling experience, particularly for older people, exposing them to new clinical and psychological risks and increasing their dependency.¹¹⁹ The use of acute hospital beds for older people can be reduced through avoiding emergency admissions.

A number of factors, described above, are associated with increased rates of admission, and are important to consider when targeting interventions to reduce avoidable admissions as well as identification of people who may be at high risk of admission to hospital.

Understanding which admissions are avoidable also aids in targeting interventions and resources. Ambulatory or primary care sensitive conditions (ACSCs) are those for which hospital admission

¹¹⁸ Blunt I, Bardsley M, Dixon J (2010). ‘Trends in emergency admissions in England 2004-2009: is greater efficiency breeding inefficiency?’ London: Nuffield Trust.

¹¹⁹ Hoogerduijn JG, Schuurmans MJ, Duijnste MS, de Rooij SE, Grypdonck MF (2007). A systematic review of predictors and screening instruments to identify older hospitalized patients at risk for functional decline. *Journal of Clinical Nursing*, 16(1): 46–57.

could be prevented by interventions in primary care.¹²⁰ At present, different sets of ACSCs are used in different situations. Some admissions (eg those for dementia) may not be perceived to be avoidable, as the disease course is not significantly modifiable. However, the availability of more suitable alternatives to an acute hospital admission – for example, respite care or home care – can result in admission avoidance in the acute situation. Thus an ACSC may be dependent on availability and referral to an alternative service, not only availability of traditional or primary care.

A recent report by the King's Fund identified interventions where there is evidence of an impact on hospital admissions, those where there is evidence that the intervention has no beneficial effect and a range of interventions where more evidence needs to be built in order to determine whether they have the potential to significantly reduce admissions.¹²¹



Interventions with evidence of little or no beneficial effect included:

- Pharmacist home-based medication review
- Intermediate care
- Community-based case management (generic conditions)
- Early discharge to hospital at home on readmissions
- Nurse-led interventions pre- and post-discharge for patients with chronic obstructive pulmonary disease (COPD)

Interventions for which further evidence is required included:

- Increasing GP practice size
- Changing out-of-hours primary care arrangements
- Chronic care management in primary care
- Telemedicine
- Cost-effectiveness of GPs in A&E
- Access to social care in A&E
- Hospital-based case management
- Rehabilitation programmes
- Rapid response teams

¹²⁰ Purdy S, Griffin T, Salisbury C, Sharp D (2009). 'Ambulatory care sensitive conditions: terminology and disease coding need to be more specific to aid policy makers and clinicians'. *Public Health*; (123)2: 169–73.

¹²¹ King's Fund (2011). *Avoiding hospital admissions: What does the research evidence say?* London: The King's Fund.

Interventions where there is evidence of positive effect are discussed below in greater detail:

INTERVENTIONS SHOWN TO BE EFFECTIVE AT REDUCING ADMISSIONS

Continuity of care with a GP

High continuity of care with a family doctor may be associated with lower risk of an ACSC admission for all age groups.¹²²

Hospital at home as an alternative to admission

For selected patients, avoiding admission through provision of hospital care at home yielded similar outcomes to inpatient care, at a similar or lower cost and with greater levels of satisfaction, particularly among older people.¹²³

Assertive case management in mental health

Assertive case management by multidisciplinary teams may reduce mental health admissions. Teams can best reduce hospital use by organising themselves in the assertive community treatment model and by focusing on patients with a history of frequent hospital use.¹²⁴

Self-management

There is evidence from systematic reviews that self-management seems to be effective in reducing unplanned admissions for patients with COPD and asthma. Self-management education for patients with COPD reduces the risk of at least one hospital admission by about 36% compared with usual care. Self-management education was associated with a reduction in shortness of breath and an improved quality of life.¹²⁵ Education or a brief self-management programme for adult patients with asthma attending A&E with an acute exacerbation significantly reduced admission to hospital by 50% and also reduced post-discharge morbidity and re-admission.¹²⁶ Not all studies of self-management demonstrate reduced hospital or A&E department use, and there is some debate over which 'active ingredient' in self-management is the most effective. One review suggested that a self-management action plan is a useful component.¹²⁷

Early senior review in A&E

Making a senior emergency medicine clinician (a consultant equivalent or middle-grade experienced specialist trainee) available to review patients in the emergency department has been shown to

¹²² Menec V, Sirski M, Attawar D, Katz A (2006). 'Does continuity of care with a family physician reduce hospitalizations among older adults?'. *Journal of Health Services Research & Policy*, vol 11, pp 196–201.

¹²³ Shepperd S, Doll H, Angus R, Clarke M, Iliffe S, Kalra L, Riccaud N, Tibaldi V, Wilson A (2009a). 'Avoiding hospital admission through provision of hospital care at home: a systematic review and meta-analysis of individual patient data'. *Canadian Medical Association Journal*, vol 180, no 2, pp 175–82.

¹²⁴ Burns T, Catty J, Dash M, Roberts C, Lockwood A, Marshall M (2007). 'Use of intensive case management to reduce time in hospital in people with severe mental illness: systematic review and meta-regression'. *British Medical Journal*, 335; 336.

¹²⁵ Effing T, Monninkhof EEM, van der Valk PP, Zielhuis GGA, Walters EH, van der Palen JJ, Zwerink M (2007). 'Self-management education for patients with chronic obstructive pulmonary disease (Cochrane Review)'. *Cochrane Database of Systematic Reviews*, issue 4, article CD002990. DOI: 10.1002/14651858.CD002990.pub2.

¹²⁶ Tapp S, Lasserson T, Rowe B (2007). 'Education interventions for adults who attend the emergency room for acute asthma (Cochrane Review)'. *Cochrane Database of Systematic Reviews*, issue 3, article CD003000. DOI: 10.1002/14651858.CD003000.pub2.

¹²⁷ Bodenheimer T, Lorig K, Holman H, Grumbach K (2002). 'Patient self-management of chronic disease in primary care'. *Journal of the American Medical Association*, vol 288, no 19, pp 2469–75.

reduce in-patient admissions by 12% and specifically reduced admissions to the acute medical assessment unit by 21%.¹²⁸

Multidisciplinary interventions and tele-monitoring in heart failure

There is some evidence to suggest that case management interventions are associated with a reduction in admissions for heart failure, but the effective components of the case management interventions are difficult to identify. One randomised controlled trial of a multidisciplinary intervention showed reduced heart failure-related re-admissions in the short term.¹²⁹ Recent evidence from the American College of Cardiology also suggests that optimum observation unit management in A&E could prevent up to 50% of patients being admitted. Particularly low and moderate-risk patients, could be safely discharged after a brief period of observation, thus avoiding unnecessary admissions and minimizing readmissions.¹³⁰

Integration of primary and social care

There is evidence from a recent review by The King's Fund that integrating primary and social care reduces admissions and that older people with long term conditions who received shared health and social care had fewer unplanned admissions than those receiving usual care. Data from Torbay in the UK shows that providing integrated care to the highest-risk older people, who require intensive support, has resulted in a reduction in hospital admissions.¹³¹

Integration of primary and secondary care

Evidence indicates that integration is effective and highlights the importance of integrating not just at the health system level, but also at the disease management and individual patient levels. Within the Kaiser system it has been shown that integrated care can result in fewer admissions.¹³²

Integrated care designed to include the medical home concept in which financial mechanisms provide an incentive for physicians to co-ordinate care over time and across sectors has been shown to reduce all-cause hospital admission rates by 20%.²¹ Managed disease networks in Scotland demonstrated a reduction in emergency admissions for ACSC in patients with angina and diabetes in the three years after networks were implemented.¹³³

¹²⁸ White A, Armstrong P, Thakore S (2010). 'Impact of senior clinical review on patient disposition from the emergency department'. *Emergency Medicine Journal*, vol 27, no 4, pp 262–5.

¹²⁹ Taylor S, Candy B, Bryar R, Ramsay J, Vrijhoef H, Esmond G, Wedzicha J, Griffiths C (2005b). 'Effectiveness of innovations in nurse led chronic disease management for patients with chronic obstructive pulmonary disease: systematic review of evidence'. *British Medical Journal*, 331(7515): 485.

¹³⁰ Collins SP1, Pang PS, Fonarow GC, Yancy CW, Bonow RO, Gheorghiade M (2013). Is hospital admission for heart failure really necessary? The role of the emergency department and observation unit in preventing hospitalization and rehospitalisation. *J Am Coll Cardiol*. 61(2):121-126

¹³¹ Curry N, Ham C (2010). *Clinical and Service Integration. The route to improved integration*. London: The King's Fund. Available at: www.kingsfund.org.uk/publications/clinical_and_service.html.

¹³² Feachem RGA, Sekhri NK, White KL (2002). 'Getting more for their dollar: a comparison of the NHS with California's Kaiser Permanente'. *British Medical Journal*, 324: 135–143.

¹³³ Guthrie B, Davies H, Greig G, Rushmer R, Walter I, Duguid A, Coyle J, Sutton M, Williams B, Farrar S, Connaghan J (2010). 'Delivering health care through managed clinical networks (MCNs): lessons from the North'. Report for the National Institute for Health Research Service Delivery and Organisation Programme. National Institute for Health Research website. Available at: www.sdo.nihr.ac.uk/files/project/103-final-report.pdf

INTERVENTIONS SHOWN TO BE EFFECTIVE AT REDUCING RE-ADMISSIONS

Avoiding re-admissions is also a critical component to consider when aiming to prevent escalation of health and care need. The current health care system attempts to discharge elderly patients quicker from acute care facilities. Consequently, hospital re-admission is common; however, re-admission may be only one aspect of important adverse outcomes, particularly when considering the impact on social care. Early recognition of risk factors might ensure a successful transition from the hospital to the home, allow targeting of specific interventions to prevent re-admission and inform decisions concerning care setting placement/package required. A systematic review conducted by Preyde M et al, identified factors associated with adverse outcomes in older patients discharged from hospital to home.¹³⁴ Factors were characterized in five domains: demographic factors, patient characteristics, medical and biological factors, social factors, and discharge factors. The most frequently reported risks were:

- Depression
- Poor cognition
- Multimorbidity
- Length of hospital stay
- Prior hospital admission
- Functional status
- Patient age
- Multiple medications
- Lack of social support.

Structured discharge planning and personalised health care programmes

There is strong evidence that an individualised discharge plan for hospital inpatients is more effective than routine discharge care that is not tailored to the individual. Re-admissions to hospital were significantly reduced by 15 %for patients allocated to structured individualised discharge planning.¹³⁵

There are several important limitations surrounding the evidence presented: 1) Real-life practice does not necessarily reflect the environment of research studies – interventions to reduce emergency admissions take place within a complex environment, in which the nature and structure of existing primary, secondary and social care services, individual professional attitudes, patient and family preferences, and general attitudes to risk management all combine to influence both the implementation process and the eventual outcome of successful implementation; 2) Evidence relating to the implementation of change in complex environments suggests that it is the interaction of the intervention with the particular social context in which it is embedded that determines outcomes - what works in one health care environment may not be generalisable to another situation.

¹³⁴ Preyde M, Brassard K (2011). Evidence-based risk factors for adverse health outcomes in older patients after discharge home and assessment tools: a systematic review. J Evid Based Soc Work. 8(5): 445-468.

¹³⁵ Shepperd S, McClaran J, Phillips CO, Lannin NA, Clemson LM, McCluskey A, Cameron ID, Barras SL (2010). 'Discharge planning from hospital to home (Cochrane Review)'. Cochrane Database of Systematic Reviews, issue 1, article CD000313. DOI: 10.1002/14651858.CD000313.pub3.

EXPERT OPINION

However to further inform the evidence around these interventions the King's Fund Group conducted a Delphi study to elicit the views of an expert panel of health professionals on the interventions that were most helpful in reducing unplanned admissions.¹³⁶ The Panel identified the following as key interventions to reduce admissions:

- Direct delivery of rapid access care in the community
- Access to rapid response nursing and social care at home
- Intermediate care and acute nursing home beds
- Mental health crisis teams
- Rapid access specialist clinics
- Increased nursing home capacity for acute illness.

It is important to emphasise that not all admissions are bad. There is a high prevalence of mental health conditions, including dementia, complicating the care of older people admitted to general hospitals.¹³⁷ It is taken for granted that hospitals are bad places for old and frail people and that the policy directive should be towards alternative forms of provision. However, hospital care is often inevitable and appropriate; eg 50% of all people with hip fractures have dementia and these people need a prompt and skilled operation that cannot be carried out elsewhere. Therefore the ideal model to reduce escalation of need would need to allow for immediate urgent care to be given, enable those who need admission to be correctly identified and facilitate systems to appropriately manage those who can be managed in an ambulatory setting to be managed in the community.

7.2.3 PREVENTING ADMISSIONS TO CARE SETTINGS

There is a clear link between hospital admissions and subsequent admission to care home with more than 30% of older people previously living at home in the community being discharged to a care setting after a hospital admission. This figure doubles for people living with dementia.¹³⁸ Most of the literature exploring admissions to care homes focusses more on identifying the risk factors that are associated with increased risk of admission to care homes settings, thereby providing options for targeted intervention. Key risk factors for care home admission include:^{139,140,141}

- Age, sex, ethnicity
- Deprivation
- Morbidity

¹³⁶ Purdy S, Griffin T, Salisbury C, Sharp D (2010c). 'Prioritizing ambulatory care sensitive hospital admissions in England for research and intervention: a Delphi exercise'. Primary Health Care Research & Development, vol 11, pp 41–50.

¹³⁷ Royal College of Psychiatrists. Who Cares Wins. Improving the Outcome for Older People Admitted to the General Hospital: Guidelines for the Development of Liaison Mental Health Services for Older People. Report of a Working Group for the Faculty of Old Age Psychiatry. London: Royal College of Psychiatrists; 2005.

¹³⁸ Lafont C, Gérard S, Voisin T, Pahor M, Vellas B; Members of I.A.G.G./A.M.P.A Task Force (2011). 'Reducing "iatrogenic disability" in the hospitalized frail elderly'. Journal of Nutrition, Health & Aging, 15(8): 645–660.

¹³⁹ Barton, P., Bryan, S., Glasby, J., Hewitt, G., Jagger, C., Kaambwa, B., Martin, G., Nancarrow, S., Parker, S., Regen, E. & Wilson, A. (2006). A National Evaluation of the Costs and Outcomes of Intermediate Care for Older People, Leicester: Leicester Nuffield Research Unit.

¹⁴⁰ Lewis, G. (2007) Predicting Who Will Need Costly Care: How Best To Target Preventive Health, Housing And Social Programmes, London: Kings Fund, DCLG, DoH.

¹⁴¹ Wenger, G.C. (2000). How important is parenthood? Childlessness and support in old age in England. Ageing and Society, 20(2): 161-182.

IMPROVING CARE MANAGEMENT: TARGETING AND INTERVENING LONG TERM CONDITIONS JSNA

- Health service use
- Drugs prescribed
- Patterns of social care needs and usage
- dementia/cognitive impairment
- Activities of daily living (ADL) restriction
- Number of family members,
- Use of day services.
- People living alone, in particular, older men without partners despite lower levels of disability than lone older women.

All of these factors are potentially open to 'upstream', preventive intervention. However, it is still unclear, how, when or where best to invest.

Oxfordshire County Council worked in partnership with the Institute of Public Care on a study of the pathways of older people who had entered a care home to identify the critical characteristics, circumstances and events which led to a care home admission in order to provide appropriate services to prevent or delay such an admission. The study found that certain conditions and experiences were particularly prevalent and led to admission to care:¹⁴²

- Urinary incontinence 45%
- Dementia 40%
- Bowel incontinence 34%
- Depression 25%
- Visual impairment 21%
- Stroke 19%
- Diabetes 17%
- COPD 6%
- Learning disability 2%

Similar rates of dementia and stroke have been reported by other studies with varying levels of incontinence, depression and visual impairment.^{143,144} More than half of those in the Oxfordshire audit had multiple health problems at the time of admission: 56% with 3 or more conditions. Common combinations included: dementia and incontinence (19%); dementia and depression (17%); dementia and stroke (10%); and dementia and diabetes (9%).

Although certain conditions are particularly prevalent, individual situations are often varied and complex. Therefore, delivering services at a population-level is challenging. Most people going into care homes do have high levels of need, however, lengthy periods of deterioration often coupled

¹⁴² Taylor R, Cairncross C, Livadeas S (2010). Oxfordshire County Council's research into preventing care home admissions and subsequent service redesign. Research, Policy and Planning 28(2): 91-102.

¹⁴³ Bebbington, A., Darton, R. & Netten, A. (2001) Care Homes for Older People, Volume 2 Admissions, Needs and Outcomes, The 1995/96 National Longitudinal Survey of Publicly-Funded Admissions, Kent: PSSRU.

¹⁴⁴ Woolham, J., Benton, C., Pittam, L. & Peter, D. (2009) Factors associated with the permanent admission of older people into residential care: the policy environment, research evidence of causes, local practice and possible remedies', Northamptonshire County Council: Unpublished Report.

with a service interface with social care and health suggests that there are likely to be opportunities earlier along the pathway to support people to remain independent longer.

7.2.4 A MODEL FOR PREVENTING ESCALATION OF NEED

Work by Andrew Kerslake at the Institute of Public Care in Oxford Brookes argues¹⁴⁵ that escalation of health and care needs happens in steps rather than a continuous steady decline. For example, the death of a partner precipitates a quick decline in health and wellbeing, followed by maintenance of about the same level until a fall, which triggers a sudden decline because (for example) a loss of confidence in getting about. Resilience is thus impacted suddenly and sharply rather than gradual decline. Evidence therefore suggests that the focus in terms of reducing escalation should be on preventing specific events occurring (or managing the impacts of those specific events if they are unpreventable).

Kerslake's work suggests that there are a set of factors that are most commonly associated with care home admission, ie maximum escalation of underlying health and care needs. These factors are relatively familiar, eg incontinence, dementia, stroke, social isolation, and there exists substantial literature about what good support for people with these conditions looks like. Furthermore, there were services based on good evidenced practice available – but people had not used them. So the existence of a condition did not mean that they were getting support. The first principle of good care management to reduce escalation of needs in a population therefore seems to be getting the right services to the right people.

Based on their work, the IPC suggest a three-tiered model of approaching the organisation of services across the health and social care spectrum to ensure health and care needs do not escalate, to ensure a focus on reducing demand rather than meeting it:

- Services that seek to support a person's lifestyle and engagement with their community.
- Integrated services that seek to maintain a person within the community.
- Targeted interventions that aim to restore a person back to a preceding state of health and well-being.

These three tiers are described in more detail below:

The lifestyle offer	
Aim	<ul style="list-style-type: none"> • To deliver a range of health and well-being services designed to promote independence and continue older people's active involvement in their community • Services should be incentivised to target older people who have pre-disposing factors likely to indicate high health needs or likelihood of later care home admission.
Services provided	<ul style="list-style-type: none"> • Basic care and support; eg, community alarm services, toenail cutting, access to dentistry, meal services and meal sharing schemes • Exercise; eg access to leisure facilities either in own home or community facilities, personal trainers • Community access and involvement; eg accompanied transport to social activities and health services, visiting and companionship services.

¹⁴⁵ (From presentation by A Kerslake, Home Care Workshop, Cambridge, 17 April 2015)

IMPROVING CARE MANAGEMENT: TARGETING AND INTERVENING
LONG TERM CONDITIONS JSNA

Service user group	<ul style="list-style-type: none"> Open to all but targets populations most at risk.
The maintenance offer	
Aim	<ul style="list-style-type: none"> To sustain within the community older people who require help and support to meet their health and care needs. In providing support to always identify how greater independence can be encouraged and supported.
Services provided	<ul style="list-style-type: none"> Existing home care services (staff supported by extra training) plus care and repair, community alarm, aids and adaptations and district nursing How, when and which services are provided to be agreed between the service user and the provider. Outcomes focus. Statutory funding provided on that basis only.
Service user group	<ul style="list-style-type: none"> Open to all who wish to pay, or for whom the service has been arranged. Users may make a contribution to their Personal Budget depending on their financial circumstances.
The rehabilitation offer	
Aim	<ul style="list-style-type: none"> To take older people with identified risk factors who have suffered a critical incident, eg, fracture, and restore them to a state prior to the incident.
Services provided	<ul style="list-style-type: none"> Brings together reablement intermediate care and community health provision post hospital. Focuses on key conditions that lead to repeat admissions and lengthy hospital stays, eg, falls strokes, dementia Brings together home care, physiotherapy, occupational therapy, personal trainers, community nursing (including mental health) other GP led services.
Service user group	<ul style="list-style-type: none"> Only serves a tightly targeted population. People who have had a critical incident that could either lead to a care home admission, a hospital admission or a restoration into the community, post hospital, of older people. Funded by health and social care but for consumers free to all who satisfy the admission criteria.

7.3. EVIDENCE FOR THE INCLUSION OF MENTAL HEALTH INTERVENTIONS IN THE MANAGEMENT OF PHYSICAL CONDITIONS

A literature review to explore the evidence for particular mental health strategies within specific LTC care pathways was recently completed for Cambridgeshire and Peterborough CCG. The main findings are described briefly in this section.

PURPOSE OF THE EVIDENCE REVIEW

This review aims to summarise the evidence base that exists to support particular mental health strategies within specific LTC care pathways, to determine which is most likely to produce the best outcomes for patients and to provide the best possible return on investment.

As described in section 3.3 Common mental disorders (CMD's), which include depression and anxiety, are highly prevalent with long term conditions. Evidence consistently demonstrates that people with long term physical health conditions (LTC's) are two to three times more likely to experience mental health problems than the general population, with much of the evidence relating to affective disorders such as anxiety and depression. Compared with the general population, people with diabetes, hypertension and coronary artery disease have double the rate of mental health problems, and those with chronic obstructive pulmonary disease, cerebro-vascular disease and other chronic conditions have triple the rate. People with two or more long term conditions are seven times more likely to have depression.

A detailed review was completed on mental health strategies within specific LTC care pathways

Due to the size of the scope of the review, the review was carried out in seven sections which were condition specific and include diabetes mellitus, cardiovascular disease, COPD, musculoskeletal disorders (including arthritis), asthma, cancer and chronic pain. For each condition a comprehensive search of three databases was carried out, including the Cochrane Library, EMBASE and MEDLINE. A separate search was carried out of the NHS Evidence site to obtain other sources of published evidence not held on research databases (for example NICE and SIGN documents).

SUMMARY OF THE FINDINGS AND RECOMMENDATIONS

Screening for depression and/or anxiety:

- Across all conditions there was found to be insufficient evidence to support the implementation of routine screening for depression / anxiety.
- The routine clinical management of long term health conditions should include the successful identification of those requiring individual assessment for depression / anxiety. NICE recommend the use of depression identification questions for this purpose and these should be incorporated into the initial patient assessment within pathways of care for long term health conditions.

Psychological Interventions:

- Across most of the conditions, evidence supports the beneficial role of psychological interventions, but is inconclusive in determining the most effective intervention for a specified patient group.

There is insufficient evidence for routine screening for depression or anxiety; routine clinical management should include identification of those requiring individual assessment

IMPROVING CARE MANAGEMENT: TARGETING AND INTERVENING LONG TERM CONDITIONS JSNA

- It is recommended that NICE guidance be applied, offering a choice of psychological intervention dependent on patient preference and assessed severity of depression / anxiety.
- The current suite of psychological interventions commissioned should be reviewed to ensure a comprehensive choice is offered.
- Access to commissioned psychological interventions directly from care pathways for long term health conditions should be reviewed to ensure that direct and timely access is available.

Pharmacological Interventions:

- Evidence supports the beneficial role of antidepressants in the treatment of comorbid depression in those with a long term physical health condition. Condition-specific studies have reported varying effectiveness of selected agents.
- Where clinically indicated the use of antidepressant therapy in the management of comorbid depression / anxiety and long term health conditions should be supported. The treatment of choice remains a clinical decision on an individual case basis, in accordance with current clinical guidance.

Exercise:

- There is not sufficient evidence to make recommendations for the prescription of exercise for the management of depression and/or anxiety in those with a long term health condition. However the benefits of exercise as a component of management programmes, such as pulmonary and cardiac rehabilitation, have been observed.
- NICE recommends the offer of a structured group physical activity programme in the presence of identified sub-threshold depressive symptoms in those with a long term physical health condition.



Source: [Make sport fun](#)

Rehabilitation and Support Programmes:

- The availability of evidence varies significantly across specific physical health condition groups, in accordance with current programme delivery. Evidence exists to support the effectiveness of pulmonary rehabilitation and cardiac rehabilitation programmes.
- Pulmonary Rehabilitation has been shown as an effective management strategy to improve symptoms of depression / anxiety in those with Chronic Obstructive Pulmonary Disease (COPD). Evidence would support a recommendation that patients diagnosed with COPD should have undelayed access to a programme of Pulmonary Rehabilitation.
- The use of a multicomponent cardiac rehabilitation programme for those patients with heart failure and post myocardial infarction will improve quality of life. Evidence supports the inclusion of exercise and psychological interventions to improve outcomes for depression and anxiety.
- For those with multiple long term physical health conditions it would seem reasonable to recommend access to a relevant rehabilitation programme, and to recommend the development of appropriate programmes where these may not currently be in delivery.

Cost-effectiveness:

- Poor mental health, in the presence of a long term physical health condition, is associated with an approximate 45% increase in service usage costs to the NHS. Collaborative care has been found to be cost-effective in diabetes mellitus management, with US studies also supported by a model assessment relevant to the UK. A single study has suggested the cost effectiveness of the identification and management of depression in cancer, but considered alone this is insufficient to make recommendations.
- A collaborative model of care where patients have their comorbid depression managed through a combination of primary care support and antidepressant treatment, alongside their diabetes management, is indicated for practice.

7.4 LOCAL EXAMPLES OF CARE MANAGEMENT OF THE HIGH RISK POPULATION

In Cambridgeshire there are programmes and projects focussed on improving care by identifying and reaching those at risk of adverse outcomes, and providing appropriate high value care. Several of these are described in this section.

7.4.1 HEALTH AND WELLBEING NETWORK, PILOT PROJECT – ISLE OF ELY

A recent local project has focussed on targeting older people who are not actively case-managed to offer them support and explore the need for preventative interventions.

Background:

Health and Wellbeing Network (HWN) was established to be the lead partner in a consortium of third sector organisations. HWN aims to link individuals with voluntary sector services that will help improve their general wellbeing. By assisting frail and vulnerable individuals to access



support we contribute to the objective of reducing unplanned non-elective admissions across the county.

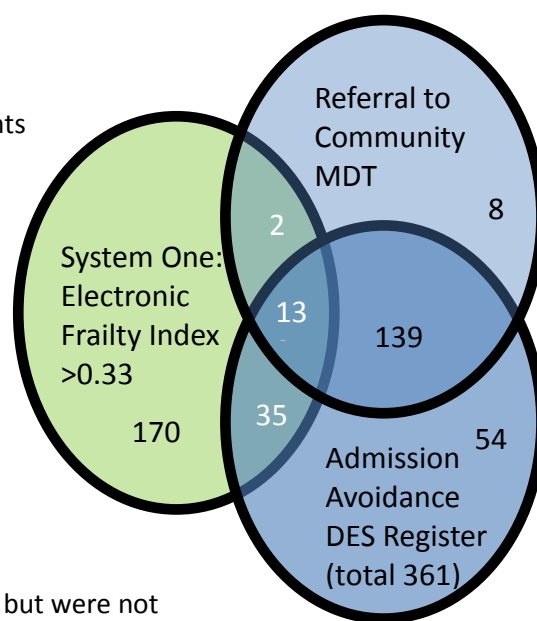
The vision is a service that meets a range of different needs; some intricate, some more simple. The HWN team receives professional referrals for individuals whose needs are relatively complex, and where a higher level of needs assessor competence and understanding is required. This model is resource hungry as each assessor can only manage a limited case load. We recognised there was also a need to offer a simpler triage model to vulnerable and frail individuals who were generally well. The target group is aged 65 and over.

Wellbeing triage:

The triage model is based around a telephone interview; an individual calls the Health and Wellbeing Network number (and speaks with a Community Navigator. Following a standard protocol each person is asked about their general wellbeing and their specific needs. Where the person is deemed to be confident and able, they are signposted towards the voluntary sector organisations that could potentially meet their needs in their locality. The individual's name is stored in the CharityLog database, which is updated with information from the various service providers who are supporting the individual.

Pilot:

The pilot medical practice identified three groups of patients on their register: a total of 282 had been referred to the Community MDT; 361 were on the Admissions Avoidance Register; and 340 had a score greater than 0.33 on the Electronic Frailty Index. Within each group there were overlaps; for example 133 patients were in all three groups, whilst 54 were only on the Admissions Avoidance register. The practice had a Multi-Disciplinary Team (MDT) Co-ordinator. That meant patients in MDT or Admissions Avoidance group had support from that resource to help manage their case.



There were 170 patients who had an elevated frailty score but were not actively being managed by the practice; this was the group targeted. A letter, on practice letterhead, was sent to each of these individuals. They were asked to call the HWN telephone number and answer some short questions to determine their wellbeing status. After 3 weeks the response rate was 13%. Most respondents had simple needs (befriending, shopping, transport, handyman, security, etc.) and were signposted, whilst others simply wanted to register their name with the service for future reference. However, there were a small number that required a more in depth assessment and were referred to support providers.

This pilot project confirmed that there is demand for this service. HWN identified at risk individuals who were connected with support providers to improve their wellbeing status. A small group had more complex and immediate needs.

Future:

The plan is to extend the service across the county. By having a single database with information about an individual's interaction with the voluntary sector, we are able to improve their experience. We are able to provide a simple communication pathway for health and social care professionals wishing to know what support services an individual has received which should improve efficiency. We can improve choice for the individual by maintaining an accurate database of service providers in each locality. And, by helping the at-risk individuals, we are contributing to reducing costs across the healthcare system and freeing up beds that might otherwise be blocked because of unplanned non-elective admissions.

7.4.2 UNITINGCARE APPROACH

UnitingCare (UC) is a NHS partnership responsible for providing older people's healthcare and adult community services across Cambridgeshire and Peterborough. UC's role is to integrate health services in Cambridgeshire and Peterborough to ensure that care is joined-up around the needs of local communities.



Key features of the UnitingCare care model include:

- **Integrated teams** - 17 neighbourhood teams across Cambridgeshire and Peterborough, each will support up to six GP practices, and will provide community-based healthcare centred around the patient. Teams will each include a combination of community nurses, psychiatric nurses, allied health professionals and support workers. Neighbourhood teams will be supported by specialist health care professionals in four integrated care teams, based in Huntingdon, Peterborough, Cambridge and Fenland/Ely. These teams will include a housing co-ordinator, consultants, geriatricians, psychiatrists, cardiologists, respiratory physicians and palliative care consultants.
- **OneCall** - single point of co-ordination accessible via a single telephone number and staffed by professionals with access to expert clinical advice to provide guidance and advice as well as signposting to relevant services or support.
- **Co-ordinated care for those most at risk** – UC proposes to work with GPs and their teams to identify the patients at greatest risk of deterioration or future hospital admission and then co-ordinate their care through regular reviews by a multidisciplinary team (MDT) comprising health, social care and housing support professionals.
- **Joint Emergency Team (JET)** - 24/7 emergency service that will work alongside ambulances and out of hours GPs to undertake assessments and provide immediate treatment or care.
- **Wellbeing and prevention** – third sector led services

- **Technology** – aim to provide single view of the whole patient record which patients will also be able to view.

7.5 WHAT IS THIS TELLING US?

- An accurate method should be available to identify high risk patients in order to prevent escalation of need
- There remains an emphasis in national policy on the use of predictive modelling, however specific limitations exist. Alternative approaches are available and with the addition of a more formalised recognition of the patient context, which could be built around a patient activation framework, an approach more appropriate for use with multimorbidity may be developed.
- The identification of a high risk groups necessitates appropriate responses and interventions to be accessible and available to ensure needs are met.
- Joined-up, adequately resourced systems for care management could facilitate appropriate identification of high risk populations to ensure timely intervention.
- There is a need to fully understand and bring together the factors that can trigger an escalation in health or social care need to design responsive systems.
- A range of evidence-based interventions to avoid unnecessary hospital admissions have been reviewed and could be integrated into local care models. A greater understanding of which admissions are also necessary would help to distinguish at risk groups and support vulnerable populations who require intensive services.
- Models that support people's lifestyle and engagement with their community; integrated services; and targeted interventions that aim to restore a people's independence and wellbeing, offer joined-up solutions to address the needs of high risk LTC groups.
- Poor mental health, in the presence of a long term physical health condition, is associated with substantial costs. A collaborative model of care is indicated for practice to improve both mental health and LTC outcomes.
- Strong local assets exist which could provide levers to improve collaboration and integration of care, the adoption of preventative interventions and extended case management to ensure the potential for prevention of escalation of health and care needs is optimised.

8. IMPROVING CARE MANAGEMENT: SUPPORTING SELF-MANAGEMENT

The role of patients and carers in the day-to-day management of LTCs is essential and engaged, informed patients and carers is a pillar of the house of care model. This section will examine the principles of supporting self-management, considering:

- What is self-management?
- Does it work? What impact does it have?
- Who does it work for? Who may benefit from additional support?
- How is it working locally?

8.1. SELF-MANAGEMENT

It is recognised that during each year for a person with long term conditions, only a few hours are spent in the presence of health care professionals.¹⁴⁶ The vast majority of care is 'self-care' or 'self-management' of health conditions within the normal context of peoples' lives. There is increasing recognition of the opportunities in providing self-management support to optimise health outcomes for the person with LTCs, and their social and support network. A key element of this support is to help manage demand on the health and care system.

Self-management varies in definition and is usually considered synonymous with self-care. The longstanding Department of Health definition (2005) is that: *Self-management refers to an individual's ability to effectively manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes associated with living with a LTC.*¹⁴⁷ The definition used by Panagioti and collaborators for the Recursive study described below (2014), is more detailed: *'the care taken by individuals towards their own health and wellbeing: it comprises the actions they take to lead a healthy lifestyle; to meet their social, emotional and psychological needs; to care for their long term condition; and to prevent further illness or accidents.'*¹⁴⁸

Self-management: the care taken by individuals towards their own health and well being: it comprises the actions they take to lead a healthy lifestyle; to meet their social, emotional and psychological needs; to care for their long-term condition; and to prevent further illness or accidents'

Self-management, therefore, encompasses activities focussed on the health condition(s), such as a person's regulation of insulin levels in diabetes, approaches towards daily living such as pacing and relaxation, and wider lifestyle choices. The different forms of self-management have been variously described; for example researchers back in 1978 described four forms of self-management:¹⁴⁹

- Regulatory self-management (eg eating, sleeping and bathing).
- Preventative self-management (eg exercising, dieting and brushing teeth).

¹⁴⁶ Coulter A, Roberts S, Dixon A. (2013) Delivering better services for people with long-term conditions: Building the house of care. The King's Fund October 2013, London.

¹⁴⁷ NHS (2005) Promoting Optimal Self Care – Consultation techniques that improve quality of life for patients and clinicians.

¹⁴⁸ Panagioti, M., Richardson, G., Small N., et al. Self-management support interventions to reduce health care utilisation without compromising outcomes: a systematic review and meta-analysis. BMC Health Services Research 2014, 14:356.

¹⁴⁹ Barofsky I. Compliance, adherence and the therapeutic alliance: steps in the development of self-care. Soc Sci Med 1978;12:369–76

- Reactive self-management (eg responding to symptoms).
- Restorative self-management (eg adherence to treatment regimens).

There is a growing field of research into the interventions that empower people with LTC to self-manage their conditions effectively. Supporting self-managing has also been described as one tenet of providing person-centred care.¹⁵⁰ Indeed self-management support itself can be viewed in two ways: *as a portfolio of techniques and tools to help patients choose healthy behaviours; and as a fundamental transformation of the patient-caregiver relationship into a collaborative partnership.*¹⁵¹ The House of Care Model described above, incorporates the pillar of ‘engaged, informed patients and carers’ as critical for optimal outcomes.

Self-management, a collaborative partnership enabling ‘engaged, informed patients and carers’

Not all patients and carers experience the same levels of motivation towards self-management, nor may they have the knowledge and skills and resources to enable them to make appropriate changes. However, this is not fixed, the evidence shows that with effective support and education, these skills can be developed and strengthened, even among those who are initially less confident, less motivated or have low levels of health literacy. ‘Patient activation’ may be defined as ‘an individual’s knowledge, skill, and confidence for managing their health and health care’.¹⁵² Further details on patient activation are described in section 7.1.

At the broadest definition, self-management support may include other care management tools such as the use of decision aids, health coaching, and assistive technology. Recent work by the Richmond Group of Charities and The King's Fund called for patients to be offered the opportunity to co-create a personalised self-management plan including:

- Patient and carer education programmes.
- Medicines management advice and support.
- Advice and support about diet and exercise.
- Use of telecare and telehealth to aid self-monitoring.
- Psychological interventions (eg coaching).
- Telephone-based health coaching.
- Pain management.
- Patient access to their own records.

The Richmond and King’s Fund report acknowledges the role of planning and collaborative care, also at the heart of the ‘house of care’ and the list above highlights that many of these components are

¹⁵⁰ Coulter A, Roberts S, Dixon A (2013) Delivering better services for people with long-term conditions: Building the house of care. The King’s Fund October 2013, London.

¹⁵¹ de Silva D (2011). *Helping People Help Themselves*. London: The Health Foundation.

¹⁵² Hibbard J, Gilbert H (2014) Supporting people to manage their health: An introduction to patient activation. The King’s Fund, May 2014, London.

cross cutting – activated and engaged patients cannot be separated from the culture of partnership working and other supportive components of high value care.¹⁵³



Richmond Group of Charities

8.2. EVIDENCE FOR INTERVENTIONS TO SUPPORT SELF-MANAGEMENT

A rapid evidence review was carried out to consider self-management support interventions, particularly exploring the question of which self-management support interventions may improve health outcomes for those with multiple conditions and the evidence for cost savings.

NATIONAL INSTITUTE FOR HEALTH RESEARCH REVIEWS

Two very relevant major studies of the literature by the NHS National Institute for Health Research (NIHR) were published in December 2014.

A rapid synthesis of the evidence on interventions supporting self-management for people with long term conditions: PRISMS - practical systematic review of self-management support for long term conditions¹⁵⁴

There were several phases to the PRISMS project. Through expert opinion workshops, the team developed a layered description of self-management support interventions with the following dimensions:

1. Recipients: patients, carers, health care professionals, organisations.
2. Components: education, information about resources, specific action plans and/or rescue medication, equipment, safety netting, regular clinical review, training to communicate with health care professionals, training for activities of daily living, training in psychological strategies, training for practical self-management activities, social support, monitoring with feedback to the patient, practical support with adherence, lifestyle advice and support.
3. Modes of delivery.
4. Personnel delivering the support.

LTCs were characterised within four clusters (as shown in the table below) and exemplar conditions were selected for the review.

¹⁵³ Richmond Group of Charities, The King's Fund (2012). *From Vision to Action: Making patient-centred care a reality*. London: The King's Fund. Available at: www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/Richmond-group-from-vision-to-action-april-2012-1.pdf

¹⁵⁴ Taylor SJC, Pinnock H, Epiphaniou E et al. (2014) A rapid synthesis of the evidence on interventions supporting self-management for people with long-term conditions: PRISMS – Practical systematic Review of Self-Management Support for long-term. *Health services and delivery research*. December 2014, 2:3.

Table 8.1: Characteristics of long term conditions

<i>Cluster</i>	<i>Exemplar Conditions</i>
1. Long term conditions with marked variability in symptoms over time	Asthma; low back pain; type 1 diabetes; chronic pain; depression; schizophrenia; inflammatory bowel disease; migraine; endometriosis
2. Largely asymptomatic long term conditions in which management is directed at stopping an event or reducing complications	Hypertension; type 2 diabetes; epilepsy; allergy/anaphylaxis; atrial fibrillation; chronic kidney disease
3. Ongoing symptomatic long term conditions with exacerbations	Chronic obstructive pulmonary disease; congestive heart failure; multiple sclerosis
4. Ongoing symptomatic long term conditions with little variability	Osteoarthritis; dementia; chronic fatigue syndrome; progressive neurological conditions (Parkinson's, multiple sclerosis, motor neurone disease)

Source: PRISMS 2014

A systematic review of quantitative and qualitative literature was completed. The team searched for unpublished and in-progress studies, so it is unlikely that many papers have been published since. The search identified 30 qualitative systematic reviews (including 515 unique studies), 102 quantitative systematic reviews (including 969 RCTs) and 61 studies in the implementation systematic review.

Key findings that emerged from the reviews across the conditions included:

- Supporting self-management is inseparable from high-quality care for people with long term conditions.
- Supported self-management must be tailored to the individual, their culture and beliefs, and the time point in the condition.
- Communication - a sense of 'not being listened to', with examples of mismatch between professionals' and patients' understanding and aims for self-management behaviours was present in the qualitative reviews; an ongoing collaborative relationship was highly valued.
- Support with psychological impact of long term conditions was mentioned as potentially helpful in the qualitative meta-reviews for virtually all the conditions, and the majority of self-management interventions included an element of psychological support. Overall, there was variable evidence for the effectiveness of these components across the different conditions, and in some conditions, benefit was not sustained long term.
- Practical support for physical care - coping with ADL was a key challenge for people with disabling conditions and occupational and physiotherapists played an important role in enabling patients to self-manage and maintain as much independence as possible.
- The need for social support was a major issue highlighted in the qualitative reviews of some conditions such as T2DM and stroke.
- It was not possible to identify a 'preferred professional' to deliver self-management support.
- Organisational support is crucial. Without the active support of their health-care organisation, our implementation review revealed professionals struggle to integrate self-management support into their routine clinical care. Promotion of effective self-

Support with psychological impacts was highlighted, although evidence was variable

management support requires a health-care setting in which everyone believes that care should be based on shared decision-making, and patients need to be equipped with the skills, knowledge and support to self-manage (implementation review). The organisation is responsible for providing the means (both training and time/material resources) to enable professionals to implement self-management support, regularly evaluating self-management processes and clinical outcomes and providing ongoing encouragement to maintain good practice.

In addition, there were components that were specific to certain LTCs:

- Action plans were associated with conditions in which there was significant variability or risk of (serious/high-cost) exacerbations.
- Therapy rehabilitation was a feature of self-management support for several of the disabling conditions. Although the term self-management was not used, key aspects of therapy rehabilitation addressed coping with disability and rehearsing ADL.
- The only LTC reported as benefiting from self-monitoring and feedback was hypertension – an asymptomatic condition.
- Intensive education may have a particular role in complex medical conditions (such as T1DM, or home dialysis in severe CKD) when specific training can enable patients to self-manage clinical tasks.

Furthermore, in implementing a whole-system approach to self-management support, the importance of leadership was identified:

- Several studies described strategies for achieving the necessary organisational change to implement effective self-management support. Key messages were the need for strong clinical leadership and commitment at the highest level to ensure that a self-management support was prioritised, involving stakeholders to ensure that professionals are motivated and ‘bought in’ to the process of change, training to ensure all staff have appropriate skills, availability of resources to enable ongoing delivery of self-management programmes, and regular oversight and evaluation to sustain the programme.

Healthcare professionals
require organisational
support to integrate self-
management in clinical care

Notably, the PRISMS review did not consider multimorbidity. The authors noted that *‘it is inevitable that most of the adult patients include within the systematic reviews would have had more than one LTC. We would have liked to consider this important issue of multimorbidity but, unfortunately, it was not discussed in any detail in any of our included systematic reviews, perhaps because it has only recently become an area of particular concern to health services’*.

Reducing care utilisation through self-management interventions (RECURSIVE): a systematic review and meta-analysis¹⁵⁵

The RECURSIVE study 2014 used systematic review with meta-analysis to determine which models of self-management support are associated with significant reductions in health services utilisation

¹⁵⁵ Panagioti M, Richardson G, Murray E et al. (2014) Reducing Care Utilisation through Self-management Interventions (RECURSIVE): a systematic review and meta-analysis. Health Services and Delivery Research, December 2014; 2:54.

(including admissions) without compromising outcomes, among patients with long term conditions. Multiple databases were searched in 2012. 184 studies met the inclusion criteria for the study and provided data for analysis. Of those 35% were conducted in the USA and 23% in the UK. The most common categories of long term conditions included in the studies were cardiovascular (29%), respiratory (24%) and mental health (16%).

The primary findings were that:

- Self-management support was associated with small but significant improvements in Quality of Life, with the best evidence for diabetes, respiratory disorders, cardiovascular disorders and mental health.
- Only a minority of self-management support studies reported reductions in health-care utilisation in association with decrements in health.
- Evidence for significant reductions in utilisation following self-management support interventions was strongest for respiratory disorders and cardiovascular disorders.

The review authors found evidence that studies, at higher risk of bias, were more likely to report benefits on some outcomes and noted the limitation of poor reporting of health-care utilisation and cost outcomes in the included studies.

Nonetheless, the implications of the study for policy and practice were:

- Self-management interventions generally did not compromise patient outcomes.
- Self-management interventions generally led to small but significant reductions in some forms of utilisation in patients with respiratory and cardiovascular conditions.
- The impact of self-management interventions on certain forms of utilisation (such as hospital admission) may overstate the overall impact on total costs.

Evidence that self-management support increases quality of life: small but significant impact

Understanding the impact of self-management in multimorbidity was identified as a priority research need. Although some of the trials included in this review excluded patients with multimorbidity, others were more inclusive, and there was variable reporting of the levels of comorbidity. It is likely that many patients in the meta-analysis had multimorbidity. The analyses, in this review, suggested that the impact of self-management support on utilisation was related to the type of clinical condition. Further research would be needed to explore whether or not the impacts identified here were influenced by the presence of multimorbidity. The authors view is that *'patients with multimorbidity potentially face significant barriers to self-management support, but may also have the greatest capacity to benefit'*.

8.2.2 Self-management and multiple conditions

As identified in the comprehensive NIHR reviews described above, trials and research studies have explored the role of self-management across the vast range of long term conditions. There are multiple reviews exploring the complexity of self-management support interventions and LTCs. For example an evidence summary for 'National Voices', published in YEAR, on supporting self-management drew information from 228 systematic reviews.

Only a few systematic reviews have focussed on self-management support interventions for people with multiple conditions.

Liddy and colleagues,¹⁵⁶ 2014, published a systematic review of the qualitative literature, exploring the perspectives of patient with multiple chronic conditions. They identified 23 relevant qualitative studies, satisfying the Critical Appraisal Skills Programme Quality Rating; the majority were from the US, three were from the UK. The reviews were synthesised using a four dimension conceptual framework for person-centred care, including the following findings:

The evidence for the impact of self-management interventions on utilisation is condition-specific; research has not yet established how self-management for multimorbidity affects utilisation

- 1) Patient as person:
 - the interdependency of symptoms: with multiple conditions, physical and emotional symptoms can compound and build off of each other, resulting in a larger negative effect on daily lives; the symptoms of one condition can be aggravated by the symptoms, treatment or medications of another;
 - many patients reported that their pain was one of the biggest factors limiting their ability to self-manage effectively;
 - depression featured prominently.
- 2) Biopsychosocial perspective:
 - in many patients changing their cognitive approach was the best way to deal with their symptoms and limitations eg prioritising conditions; reframing their situation; engaging in life and body listening; relinquishing control to another source (eg God);
 - in some cases, the more conditions someone had, the better they considered themselves at self-management because they had developed self-monitoring and self-advocacy skills;
 - having appropriate social support was a strong enabler to successful self-management.
- 3) Therapeutic alliance:
 - many patients reported confusion and contradictory information about conditions, as multiple information sources exist;
 - problems related to medication were a barrier to self-management.
- 4) Sharing power and responsibility
 - tailored, written information and mutually agreed care plans, and respect for the patient's priorities and agendas were identified as simple;
 - peoples also wanted to be assisted with locating resources, in particular better access to mental health care resources.

The authors found what they felt to be a mismatch between patient concerns and interventions. There was the absence of discussion among patients related to specific medical conditions, symptoms and tasks, and instead, patients reported difficulties in dealing with physical and

¹⁵⁶ Liddy, C., Blazkho, V., Mill, K. *Challenges of self-management when living with multiple chronic conditions. Systematic review of the qualitative literature.* Can Fam Physician 2014; 60:1123-33.

emotional symptoms, in particular depression, pain and fatigue. Yet medical task management eg blood pressure checking, and patient education, often targeted towards single conditions, remains the focus of the medical community.

Patients may value support in dealing with depression, pain and fatigue. Yet many self-management interventions focus on medical care tasks.

Smith and colleagues¹⁵⁷ published a systematic review of interventions in primary care and community settings to manage patients with multimorbidity in 2012; some of these interventions included self-management components. Through the search they identified 10 multicomponent randomised controlled trials, six of which were classified as organisational (case management, care coordination, enhancement of the skill mix in multidisciplinary working) and four studies were predominantly patient orientated. The patient-orientated studies, not linked to healthcare delivery, seemed less effective, with one exception: a professional led patient orientated intervention focussed on functional difficulties was associated with significant improvements, including a reduction in mortality in the intervention group.

There is some additional relevant primary research and qualitative study evidence. A study by Kenning et al,¹⁵⁸ 2013 used thematic analysis on semi-structured interviews with 20 primary care practitioners (GPs, trainer GPs, practice nurses) and 20 patients with at least two LTCs, purposively sampled on number and type of LTCs, age, gender and postcode deprivation score to explore their views on multimorbidity and the role of self-management. The main thematic findings from the Practitioners interacting with patients with multimorbidity were:

1. Complexity – in terms of presentation, symptom management and patient characteristics.
2. Uncertainty – in terms of treatment and management.
3. Emotional strain – associated with managing complex patients who show little improvement or willingness to engage in their own care.

In terms of self-management, healthcare practitioners primarily viewed it as three key health behaviours: appropriate health-seeking; compliance with medication; healthy lifestyle choices – with the main interest for practitioners in reducing service use. In contrast, the motivation for patients on self-management was to reduce the impact of their conditions on their daily routine and lifestyle and not premised on reducing use of healthcare.

Practitioner and patient priorities and motivation for self-management may differ.

Since then, Bratzke and colleagues have published a narrative review¹⁵⁹ exploring priority setting and decision-making for self-management in adults with multimorbidity, examining thirteen studies (majority qualitative). The main findings were that:

¹⁵⁷Smith SM, Soubhi H, Fortin M et al. (2012) Managing patients with multimorbidity: systematic review of interventions in primary care and community settings. *BMJ* 2012;345:e5205

¹⁵⁸Kenning C, Fisher L, Bee P, Bower P, Coventry P. (2013) Primary care practitioner and patient understanding of the concepts of multimorbidity and self-management: A qualitative study. *Sage Open Medicine*. 2013;1.

¹⁵⁹Bratzke LC, Muehrer RJ, Kehl KA et al (2015). Self-management priority setting and decision-making in adults with multimorbidity: A narrative review of literature *International Journal of Nursing Studies* 52:744–755.

- Priority setting and decision-making are iterative process that go hand-in-hand in self-management of multimorbidity.
- Individuals' self-manage multimorbidity, in part, by identifying a dominant chronic illness that takes priority over other co-morbidities. Reprioritization of the dominant illness occurs as effects of chronic illnesses and their treatments change over time.
- Priority setting and decision-making in multimorbidity are influenced by individual processes and factors including personal beliefs, preferences, attitudes and perceptions of one's capacity to engage in the self-management behaviour.
- Various facilitators (eg home-based self-management programmes) and barriers (eg lack of resources, conflicting or confusing treatment recommendations, and treatment side effects) impact priority setting and decision-making in self-management of multimorbidity.

Harrison and colleagues¹⁶⁰ used data from a randomised controlled trial for a secondary analysis to explore the patterns in multimorbidity among patients who were benefitting from a chronic disease self-management programme. They compared the impact of this programme between four groups:



- (1) Single physical condition.
- (2) Multiple physical conditions.
- (3) Single physical condition plus 'probable depression'.
- (4) Multiple physical conditions plus 'probable depression'.

(The measure of mental health was made using the MHI-5 scale, coding patients as 'probable depression' for a score of ≤ 60). The groups were found to be different at baseline in their demographic variables, and in their self-management: for example patients with 'probable depression' report less use of diet, complementary therapy or relaxation, and all groups with multimorbidity reported less exercise. These differences were controlled for in the statistical analysis. The results found that multimorbidity moderated the impact of the self-management programme on three out of six outcomes – vitality, health-related quality of life, and mental wellbeing. Patients with the highest level of multimorbidity burden and 'probably depression' gained substantially on these outcomes relative to controls. The authors noted: *Our findings confirm previous research which shows that although coexisting mental and physical health problems increase illness burden, the therapeutic benefits of intervening with such patients are potentially magnified.*

Secondary analysis data indicates that patients with multimorbidity and probably depression may particularly benefit from a self-management programme

¹⁶⁰ Harrison M, et al. (2011) A secondary analysis of the moderating effects of depression and multimorbidity on the effectiveness of a chronic disease self-management programme. Patient Educ Couns.

8.2.3 Summary of evidence

Overall, there is a lack of evidence available on the impact of self-management support interventions in the context of multiple conditions. The majority of research studies have focussed on controlled interventions for single conditions. Nonetheless, many researchers hold the view that, people with multimorbidity may gain more from self-management/patient education programmes than those with single conditions. There is also recognition in the evidence base, particularly in the qualitative reviews, that 'self-management support interventions' are only one element of supported and collaborative care.

Extrapolating the research findings from the available studies may suggest that:

- Self-management support should be considered within the context of a collaborative patient and health care professional relationship.
- Self-management support may have a small effect size on health and social care utilisation and costs, and a larger effect size on patient quality of life outcomes.
- Self-management support for people with multiple conditions may be particularly applied to common functional challenges, and the difficulties in managing physical and, especially emotional, symptoms.

8.3. POPULATION GROUPS REQUIRING ADDITIONAL SUPPORT WITH SELF-MANAGEMENT AND CARE PLANNING

There are a range of population groups of people with LTCs or caring for people with LTCs who may benefit from alternative or additional support in self-management for their conditions, particularly in supporting behaviour changes, increased skills, and maintaining motivation. For some of these groups, the core issue is effective communication and appropriate information and advice. In others, developing health literacy and skills may require specific training and support.

Tailored self-management may be supported through collaborative care planning

Achieving appropriate support for self-management may be mediated through collaborative care planning to identify particular needs, and appropriate solutions, such as some of the innovative telecare or telehealth products, set goals and link individuals with resources in the community.¹⁶¹

8.3.1 PEOPLE WITH LEARNING DISABILITIES

The 2001 White Paper on the care of people with learning disabilities, brought the definition that: *'Learning disability includes the presence of:*

- *a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;*
- *a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development'*¹⁶²

¹⁶¹ Coulter A, Roberts S, Dixon A (2013) Delivering better services for people with long-term conditions: Building the house of care. The King's Fund October 2013, London.

People with learning disabilities die younger and have poorer health than the general population; many people with learning disabilities have physical and mental LTCs.¹⁶³

The Department of Health good practice guidance from 2008, emphasises the benefits of writing a health action plan for people with learning disabilities, and that skilful health facilitation and health action planning is an important tool in helping people to remain as independent as possible.¹⁶⁴

Effective support for people with learning disabilities includes engagement in service planning and care planning for individuals

Learning disabilities was a clinical priority for the Royal College of GPs from 2010-2012 in recognition that people with a learning disability are not getting equal access to healthcare. Targeted annual health checks may be used to detect unmet health needs and changes in conditions.

The ten year vision for NHS East of England¹⁶⁵ highlights 'people as experts': people with a learning disability and family carers have key roles as experts in how they are best supported. This is particularly important in terms of patient experience and the quality of services, and in the design of services. The vision for 2011-2021 identifies some current gaps to be addressed, including ensuring access to mainstream health services, and the needs for appropriate training, communication materials and expertise. A key feature in achieving this vision is that effective care and support plans for people with a learning disability and family carers require a greater focus on choice and control for people, particularly through achieving person-centred approaches and the implementation of



personal health budgets. Through full engagement with people with learning disabilities as stakeholders and experts in local partnerships, and appropriate care planning on an individual level in health services, people with learning disabilities will be supported more effectively.

There is some specific research on self-management principles among people with learning disabilities. An exploratory qualitative study on self-management of cardiovascular disease found that facilitated service user involvement in self-management decision

making was highly valued among people with learning disabilities, carers and health professionals.¹⁶⁶

The authors noted that: *Evidence points to limited impact of health improvement advice alone. The active involvement of service users, family and carers in decision making and in creating opportunities for healthy living is fundamental. Health-related informed decision-making is likely to be enhanced for people with learning disabilities if specially adapted information materials are used.*

¹⁶² Department of Health (2001). *Valuing People: A New Strategy for the 21st Century*.

¹⁶³ Royal College of GPs, Improving Health and Lives Public Health Observatory, and Royal College of Psychiatrists (2012) *Improving the Health and Wellbeing of People with Learning Disabilities: An Evidence-Based Commissioning Guide for Clinical Commissioning Groups (CCGs)*. Published: October 2012. Available at: <http://www.rcgp.org.uk/learningdisabilities>

¹⁶⁴ Department of Health (2008). *Health Action Planning and Health Facilitation for people with a learning disability – good practice guidance*. Available at: http://ix.iriss.org.uk/sites/default/files/resources/DH_096506.pdf

¹⁶⁵ NHS East of England. *Better health and wellbeing for people with a learning disability and their families: the vision for achieving the best, together in the east of England 2011-2021*.

¹⁶⁶ Young AF, Naji S, Kroll T. (2012) Support for self-management of cardiovascular disease by people with learning disabilities. *Family Practice* 2012; 29:467–475.

Also, the need for progressive opportunities combining physical and psychosocial approaches has been highlighted. Thus, a multifaceted interdisciplinary approach encompassing social, lifestyle, medical and educational factors is needed to facilitate inclusion.

8.3.2 PEOPLE WITH SENSORY IMPAIRMENTS

Sensory impairments encompass visual impairment (including blind and partially sighted), hearing impairment (including profoundly deaf, deafened or hard of hearing) and dual sensory impairment (deafblindness). Sensory impairments particularly affect the older population and appreciably may coexist with other long term health conditions.

Sensory impairment is associated with social isolation, depression and other psychological problems; the links with other avoidable health problems include the correlation between eye disease and falls in older people.¹⁶⁷ There are acknowledged poorer health outcomes for the deaf community, despite similar patterns of risk factors to the general population.¹⁶⁸

Some of the health difficulties faced by those with sensory impairments are the general access barriers in using healthcare services such as consulting with their GP;¹⁶⁹ these may be particularly pertinent for those with (multiple) LTCs. There may also be particular difficulties in particular tasks necessary for managing conditions, for example taking medication as prescribed. A recent case-control study in 314 older people aged ≥ 65 years compared the adherence to medication between those with and without visual impairment, and found that the group with visual impairment had difficulty distinguishing different tablets and needed help managing medication from friends, pharmacists or social service support.¹⁷⁰ The authors recommended that an appropriate care management plan for someone with visual impairment might consider resources that can support self-management such as large-print labels or talking labels, or different textures and shapes of containers, and dosette boxes.

8.3.3 PEOPLE WITH DEMENTIA AND COGNITIVE IMPAIRMENTS

Dementia is characterised by a decline in a person's memory, reasoning and communication skills and their ability to carry out daily activities.¹⁷¹

There is increasing interest in the provision of self-management support for people with dementia. In particular, the early stages of dementia have been described as falling within a 'care gap'.¹⁷² Self-

¹⁶⁷ NHS England (2014) Improving eye health and reducing sight loss – a call to action. June 2014; Gateway reference: 01731. Available at: <http://www.england.nhs.uk/wp-content/uploads/2014/06/eye-cta-pack.pdf>

¹⁶⁸ Signhealth (2014) A report into the health of deaf people in the UK. Available at: <http://www.signhealth.org.uk/sick-of-it-report-professionals/>

¹⁶⁹ Ringham L (2013). Access all areas? A report into the experiences of people with hearing loss when accessing healthcare. Action on hearing loss. Available at: <http://www.actiononhearingloss.org.uk/supporting-you/policy-research-and-influencing/research/access-all-areas.aspx>

¹⁷⁰ McCann RM, Jackson J, Stevenson M, Dempster M, McElnay JC, Cupples ME (2012) Help needed in medication self-management for people with visual impairment: case-control study. Br J Gen Pract 2012; DOI: 10.3399/bjgp12X653570.

¹⁷¹ Goodwin N, Curry N, Naylor C, Ross S, Duldig W. (2011). Managing people with long-term conditions. Research paper: An Inquiry into the Quality of General Practice in England. The King's Fund.

¹⁷² Martin F, Turner AP, Wallace LM, Choudhry, K and Bradbury N. (2013) Perceived barriers to self-management for people with dementia in the early stages. Dementia: The International Journal of Social Research and Practice, volume 12 (4): 481-493.

management for people with dementia or mild cognitive impairments is likely to comprise a focus on physical health, the use of assistive technology, and living well with dementia. A qualitative study, using participative discussions to understand priorities for a self-management programme, identified the following key topics:¹⁷³

Topic	Dimensions
Understanding dementia	Full and timely information about the condition and what to expect
Rethinking dementia	Dementia as part of a process of change, health, wellbeing and activity, enabling environments
Living with dementia	Making the most of routines, memory maintenance, strategies to manage memory loss
Relationships	Building and maintaining friendships, husbands, wives and partners, rediscovering relationships
Keeping mentally well	Recognising and overcoming depression, managing anger, managing anxiety
Experiencing wellbeing	Volunteering, hobbies, leisure
Dementia and daily living	Using everyday technology, managing finances, home and community safety
Keeping physically well	Eating and nutrition, sensory impairment, developing healthy bladder and bowel habits, managing medication, sleep, managing fatigue
	Managing other physical conditions
Building and developing skills	Grading activity, problem solving strategies, learning new skills
Keeping connected	Maintaining community connectedness, accessing outside opportunities, transport and driving
Maintaining a sense of self	Dressing and identity, self-esteem, spirituality, keeping faith
Planning for the future	

A recent review identified 15 group-based psychosocial interventions for dementia or mild cognitive impairment. The most common self-management components were information, communication, social support and skills training, although the effectiveness of these programmes was not examined.¹⁷⁴

Dementia or cognitive impairment is prevalent with other physical and mental health conditions. For example, people with diabetes are at nearly double the risk of the general population of developing cognitive impairment and dementia. Yet cognitive impairment may limit the capacity for self-management; a cross sectional analysis of 1,398 older adults with type 2 diabetes found that as cognitive impairment worsened, adherence to each diabetes self-care task decreased.¹⁷⁵ Therefore, a 'living well' approach emphasises self-management where possible, with appropriate professional care management alongside. The NICE Quality Standard QS30 Supporting People to Live Well with Dementia, includes standard 6 that: *People with dementia are enabled, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing.*¹⁷⁶

¹⁷³ Mountain GA, Craig CL. (2012) What should be in a self-management programme for people with early dementia? *Aging & Mental Health*. Vol. 16, No. 5, July 2012, 576–583

¹⁷⁴ Quinn C, Toms G, Anderson D, Clare L. (2015) A review of self-management interventions for people with dementia and mild cognitive impairment. *J Appl Gerontol*. **January 21, 2015** pii: 0733464814566852.

¹⁷⁵ Feil DG, Zhu CW, Sultzer DL. (2012) The relationship between cognitive impairment and diabetes self-management in a population-based community sample of older adults with Type 2 diabetes. *J Behav Med* 35:190–199.

¹⁷⁶ NICE Quality Standard 30 [QS30]. April 2013. Supporting people to live well with dementia. Available at: <http://www.nice.org.uk/guidance/QS30>

8.4. LOCAL AND NATIONAL ASSETS FOR SUPPORTING SELF-MANAGEMENT

Formal self-management support in England is currently provided through a number of different models, including:¹⁷⁷

- Increasing access to health information.
- Deployment of assistive technologies such as telehealth and telecare.
- Facilitation of community-based skills training and support networks such as the Dose Adjustment For Normal Eating (DAFNE) and Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND) courses for particular conditions and the NHS version of the CDSMP (the Expert Patients Programme) for generic long term conditions.
- Interventions led by health professionals.

8.4.1 LOCAL ASSETS

There are a range of assets available for supporting self-management in Cambridgeshire including, but not limited to:

- A wealth of support groups for specific conditions in the county and regionally
 - For example, in preparing this JSNA we engaged with representatives from local Breathe Easy and Diabetes support groups.
 - There are groups for many different conditions, operating in different ways and providing many different arrays of support.
- A strong and active voluntary and community sector that provide social and practical support in multiple forms.
- Addenbrooke's (Cambridge University Hospitals) has a centre for self-management support.



IAPT provision

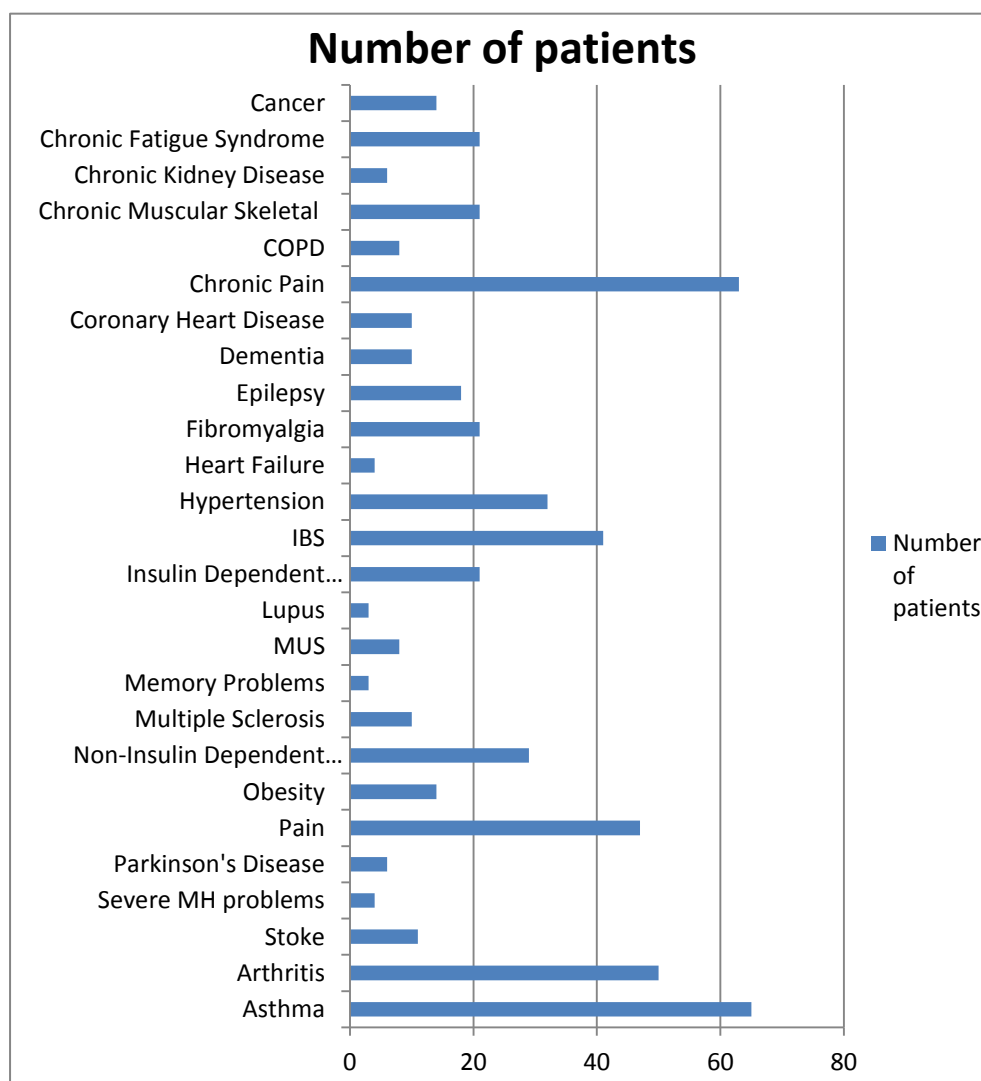
Since February 2014, Cambridgeshire and Peterborough NHS Foundation Trust (CPFT) 'Increasing Access to Psychological Therapies' (IAPT) service has included the IAPT Long Term (physical health) conditions team to offer specialist input. The IAPT LTC team includes three high intensity CBT therapists and three psychological wellbeing practitioners, working to address psychological needs in patients with LTCs.



Early service data shows in total, 690 IAPT patients had an LTC recorded against their case from April to October 2014. The chart below shows the breakdown of patients and their primary long LTCs seen by all IAPT services April to October. 150 patients had diagnosis recorded as 'other', which may be due to the wide range of conditions seen. Of the 690 patients, 575 were seen by CPFT Adult IAPT and 197 were seen specifically by the specialist LTCs team in IAPT.

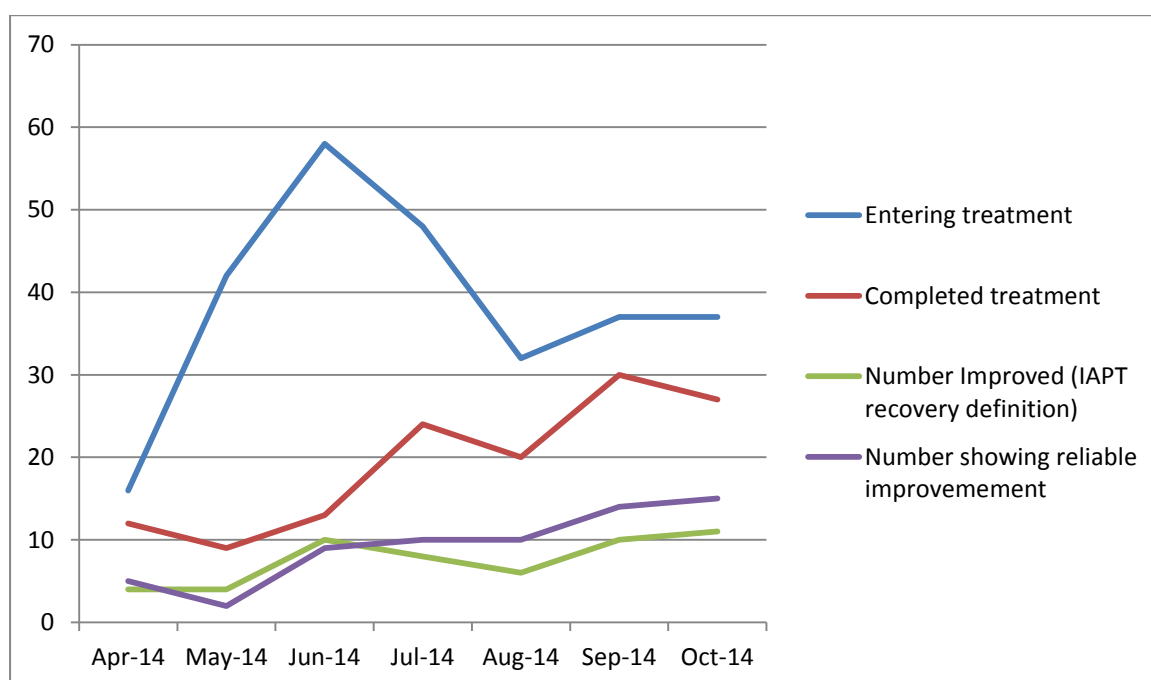
¹⁷⁷ Taylor SJC, Pinnock H, Epiphaniou E et al. (2014) A rapid synthesis of the evidence on interventions supporting self-management for people with long-term conditions: PRISMS – Practical systematic Review of Self-Management Support for long-term. Health services and delivery research. December 2014, 2:3.

Figure 8.1 Breakdown of Long Term Conditions over 7 month period seen by IAPT Cambridgeshire and Peterborough services (April to Oct 2014)



Source: IAPT team, Cambridgeshire and Peterborough NHS Foundation Trust.

The IAPT LTC team were undertaking various aspects of service development during the first three months, developing service criteria, visiting other services, looking at best referral sources, where best to focus and also avoiding duplication of services already provided. The activity graph below does show a gradual upward direction of activity and also a recovery figures, but it is anticipated there will be some variation in this. The added complexity of physical health issues, may impact on recovery statistics, but so far this seems positive. The gap between the numbers entering treatment does vary over the period above. This is because a small team some patients will be passed to the rest of the IAPT team as not all patients with LTCs will need specialist input.

Figure 8.2 showing performance of the LTC team: First seven months (April to Oct 2014)

Source: IAPT team, Cambridgeshire and Peterborough NHS Foundation Trust.

8.4.2 NATIONAL ASSETS

There are many websites and organisations for people with specific conditions which provide a range of forms of information, advice and support. Many organisations also make use of digital forums to allow peer support. Similarly there are major work programmes emphasising the centrality of collaborative and person-centred care:

- RCGP programme on 'Collaborative Care and Support planning'
- Coalition for Collaborative Care
- Health Foundation Co-creating health (since 2007) and self-management resource centre
- National Voices: Narrative for Person-centred coordinated care



Further national platforms include:

- NHS Self-care forum and national 'self-care awareness' week identifies support for people with LTC and emphasises first aid and appropriate use of health services across the whole population
- **NESTA's People Powered Health programme** seeks to support the delivery of innovative services focusing on self-management.

- The **Expert Patients Programme** provides courses aimed at helping people manage their condition. This is now co-owned by '**Self Management UK**'
- **Health unlocked** (healthunlocked.com) - is a social movement to support increased health information and peer support.

8.5. WHAT IS THIS TELLING US?

The vast majority of care is in the normal context of peoples' lives and, therefore, supporting self-management of LTCs within day-to-day life is intended to optimise health outcomes and help manage demand on health and care. There is evidence that interventions to support self-management and support patients and carers to be engaged and informed, may have a positive impact on patient metrics, and it is indicative that they may have some impact on health service utilisation, although may have limited impact on reducing overall demand.

The research on self-management support interventions has primarily focussed on single conditions, and there is some evidence to suggest that support around emotional and practical impacts of living with conditions are not being addressed as comprehensively as patients would like. And there is an increasing policy emphasis on the role of self-management as part of an ethos for high quality care beyond the provision of specific programmes in achieving patient-centred and collaborative approaches; the effectiveness of this has not been examined in the self-management literature. Therefore there is some difficulty in determining the full impact of supported self-management for people with multiple conditions and the potential impact in Cambridgeshire.

There are particular population groups who may particularly benefit from support with self-management that is person- and carer- orientated including people with learning disabilities, sensory impairment, dementia and cognitive impairment. Cambridgeshire has important local assets, in particular the provision of psychological therapies for people living with LTCs. There may be further opportunities to particularly ensure support for self-management for those with multiple conditions across all the levels of health and care.

9. KEY FINDINGS AND CONCLUSIONS

This JSNA provides important evidence and information to support the commissioning of preventative services and interventions for long term conditions across health and social care in Cambridgeshire. The evidence and information may be used by providers to develop effective integrated pathways of care for adults and older people. The process and production of the JSNA is also timely as new structures and service design models are currently in effect across the County, and for which this piece of work will provide a base and foundation for further work across several local priority areas.

A number of key findings have been identified by the JSNA working group with stakeholders from across the area for consideration:

- There are a substantial proportion of people with multiple LTCs conditions in Cambridgeshire. Nearly 20% of people aged 18-64 years have more than one LTC and 70% of people over the age of 65 have more than one LTC. Levels of limitation are high in both groups.
- The co-occurrence of mental health conditions and LTCs is marked and has clear commissioning and service implications.
- Those with multimorbidity are often at higher risk of escalation of health and social care. Those with multimorbidity and significant levels of limitation, pain and mental health conditions are at even higher risk or poorer health and social outcomes.
- LTCs and specifically multimorbidity are heavily socioeconomically patterned. People living in deprived areas may present up to 15 years earlier with multimorbidity. This emphasises a need for the development of targeted interventions to address health outcomes in the most vulnerable groups.
- There is clear fragmentation in service design across levels with an urgent need to join up around the person and engage differently to achieve real integration of care and demonstrable improvement in health and care outcomes for patients, their families and communities.
- A person-centred focus and services that are built together with and in response to the citizen voice are fundamental to achieve both integration and improved outcomes. A culture of effective communication and co-production between levels of care, and between people and the health and social care staff they interact with would support this.
- The impact of self-management approaches need to be addressed within a local context. An integrated service designed around optimal self-management and self-care and could prove more effective than current patterns of use.
- A lifecourse approach provides a framework from which to design preventative interventions that address physical and social risk factors as well as the wider determinants of health.
- A stronger emphasis and implementation of evidence-based models and interventions to support appropriate hospital and care admissions avoidance should be at the core of all LTC agendas.

The assessment of needs in this JSNA provides a base from which further in-depth analysis could be generated. Further steps in the development of this work might include:

- Further analysis of the quantitative data to seek patterns that might further inform targeting approaches.
- Exploration of innovative models for providing services to people with multiple LTCs including visits to areas of good practice.
- Cross-system join-up across sectors.

In conclusion, this JSNA highlights opportunities for future work including:

- Development of approaches responsive to those at high risk of future care.
- Integration of care across levels and agencies and development of a lifecourse approach to LTCs.
- Development of a person-centred approach to care.
- Reduction of avoidable hospital admissions and admissions to social care.
- Promotion and provision of support to facilitate effective and appropriate self-management.